Putting the Pieces Together: An Adult Perspective on Growing Up with a Sibling with Autism Spectrum Disorder

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Dedication

I dedicate this thesis to my father Pierre Edery, a true Mensch, who although was not physically here to see me complete this thesis or my Master's Degree, was undoubtedly there spiritually.

Dad, thank you for the countless hours spent reading and editing several masters applications over the years. I am so grateful that I got to celebrate the milestone and dream of getting into Clinical Psychology Masters with you!

You taught me the importance of a strong work ethic and to always strive for what you want. I deeply missed your support and guidance throughout this process as I have had in my past academic endeavours, however at times of being stuck I sat and talked it out, weighing the various arguments out, as if I was talking to you.

Dad, you were a significant part of my master's journey - a memory that I will forever cherish, and you will continue to be a part of my unfolding journey as a clinical psychologist.

I love and miss you.

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Abstract

Sibling relationships are one of the longest relationships of an individual's life and a prominent means of encouragement, camaraderie, and influence on one's development throughout one's lifespan, yet there are various aspects that may alter the sibling relationality, such as autism spectrum disorder. This qualitative research study set out to explore the lived experiences of adult individuals who grew up with a sibling on the autism spectrum. Adult voices have long been negated in such discourse, with an over reliance on parental, child, and adolescent voices. Whilst these narratives have made prominent strides in elucidating the sibling relationship with a sibling on the spectrum, little is known about the adult sibling relationship and an adult perspective on the sibling relationship across siblinghood. Thus, through exploring retrospective and current experiences of siblinghood, this study sought to garner insight into how eight adults perceive, think, feel, and reportedly experience their relationship with their sibling on the spectrum, in their own words. In doing so, the study aimed to gain an experiential understanding of adult individuals' meaning making and intrapsychic resonances. The data underwent an interpretive phenomenological analysis, an approach that views participants as experts and emphasises their agency within the creation and meaning making of their experiences. This method enabled rich and insightful understandings of the lived experiences of adult siblings with their siblings on the autism spectrum. The findings suggest a sibling relationship characterised by an ebb and flow relationality of a nuanced and dynamic sibling dyad across siblinghood, challenging reported rigid, absolute, and hypothesised notions of siblinghood as it evolves throughout the lifespan. Subsequently, recommendations for clinical practice and future research are addressed.

Keywords: adult perspective, autism, disability, sibling, sibling relationship, siblinghood

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CHAPTER ONE: INTRODUCTION AND RATIONALE

Sibling relationships are among the longest relationships of an individual's life and a salient source of support, companionship, and influence on one's emotional, cognitive, and social development throughout one's lifespan (Beyer, 2009; Diener et al., 2015). Subsequently, siblings play a significant role in facilitating each other's growth. The collective experience across siblinghood affords siblings the opportunity to develop and form special understandings of one another as well as resemble and maintain various fixtures throughout one's life such as sources of refuge and encouragement, contention, and resentment or unhappiness and indifference (McHale et al., 2016). Consequently, whilst similar features may be found in sibling relationships, they are also characterised by significant variability and difference (McHale et al., 2016).

Despite the significance of the sibling dyad, literature has largely focused on the parent-child subsystem with slightly less attention on the sibling-sibling subsystem (Noonan et al., 2018). Whilst a shift in focus has been noted and is commended, research has traditionally depended on maternal reports to discern sibling relationships, regardless of reported discrepancies between parent and child perspectives of the sibling relationship (Noonan et al., 2018). However, substantial strides have been made by including young people's voices in the discourse (Noonan et al., 2018). This is evident in the vast amount of research exploring sibling relationships and various determinants embedded in the relationality of such sibling dyads, such as exploring the sibling relationship when one sibling has a neurodevelopmental disability such as autism spectrum disorder (ASD) (Beyer, 2009; Latta et al., 2014; Petalas et al., 2009; Petalas et al., 2015).

A sibling relationship with a sibling on the spectrum has been an area of exploration due to the dyad being a cornerstone for developmental influence, as an individual's early learning and social experiences are typically encountered and shared with one's primary social partner(s) (sibling(s)) and enacted based off one's sibling(s) observations (Howe & Recchia, 2006). Consequently, it has been postulated that the presence of ASD within a sibling relationship may alter one's learning and developmental experiences (Howe & Recchia, 2006).

Attempts to ensure a more comprehensive understanding of the sibling experience by including young voices of children and adolescents into the discourse, whilst substantial in enhancing the understandings of the sibling relationship, has also had some drawbacks. This is especially noteworthy in ASD sibling research. Majority of the studies about individuals with a sibling on the autism spectrum have focused primarily on neurotypical siblings' experiences and outcomes in childhood and adolescence (Diener et al., 2015). Whilst these findings have been considerable in enhancing understandings of nuanced sibling relationships with a sibling on the spectrum, this particular experience from an adult's point of view has been heavily negated (Doody et al., 2010; Hall & Rossetti, 2018; Orsmond & Seltzer, 2007a; Orsmond & Seltzer, 2007b). Consequently, rigid, absolute, and hypothesised narratives of siblinghood beyond childhood and adolescence have emerged.

Studies exploring the sibling relationship with a sibling on the spectrum from an adult perspective predominantly focus on the neurotypical adult sibling's caregiving responsibility, their relationship with service delivery, or have explored this sibling relationship in a combination of intellectual and developmental disabilities (Hall & Rossetti, 2018; Heller & Arnold, 2010; Orsmond & Seltzer, 2007b). Few studies have focused specifically on adults and their reported relationship with brothers or sisters on the autism spectrum (Moss et al., 2019, Noonan et al., 2018; Tozer et al., 2013). Subsequently, there is little research exploring adult siblings' emotions, reactions, thoughts, and perceptions regarding the presence of ASD within their sibling relationships, leading to an experience that is largely excluded and unknown.

An adult perspective is an essential piece in enhancing the understandings of sibling relationships with a sibling on the spectrum as adult sibling relationships evolve across the life course and offer a complex and nuanced perspective (Avieli et al., 2019). Thus, adults can provide retrospective and current accounts of their lived experiences of siblinghood, allowing for descriptive and insightful understandings and representations as opposed to limited understanding of siblinghood derived from a specific focus on a time in one's life, such as childhood or adolescence. Given the dearth of information surrounding the psychological experience of growing up with a sibling with autism, from the voices of adult participants, the current study intended to address this gap so as to add to the existing, predominantly child-based literature on this topic.

Moreover, this scope of research frequently adopts a quantitative paradigm, negating the rich accounts derived from exploratory studies (Doody et al., 2010; Ward et al., 2016). Thus, this study employed a qualitative approach, with an interpretive phenomenological framework to enable exploration into the lived experiences of adult individuals' sibling relationships with a sibling on the spectrum, in their own words.

1.1 Research Aims

This proposed study aimed to explore current, and retrospective lived experiences of siblinghood from the perspective of adults who have grown up with a sibling on the autism spectrum. Thus, accessing stories from siblings without autism. In doing so, this study intended to understand adult participants' thoughts and emotions with regards to growing up with a sibling who has a neurodevelopmental disorder, specifically autism spectrum disorder, without trying to remediate it. This study also aimed to contribute to the practice of psychology, particularly for service providers working with individuals with ASD, their siblings, their families, and within the field of autism in general as well as contribute to the limited ASD research in South Africa.

1.2 Structure of the Thesis

Chapter one provided the introduction to the study, outlined the rationale for the study, and noted the research aims. Chapter two offers a literature review exploring key concepts, themes, and interactions necessary to substantiate the intention of exploring adults' lived experiences of growing up with a sibling on the spectrum. Chapter three delineates the methodological approach employed in the current study as well as states the research questions the study sought to explore. Chapter four presents the analysis undertaken and a discussion on the findings discovered. The study will close with conclusions, contributions, limitations, and recommendations for clinical practice and future research in Chapter five.

CHAPTER TWO: LITERATURE REVIEW

The literature review will begin with an introductory outline of the key concept integral to the study namely sibling relationships. Thereafter an overview of the different theoretical models conceptualising disability will be provided and in doing so the connection between sibling relationships and disability will be explored. This is followed by a delineation of the specific disability explored, that of autism spectrum disorder. Under this section, oversaturated narratives and discourses identified in previous work in relation to sibling relationships with a sibling on the spectrum will be discussed. This is necessary to help illuminate the distinct gap in the literature so as to situate the current study in the literature and motivate the need for an exploration into adult perspectives on siblinghood with a sibling with ASD. This chapter will conclude by noting the research questions guiding this study.

2.1 Sibling Relationships

Siblings represent a unique position in an individual's life, as the sibling relationship is often among the longest and most enduring relationships of one's life (Beyer, 2009; Braconnier et al., 2018; Diener et al., 2015; Hall & Rossetti, 2018; Sommantico et al., 2020, Tozer & Atkin, 2015).

Cicirelli (1995) conceptualises the sibling relationship as:

> The total of the interactions (physical, verbal, and nonverbal communication) of two or more individuals who share knowledge, perceptions, attitudes, beliefs, and feelings regarding each other, from the time that one sibling becomes aware of the other. A sibling relationship includes both overt actions and interactions between the sibling pair as well as the covert subjective, cognitive, and affective components of the relationship (p.4).

This notion that the sibling relationship begins from the time one sibling becomes aware of the other illuminates the magnitude of such a relationship. The acknowledgment and awareness of the other sparks the beginning of the influence each sibling has over one another's developmental experiences – social, emotional, cognitive, physical, and moral (Diener et al., 2015; Nielsen et al., 2012; Sommantico et al., 2020; Van der Merwe et al., 2017). Thus, sibling relationships are a vital component of child development and adaption (Nielsen et al., 2012). Subsequently, siblings' intimate daily interactions during childhood enables them to embody and enact various roles such as one's primary social partner, playmate, teacher, and surrogate parent (Diener et al., 2015; McHale et al., 2016; Nordone, 2014; Orsmond & Seltzer, 2007a; Van der Merwe et al., 2017). As siblings begin to navigate the world, engaging in experiences and encountering social cues, they turn to their siblings for guidance and behaviours to imitate (Nordone, 2014). This early sibling reliance and influence foreshadows siblings' influence on developing various social and moral skills such as "perspective taking, conflict resolution and communication skills" (McHale et al., 2016, p.2). As siblings experience each other and engage in shared and unshared experiences, siblings become sources of companionship, support, warmth, and encouragement, facilitating siblings' emotional development and sense of belonging (Diener et al., 2015; Hall & Rossetti, 2017; Johnson et al., 2020). This shared history enables the formation of profound and unique understandings of each other (McHale et al., 2016). However, like most influences, the outcome may not always be positive. As such, the uniqueness of the sibling relationship may also provide a catalyst for the development of aggressive tendencies and behaviours, that may result in alterations to one's developmental experiences (McHale et al., 2016). Despite this, the degree to which sibling relationships influence siblings' behavioural and psychosocial adjustment throughout one's lifespan is unparalleled (Nielsen et al., 2012).

Furthermore, sibling relationships are complex and experience degrees of change as they develop, evolve, and occupy different roles and spaces throughout childhood, adolescence, and adulthood (Beyer, 2009; Johnson et al., 2020). They are unique to a specific sibling pair and as such vary considerably (McHale et al., 2016). Siblings' influences may be direct, indirect, temporary, or long-lasting (Cicirelli, 2013). Additionally, sibling relationships may be characterised by closeness, commitment, compassion, and or intimacy, whilst others may be antagonistic, conflictual, and or indifferent (Cicirelli, 2013; Tomeny et al., 2017a; Tudor et al., 2018). Despite the multifaceted nature of sibling relationships, there is considerable research that postulates that one's sibling relationship in childhood establishes the basis for one's adolescent and adult sibling relationships, as well as predicts psychosocial adjustment outcomes in adolescence and adulthood (Johnson et al., 2020; Nordone, 2014; Petalas et al., 2015). Subsequently, positive sibling relationships in childhood are associated with positive impacts throughout adulthood, with the opposite being true with regards to negative relationships (Johnson et al., 2020). Whilst this is a dominant understanding, research does stress how such childhood relationships are merely predicators but not fixed indicators of adult siblinghood as there are a multitude of factors that may influence the trajectory of the sibling relationship through to adulthood (O'Brien et al., 2020). Such factors include age, gender, birth order, developmental contexts, altered perceptions, and particularly for the current study, the presence of disability (McHale et al., 2016; Orsmond & Seltzer, 2007a).

2.2 Disability

Disability is multifaceted. Disability may be visible or invisible (not immediately apparent), congenital (born with) or acquired, as well as stable or aggressive (progressively increasing in severity, difficulty, and impact on one's livelihood) (Harvey, 2019). Additionally, disability can be physical (e.g., certain presentations of cerebral palsy), intellectual (e.g., Down's syndrome), psychosocial (e.g., anxiety disorders) and sensory (e.g., autism spectrum disorder) (Harvey, 2019). Nevertheless, disability as a construct is a contested issue (Thomas, 2004).

Understandings of disability are generally situated within two dominant models within the literature, namely the medical model and the social model. The medical model adopts a pathological and biological view of disability (Albrecht et al., 2001; Hedlund, 2000), postulating disability as a result of substantial deficit in functioning (Nario-Redmond et al., 2013). In doing so, this model situates disability in the individual (Albrecht et al., 2001). Consequently, disability is viewed as a negative experience that should be corrected (Nario-Redmond et al., 2013). In contrast, the social model positions disability within a social context, grounding disability as a social phenomenon subjected to various societal associations, attitudes, assumptions, and responses around an individual's deficits (Albrecht et al., 2001; Harvey, 2019). Thus, the social model is in direct opposition to the medical model, in that it removes disability as residing in the individual and away from a focus on functional limitations and rather locates disability within the environment with a focus on societal oppression as the cornerstone for the experience of disability (Albrecht et al., 2001).

These two models present a rigid dichotomous stance about disability. However, the purpose of this study is to explore the presence of disability within a sibling relationship, and in doing so it implies an understanding that disability is relational, meaning it is embodied and enacted between two or more people, particularly here, in siblings' interactions (Meltzer, 2015). Subsequently, disability is neither located solely in the individual nor the environment. Thus, this study will adopt a definition of disability put forward by Marks (1999) as a "complex relationship between the environment, body and psyche, which serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs" (p. 6111).

2.2.1 Growing up with the Presence of Disability

Research regarding having a sibling with a disability has yielded mixed results (Zaidman-Zait et al., 2020). Nevertheless, findings are generally situated within two theoretical frameworks, namely a deficit model and an advantageous model (Zaidman-Zait et al., 2020). A deficit model automatically associates disability with negativity (Zaidman-Zait et al., 2020). Disability is viewed as an adverse experience that poses significant risk for an able-bodied sibling's psychosocial adjustment and outcomes, consequently influencing their sibling relationship (Hall & Rossetti, 2018). Substantial support for this view is based on the parentification and increased responsibilities imposed on able-bodied siblings encompassed by the view that able-bodied siblings sacrifice their own experiences for that of their disabled sibling (Hall & Rossetti, 2018; Meltzer, 2015; Tomney et al., 2017). Contrastingly, the advantageous model postulates disability as a positive experience, whose presence has encouraging benefits for able-bodied siblings' psychosocial development (Latta et al., 2014; Ward et al., 2016; Zaidman-Zait et al., 2020). Siblings growing up with a disabled sibling are found to demonstrate more prosocial and compassionate behaviours (Braconnier et al., 2018). More recently, research relating to the experience of growing up with a disabled sibling has indicated a sibling relationship characterised by both positive and negative effects as is typical with a sibling relationship with two or more able-bodied siblings (Meltzer, 2015).

Apart from these dominant understandings, Meltzer (2015) suggests a view of disability in sibling relationships that is not delineated by positivity, negativity, or difference. Meltzer's (2015) view is one that focuses on the relational experience of disability embedded and enacted within the sibling relationship. Adopting such a view of disability can enable one a deeper and more comprehensive understanding of what it is like to grow up with a sibling with a disability. Meltzer (2015) stresses how disability can be essential to the reason for how and why siblings enact certain normative sibling relations of encouragement, debates, banter, shared meaning, disruption, and conflict. An example includes siblings engaging in a conversation about whether they have disclosed their disability to their significant other. In this case, disability's presence constitutes a shared marker of what it means to trust a significant other to disclose personal information, a practice that is inherently normative between siblings. Additionally, a sibling's embodied disability can constitute a moment of banter between siblings, yet it can also express a broader pattern of normative sibling enactments – bantering about a variety of topics (Meltzer, 2015). Further, a sibling experiencing a change in the severity of their sibling's disability may result in a brief disruption in the sibling relationship, causing hesitancy to converse about how to feel and respond to such change – in essence a shared meaning (Meltzer, 2015). Here, disability is responsible for creating the initial disconnection but also constitutes a difficulty relative of normative sibling relationships – a hesitancy to confront that which is "new, intimate, and personal together" (Meltzer, 2015, p.139). Lastly, disability may also create the context for conflict and other intense emotions within the sibling relationship (Meltzer, 2015). This may occur when an able-bodied sibling emotionally embodies disability – emotions created and brought about by the disability. Thus, disability creates difficult emotions typical of many sibling relationships (Meltzer, 2015).

Moreover, Meltzer (2015) suggests that disability can also constitute ways for siblings to strive or accomplish a purpose for their relationship such as enacting conflict, exploitation, and awareness – characteristic of normative sibling relations. Although disability provides unique means for sibling interaction, Meltzer (2015) highlights how efforts to connect with one another resemble normative sibling relations of determining a way to be a part of each other's lives. For example, individuals of a sibling with various cognitive and communicative deficits may replace interactions governed by cognition and communication with various sensory and tactile actions such as hand tickles, arm squeezes, or rice play (not immediate choices for normative sibling interactions) (Meltzer, 2015). Thus, these unique ways of engaging are specific and expressed through disability itself. Lastly, Meltzer (2015) highlights how the presence of disability has the potential to change and intensify the experience of certain normative sibling acts (e.g., trivial conversations and striving for an awareness of understanding), amplifying the significance and complexity of these relations.

Overall, Meltzer's (2015) view of disability advocates for a more holistic understanding of sibling relations with the presence of disability. Instead of categorising such an experience within an attributional understanding, one should perhaps view disability as relational since it can be constitutive (interactions happen through disability's presence) and contextual (creates the context for interactions to happen because of its presence). Thus, adult perspectives on the sibling relationship when one sibling has a disability can further advocate for a relational understanding of disability's presence within the sibling relationship. Adult perspectives can enable rich, retrospective, and current accounts exploring the multifaceted nature of siblinghood across the sibling relationship rather than a focus on a specific period within the sibling relationship that may lead one to automatically postulate an attributional understanding of siblinghood with disability. Thus, such a divergence from the dominant views of disability stress the importance of further studies to explore the different views and experiences of disability embedded and enacted within the sibling relationship.

2.3 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is one such disability which can be present in sibling relationships. ASD is classified as a neurodevelopmental disorder as such disorders are a group of conditions with an "onset in the developmental period, [consisting of] deficits that produce impairments of personal, social, academic, or occupational functioning" (American Psychiatric Association, 2013, p.31). The DSM-5 combined three previously distinct subtypes of Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified, under one umbrella term of Autistic Spectrum Disorder, based on the view that they are not distinct conditions but rather disorders on a continuum varying in severity (American Psychiatric Association, 2013). Subsequently, ASD is considered a spectrum disorder because the manifestations vary widely in type and severity. Consequently, each person's experience with ASD is unique.

2.3.1 ASD Diagnostic features

ASD is characterised by persistent and pervasive deficits in social communication and interaction, and restricted, repetitive patterns of behaviour, activities, and interests (American Psychiatric Association, 2013). Social communication and interaction deficits may include, but are not limited to, deficits in verbal and or nonverbal communication and social-emotional reciprocity, a reduced need to share interest with others, limited or no conversational skills, poor eye contact, difficulty expressing and understanding emotions as well as struggling with developing, maintaining, and understanding relationships (American Psychiatric Association, 2013). Whereas restricted, repetitive patterns of behaviour, activities and interest may include repetitive motor movements (e.g., flapping hands), repetitive vocalisations (e.g., echolalia/idiosyncratic phrases) and stereotyped play (e.g., spinning the wheel of a car/ lining up toys) (American Psychiatric Association, 2013). It is also characterised by inflexible adherence to routines, obsessive fixation on a particular topic or object and an oversensitivity or hyporeactivity to sensory stimuli or unusual interest in sensory aspects of the environment (American Psychiatric Association, 2013). Evidently, the symptomatology of ASD is diverse and prevalent, potentially impacting a multitude of areas within one's life, including one's sibling relationship, which will be discussed in more detail below.

2.3.2 Development and Course

ASD symptoms are most noticeable in early childhood, during one's primary developmental period, and as such is generally diagnosed before the age of three years (American Psychiatric Association, 2013; Bishop, 2012). Symptoms may be noticeable prior to a child turning two years old, depending on the severity of the developmental delays. An exception to this rule may occur if symptoms are less apparent and only become noticeable in a child's preschool stage of development (older than three years of age) (American Psychiatric Association, 2013). Additionally, ASD typically becomes noticeable either when a child is on track to reach their various age-appropriate developmental milestones but then experiences a period of little to no progress (developmental plateau) or when a child who has various developmental achievements begins to display regression of previously learnt skills (American

Psychiatric Association, 2013). Consequently, early interventions such as Applied Behaviour Analysis therapy[1], have been found to be impactful in improving deficits and reducing excess behaviour, improving one's overall functioning (Kaplan & Saddock, 2014).

Detailing the symptomology, development and course of ASD, one can begin to deduce the impact of potential obstacles of ASD on sibling relationships, a relationship that is inherently reciprocal and fundamental to an individual's development (Diener et al., 2015). ASD has a significant presence in early childhood, a period that is heavily ladened with developmental explorations and formulations (Bishop, 2012; Howe & Recchia, 2014). A child's early learning and social experiences are typically encountered and shared with their primary social partners – their siblings, and enacted based off their sibling observations (Howe & Recchia, 2006). These experiences have significant impacts for one's current and future developmental capacity (Diener et al., 2015; Nielsen et al., 2012). However, the presence of ASD may alter such crucial learning experiences where cues to enhance and empower one's developmental experiences and exposures may not be acknowledged, provided, or given opportunities to occur. Thus, the presence of ASD in a sibling relationship may have potential multifaceted ramifications, and thus is argued to be an important topic to further explore.

2.3.3 Prevalence

The global prevalence of ASD is estimated to be between 1%-2% of the population, with ASD being diagnosed four times more in males opposed to females (Bishop, 2012). However, the prevalence rates within a South African context are not well established (Bateman, 2013; Malcom-Smith et al., 2013; Pillay et al., 2020; Schlebusch et al., 2016). Despite this ambiguity, based on the global prevalence it is postulated that 169,286 children under 15 years of age would be predicted to have ASD within South Africa (Pillay et al., 2020). In one South African study exploring ASD prevalence rates in the Western Cape, Pillay et al. (2020) expected to identify 11,544 children with ASD. However, their findings were substantially lower with 1 in every 1131 children known to have ASD, stressing the under-representation of ASD within a South African context (Pillay et al., 2020). Although an underwhelming rate of ASD compared to expected rates, it sheds light on the potential

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[1] Applied Behaviour Analysis therapy (ABA) is an individualised therapy that employs the behavioural principle of positive and negative consequences for skill repertoire building and reduction of excess behaviours (Roane et al., 2016).

prevalence rates within a South African context and the significant need for further ASD research in the South African context.

2.3.4 Risk and Prognostic Factors

The exact aetiological determinants predisposing individuals to ASD is unknown (Mamidala et al., 2013; Mercer et al., 2006). Nevertheless, extensive research exploring potential causes has yielded findings generally stratified along three main lines of thought, namely a genetic component, an environmental disposition, or a combination of the two (Bishop, 2012; Kaplan & Saddock, 2014; Mamidala et al., 2013; Mercer et al., 2006; Modabbernia et al., 2017). Family, twin, and adoption studies have suggested a potential genetic influence on the predisposition of ASD (Mercer et al., 2006; Orsmond & Seltzer, 2007a). Subsequently, substantiating a possible heredity element and or genetic transmission associated to ASD (American Psychiatric Association, 2013; Orsmond & Seltzer, 2007a).

Contrastingly, studies asserting environmental risk factors stress a focus on prenatal and perinatal factors (e.g., pregnancy/labour complications, low birth weight, foetal distress, and parental age) as potential contributors (American Psychiatric Association, 2013; Mamidala et al., 2013). However, other findings suggest a combination of genetic and environmental factors, whose interaction activates the genetic predisposition in an individual (Modabbernia et al., 2017). The above research also emphasises the increased risk of siblings of individuals with ASD in developing ASD traits themselves, known as the broader autism phenotype (Ferraioli & Harris, 2009; Orsmond & Seltzer, 2007a). Despite these advances, a precise cause is still undetermined (American Psychiatric Association, 2013). Thus, further studies exploring diverse topics within the autism spectrum field, such as this study, are necessary in expanding and adding to current understandings of ASD so as to aid in determining clarity on the aetiological determinants predisposing individuals to ASD.

2.3.5 Growing up with the Presence of Autism Spectrum Disorder

Due to the fundamental deficits in ASD there has been an assumption that sibling relationships of individuals with ASD are likely to be disrupted (Beyer, 2009; Mandleco & Webb, 2015; Ward et al., 2016). Deficits in emotional understanding and perspective taking, limited speech or conversational skills, difficulty initiating play coupled with difficult behaviours (e.g., aggression, self-injuring behaviour, and idiosyncratic vocalisations) have been shown to reduce sibling interactions, potentially making it more difficult for neurotypical siblings to establish satisfying relationships with their brother or sister on the spectrum (Beyer, 2009; Mandleco & Webb, 2015; Petalas et al., 2009; Ward et al., 2016). Research has reported that such reduced reciprocity within the sibling dyad resultant from deficits consistent with ASD result in less warmth and closeness between siblings (Kaminksy & Dewey, 2001). Linked to this, a negative sibling relationship has also been indicative of unfavourable and aggressive interactions between siblings and upheld adverse perceptions and beliefs of the sibling relationship with one's brother or sister on the spectrum (Mandleco & Webb, 2015). Additionally, research has found that having a sibling with ASD results in negative outcomes for neurotypical siblings' development and the sibling relationship, characterised by decreased intimacy, nurturance, and prosocial interactions (Beyer, 2009; Braconnier et al., 2018; Corsano et al., 2017; Johnson, 2020; Mandleco & Webb, 2015; Petalas et a., 2015; Petalas et al., 2009).

Furthermore, neurotypical siblings are also understood to display more negative emotions towards their sibling relationship such as anger (e.g., inability to connect, reciprocate conversations, being the recipient of the ASD sibling's behaviour, or combating ignorance of others), jealousy (e.g., lack of parental attention) and embarrassment (related to their ASD sibling's conduct) (Mandleco, & Webb, 2015; Petalas et al., 2009). These emotions are also shown to lead to resentment due to social isolation, reduced family interactions, and the intense roles neurotypical siblings have to assume (Diener et al., 2015; Latta et al., 2013; Petalas et al., 2009). Literature states that the various roles and responsibilities enacted by neurotypical siblings has the potential to spur conflict and rivalry within the sibling relationship (Avieli et al., 2019).

Consequently, the above represents a dominant trend in the early literature in that the view of having a sibling with ASD was based on the premise, either implicit or explicit, that the experience would largely be negative. This assumption was largely corroborated as a result of literature comparing ASD sibling relationships with other disability sibling relationships such as Down's syndrome, an overreliance on parental perspectives of the sibling relationship, and a dependence on quantitative studies exploring such sibling relationships (Hall & Rossetti, 2017; Heller & Arnold, 2010; Latta et al., 2014; Orsmond & Seltzer, 2007a; Sommantico et al., 2020; Ward et al., 2016). It is noteworthy to acknowledge that parental reports on ASD sibling relationships tend to be less positive as opposed to sibling self-reports (Rivers & Stoneman 2003).

Despite the overwhelming rigid assumption that growing up with a sibling on the autism spectrum is aversive to the sibling relationship, research also supported findings for the existence of positive sibling relationships. This was substantiated indirectly through reported positive outcomes and directly through siblings' self-reports. A positive sibling relationship was evident by the positive impacts on the neurotypical siblings' personality, such as a greater acceptance and understanding for others and increased compassion and maturity (Diener et al., 2015; Petalas et al., 2015; Stampoltzis et al., 2014). Additionally, research found that having a sibling with ASD resulted in greater encouraging behaviours from the neurotypical sibling (Braconnier et al., 2018; Latta et al., 2014; Ward et al., 2016). Furthermore, a positive sibling relationship was characterised by heightened affection, companionship, connection, and less competition between ASD sibling dyads when compared to able-bodied sibling dyads (Benderix & Sivberg, 2007; Latta et al., 2014; Petalas et al., 2015). Likewise, a positive sibling relationship resulted in siblings of individuals with ASD demonstrating greater psychosocial and emotional development as well as increased interpersonal skills (Latta et al., 2014; Ward et al., 2016).

Moreover, neurotypical siblings' self-reports of their sibling relationship provided further evidence to contradict the predominant view of an overly negative sibling relationship. Siblings accounts demonstrated an understanding of difference that was not detrimental to the sibling relationship but rather enhanced such a relationship (Moss et al., 2019; Petalas et al., 2009). Siblings reported a greater appreciation for time spent with their ASD sibling, as well as the uniqueness of their relationship with regards to intimacy, connection, and interaction (Moss et al., 2019; Petalas et al., 2009). Likewise, siblings expressed enjoyment with connecting with their sibling on the spectrum and predicted enduring, close relationships (Heller & Arnold, 2010; Rossetti & Hall, 2015). Additionally, siblings displayed greater admiration and pride for their sibling on the spectrum and emphasised the importance of their sibling's attainment, illustrating a supportive and encouraging sibling relationship (Kaminsky & Dewey, 2001; Petalas et al., 2009). In addition, neurotypical siblings reported contentment with the overall quality of their sibling relationship with their sibling on the spectrum (Avieli et al., 2019; Petalas et al., 2015). Furthermore, siblings contradicted the assumption that a sibling with ASD resulted in reduced family interaction, but rather enhanced familial support and engagement (Moss et al., 2019). Likewise, contrary to dominant viewpoints that ASD disrupts the sibling relationship, a study conducted by Petalas et al. (2015) found that individuals of siblings with ASD conveyed an experience of typical sibling relationships. Moreover, research found that as one's knowledge of ASD improved, siblings reported a more positive relationship with their sibling on the spectrum (Jones et al., 2019). Thus, this enhanced knowledge acted as a buffer to potential adverse ramifications of ASD related stressors and obstacles resulting in better sibling relationships (Coffman et al., 2021).

Despite an automatic assumption of delineating the experience of growing up with a sibling on the autism spectrum as either negative or positive, research evolved. Focusing specifically on ASD sibling relationships and using a multitude of perspectives not just maternal perspectives (e.g., paternal, siblings and ASD siblings), research moved away from postulating an either-or approach and in doing so indicated mixed results on the experience of growing up with a sibling with ASD (Angell et al., 2012; Nordone, 2014; Petalas et al., 2015). These mixed findings highlight how sibling relationships when one sibling has ASD are representative of normative sibling relationships in that they are characterised by combinations of, and changes between, positive and negative aspects and feelings (Diener et al., 2015; Petalas et al., 2015). These findings essentially stress a relational embodiment and enactment of disability put forward by Meltzer (2015). Although these insights have made significant contributions to extant literature on the sibling relationships when one sibling has ASD, it is important to note that these insights have focused predominantly on accounts during childhood and adolescence and are from children and adolescents, respectively. However, little is known about the sibling relationship in adulthood and or from the perspectives of adult siblings with a sibling on the autism spectrum (Doody et al., 2010; Hall & Rossetti, 2018; Heller & Arnold, 2010; Moss et al., 2019; Orsmond & Fulford, 2018; Orsmond & Seltzer, 2007b; Tomeny et al., 2017a; Tozer et al., 2013; Van der Merwe et al., 2017).

2.3.6 ASD from an Adult's Perspective

Limited research on adult sibling relationships with a sibling on the autism spectrum has overwhelmingly been characterised by reduced emotional closeness, decreased contact and engagement, and less positive affect between siblings (Doody et al., 2010; Hall & Rossetti, 2018; Orsmond & Fulford, 2018; Orsmond & Seltzer, 2007b). Potential explanations for this dominant depiction of adult sibling relationships with a sibling on the spectrum have been explained as a result of various contextual factors in adulthood mediating and moderating the sibling relationship, such as developing a career, establishing one's own family, geographical distance, confronting the aging of parents, in addition to the barriers created by ASD's inherent symptomatology (Doody et al., 2010; Orsmond & Fulford, 2018; Tozer et al., 2013). Alternatively, research has also indicated that such a depiction is an adverse reaction to one's past experiences of an intense sense of responsibility and commitment to their sibling with ASD and dissatisfaction of maintaining a reciprocal relationship (Orsmond & Fulford, 2018).

The above insights, whilst important to the existing literature, represent a dominant theme in the limited literature with regards to adult perspectives. Limited research exploring adult perspectives on the sibling relationship where one sibling has ASD predominantly focuses on siblinghood in adulthood as well as parentification and other roles adults assume (Hall & Rossetti, 2018; Orsmond & Fulford, 2018; Tomeny et al., 2017a). Additionally, one's relationship with service delivery and one's worries for the future also saturate the literature (Heller & Arnold, 2010; Tozer & Atkin, 2013; Tozer et al., 2013). Furthermore, research tends to combine retrospective accounts of siblinghood with a combination of intellectual and developmental disabilities, opposed to specifically ASD (Doody et al., 2010; Orsmond & Seltzer, 2007b; Tomeny et al., 2017b). Lastly, this scope of research frequently adopts a quantitative paradigm, negating the rich accounts derived from exploratory, qualitative studies (Doody et al., 2010). Contrastingly, there are only a few studies that have explored adults' reported relationships with brothers and sisters on the autism spectrum (Moss et al., 2019; Noonan et al., 2018; Tozer et al., 2013). Thus, this dearth of information surrounding the psychological experience of growing up with a sibling with ASD, from the voices of adults, stresses the need for further inquiry and insight to add to the predominantly child and adolescent voices existing in the field.

2.4 Research Questions

1. How do adults currently as well as retrospectively perceive and reportedly experience their relationship with their sibling on the autism spectrum?
    a. How, if at all, has a sibling on the autism spectrum influenced the sibling relationship?
    b. What are the psychological experiences of having grown up with a sibling that is different to oneself, particularly one with a neurodevelopmental disorder such as ASD?
    c. How has one's sibling relationship changed (if at all) overtime?

CHAPTER THREE: RESEARCH METHODOLOGY

This chapter unfolds with an exploration of the qualitative research design and interpretive phenomenological methodology within which the study is situated within. Thereafter, the study outlines the characteristics of the participants and sampling strategy used. Subsequently, a description of the procedure through which the data was collected and analysed is provided. This is followed by a delineation of the ethical considerations adhered to. The chapter then concludes with a reflective exploration into the researcher's subject position, as well as a description of the rigour of the study.

3.1 Research Design and Theoretical Framework

This study adopted a qualitative paradigm, as this is a paradigm that places emphasis on human experience over quantifying phenomena (Babbie, 2020). Additionally, qualitative research empowers participants to express themselves in their own words, and in doing so describe their experiences from their own viewpoint (O'Day & Killeen, 2002). Subsequently, qualitative research is befitting to offer insight into lived experiences (Leedham et al., 2020). This was appropriate as this study was interested in examining how adults themselves perceived, felt about, and experienced their relationships with their sibling on the autism spectrum across their siblinghood. A qualitative approach was also well aligned with the methodological framework guiding this study given that Interpretive Phenomenology (IP) was employed. IP strengthened the efficacy and intent of this study, as phenomenology stresses the study of an individual's lived experience within the world (Alase, 2017). The hermeneutic foundation of IP affords a researcher the ability to surpass superficial descriptions of findings, to provide nuanced interpretative accounts of the lived experiences of participants (Peat et al., 2019). Thus, IP enabled the researcher of this study to capture, interpret, and amplify the depth and complexity of participants' stories of siblinghood with a sibling on the spectrum by uncovering prominent themes that emerged from participants' accounts of their personal world (Petalas et al., 2015).

Accordingly, IP considers meaning making to be rooted in various contexts (Petalas et al., 2009) which was significant for this study as disability, autism, and siblinghood are also embedded and influenced by a variety of contexts. Subsequently, IP views individuals as active agents in the construction of their experiences, experiences that are dynamic and shared (Petalas et al., 2015). Thus, the participants are viewed as experts and understanding their perspectives and experiences is crucial to answering the research question(s) (Petalas et al., 2009). As such, the study sought to explore from an adult perspective how siblings experience and understand their relationships with their sibling on the autism spectrum, in their own words.

Moreover, Interpretive Phenomenological Analysis (IPA) was used to analyse the participants accounts. An inevitable tenet of IPA is the dual aspect of interpretation which positions the researcher as an essential element of the research process, situating the researcher in an interpretative-analytic relationship with the interview data (Petalas et al., 2009). The researcher aspires to comprehend the participants making sense of their world (Peat et al., 2019). Consequently, within an IPA framework it is imperative that a researcher acknowledges the influence of one's personal perceptions when accessing participants' personal accounts (Petalas et al., 2015). This is necessary as these perceptions could have the potential to make specific aspects of the participants' accounts more prominent than others, thereby altering the themes chosen. Thus, a researcher should engage in consistent critical reflection throughout the research process to effectively navigate potential biases, guaranteeing and safeguarding the engagement of wonder and openness.

3.2 Sample and Sampling

Eight adult individuals who have a full blood sibling on the autism spectrum were interviewed (see Table 1 on p.19). After the researcher had interviewed the eight participants, the data was found to be adequality rich to address the research questions, so the sample was capped at eight participants. More specifically, adult individuals between the ages of 25 and 60 years old were chosen as 25 years of age allowed for the transition of the sibling relationship into an adult one, enabling participants the opportunity to provide rich, descriptive, retrospective, and current accounts of their lived experiences of the sibling relationship throughout their life. Although an individual legally attains adult status at the age of 18, this study adopted the view that individuals between the age of 18 and 25 years are within the emerging adulthood phase of development (Arnett, 2007; Hamilton, 2016). This phase stresses an understanding of being in-between, where one is "no longer an adolescent but only partly an adult, emerging into adulthood but not yet there" (Arnett, 2007, p.70). Although there is contestation around the validity of emerging adulthood (Arnett, 2007), addressing it was beyond the scope of this study. Thus, 25 years of age was chosen for this study as being indicative of the beginning of adulthood.

Furthermore, the participants' siblings could be older or younger than them, yet the participants needed to have lived with them for all or most of their childhood, as the study sought to gain insight into the nuanced sibling relationship across siblinghood. A further sample criterion for inclusion was that the participants' siblings needed to have been given an autistic diagnosis by a professional (e.g., psychiatrist, psychologist, neurologist), although this could be a mild to more severe autistic diagnosis. It is important to note that the DSM-5 has combined the three previously distinct subtypes of Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified, under one umbrella term of 'Autistic Spectrum Disorders', based on the view that they are not distinct conditions but rather disorders on a continuum varying in severity (American Psychiatric Association, 2013). With this in mind, this study did not exclude participants who received a diagnosis of one of the previous three subtypes prior to the DSM-5 classification.

Moreover, a non-probability purposive sampling strategy was used. This sampling strategy was effective as the participants comprised of a targeted and intentional sample who met specific criterion and were identified as being likely to be able to answer the particular research questions (Orsmond & Seltzer, 2007b). Furthermore, non-probability sampling is predominantly valuable for exploratory research where there is limited research in an area (Orsmond & Seltzer, 2007b), as was the case with this study. Therefore, this sampling strategy enabled a comprehensive and rich exploration from an adult's perspective into siblinghood where one sibling is on the autism spectrum. Once ethical clearance had been obtained (please see Appendix A), the researcher garnered participants through means of a brief invitation (please see Appendix B) posted on various social media platforms (the researcher's personal Facebook and Instagram accounts; Autism Facebook groups; community Facebook groups), inviting adult siblings who wished to share their experience of siblinghood with a sibling on the spectrum. Additionally, participants were accessed by contacting professional services for people with ASD (Autism South Africa, Action in Autism, Els for Autism, Neurodiversity Centre, Centre for Autism Research in Africa) and Autism schools, enquiring whether individuals who utilised their services had siblings who met the criteria and would be interested in, and willing to, participate in the study.

Table 1

Participant Information

Participant's Pseudonym*	Participant's Gender	Participant's Age	Participant's Race	Time Lived with ASD Sibling	ASD Sibling's Gender	ASD Sibling's Age	Other Siblings and Age
Amy	Female	26	Caucasian	7 years	Male	13	Brother 15 Sister 6
Khani	Female	25	Black	10 years	Male	10	Brother 32
Kim	Female	37	Caucasian	18 years	Male	34	Brother 30
Nishka	Female	33	Indian	10 years 4 months	Female	10	Brother 28
Peter	Male	25	Caucasian	13 years	Male	23	Sister 18
Samantha	Female	27	Caucasian	18 years	Male	29	NA
Terri	Female	31	Indian	15 years	Male	21	Brother 30
Timothy	Male	25	Caucasian	16 years	Male	22	NA

*These names given are pseudonyms and not the actual names of the participants.

3.3 Instruments

Aided by the tenets of IPA, this study employed the use of semi-structured, in-depth, one-on-one online interviews (Peat et al., 2019). This method enabled participants to express detailed and descriptive accounts of their lived experiences (Diener et al., 2015), regarding their sibling relationship with their sibling on the autism spectrum. The researcher generated their own interview schedule (please see Appendix C) after reviewing the relevant literature, which enabled them to effectively explore the specific research scope. The interview schedule acted as a basis for conversation but was not prescriptive or restrictive in the sense of disregarding the expressed interest of the participants or their ability to tell their own stories in their own words. Open-ended questions aided the researcher's flexibility to add follow-up questions to explore and expand on the participants' responses, when necessary, as well as anchor the participants in their experiences and feelings. The interviews occurred online through Zoom to accommodate the necessary COVID-19 social distancing protocols at the time. Additionally, the interviews were audio recorded (the Zoom platform enables one to save an audio only recording) and then transcribed verbatim for data analysis.

3.4 Procedure

Upon obtainment of ethical clearance from the Human Research Ethics Committee (Non-medical) at the University of the Witwatersrand (please see Appendix A), a brief letter of invitation (please see Appendix B) inviting potential participants to volunteer was disseminated on various social media platforms. This letter of invitation included a summary of the purpose of the study, the duration of the interview (60 to 90 minutes), the location of the study (online interview using Zoom), and contact details should individuals have wished to have participated. Additionally, the researcher contacted South African autism organisations and schools and enquired whether individuals who utilised their services had siblings who met the criteria and were interested in, and willing to, participate in the study. Individuals who were interested in participating contacted the researcher via email and thereafter participants were emailed a participant information sheet (please see Appendix D) to fully inform them of what was required by participating in the study. Once individuals had agreed to take part in the study, they were asked to sign a consent form (please see Appendix E), giving written consent to be interviewed and audio recorded. Furthermore, a date and time that accommodated both the researcher and participant was organised and specific Zoom meeting details were provided.

During each interview, participants were reminded that they were free to withdraw from the study at any time prior to the data analysis, without facing any negative repercussions. Additionally, if there were any specific questions during the interview that participants felt were difficult to answer, they were able to refrain from answering them. The researcher also discussed issues of confidentiality with the participants (refer to the below ethical considerations section on information regarding the maintenance of confidentiality and anonymity when reporting results). Furthermore, participants were reminded that the interview would be audio recorded for analysis purposes. Towards the end of the interview, the researcher provided a debrief session as a means of containment (please see Appendix C) where participants were reminded of the free counselling services from the Emthonjeni Community Centre at The University of the Witwatersrand (mentioned on the participant information sheet), should they have felt unduly stressed or wished to have explored something further. Lastly, each interview was transcribed verbatim and analysed.

3.5 Data Analysis

Once an interview was completed, it was transcribed. Participants were given pseudonyms and identifying details were disguised in the process of transcribing to ensure confidentiality and the final anonymity of each participant. The interview data was then analysed according to IPA. IPA was a suitable mode of analysis as it interprets and heightens the lived experiences of research participants and postulates that experiences can be understood by way of examining the various meanings individuals attribute towards them (Alase, 2017). The researcher read through each interview transcript several times becoming accustomed with the research content. Subsequently, the researcher read the transcript line by line making note of descriptive comments with a phenomenological focus (e.g., initial interpretations, summaries of the meaning content) (Petalas et al., 2015). Once achieved, the researcher proceeded to re-read the transcript with a focus on extracting the themes within the data (Petalas et al., 2015). The researcher continued this process until pleased that all the necessary themes had been extracted (Petalas et al., 2015). The above process was completed for each transcript. The researcher then grouped the emerging themes together and ended up with a final list of themes and verbatim quotes (Petalas et al., 2015) that illustrated adult perspectives around their experience of growing up with a sibling on the spectrum.

3.6 Ethical Considerations

Before the research process began, ethical clearance was sought and obtained from the Human Research Ethics Committee (Non-medical) at the University of the Witwatersrand. Obtaining ethical clearance ensured that the research carried out was done in a morally responsible manner (Forrester & Sullivan, 2018). Doing so also protected the welfare of the participants (Leach et al., 2012). Potential participants were given a participant information sheet (see Appendix D) that fully informed them about the nature of the research and the expected level of involvement. Thereafter, once individuals agreed to take part in the study, they provided their signed consent to participate and be interviewed (see Appendix E). The participants were informed that they had the right to withdraw from the study at any time prior to the data analysis, without facing any negative repercussions. Furthermore, it was noted that if there were any questions during the interview that were deemed difficult to answer, they were able to refrain from answering them.

The participants were informed that confidentiality (as far as possible) was ensured by storing the recordings and transcripts in a password-protected computer folder that was only accessible to the researcher and their supervisor. Further, interviews took place in a secured Zoom meeting, using a specific meeting ID and password, only accessible to the specific participant and researcher. Additionally, the researcher conducted interviews in a private setting which ensured privacy of information shared and prevented interruptions. Although complete anonymity was not guaranteed as face-to-face interviews with the researcher had taken place, no identifying information was used, and participants were given pseudonyms to aid final anonymity in the use of direct quotes being included. Thus, participants' confidentiality and final anonymity in this study was assured.

As this study invited participants to share and express their lived experiences of siblinghood, some questions may have potentially elicited and or evoked sensitive and complex emotions. Subsequently, it was necessary to conduct a debrief session at the end of each interview (please see Appendix C), as a means of containment. Questions such as "how did you experience the interview in terms of talking about your sibling relationship?" and "were you surprised at anything that arose?" were asked to the participants at this stage to ensure participants were satisfied to end the interview process. The details for free counselling services at the Emthonjeni Community Centre at the University of the Witwatersrand were provided for participants who felt unduly stressed or wished to explore something further (see the participant information sheet for these details). None of the eight participants voiced the need for additional debriefing and or counselling following the interviews.

Moreover, given the subjective nature of the study's qualitative IPA design and the aforementioned dual interaction of the researcher, the researcher was rendered an active respondent in the research process (Chambliss & Schutt, 2010; Petalas et al., 2009). This dual role could have led to prejudices in the analysis as the onus of interpretation lies with the researcher (Shaw, 2010). Thus, it was essential that the researcher be transparent in the potential way in which their personal biases may have influenced the analytic process (Petalas et al., 2015). This was especially necessary for several reasons: the researcher and their siblings were able-bodied; the researcher was conducting research within the field of disability and had four and a half years of work experience of working with children and adolescents on the autism spectrum (and their siblings). Subsequently, it was essential that the researcher engaged in frequent critical reflections on their potential prejudices, expectations, and personal experiences that may have shaped their perceptions of siblinghood and ASD siblinghood. This was necessary as these perceptions may have had the potential to make specific aspects of the participants' accounts more prominent thereby altering the data chosen. Thus, the researcher made use of a reflexive journal noting any personal prejudices and emotions as they arose throughout the research process that were thought to possibly impact the way data was collected, interpreted, and analysed. Additionally, the researcher could consult with their supervisor about the above potential biases in order to effectively navigate them and their implications. Confidently, these provisions ensured a more authentic and ethical study. Therefore, in the vein of transparency, the section to follow aids the contextualisation of the analysis taken.

3.7 Researcher Reflexivity

I understand that my able-bodied position and that of my siblings, is not simply based on bodily classification but that my position has enabled me specific benefits, agency, and developmental experiences based on my siblinghood, which individuals with a sibling on the autism spectrum may have otherwise not had. Moreover, as a twin I have been privy to a unique sibling relationship and specific formulations of siblinghood that may be different to the siblinghood of many individuals. As such, my positioning (an able-bodied individual of able-bodied siblings and being a twin) may present potential challenges to the research, in the form of biases about my conceptions and experiences of siblinghood (e.g., a close sibling bond, an innate understanding for one another, adoption of similar roles and responsibilities, and a relationship that is equal in treatment from others).

In addition, my positioning as an abled-bodied researcher poses further potential ethical challenges with regards to concerns around opinion and representation. These challenges occur in terms of the long-standing unjust ascendancy of the disabled by abled individuals (Shakespeare, 2010). Thus, I am aware that as an able-bodied researcher investigating the relationality of disability in ASD sibling relationships, the research claims which I interpret based off the participants' accounts may be criticised in a similar vein. However, in offering a potential counter argument, it can be purported that by employing an IPA methodological framework, that enables individuals to convey their lived experience around their relationality with ASD in their own words, it is less probable for this study to reproduce knowledge about disability through an ableist lens, representation which may cause harm to the autism and disabled communities.

The above counterargument is not intended to postulate that my position as researcher remains impartial. Subsequently, it was important to acknowledge the ways in which I have been socialised into certain opinions about disability, more specifically autism, notably as an abled-bodied individual. Accordingly, it was vital that I reflect on my personal experiences which have influenced my perceptions of what the autism sibling experience entails. This was a significant undertaking as these perceptions possibly altered the data collection process, by making particular aspects of the participants' accounts more salient to me. I have had four and a half years work experience of conducting one-on-one Applied Behavioural Analysis therapy to children and adolescents (aged 2-19 years) with autism spectrum disorder at a centre, on a home basis, as well as school facilitation. Having worked with ASD children and adolescents, I experienced the symptomology of ASD and the impact this had on all areas of their lives, but in the same vein was able to experience their tenacity, compassion, personalities, and achievements. Additionally, I frequently interacted with their family members (parents/primary caregivers and siblings), as such I was privy to sibling dynamics, interactions, level of involvement, and siblings' treatment towards their ASD sibling. Subsequently, as an observer to differing sibling dynamics, I developed a subjective opinion about the neurotypical sibling, one that was overwhelmingly characterised by impatience, misunderstanding, resentment, and exclusion. However, it is noteworthy that such an opinion was a result of always striving for the best interest of the ASD individual, but in doing so developed my interest towards the plight of neurotypical siblings' experiences, an influential factor for this study. Thus, such an experience may present potential biases either in favour of the ASD sibling (opposing the participants' accounts of their ASD sibling) or in favour of the neurotypical sibling. An example of this could be found in my emotional reaction to accounts of how the ASD sibling's behaviour and inherent ASD characteristics were experienced by the neurotypical sibling, which manifested in being saddened for the neurotypical sibling, as I too encountered and navigated various ASD relational obstacles whilst working with ASD individuals. However, on the other hand, there were moments where I felt angered for the ASD sibling due to accounts of exclusion, lack of sibling engagement, and misunderstanding. Another instance of how my increased awareness of my able-bodied status influenced the analytic process was my caution around making interpretations which emphasised neurotypical sibling relationships and experiences as the norm. When this arose, I made certain that it was the participants' own words and not merely my interpretation of their meaning making, which could be portraying it in this manner.

Furthermore, I encountered some perplexity ascertaining whether certain narratives reported by the participants challenged or perpetuated outdated and rigid understandings of sibling relationships with a sibling on the spectrum. It can be postulated that this is attributed to a process of interpellation, whereby I as an able-bodied researcher, who has worked within and is passionate about the autism community, as well as read up on literature about ASD sibling relationships, recognised my own prejudicial internalisations and attitudes reflected in the participants' varied accounts of their lived experiences. Consequently, a difficulty I initially confronted was that I was looking for discrete patterns that either challenged or perpetuated understandings of ASD sibling relationships and had not considered the possibility of paradoxical feelings, experiences tinged by participants' own interpellations or retrospective and current accounts that did not distinctly delineate a varied sibling experience. Thus, introspection enabled more nuanced interpretations to be made, which was crucial amongst the fixed and heavy reliance on child and parental constructions prominent in portrayals of ASD siblinghood.

Lastly, to uphold my affinity to my value positions of disability as relational and challenging rigid constructions of ASD sibling relationships, certain language choices were intentionally made throughout this study. This research utilised the terminology of 'disabled siblings/individuals' as opposed to 'sibling/individual with disabilities', as the former situates disability within a social context, denoting that individuals with deficits are disabled by harsh societal associations, whilst the latter locates disability in the individual postulating disability as a result of substantial deficits in functioning (Albrecht et al., 2001; Harvey, 2019; Hedlund, 2000). Likewise, the terminology of 'impairment' and 'disability' are also evocative. Impairment is likened to the medical model of disability and implies individual deficiency, while disability connotates societal oppression and disablement (Linton, 2010; Shakespeare, 2010). Subsequently, this study employed the use of disability, aligning with the researcher's value positions. Lastly, the term 'able-bodied' and 'neurotypical' – terminology used by the participants themselves, were used opposed to 'non-disabled'. Taken together, the above language was employed to appropriately manage the ethical dilemma of re-representation of reported ideas of disability and ASD with sensitivity.

3.8 Rigour of the Study

Transparency is significant for ethical research practice (Levitt et al., 2018). Subsequently, Lincoln and Guba's (2016) criteria for qualitative rigour were adhered to within this study. Credibility was achieved through the use of an appropriate sample, who were applicable to answer the research questions and subsequent lived experience explored (Guba, 1981). Further, indicating how a research endeavours to remain open to emerging data strengthens the credibility of the claims in a study (Levitt et al., 2018). Subsequently, a reflexive journal was used to note and account for personal biases that arose which ensured sufficient depth, relevance, and reliability across the data collection and analysis. Likewise, conformability was established through the use of data saturation, grouping of related themes supported by verbatim quotes highlighting participants' voices of their meaning making, reducing the bias of the researcher, as well as through the guidance and evaluation of the researcher's supervisor (Houghton et al., 2013). Furthermore, dependability of the data was accomplished through ensuring the maintenance of a high standard across the recording, transcribing, and documentation of the study (Houghton et al., 2013). Lastly, transferability of the findings was ensured as far as possible through employing a stringent inclusion criterion, enabling a deliberately distinct sample (Lincoln & Guba, 2013). Additionally, a detailed description of the methodological framework further enhanced the transferability of this study (Houghton et al., 2013).

CHAPTER FOUR: RESULTS AND DISCUSSION

The purpose of the current study was to explore adult individuals' current, and retrospective lived experiences of growing up with siblings on the autism spectrum. The aim was to provide insight into the sibling relationship as it evolves over time throughout one's life, and to add adult experiences to the predominantly child and adolescent voices existing in the literature. In this chapter, the results of the research will be presented under themes, subthemes, and sub-subthemes. These themes emerged following an Interpretive Phenomenological Analysis of the data collected during the research process of interviewing eight adult individuals with siblings on the spectrum. A discussion of the findings will also be integrated into this chapter, highlighting areas of convergence and divergence between these findings and the relevant empirical and theoretical literature.

4.1 Results of the Interpretive Phenomenological Analysis

The main themes, subthemes and sub-subthemes that emerged from the Interpretive Phenomenological Analysis are summarised in Table 2. The first theme represents the relational vacillations within the sibling relationship across siblinghood – childhood, adolescence, and adulthood. There are three subthemes to this first theme, each signifying a different dimension of relationality within ASD sibling relationships. The second theme explores the complexities of siblinghood that challenge and support the adage 'am I my sibling's keeper?' There are three subthemes each detailing a key characteristic associated with a sibling's function within the sibling relationship. The third theme describes the process of discovering a balanced sense of self amidst experiences that alter and enhance self. There are two subthemes in this theme, which illustrate the two different journeys involved in arriving at a balanced self. The fourth theme demonstrates the way individuals embark on understanding and making sense of their lived experiences of having a brother or sister on the spectrum. There are three subthemes to this fourth theme, each exploring a vital component of one's continuous meaning making process. The themes, subthemes and sub-subthemes will be described and explored further with corroboration from participants' quotes to illustrate their lived experiences of growing up with a sibling on the spectrum across their sibling relationship up to and including adulthood.

Table 2

Identified themes, subthemes, and sub-subthemes

Main themes	Subthemes and Sub-subthemes
Theme One – Relational Ebb and Flow	Feeling Distant ∞ Communication and Interaction ∞ The Impact of Behavioural Characteristics of ASD on the Sibling Relationship ∞ Self-imposed Distance Achieving Closeness An Evolving Dynamic
Theme Two – Am I My Sibling's Keeper?	Roles Responsibilities Support
Theme Three – Balancing the Self	Being Unseen Seeing the Self
Theme Four – Making Meaning	Understanding ASD ASD and Disability Sibling to Sibling

4.2 Theme One: Relational Ebb and Flow

All participants recognised that their experiences of growing up with a sibling on the spectrum are unique given the multifactorial nature of ASD. Nonetheless, participants' accounts of their lived experiences across their sibling relationship depicted a relational ebb and flow of feeling distant, achieving closeness, and an evolving dynamic between themselves and their sibling as they continue to grow. This notion of a relational ebb and flow is corroborated by literature that stress that the experience of siblings is not fixed but rather one that is subject to change, separation, growth, and newness (Gorjy et al., 2017; Noonan et al., 2018; Orsmond et al., 2009).

4.2.1 Feeling Distant

Participants reported experiencing various degrees of distance with their sibling with ASD. For some, early accounts of relational distance were sparked by confusion in childhood and adolescence trying to understand autism and make sense of their sibling's behaviour:

> *As a child like there were things that I couldn't connect, like, you know, I couldn't understand why my brother acted the way he did at times. It was so hard… I didn't know how to make sense of it myself* ***(Samantha)****.*
>
> *I think probably a lack of understanding… from my side as to why can't you just be normal, like why can't you just act normal? Why do you have to break into song?* ***(Kim)****.*
>
> *We [hadn't] really heard about autism, we didn't really understand what it meant* ***(Nishka)****.*

Feelings of distance were noticeably evident by participants' desires for connection (physical, social, and emotional) and the difficulty of having to actively work at something that was intrinsic to the sibling relationship. This process was captured succinctly by Timothy who stated:

> *I just remember it being very difficult to connect with him and it being frustrating too, like, try and connect with him when it was so difficult… also it being very difficult to love him because of how like difficult and sometimes uninterested in any kind of affection he was, he very much kept to himself and was very easily overstimulated. I think when I was younger, I was more keen to try and connect with him. I think I got a bit burned out from trying.*

Likewise, Kim stressed an understanding for such difficulties, highlighting the loss of an emotional sibling connection, a finding consistent with research which found that siblings of children with ASD felt less emotional closeness compared to people with siblings without ASD (Hall & Rossetti, 2018; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b; Tozer et al., 2013):

> *It's been very kind of functional, which makes sense because he requires things from us… to take care of him and his needs and his wants but we've not really had that emotional thing, I guess it's been quite one sided.*

4.2.1.1 Communication and Interaction.

The feelings of distance that were embedded in the difficulty connecting with their autistic siblings were amplified by the difficulties around communicating and interacting with their siblings – a prominent characteristics of ASD. This finding is consistent with research that states that the nature of ASD may impact the sibling relationship (Braconnier et al., 2018; Diener et al., 2015). Communication difficulties were frequently noted within the literature as a barrier to developing satisfying or closer sibling relationships (Beyer, 2009; Rossetti & Hall, 2015). This complexity was captured by Peter as he reflected on the difficulty, impact, and feelings of loss that ASD had on his sibling relationship:

> *I'd say it's different in that there's a lack of a relationship in the sense that you can't communicate with someone like how I would communicate with my sister who's not autistic. There's just nothing there. You could try to talk to him, he might say something to you, but there's never any extended periods of conversation… there's no like, depth of conversation that you might have with someone else… It's in a sense, like, you could talk but it's like pulling teeth, you know, trying to have conversation, so like, it just wasn't there.*

Peter's sentiments reflect that of the literature which found that social difficulties consistent with ASD are postulated to reduce reciprocity amongst siblings (Orsmond & Seltzer, 2007a; Ward et al., 2016). His anger and sadness over the limited, almost non-existent reciprocity with his sibling and difficulty attempting communication was shared by many of the participants (Timothy, Samantha, and Amy) and is substantiated by research which expressed similar viewpoints from individuals of siblings with ASD (Tozer et al., 2013). Anger was a dominant emotion expressed by the participants in this study especially in relation to communication difficulties, and is often a reoccurring emotion in the literature (Angell et al., 2012; Petals et al., 2009). This lack of connection resultant from the paucity of communication between siblings may intensify feelings of distance within the sibling dynamic, and as expressed by the participants, resulted in resentment and anger for being deprived of a *"typical sibling relationship" (Samantha).* Likewise, Peter's narrative of the impact that communication barriers had on his sibling relationship, to the point that there was a lack of a relationship, further stresses the despair and frustration around the loss of an imagined relationship, which was shared by some of the other participants too (Timothy, Samantha, and Nishka). Peter succinctly expands on such loss of an imagined sibling relationship as he reflected on his relationship in childhood:

> *When I was younger, it's not that you have very deep extended long strung-out conversations as a 10-year-old anyway, it's just, even those kind of, I think, shallow interactions that you might have with a sibling aren't just there, it's just, it's not there.*

This sense of loss of not having an imagined, reciprocal sibling relationship was evident in the literature exploring sibling relationships with the presence of ASD (Tozer et al., 2013). Whilst such a viewpoint has been challenged with research stressing the nuanced nature of such a sibling relationship, it is nonetheless substantiated by numerous sibling reports (Noonan et al., 2018). These reports reflected siblings' complex feelings around loss of a sibling relationship, which further intensified distance within the dynamic (Noonan et al., 2018). Participants' narratives are consistent with findings of siblings yearning for a greater connection with their sibling through communication and interaction – the basic building blocks of any reciprocal relationship, to counteract feelings of loss and anger. However, such desires are quickly extinguished when met with little to no response from their siblings, intensifying the participants' awareness of loss within their sibling relationship.

Although siblings' experiences differ, endeavouring to understand one another is a prominent aspect in sibling relationships (Kuba, 2011). Despite some participants expressing how communication difficulties were resigned to earlier years within the sibling relationship, some participants indicated how communication difficulties continued into adulthood. Timothy illustrated how his relationship with his brother in adulthood continues to be hard due to communication barriers. However, within his narrative he also expressed the importance and desperation to communicate with his brother when encountering such boundaries, heightening feelings of distance:

> *Sometimes I just feel stumped when he's trying to tell me something and I'm not sure what he's trying to tell me. It doesn't feel fair to him that, like, he has very limited ways of communicating and I feel like I have a responsibility to understand what he's trying to say both for frustration on his part and because I feel like it's quite important that we are able to communicate with each other.*

Timothy’s desire to be able to communicate with his sibling was shared by many other participants (Peter, Samantha, Amy, and Khani), a longing consistent with the literature (Ward et al., 2016). Likewise, his responsibility to understand his sibling in adulthood, resultant from perhaps guilt of not understanding him or sadness around his brother’s limited means of communication, are consistent with findings of siblings having a strong sense of commitment towards their autism sibling relationship in adulthood (Noonan et al., 2018). However, Timothy’s experience of distance within communication limbo is reminiscent of research which found that disability impacts the degree to which siblings can understand each other and the methods in which they seek to create an improved understanding of one another (Meltzer, 2018). This complex experience of navigating the relationality of ASD within the sibling relationship was expressed by many participants in this study (Amy, Khani, Peter, Samantha, and Timothy), who had to engage in a dance with their sibling dynamic, navigating the boundaries defined by ASD. However, most expressed the notion that when it came to attempting to understand their ASD sibling or establish some form of communicational exchange, it was as if they were dancing to two different rhythms. Meltzer (2018) explains how siblings’ “perceptions of the effect or embodiment of their siblings’ disability becomes enacted as a deep feeling of not being able to access or know the experience of the other in the relationship. It thus becomes enacted as part of their perceptions and feelings regarding the boundaries of the relationship” (p.1226). Consequently, distance ensues as siblings attempt to understand one another. As their view of ASD becomes embodied within their understandings and feelings about one another, it impacts how they act out the emotional processes of understanding and attempting to understand within the sibling relationship (Meltzer, 2018).

Furthermore, in the participants’ exploration of communicational barriers within the sibling relationship, this study found that such barriers resulted in the formation of a different relationship, characterised by distance. This relationship style was noticeably evident when some participants (Amy, Kim, and Samantha) expressed that although they were able to communicate with their siblings from early on in their sibling relationship, such communication was limited, an experience that some expressed as uncharacteristic for sibling engagement, intensifying, and cementing the feeling of distance. This different experience was captured by Samantha who reflected:

> *But we also didn't have these like profound conversations, you know, it was just regular conversations about what's going on. I can't even remember, like, just sitting down and talking to my brother, like going into his room and sitting in his room and talking to him. That never happened, like at all and I know other siblings do that.*

The above reflects the participants' awareness of difference within their sibling relationship and the repercussion such difference ensues. Despite some participants (Amy, Kim, and Samantha) being able to communicate with their ASD siblings, it was still different from their imagined, desired, and observed sibling dynamics, due to the inherent nature of ASD. This difference resulted in increased feelings of distance and detachment within the sibling dyad, as desired sibling engagement was absent. Such distance by difference creates a sibling relationship demarcated by invisible yet rigid boundaries. Although such a finding could not be substantiated by existing literature, it is significant nonetheless as it stresses the nuance and complexity of the participants' experience of their sibling relationship with a sibling on the spectrum. Similarly, Amy resonated with a different relationship characterised by distance as she expressed how such altered means of communication with her brother continued into adulthood and created feelings of distance as it defined the means of communication within their relationship:

> *I can't go make sarcastic jokes with him because he doesn't understand sarcasm so our conversations are different and if I explain something to do with work or something, I can't speak to him about that stuff, he won't understand that. It is just very different, I can't send him a text or a message because he can't read it, I would have to phone him if I want to talk to him, and then he gets bored very easily so he would just hang up when he feels like it, so in that sense, it's just very, very, very different.*

Amy's account further highlights the uniqueness that is a different relationship characterised by distance, shared by many other participants (Peter, Timothy, Samantha, and Khani). Her narrative illustrates feelings of anger, frustration, sadness, and loss that encapsulates her apparent different sibling relationship. This experience echoed by other participants, stresses a possible view that patterns of communication within such a sibling dynamic are predetermined and controlled largely by the inherent nature of ASD. Such specificity within the sibling relationship may fuel distance as such dynamic is void of manoeuvrability. This finding is significant as it posits that predictability and routine (inherent characteristics of ASD) may work against forming a sibling connection. Thus, restricted means of communication and the resultant anger and despair from accepting and challenging such delineations may only further fortify distance in the sibling relationship. The fortification of feeling distant within the sibling relationship due to the implications of the boundaries defining the means of communication and subsequent connection, was noticeably evident when Peter reflected:

> *I think I probably got to a stage where I didn't seek [interaction] out, you know, just because, you know, there's not going to be any conversation.*

The above quote displays the despondency and sadness shared by many of the participants in their attempts to form a connection with their sibling on the spectrum. Perhaps conceding to the situational circumstances was a means to prevent further frustration, resentment, and distance within the sibling relationship. Nonetheless, such an expression of loss reinforces participants' accounts of the challenges and emotions associated with communicational barriers encountered across their sibling relationship – a different relationship characterised by distance. Perhaps such a relationship characterised by multifaceted distance is the impetus for a dominant view in the literature that adult sibling relationships with a sibling on the spectrum consist of reduced contact and less closeness between siblings (Braconnier et al., 2017; Hall & Rossetti, 2018; Orsmond & Seltzer, 2007b).

Moreover, participants expressed various activities that they engaged in with their autistic siblings (especially during their childhood and adolescence), such as drives, walks, watching TV, and swimming. Research has found that interactions within such sibling relationships are generally oriented to the interest of the sibling on the spectrum (Orsmond & Seltzer, 2007a). This is consistent with the current study, however participants expressed how their attempts to grasp some form of connection by entering their sibling's way of being in the world only made such distance more apparent:

> *There was definitely distance there because I couldn't find really any common ground to interact with him. A lot of my interaction was like reading him stories… all of my interactions with him [were] more generally based on his interests, because it was difficult to find some kind of common ground between us and so being the one who was more able to make compromise, it was generally me making compromises to find a way to interact with him* ***(Timothy)****.*

> *I think maybe when I was younger, we might have like, watched maybe a bit of TV together and that kind of thing, like cartoons, but then I kind of grew out of that and he didn't really... I'm not gonna like, you know, sit down in the lounge and chat, or sit down and play cards it's just non-*existent ***(Peter)***.

These accounts stress the nuanced sibling relationship with a sibling on the spectrum. Restricted interest and inflexibility to sharing in others' interests challenge the sibling dynamic and level of engagement. This disparity between siblings' lived experiences intensifies feelings of frustration for having to frequently engage in the ASD sibling's interests, resentment for their sibling not engaging in their interest, as well as sadness for missed bonding opportunities. Consequently, feeling distant is amplified with the awareness of difference and loss of an imagined sibling relationship, one characterised by togetherness and shared experiences. This is consistent with research which found that at times siblings feel disconnected from their ASD siblings since they cannot always relate to them (Conn & Drew, 2017). Reminders of the constraints that constitute their sibling relationship further reinforce distance within the sibling dyad.

Feeling despair and disconnected due to the lack of sibling interaction and engagement was also experienced in adulthood:

> *Even now when I'm home… he has his schedule and his routine every day and it doesn't really include us* ***(Kim)****.*

> *A lot of the time (interactions today in adulthood involve) hanging out in the same room, watching TV together, going for walks with him and my mom, but it still feels like we're strangers* ***(Timothy)****.*

A sibling's schedule and parallel interactions were common occurrences in many of the participants' lived experiences of growing up with a sibling on the spectrum, especially in adulthood resultant from potentially established patterns of engagement. These characteristics reiterated the atypical nature of the reported interactions between the participants and their ASD sibling. The sombre and loss apparent in the above accounts, alludes to loss of connection within adulthood for some of the participants' sibling relationships. These sentiments of feeling detached stresses the lack of meaningful interaction characteristics of some of the participants' adult sibling relationships. This depiction is in line with research which found that siblings experience distance as a result of being together but feeling apart (Avieli et al., 2019). This notion was further evident in majority of the participants' accounts resulting in the frequent phrase of *"it's one-sided"*. Such a delineation heightens the awareness of the restricted and limited sibling engagement expressed by many of the participants (Khani, Kim, Nishka, Peter, and Samantha). This view of a sibling relationship being one-sided for some meant a resignation to self, as captured by Peter:

> *Spending time it's non-existent, no interaction, which kind of makes it one sided, so most of the time, I'll just end up doing my own thing, so I'll spend most of my time by myself.*

Solitude within such a sibling relationship is consistent with research which found that resignation is a result of the difficulty of neurotypical siblings having the responsibility of maintaining the sibling relationship (Kramer et al., 2013; Tozer et al., 2013). Likewise, such resignation is consistent with research that found that older siblings partake in more adverse coping mechanisms in response to increasing dissatisfaction with the reality that their sibling's ASD symptoms may never be lessened (Johnson et al., 2020). Additionally, the current study found that for some participants the one-sided experience led to sadness and uncertainty about their place in their autistic sibling's life and their sibling's willingness to want to engage with them both in childhood and adulthood, intensifying distance and ambivalence within the relationship:

> *Most of the time, it was a bit one sided… So, interacting with [my brother] a lot of the time felt like maybe for him, the way I perceived it was that he was part of something, but not necessarily something that he would have initiated or willingly engaged with* ***(Timothy)****.*
>
> *The problem is, you know, I'm very fond of my brother, but I don't really know how he feels about me, cause it's just, I feel like it's just one sided sometimes* ***(Khani)****.*
>
> *In terms of the material interactions today [in adulthood], it's vastly different but it's hard, because like relationships are a two-way street, so you don't know exactly how he feels* ***(Peter)****.*

Difficulty understanding how one's autistic sibling feels and thinks is a common trend within the literature (Conn & Drew, 2017; Petalas et al., 2015). This study postulates that sitting with the unknown and concealed opinion of one's positioning within the relationship from their ASD sibling's viewpoint creates a unique form of distance within the sibling relationship. Such opinion would fill the connective void apparent in the participants' accounts, but the absence of which intensifies the loss of an emotional bond hindering the relationship. Lack of emotional intimacy in such sibling relationships fosters loneliness, and strains connection and mutuality, findings consistent with the literature (Chu et al., 2021; Kaminsky & Dewey, 2001).

Moreover, participants' reflections on their current and retrospective sibling interactions also brought about awareness of the atypical sibling experience, as captured by Peter's explanation of it being *"chalk and cheese"*, a sentiment that signified feelings of disconnection, difference, and loss shared by many of the participants:

> *I knew that my relationship was different to the friends in my class… The girls would always talk about their big brother who I don't know takes on that whole like masculine thing… he's the one who's taking them out to parties and all that stuff and there was like absolutely none of that with my brother. I was very aware that our dynamic wasn't the same as what my peers was… I will never tell him my fears and my plans and ambitions and stuff like that, I guess our relationship isn't like that* ***(Samantha)****.*
>
> *There's a lot that's quite different from my idea of what a normal sibling relationship would be, which is, I guess the lack of common interests and the lack of interacting on a day-to-day level. I would have loved to be able to like play video games with him … like talk about nerdy stuff with him* ***(Timothy)****.*
>
> *The thing that I do feel a little bit sad about is… I would always like that relationship where I could like take her to the movies and like take her out like when I'm going out with my friends… I would like to do those sorts of things with her, that becomes a bit difficult as she might get away from me or I might not be able to actually physically control her. So that's, I think that is the difference. You know, even if I was an older sibling to a child who was neurotypical… every weekend, we'd go to movies, or we'd do things together, or like now that I've moved out she'd come to my place, you know, like once in a while, you know, you go to the movies, [but] because she's on the spectrum, those things are not a possibility you know* ***(Nishka)****.*

This awareness of the typical versus atypical experience is not unusual in sibling relationships with a sibling on the spectrum (Hall & Rossetti, 2018; Petals et al., 2013). Nonetheless, such comparisons of a different sibling experience postulates loss of an idealised sibling relationship, predominantly with regards to desired means of interaction. These accounts illustrate the loss of opportunities for affection, connection, and engaging in *"normal"* sibling dynamics *(Timothy)*. Within the overarching theme of loss, lies a wish for a different experience, one in which the participants could experience desired sibling tropes, activities, and experiences with their siblings without the presence of ASD. However, it is this hope that makes such difference and loss more painful and difficult to accept. Consequently, some participants (Peter and Timothy) resigned themselves to accepting their sibling relationship, whilst others (Kim and Terri) described dealing with a different normal – removing an atypical view of their relationship. This was noticeably evident when some participants normalised such feelings by noting that the distance, detachment, and disconnection they sometimes experienced was akin to typical sibling relationships. Samantha captured this as she stated:

> *Growing up, so in our childhood, I think like we didn't share interests, we didn't share. I mean with somethings, yeah, because we had a common experience you know, like we would share that, but we weren't into the same things and into the same hobbies and because I was always like frustrated with him, I didn't like take the time to be his friend, if that makes sense. Like we weren't close, I guess like other siblings. However, you also get these siblings who are such good friends, but it wasn't us because we just didn't feel the same way about things.*

4.2.1.2 The Impact of Behavioural Characteristics of ASD on the Sibling Relationship. Consistent with previous research (Tudor et al., 2018; Van der Merwe et al., 2017), the current findings indicate that feeling distant due to not being able to connect with one's ASD sibling was also created and amplified by their sibling's challenging behaviour, typical of individuals with ASD. Learning to navigate the behaviour typical of individuals with ASD sparks negative feelings (Ariel & Naseef, 2005) which some participants resonated with as a factor that largely affected their sibling relationship and reinforced feelings of distance, especially in childhood:

> *I guess everything that I'm going to say when I viewed it as a child is gonna sound quite bad but like he put my parents through so much you know, unnecessarily complicated everything, that's how I viewed it. Like, it was just almost like an inconvenience, like why are you doing this the whole time? Why are you acting like this? Why are you making things so difficult for everybody?... Why are you suddenly not eating chicken now, now what must Dad make for supper or other weird things like that and that caused resentment from my side* ***(Samantha)****.*

> *When he was like eight, he would have fits and it's so overwhelming and so emotionally overwhelming and frustrating, so you do kind of get angry with it. I think in reaction to particular scenarios… you kind of maybe do hold some like resentment or like just frustration of like why does it have to be like this, and all that kind of stuff, but you know, I think yeah, I think it was kind of just frustrating* ***(Timothy)****.*

The fuelling of negative emotions brought about by the participants' siblings engaging in certain behaviour acts as a potential barrier to the sibling relationship. Research postulates that such behaviour has an adverse effect on developing and maintaining the sibling relationship (Orsmond et al., 2009; Petals et al., 2013). Braconnier et al. (2018) stressed how individuals with a sibling with ASD often expressed a lack of understanding regarding how to manage the negative behaviours, stating that some behaviours were frightening. Angered by the confusion that ensues or resentful for the impact such behavioural manifestations had on one's immediate environment, ignited and or strengthened some participants' distance within the early stages of the sibling relationship. Additionally, such accounts stress the emotional turmoil such behaviour had on some of the participants in childhood. Faced with likely occurrences of being impacted and annoyed by one's sibling's behaviour, it is postulated that siblings of autistic people react in a manner that may inadvertently foster distance and avoidance within the sibling relationship.

Furthermore, such behaviour was found to have an impact on participants' family and social life. Peter's sentiment that *"having a sibling on the spectrum systematically makes your family home life different than a normal family"* was shared by some of the other participants too (Terri, Timothy, and Samantha). Several participants expressed feeling overlooked or dismissed across their life as their parents were engrossed in the needs of their autistic sibling, an experience consistent with the literature of individuals with a sibling with ASD (Mandleco & Webb, 2015). Consequently, some participants (Khani, Nishka, Peter, and Timothy) received different amounts of attention to that of their sibling, a finding in accordance with the research (Petals et al., 2013; Ward et al., 2016). Reported changed dynamics in the parent-neurotypical sibling dyad, resultant from the sibling with autism, left some participants feeling unseen and frustrated, substantiating feelings of distance:

> *I would say it was pretty hard at times because you know, when you're a teenager, you want your mother's like attention and you need help with certain things and you try but*

> *most of the time, she's too exhausted to like give you advice or attention, because so much of that is going to my brother. I feel a bit resentful at times* ***(Khani)****.*
>
> *Even now that I'm in my 30s, sometimes I find it very difficult to have a conversation with my mother because she's so focused, that she doesn't really have time to give me any sort of attention, even just to have a conversation* ***(Nishka)****.*
>
> *I think a lot of your life takes a backseat. We got on, that was the life, you just get on with it and we did it, you know, we did what we needed to be very self-sufficient. I think, a lot more independent, a lot more resilient as well, just to navigate home life. [My mother] just didn't have the time to like do anything else, it was autism… I couldn't depend on my parents to do stuff... When I was a teenager, [I would] get angry, you feel like no one's hearing you… you expected to get on with it* ***(Terri)****.*

The resultant emotional reactions and instilling of resilience across the participants' accounts, whilst consistent with previous research (Fisman et al., 2000; Mandleco & Webb, 2015), may be indirectly expressed towards their ASD sibling, furthering distance within the sibling relationship. Experiencing differing degrees of neglect and a lack of parental support, guidance, and time, may result in the tendency to blame one's ASD sibling for such differential treatment. Subsequently, the awareness and experience of such disparity may cause animosity within the sibling relationship fuelling detachment and aiding disconnection between the siblings.

Likewise, some participants expressed how having a sibling with ASD also impacted family recreational activities and social interactions both in childhood and adulthood. Such a disruption in interpersonal functioning created feelings of distance for some as it redefined and determined the frequency and quality of sibling and familial engagement:

> *We might not do some things that a normal family would do like saying, you know, going for a late dinner or going out for drinks and that kind of thing. You know it made it a bit different in that sense* ***(Peter)****.*
>
> *So, taking her to places, that is very challenging. She is becoming a lot more mature now and she can sit still for a little while but most of the time not and people's homes are not like childproof or [sister] proof, like there are a lot of breakable things. Yeah, those sorts of things are very challenging. So, like we haven't been able to socialise in the same way that we ordinarily would* ***(Nishka)****.*

Participants' accounts of family life being restricted by the need to adapt to autism-friendly routines was consistent with previous research with siblings of individuals with ASD. Some studies found that siblings experienced limited family interactions or disruptions in family life (Latta et al., 2014; Moss et al., 2019; Petals et al., 2009; Tozer & Atkin, 2015). Other studies indicated that siblings expressed feelings of engaging in different family interactions, where certain members of the family were not always present during 'family time' (Leedham et al., 2020; Petals et al., 2013). Nonetheless, such accounts stress the difference of family engagement within some of the participants' lived experiences with a sibling on the spectrum. Contrasting such research, Terri noted that whilst her family life was restrictive and took more effort to create and maintain, it was nonetheless a *"normal"* family life:

> *Growing up in that space… we still did important normal stuff, going on excursions, and extra curriculum activities. We were lucky, we still did that kind of stuff, but it was just harder to navigate in our world. We had to like go to parks and beaches early in the morning before it got busy because those are things that my brother could do, those are things that we could do as a family. Like even [with] family holidays… we go off peak.*

This account stresses the notion that families of children on the spectrum still enact typical familial activities, though the means of doing so are made challenging by having a sibling with ASD (Benson & Karlof, 2008). It is noteworthy to acknowledge literature that posits that time spent together is mediated by less severe ASD symptomatology (Bachraz & Grace, 2009; Meyer, 2010; Orsmond et al, 2009). Thus, it can be deduced that milder ASD symptomology enables the aforementioned familial activities to be easier to enact. Nonetheless, whilst a depiction of a different normal is conveyed in the above extract, the difference is still apparent. Although such difference is navigated out of the love for one's sibling, and perhaps for self-preservation of a family lifestyle, it is postulated that adherence to such navigation may exhaust and or run the risk of causing unconscious feelings of resentment towards one's sibling on the spectrum. Unlike Terri's endurance of a different normal, Timothy's attempt at a *"normal"* family life sometimes meant excluding his ASD brother:

> *I think my parents have tried to let me have as normal a life as possible and have tried to be quite accommodating for me in that, like, we've travelled a lot, a lot of the time without [my brother] because that was too much of a nightmare to bring him onto a plane.*

Despite parents' best efforts, marked separation within the family dyad has the potential to enhance feelings of loss and distance within the sibling relationship. Individuals may develop a reference for experiences without one's sibling on the spectrum, resulting in resentment when such time cannot be repeated or recreated when their sibling on the spectrum is present. Additionally, such family time without one's sibling on the spectrum may heighten awareness of the difference characteristic of their lived experience. Therefore, creating a distinction of what and who constitutes family time can create a division in the sibling relationship. Thus, in the above account the presence of ASD within the family results in separation, exclusion, and othering, aspects that counteract togetherness, warmth, and connection within the sibling relationship.

Additionally, research found that having a sibling with ASD can impact one's relationships with others outside of the family. Siblings of individuals with ASD often describe their sibling's ASD as having a negative impact on their friendships (Benderix & Sivberg, 2007; Petalas et al., 2009; Tomeny et al., 2017b). These finding were supported by the study as participants (Peter, Samantha, and Timothy) shared a common experience of how growing up, interactions with friends were resigned to school and other people's houses, a feeling of being unable to invite friends over to their houses. For some participants this was due to fears about the unpredictable behaviour of their sibling, and for others it was a means to avoid peer reactions, reasons consistent with previous literature (Benderix & Sivberg, 2007; Corsano et al., 2017; Dansby et al., 2018; Tomeny et al., 2017b). Such fears may have resulted in feelings of humiliation and frustration, leading to social exclusion, feeling the need to detach and / or intensifying feelings of distance between siblings. Consequently, whilst some participants (Kim, Nishka, and Terri) spoke about their sibling with ASD, some participants (Peter, Timothy, and Samantha) decided not to talk to their friends about their sibling due to fears of embarrassment or misunderstanding, as well as expected explanations that ensued, and stressed that it was about trust and comfort of letting people in. This disparity around talking about ASD is consistent with literature on maintaining privacy and welcoming discussions about it (Gomes, 2020). These experiences of navigating friendships support a finding by Dansby et al. (2018) which revealed that friendships can be complicated to negotiate when one's sibling has ASD, as well as reiterated the notion of a different relationship characterised by distance as succinctly captured by Samantha:

> *[Growing up] if someone wasn't close to me, I never mentioned my brother at all. Like, they know, I've got a brother and that's it. I wasn't inviting people over to my house that*

> *I wasn't super close with, I would go to their house, I just, I didn’t want them to be aware of the situation… but like the friends that I was close with, they just knew that I had a strange brother and they experienced it when they came to the house and that was like, yes, okay like, they know that I've got this strange brother and that's that. Then I have friends that were, like, super-duper, like accommodating towards him… So yeah, I was very aware of it as a child, and I was very aware of who I was inviting to the house and who I was telling. I guess it's just then who I ended up letting in.*

Although some participants expressed that the impact of their sibling’s ASD has changed in their adulthood due to a growing comfort and acceptance, some still expressed difficulty with this. Perceptions, social isolation, and anxiety introducing their sibling to others and explaining ASD seemed for some to still strengthen the presence of distance within their sibling relationship:

> *I think it's always been, if it doesn't come up, I'm not going to offer it… most recently, someone was asking me if I wanted to go surfing with them, and then offered if like my brother would be interested and I said he's actually autistic and like explained a bit about it* ***(Timothy)****.*

> *Even now, I'm very conscious about talking about my brother, I become very aware when I'm like at the workplace, and he's there because I know I am going to have to explain things* ***(Samantha)****.*

Comparatively, some participants reflected on experiences of social exclusion whilst growing up due to being associated with a sibling who was viewed as different, potentially heightening distance within the sibling relationship:

> *There were some instances when we were little where I wasn't invited to parties or things like that, because the people were scared that my mom was going to bring my brother and he would make a scene or something like that. There were a lot of things that I wasn't invited to* ***(Kim)****.*

Such reoccurring exclusion in childhood may have acted as a catalyst for either the participant detaching themself from their sibling to lessen associational treatment, or for the formation of anger and resentment towards their ASD sibling, hindering the development of connection and warmth. Whereas other participants noted that their responsibilities towards their sibling limited their availability to socialise across their childhood, heightening negative feelings and fuelling distance within the sibling relationship. This difficulty was captured by Khani as she recounted the complexity of her sibling relationship:

> *Obviously, my mom can't take him absolutely everywhere because he gets a bit overwhelmed at certain places, so [if] I would like to go to a friend's place, maybe I can't go because my mom has to go somewhere, and she can't take him with, so I had to take care of him. I felt resentful at times.*

Khani's lived experience is consistent with a theme in the literature that found that siblings of autistic people felt strained by having to consider their sibling's wellbeing before making social arrangements (Dongola, 2018). Such experiences reinforce a dominant and somewhat skewed view in the literature that having a sibling with ASD predominantly negatively impacts one's social life (Beyer, 2009; Diener et al., 2015; Macks & Reeve, 2007; Mandleco & Webb, 2015).

Moreover, the resultant embarrassment in childhood and adolescence when the participants' siblings enacted their behaviours in public was another common thread amongst participants' reasoning that affected the degree of closeness within the sibling relationship. These reports of experiencing embarrassment in social situations and public spaces are consistent with the literature (Gorjy et al., 2017). This was captured by Kim's account of her adolescent years as she reflected:

> *As I became a teenager you know, his stimming and running around naked because of his sensory – [he] didn't like wet clothes or anything like that, obviously that became really embarrassing. I'd say through teenage years, it was it was mainly embarrassment, or scared that he was going to embarrass me by breaking into song in a restaurant or flapping or shouting or causing a scene.*

Although such distancing from one's sibling in adolescence and young adulthood is common as one's sibling sometimes becomes embarrassing (Petalas et al, 2015), behaviour inherent to ASD can make such distancing more pronounced to combat a stressful sibling experience (Angell et al., 2012; Pilowsky et al., 2004). Opportunities for closeness become impacted as individuals may distance themselves from their sibling to reduce embarrassment by association. Likewise, emotional reactions such as frustration and discomfort targeted at the sibling on the spectrum may exacerbate distance in the sibling relationship. Additionally, consistent with previous research (Noonan et al., 2018), such embarrassment noted by the participants in their earlier years of their sibling relationship was largely resultant from bystanders' reactions towards their ASD sibling's behaviour and the emotional impact that such reactions caused on the self. For some, this experience resulted in frustration and lack of control, deepening distance in the sibling relationship. This was succinctly captured by Peter:

> *When I was younger, something that like was tough [was that my brother] could throw really nasty tantrums and fairly often and often people could tell say if you just pass by, you could tell something was different. He's different and you often felt like people were just looking at you and your family and stuff like that and that wasn't a great feeling.*

This experience of public scrutiny was corroborated by research which found that the looks and questions one receives from bystanders is not only a result of prejudice and misconceptions, but also adds to the neurotypical sibling's feelings of shame, distress, loneliness, and frustration (Franz et al., 2017; Meltzer & Kramer, 2016). Experiencing contradictory and overwhelming emotions has the potential to complicate connection within the sibling relationship. Although some participants expressed that public perception had been normalised in adulthood, they indicated that it still left residual feelings of disconnection within the sibling relationship when reflecting on retrospective feelings of despair and sorrow for their autistic sibling's experience:

> *Definitely embarrassing when we were in public, but it was also just something that had become normalised for me. Knowing that, like being in a new environment would set him off and I don't know, I have a lot of like, there's definitely a very distinct sadness in my memories* ***(Timothy)***.

Awareness of the difficulty of public engagement for autistic individuals by their siblings stresses another facet of distance within the sibling relationship. Feeling disempowered and helpless to aid their sibling in such experiences not only reinforces one's feelings of disconnection, but also presents an individual with an experiential reminder of the difference apparent in their sibling experience. Evidently, the participants' accounts stressed how the ramifications of embarrassment on the self and the sibling relationship are multifaceted. Subsequently, it can be deduced that embarrassment has the ability to shift the tides of an impressionable child or adolescent of a sibling on the spectrum, as they find their way in the world. Although such accounts were predominantly based on participants' childhood and / or adolescent years, some participants (Peter and Samantha) indicated how such feelings and experiences around embarrassment tinged their sibling relationship in adulthood too.

4.2.1.3 Self-imposed Distance. Lastly, reflecting on their experiences of growing up with a sibling on the spectrum, some participants expressed feelings of distance that were self-imposed. Feelings of guilt, fear, and shame predominantly characterised these self-imposed feelings of relational distance. Timothy captured the complexity of guilt that at times deepened such feelings of distance and at other times sabotaged any means to combat such feelings of distance:

> *[I had] a lot of guilt I feel growing up with him and feeling like I could do more to connect with him and interact with him, because there was definitely a period where I felt like I had almost given up on interacting with him and that's still quite a painful memory to this day, or quite a painful thought. [This guilt] in itself kind of paralysed me from interacting with him even more. [Today] it's still quite distant, a lot more distant than I would like it to be. It still feels like we're strangers. There's quite a significant divide between us.*

Guilt regarding past feelings of regret about the dynamics of the sibling relationship was echoed by a few other participants (Samantha, Kim, and Peter) and was a common emotion in the literature (Rossetti & Hall, 2015). Reflecting on one’s remorse over something they did and or failed to do may reignite or re-entrench feelings of disconnection and distance within the sibling relationship in adulthood, aided by one’s self-deprecating thoughts. Additionally, it is postulated that the embodiment of guilt can incapacitate one from combating such feelings by attempting to build a connection with one’s ASD sibling, to the extent that it widens the divide between the sibling dyad. Perhaps combating guilt is about challenging one’s sense of over-responsibility, a shared experience felt by many of the participants. For others, guilt involved an awareness of not considering their sibling’s perspective, acknowledging their different life experiences from that of their sibling on the spectrum, and around their obligation to take care of their sibling in adulthood, intensifying feelings of distance:

> *I almost feel the sense of guilt. I just feel like, oh I never actually thought too much of things from his perspective, like oh could he be missing me?* ***(Kim)***

> *I feel like there’s a lot of guilt around like, I'm trying to work through, and I have come a long way, but I used to feel like that a lot. I used to feel like that it's very unfair, like, why did I have this normal life, a great education, and the ability to communicate so well… and then I have my sister who doesn't speak at all, and it's so unfair, so I did have a lot of guilt around that and carrying that with me* ***(Nishka)****.*

> *There's a large amount of guilt because I know that… it would be better if he were staying with me, it would be better if I was just making sure everything's fine, that he's doing well and that he's doing okay, because he doesn't have that now, he doesn't have friends… my dad's [overseas], my mom passed away, like he doesn't have people, I'm his people. It's not fair, but I think like, subconsciously, or I guess I'm saying that I do view him as a liability, which is not fair, but I think I still am at that place* ***(Samantha)****.*

Not considering the other may be seen as a possible outcome for experiencing guilt. Nonetheless, this finding is supported by research which found that when reflecting on one's relationship with a sibling on the spectrum some participants expressed shame for the realisation of largely never attempting to think about the sibling dynamic from their ASD sibling's perspective (Rossetti & Hall, 2015). Interestingly, perspective taking, a skill many individuals with ASD struggle with (Peters & Thompson, 2018), is a skill many of the participants failed to employ in their sibling relationship. This realisation has the potential to strengthen distance in the relationship as one may feel that they perhaps did not give equal consideration to their sibling's relational needs which would have possibly aided mutuality and connection within the relationship. Likewise, McHale et al. (2016) found that individuals have an inherent impulse to appraise the self in comparison to others and given the shared family experience siblings are an apparent target for social comparison. Evidently guilt around comparing one's life to that of their sibling on the spectrum has been corroborated by previous research (Rossetti & Hall, 2015). However, the current study postulates that such comparisons can prompt feelings of self-blame, pity for one's ASD sibling, and create a view of one's sibling as not good enough, ramifications for increasing distance to combat such feelings. Moreover, whilst guilt stemming from viewing future care of one's sibling as a burden is consistent with previous research (Jones et al., 2019), constant feelings of needing to do more than one can as expressed by participants (Samantha and Nishka) has the potential to fuel feelings of anger and resentment, intensifying distance within the relationship.

Furthermore, aspects of fear were evident in the experience of various participants accounts, primarily around the future of their sibling relationships and their sibling's future:

> *I don't want it to become where we have no relationship at all, where [my brother's] just overseas somewhere living his life completely separate from me and I get to a point where I no longer think about him because that's a horribly depressing thought for me. I always like to maintain a relationship and trying to build one or try to build more of*

> *a relationship, but my concern is that it's going to be difficult when we're even further apart* ***(Timothy)***.

> *There is a lot of fear around you know what is going to happen and what does the future hold for her* ***(Nishka)***.

Fear around the future of one’s sibling relationship has been expressed in a few studies exploring sibling experiences of living with a sibling on the spectrum (Meyer, 2010). The current study postulates that fear of the sibling relationship deteriorating is attributed to current patterns of relating between siblings and experiences of challenges and barriers to creating meaningful connection. Awareness of such difficulties may result in hopelessness in reducing distance, increasing the likelihood of such relational distance deepening. Likewise, Meyer (2010) found that trepidation and uncertainty concerning the future of one’s sibling with ASD are normal feelings for neurotypical siblings. Such fear is attributed to future care but also to anxiety over one’s sibling’s prospects and life outcomes (Jones et al., 2019; Moss et al., 2019; Tozer & Atkin, 2015). The inherent challenges of ASD, social stigma, and lack of inclusion and accommodation for individuals with ASD in society creates an impression of a ‘doom and gloom’ future for such individuals. Although such views are corroborated by research (Hendricks, 2010), there are studies that have shown the possibility of individuals with ASD leading fulfilling lives (Shattuck et al., 2012; Walsh et al., 2014). Nonetheless, such symptomology and societal barriers influence one’s distress for their sibling’s future. This distress may result in self-imposed relational distance as it may impact one’s perception of their sibling with ASD and their capabilities.

Moreover, shame was an emotion that was evident in some of the participants’ retrospective explorations of their lived experiences. Samantha captured the shame that accompanied self-imposed distance as she reflected:

> *[When I was younger] I think I was quite dismissive towards him, which was negative in the relationship. I just kind of brushed everything aside, and like, didn't consider really much of what he had to say and do, and I think when like he could feel my shame… I think that negatively impacted the relationship.*

Shame has been shown to be a prominent emotion displayed by individuals towards their siblings on the spectrum (Rossetti & Hall, 2015). It serves a function of regulating and maintaining social norms, to prevent the social cost of shame inducing transgressions (Fessler 2004; Keltner & Buswell, 1997). Additionally, shame is often associated with negative feelings to avoid and justify expressing such emotion (Tangney & Dearing, 2002). Subsequently, research has postulated that shame has the potential to impact sibling relationships as it reduces emotional connections by impeding the development of empathy (Tangney & Dearing, 2002). Consequently, expressing shame or it's associated negative feelings of annoyance, unworthiness, or anger towards one's sibling on the spectrum may result in one's sibling feeling rejected and othered, enhancing feelings of distance in the relationship.

4.2.2 Achieving Closeness

Although participants expressed feelings of distance and disconnection throughout their sibling relationship, their relational experience also brought about contradictory feelings of affection and genuine connection. As participants reported on their lived experiences, such relational ebb and flow also illustrated experiences and moments of achieving closeness within their sibling relationship.

By following their sibling's lead and joining in on their sibling's various interests, some participants spent quality time with their siblings, both in later adolescence and adulthood. This interaction counteracted feelings of distance and resulted in bonding and connection:

> *I try to like spend more quality time with her in terms of like doing things that she wants to do… I let her guide whatever it is that we're doing and try to like go into her world instead of like forcing her into mine* ***(Nishka)****.*

This notion of entering one's ASD sibling's world by engaging in their interest and activities has been associated with positive ASD sibling relationships (Masch & Boucher, 2006). Whilst acknowledging some of the participants' childhood accounts that depicted frustration and anger from limited interactions or engaging primarily in their sibling's interest, this finding simultaneously captures the nuanced and dynamic nature of these sibling relationships across siblinghood. Subsequently, some participants were able to establish relationality in adulthood by joining in sibling-led interactions, contradicting their relational distance felt during their upbringing. Thus, this finding challenges literature that states adult sibling relationships are characterised by reduced interactions (Braconnier et al., 2017; McHale et al., 2016). Likewise, for other participants adulthood enabled a genuine connection to be achieved through their interactions, despite challenges to connecting brought about by the inherent characteristics of ASD:

> *Honestly, I quite like just talking to him and I guess having frank conversations with him, even if they're very one sided. I think he knows what we're saying but it's difficult for him to communicate back… I know that he can understand me, and I guess that's what's quite rewarding for me* ***(Timothy)****.*

This finding is consistent with previous research which found that despite communication barriers within the sibling relationship, the amount of time spent together aids the natural development of the relationship (Orsmond & Seltzer, 2007a). Thus, whilst such sibling dynamics have been characterised and reported as different, the above account stresses the presence of comfort living alongside the presence of ASD. This postulates adulthood as a significant stage within siblinghood as a marker for potentially fostering connection, closeness, and warmth within the ASD sibling dyad.

Furthermore, Terri reflected on how her role as carer across her sibling relationship enabled a means of connection and a strengthening of her sibling bond:

> *Caregiving, I think, of course, it makes you really close to someone like you see them in their everyday lives, you know, and helping them and supporting them so, I'm really close to my brother, and I think that's a good thing and I'm so happy that he has me, and I have him. I'm always learning from him all the time, he's so intelligent and has a funny sense of humour and yeah, I love spending time with him.*

The broader literature suggests that individuals who took on intense caring roles and assumed responsibilities for their sibling on the spectrum reported closer relationships and increased sibling interactions (Chu et al., 2021). Thus, such roles were found to be a basis for deepening the sibling relationship (Mitchell, 2017). Although this was not the experience of all participants or accounts in the literature, such support for roles aiding closer sibling relationships stresses the positive implications of the increased roles and responsibilities enacted by individuals with a sibling on the spectrum.

Whilst reflecting on their lived experiences across their sibling relationship, several participants expressed how closeness and connection was achieved on their sibling's terms:

> *He would sit in front of me and asked me to tickle his back and then his face would look like he's going to fall asleep, and I was the only one that he would come to, he only asked me to do that… Considering he doesn't like touch, so when he came to me for affection, that was quite special* ***(Amy)****.*

> *When he gets particularly excited, he'll like grin and like grab your face and that always like, there's a lot of those memories dotted around. I always remember feeling happy with that, because it felt like I was getting some kind of connection with him that I'd been craving for a long time* ***(Timothy)****.*

> *He used to call me my little princess, it was just different ways of him communicating because obviously he didn't you know, he couldn't tell me how he felt… I'm not sure where he got it from, but he used to after a meal… he'd always make dessert for himself from whatever sweet thing was available in the fridge and you know he would come to put some down in front of me and go "here you are my little princess", which was really sweet. At the time I just laughed because I thought it was you know, an echo but now that I've got my little one, I realised that it you know, it was appropriately placed echolalic speech that meant something to him. So, yeah, that was really nice thing that I knew that I had a connection with him* ***(Kim)****.*

> *He sucks his thumb… and then I'll suck my thumb and we can hook our fingers together and we can like sit for like long periods of time like that because it's just comforting for him and it's almost like a moment where we can see each other, it's I see you and it's okay to be who we are in this world* ***(Terri)****.*

Communication barriers were evident within the participants' accounts of their experience of having a sibling on the spectrum, however the above accounts are noteworthy as they stress that connection within an ASD sibling dyad can still be achieved, but that it is a different connection, achieved through unique modes of relating. Be it through sensory stimulation of tickling a sibling's back, physical signs of affection such as an autistic sibling grabbing one's face when excited, through special nicknames or shared moments of stillness enacted through the sucking of thumbs and interlocking of fingers, these accounts portray specialised modes of genuine intimacy, togetherness, and affinity between siblings. In each case, the siblings find means to create a gratifying connection, substantiating Meltzer's (2018) view that such means are done "in ways that formatively draw [one's] understanding of their sibling's embodiment of disability into how their actions are enacted. Disability is very much a part of these moments between them" (p.1225). The above accounts also stress the importance and desire of attaining some degree of connection within the sibling relationship. Notably, satisfaction of achieving a connection that was longed for, was recounted with positivity, elation, and gratitude evident in the below extracts:

> *Considering he doesn't like touch… when he came to me for affection that was quite special* ***(Amy)****.*
>
> *I was getting some kind of connection with him that I'd been craving for a long time* ***(Timothy)****.*
>
> *That was a really nice thing that I knew that I had a connection with him* ***(Kim)****.*
>
> *It's almost like a moment where we can see each other, it's I see you and it's okay to be who we are in this world* ***(Terri)****.*

Moreover, shared experiences of childhood filled with nostalgia and in-jokes reflective of shared histories were fondly reported by some participants, stressing a means in which they achieved and continued to achieve a sense of connection with their siblings. This was succinctly captured by Samantha as she reflected:

> *[There] were aspects of our relationship that was positive, but I think it's because of our shared experience as siblings in the same household… Like, often we would just sit in the lounge laughing at the stuff my gran said… Happy memories, I guess enjoying the similar TV shows, like watching the KTV TV shows together or stuff like Dragonball Z… I remember we had a helper when we were growing up, and she used to watch WWE and like, she would be laughing and everything and my brother and I thought that was the funniest thing on planet Earth and… even if I were to mention it to him now, he would be broken… Like if I mentioned anything now about my gran and the things that she did, we would start laughing and I guess nobody else would understand it. It's our memory that we share.*

A bond centred on unique understandings and shared history is consistent with findings of various research on the sibling relationship with a brother or sister on the spectrum (Avieli et al., 2019; Noonan et al., 2018; Tozer et al.,2013). Growing up together enables a platform for an enduring relationship that transcends beyond disability (Avieli et al., 2019). Likewise, Ainsworth (1989) notes that able-bodied sibling dyads "have a background of shared experience over a relatively long period of time, which not only promotes similarities in their perception of situations and in value systems that influence their decisions, but also promotes mutual understanding, without necessarily requiring explicit communication" (p.715). Evidently, Samantha's account reflects a sense of togetherness reignited, relived, and fortified through recounting shared childhood memories. Thus, this study postulates that such shared histories act as artifacts of a time within the sibling relationship that can be rediscovered at different stages, to remind one of the sibling connection or act as a means through which connection can be embodied. Subsequently, these artifacts of kinship can aid the development of relational closeness throughout siblinghood.

Furthermore, some participants expressed closeness through realising and achieving pride and joy for their sibling and their achievements as they got older, or by reflecting on their lived experience:

> *As I grew older, it became more of a I'm actually really proud of being the sibling of an autistic person. I was very, very, immensely proud of the things he did. He has an incredible singing voice, and he took part in competitions when he was in school when I was in my late teens, and then I remember like being really, really proud and crying when I went to go and see his performances and thinking, you know, how amazing he was* ***(Kim)****.*
>
> *I'm actually surprised at like, how far she's come because I'm thinking about it back, like, you know, even just to like last year, I'm very proud of like her growth* ***(Nishka)****.*
>
> *There's a lot more compassion, more understanding, and also a bit of pride when he manages to like achieve something or progress, something that I never really expected of him and there's a lot more respect for what he is actually capable of doing then I guess I would have had when I was younger, just because of his own development* ***(Timothy)****.*

Admiration and pride for their sibling's endeavours and accomplishment are consistent with previous literature (Angell et al., 2012; Kaminsky & Dewey, 2001; Petalas et al., 2009;). It is postulated that appreciating siblings and expressing pride can promote sibling bonding, encourage self-worth, and reinforce love within the sibling relationship. Moreover, majority of the participants expressed feelings of genuine connection through increased acceptance and understanding of their *"different" (Timothy)* experience as they moved into the late adolescence and adulthood stages of their sibling relationship. Some participants achieved this through changed attitudes and perceptions of their autistic sibling:

> *It's more my attitude towards him that's changed. So I'm a lot more understanding than I would have been previously, like if he lost his temper, I'd be so frustrated like, when I was younger I would be a lot more angry whereas now I wouldn't be as angry or upset*

> *or like, my kind of attitude towards is that I am a lot more empathetic towards him now than I think I was when I was younger, so I've got a lot better attitude towards him. But dynamics of the relationship haven't really changed too much in terms of like the physical, it's more like on the feeling side* ***(Peter)****.*

> *Yeah, I think respect is a big one, actually, because it feels like I understand now that there's a lot more going on in his head than he lets on because he can't communicate it. So, there's a much more deeper understanding of what maybe he's going through* ***(Timothy)****.*

> *As I grow older and I know more, I get to understand why [my brother] does certain things and so [the relationship] has changed. I understand him a bit more than I used to* ***(Khani)****.*

These accounts are supported by previous literature which indicate that siblings' perceptions of their sibling relationship changed with age (Coffman et al., 2021; Noonan et al., 2018). Likewise, it has been found that positive perceptions of one's sibling with ASD may serve a functional role in siblings' adaption to growing up with a sibling with ASD (Petalas et al., 2009). Thus, later life enables the development of changed attitudes and perceptions of one's sibling as facilitated by increased awareness of one's understanding of their sibling's circumstances and difficulties. This changed view of one's sibling is postulated to increase connection within the sibling relationship. Therefore, past reactions, and misunderstandings for one's sibling's way of being, which previously inhibited togetherness, are significantly reduced and or absent. In support of this postulation, Ali and Sarullah (2010) stress that such attitudinal shifts can also foster greater feelings of empathy between siblings, potentially aiding the establishment of relational closeness in the sibling relationship. Consequently, despite past understandings and perceptions of one's sibling, age and experience afford siblings opportunities to adapt and alter their view of their sibling with ASD. Thus, such possibilities of growth within the relationship stress the dynamic nature of this sibling dyad akin to changes in typical sibling relationships, challenging an often-fixed view of such sibling dynamics.

Similarly, most participants attributed acceptance and improved relationality to acknowledging who their sibling was, as captured by Samantha:

> *I personally accepted the fact that this was my brother and now love him you know, regardless.*

Samantha’s account in adulthood supports the findings of Noonan et al. (2017) which note a shift towards acceptance and positive growth in adulthood. Likewise, acceptance of a sibling’s disability results in a stronger sibling relationship (Ali & Sarullah, 2010). Full acceptance of one’s sibling as they are may remove and diminish deeply rooted negative emotions and experiences predominantly responsible for fostering feelings of disconnection and distance throughout siblinghood. Consequently, it is postulated that a relationship characterised by greater acceptance and renunciation of expectations or desires of how things should be, enables the means to begin establishing warmth and reclaiming connection within the sibling dyad.

Other participants expressed that connection was achieved through accepting and becoming more comfortable with their sibling’s personality and demeanour, as reflected on by Amy:

> *I still can't say anything that is sarcastic or in a tone that he's not going to understand but I think we've learned to adapt, and he does make jokes and does come talk to me about his school or whatever. I think it's, it's normalised a bit.*

Likewise, Nishka became closer to her sister once she began to understand and accept her sister’s capabilities:

> *As I have gotten older, I’ve come to understand that we are each on our own journey, and I just need to support her in her journey… Although we would love to encourage her to communicate more… it might not happen and that’s okay.*

Removing expectations one has for their ASD sibling can encourage connection, as imposing expectations creates room for disappointment when they are not met. Additionally, such growth in understanding was also shared by Kim in adulthood:

> *I think there's definitely a better understanding now as adults… Today is easier because we understand his needs better now as adults, and, you know, you develop so much as a child that things are ever changing and so we had to change and adapt to his needs but now as an adult, we've fallen into this comfort of just knowing.*

This comfort of knowing, as described by Kim, stresses how adulthood aided by experiences of trial and error, enables a stage of greater stability and understanding of how to best aid one’s sibling on the spectrum. Anxiety and fear of the unknown around ASD and how to cope with ASD presentation has been demonstrated by participants as a significant factor that intensifies disconnection and divide within the sibling relationship. However, knowing reduces such trepidations in adulthood and perhaps enhances the sibling connection as one feels more satisfied and confident in their ability to assist their sibling on the spectrum.

Additionally, other participants expressed achieving closeness with their sibling by coming to terms with their *"different"* reality, removing feelings of distance, as illustrated by Terri:

> *When I was 16, I might have given you a different answer, a different experience, [I] might have emphasised just the feeling of you know it's not normal whereas now I can kind of say, well it's not normal and not supposed to be and that's okay… Our lived reality is unique and it's different but it's ours and has shaped who we are.*

Acceptance of one's *"different"* yet known lived reality, whilst hard for some, was a sentiment shared by a few other participants (Kim, Amy, and Samantha) and is consistent with literature denoting siblings' views of their lived experiences (Petals et al., 2009). Awareness of the difference is posited to aid affinity and togetherness within the relationship as it enables contentment for what such lived reality and sibling relationship allows. Moreover, some participants indicated that adulthood has enabled closeness with their sibling through diminishing, controlling, and removing self-imposed feelings of distance by obtaining greater emotional control:

> *I don't really feel any shame or embarrassment about [my brother] anymore. I feel like if other people are made uncomfortable by him then that's just because of their own lack of understanding. It's not really something I need to feel bad about or ashamed about* ***(Timothy)****.*

> *Now I'm a lot more open about it and happy to talk about it - (his brother and his autism). If somebody was rude or horrible like it might offend me, but I'm not like, I'm not scared of that conflict anymore… I think maybe some things that were difficult, I don't find that difficult anymore* ***(Peter)****.*

These accounts stress that as the participants mature so too does their sibling relationship, enhancing possibilities for connection and warmth often hindered by feelings of shame, embarrassment, guilt, hesitancy confronting public reactions, and difficulty talking about their sibling's ASD. This finding is consistent with other research which indicates that positive affect in the sibling relationship in adulthood is attributed to the diminishment of difficulties that plagued siblings' earlier experiences (Gorjy et al., 2017). Thus, the passing of time enables opportunities to create connection. Lastly, research has shown that individuals with a sibling on the spectrum demonstrate perseverance and motivation to sustain the sibling relationship regardless of external and relational obstacles (Noonan et al., 2018; Tozer & Atkin, 2015; Tozer et al., 2013). This was corroborated by the current study, as some participants' accounts emphasised how moments of genuine connection were scarce which heightened their significance, fuelling incentive to carry on sustaining the relationship. Thus, this persistence in achieving closeness and connection within the relationship provides the impetus for siblings to endure and overcome obstacles to relationality.

4.2.3 An Evolving Dynamic

Participants' accounts of their sibling relationships from childhood through to adulthood illustrated an ebb and flow state. Some described experiences that moved between distance and closeness, others expressed more structured relationships confined primarily to one state of relatedness yet indicated potential shifts within their sibling relations as they grew. Some expressed a relationship that was stagnant and less susceptible to change, whereas others noted how aspects of their childhood relating were still inherent in their adult relating along with the presence of something new, whilst some expressed a different dynamic in its entirety. Essentially, participants depicted diverse narratives, indicative of evolving sibling dynamics.

Some participants attributed a positive evolving sibling dynamic to their growth in understanding autism, their sibling, and their sibling's lived experiences, stressing how such a relationship naturally develops and changes. For some participants, this growth occurred in adolescence:

> *In my later teens I read the 'Curious Incident of the Dog in the Night-time', and I read that, and I was like, it sounds like my brother, and it sounds like a terrifying world that he's living in every single day, and I think then I became, I started to become very aware of it* ***(Samantha)****.*

For others, such a growth in understanding came in adulthood:

> *Probably, when I was younger, I didn't fully comprehend it, as I do now, because I was so young… post childhood from 20 onwards, you start to become more aware of that (sibling's experience with autism), and what it was like, kind of understand it more* ***(Peter)****.*

This growth in knowledge about ASD and one's sibling is consistent with research which found that as the sibling with ASD gets older, the neurotypical sibling obtains further familiarity with ASD (Johnson et al., 2020). This familiarity aids and shifts the sibling dynamic. Additionally, support for evolving dynamics is corroborated by research which postulates that reported positive relationships as one gets older is a result of improved abilities to understand the characteristics of ASD and manage one's sibling's ASD presentation, enabling one to become more empathetic towards their sibling (Angell et al., 2012; Van der Merwe et al., 2017).

Likewise, Timothy resonated with Peter's reflection but noted that with his newfound growth in understanding there is also a feeling of distance, stressing how such sibling relationships are nuanced and complex:

> *It's changed in complex ways, I didn't have a good understanding of what he was going through [when he was younger]… but now [in adulthood] I feel like I have a deeper understanding and a lot more empathy for him and a lot more patience with him, compared to when I was younger, but at the same time, it does feel like we've started to grow a bit apart, especially living far away from another.*

Despite the aforementioned benefits of improved understanding on the sibling relationship, the above account stresses the multidimensional intricacies of an evolving dynamic, in that connection can live alongside distance. Thus, this finding is noteworthy for understanding sibling relationships with a sibling on the spectrum, in that such dyads are perhaps not all close or all distant, challenging the absolute dichotomies encountered in the literature (Beyer, 2009; Kaminsky & Dewey, 2001; Macks & Reeve, 2007; Mandleco & Webb, 2015; Petalas et al., 2009). Rather, such sibling dyads are perhaps complex dynamics characterised by harmonic interactions of connection and disconnection.

Additionally, Terri noted that a shift in her sibling relationship was not only due to her being in the adult phase of her life but also due to a shared development and growth in understanding between her and her brother:

> *I mean, we both matured… and there's an understanding that sister's there, she got my back and I know that he's there and got my back as well, you know, and we learning with each other, and we have fun together and also now that I'm older, there's a lot of stuff that might have bugged me before whereas like I wanted to, you know, experience*

> *being young and doing all this, now, it's just like, this is it, it's beautiful with all this complexity and I just enjoy spending time with him.*

This sharedness stresses the partnership inherent in sibling relationships. Evolving together leads to a changed sibling relationship, one defined by collaboration and togetherness. Thus, such sibling dynamics are amenable to change overtime and the fixed dynamics characteristic of childhood or adolescent years do not necessarily remain. Subsequently, as sibling relationships change according to the life stages of both the sibling and the brother or sister with ASD, adulthood enables a stage for such relationships to be redefined and improved upon.

Furthermore, as participants recounted their lived experiences, they expressed a clear understanding about the ways in which their adult sibling relationships have changed to some degree. Some focused on the imminent later life responsibility and stronger duty of care, others expressed a more loving and equal sibling relationship, whilst one participant noted the implications of adult life:

> *I think it's more positive, it's probably more loving and more understanding, from my side, I think he's also changed a bit in his ways, he's a lot more calmer than he used to be. So, for me, it's like, more understanding, more loving, more empathetic, and much stronger sense of responsibility and duty of care* ***(Peter)****.*

> *My brother and I are closer… I would consider my brother, my friend, and he would consider me his friend… There was a superiority thing as a child, that's gone now, like, I know what my brother's talents are, and what he's really good at, and what he can teach me and, you know… even though I am the person that can like physically do things better, like, go to the shop and talk to people and, you know, that's got nothing to do with, with who we are, but as a child I was like, I got my stuff together, he doesn't. So that's all gone away, and I know now what I can learn from my brother and what I can gain from him, which I didn't see as a child… There's a lot of love now, that wasn't there before* ***(Samantha)****.*

> *Now that I'm in my 30s… I work a lot, like I practically live in my office, so I would like generally only spend time with her just before she was going to bed* ***(Nishka)****.*

Sibling relationships, interrupted by the demands of adult life highlights the push and pull notion evident in the literature. This refers to feeling torn between obligations to one's sibling relationship and adult commitments such as those associated with work (Rossetti & Hall, 2015; Tozer et al., 2013). Thus, dynamics characteristic of the sibling relationship may change in adulthood due to the challenges of maximising time with one's sibling while maintaining a life of one's own. Similarly, Terri noted the normative experience of sibling relationships changing as she reflected on her relationship in adulthood:

> *It's more of a, as you grow up, just like siblings (able-bodied) when they grow up as adults, relationship changes in general. I think the same thing is happening here. He can still give me advice, he can still tell me what he thinks… there's a deep care that we have for each other.*

This is an important finding as it provides evidence of how sibling relationships with a sibling on the spectrum experience changes akin to other sibling relationships. Subsequently, such relationships are subject to evolution, a viewpoint supported by emerging literature (Coffman et al., 2021; Johnson et al., 2020; O'Brien et al., 2020).

Additionally, when reflecting as adults on their sibling relationship, participants expressed feelings of both uncertainty and certainty about the future of their relationship. For some, there was a sense of ambiguity about the nature of their relationship, as captured by Peter:

> *It's hard for me to tell [if my relationship will change as I get older].*

Relational ambiguity is noted in the literature as opposing findings have been discovered. Literature states that some sibling relationships with a sibling on the spectrum become more distant and difficult overtime, whereas others change from having poor connections to being more lively and mutual overtime (Rossetti & Hall, 2015). Despite such uncertainty, Peter went on to indicate certainty in terms of how he would like or wish his relationship with his brother to progress:

> *Like spending actual time is something that I want to do more.*

So too did Timothy express a wish for the progression of his sibling relationship:

> *I hope we become closer.*

These desires for positive relational prospects reflect the findings of Gomes (2020), who found that individuals of siblings with ASD envisioned optimistic improvements for their future sibling relationships. This finding, in conjunction with the findings of this current study show that individuals of siblings with ASD are committed to improving their relationships instead of relying on old, worn-out, childhood patterns of relating. Thus, substantiating claims for the evolution of ASD sibling relationships.

Contrastingly, other participants expressed confidence in the direction of their sibling relationship:

> *I expect us to get closer and closer and even friendly and friendlier… I guess now when I got older, I imagined that he would be an amazing uncle to my children and they'll probably always think of him as the strange uncle, but he loves so deeply and he cares so deeply and I'm so excited for that, you know, and I'm so excited to see what that will bring to our relationships. So, I do anticipate even further, yeah getting closer… It really is just like the two of us sort of against the world* ***(Samantha)****.*

> *I don't anticipate anything changing massively in terms of our personal relationship because it's always just dipped in and out, as we usually do* ***(Kim)****.*

Ultimately, the participants' accounts of their sibling relationship in adulthood depicted evidence and / or desire for the progression of their various sibling dynamics. Likewise, Kim's acknowledgment that her sibling relationship *"dips in and out"* further reinforces the dynamic nature of such sibling relationships, perhaps being akin to other sibling relationships in that they are characterised by moments of distance and moments of closeness. These findings are significant as they support a growing viewpoint in the literature that states that changes transpire over time within ASD sibling relationships (Johnson et al., 2020). This understanding counteracts a consistent viewpoint in the literature that alludes to the stagnation of the sibling relationship in adulthood by constantly characterising it as a relationship of considerably less contact and less positive affect (Orsmond & Seltzer, 2007b).

4.3 Theme Two: Am I My Sibling's Keeper?

Exploring their experiences of growing up with a sibling on the spectrum, participants recounted experiences encapsulated by caring and protecting. These experiences were often enacted through various roles and maintained by responsibilities that shifted and altered throughout the sibling relationship. These accounts stressed the role of support within such a dynamic and the implications of lack of support on their sibling relationship. Roles, responsibilities, and support central to the participants' sibling relationship and lived experiences brought into question the adage of 'am I my sibling's keeper?'

4.3.1 Roles

When exploring the sibling relationship, majority of the participants began by exploring their roles they occupied within the relationship during childhood and adolescence. These roles predominantly included roles akin to parenting, such as caring and protection as well as roles of rescuing when their siblings engaged in aggressive behaviour. Whilst such roles are characteristic of sibling relationships, when one has a sibling with ASD, the support provided by the neurotypical sibling generally extends beyond what is usually displayed in other sibling relationships (Avieli et al., 2019). This viewpoint was noticeably evident in the participant accounts, whose roles were consistent with literature around the parentification of siblings with a sibling with ASD (Orsmond & Fulford, 2018; Tomeny et al., 2017a):

> *Like if my dad wasn't there for example and he needed the bathroom then I would take him. If my mom is just not there, you know, and he's having a tantrum, I have to try and calm him down and if he's being a bit physical, say, when I was in high school, towards my mom then I'd maybe stand in and kind of bridge the gap* ***(Peter)****.*

> *Growing up, I was very much the protective older sibling, because it felt like the age gap was a lot larger than it actually was. I was very protective, I felt definitely much like the older brother. I think that whole protecting role I've taken on was probably quite similar to a lot of older and younger brother sibling relationships* ***(Timothy)****.*

> *I think I played a lot of roles. I am his sister and I also cared for him* ***(Terri)****.*

Cuzzocrea et al. (2014) stress that when there is a disabled child in the family, the relationship between siblings change, and the able-bodied sibling(s) begin to play more significant roles – that is, some of the roles usually played by parents. This shift in the sibling roles was further corroborated by this study as some participants described a natural development of such parental roles. Whereas some participants expressed how such roles were embodied because of the presence of ASD within the relationship and the added responsibility that ensued:

> *For me, I think I just took on the motherly role, because I think there is just that sense of responsibility that you get, that extra sense of responsibility that you get when someone needs more needs then, you know, your average person and so I've always been the parent and my mom has sometimes called me out on it and said, you know,*

> *you need to be more you know, you need to be his sister, I'm the mom, I'm alright, you know, jobs covered but yeah, I think it's just that sense of responsibility* ***(Kim)****.*

Kim's account is further corroborated by research postulating that siblings of individuals with ASD may feel compelled to carry out certain roles to meet the needs of the family (Mauldin & Saxena, 2018). This was further evident as some participants expressed embodying various roles out of necessity, such as to support their parents by relieving them of various pressure and stress:

> *The only part that I liked [about being the role of] deputy mom was the fact that I could see that I was relieving my mom of, like, a lot of stress that she was going through* ***(Khani)****.*
>
> *You know [being a] caregiver and looking after him meant giving people a chance for respite… giving my mom a break… Caregiving can be exhausting, so just the two of us tag team* ***(Terri)****.*

These accounts of the reasons for participants enacting parental roles are in accordance with the findings of Angell et al. (2012) and Tozer and Atkin (2015). Although parentified roles are characteristic of such sibling dynamics, some participants (Amy and Kim) expressed contentment for the role(s) that they embodied and an understanding for their role(s). However, some expressed how the magnitude of such roles were uncommon for siblings their age as well as tiresome and difficult at times:

> *I did a lot of caring but that's not a normal experience. It's not a normal experience for a 16-year-old… sometimes I just wanted to be 16. Caregiving is also hard, yeah. It's hard, there were days where you didn't want to get up and do things* ***(Terri)****.*
>
> *I would basically take turns to like put her to bed or do things with her and, and then, to be honest, I felt like it did kind of become like an expectation and then, you know, I told my parents that I need to like actually focus on my own life, I can't be a third parent here, it needs to be between the two of them* ***(Nishka)****.*
>
> *To be honest, I don't really like [being the mother]. Like, I'm not happy that it's my role…. I always just think to myself it's just a card that I've been dealt, and I have to deal with it. I don't like it. It's like baggage and then there is guilt that you that you feel because you think that it's like baggage* ***(Samantha)****.*

These complex feelings around parentification expressed by the participants of ASD siblings are consistent with various findings about the atypical, time-consuming nature, and emotional burden of enacting these roles within the relationship with a sibling on the spectrum (Hall & Rossetti, 2018; Meltzer, 2015; Tomeny et al., 2017a). Subsequently, parentification can impact the sibling relationship due to the intense nature of enacting such roles. Whilst some participants embodied the aforementioned parenting and caregiver roles within childhood and adolescence, others indicated that they did not occupy the role of friend within the sibling relationship:

> *Growing up a sister, like just a sister, not a friend… not even really a companion* ***(Samantha)****.*
>
> *I don't think it was intended (not being a friend), maybe because of the age gap but I do think it was more of a motherly relationship, even though I was very, very young* **(*Amy*)**.
>
> *Rarely was I the friend growing up* ***(Khani)****.*
>
> *It's quite hard to have you know that friendship connection that you would imagine* ***(Kim)****.*

Although, participants' accounts of the roles they embodied throughout their childhood and / or adolescence largely fell within the typical parentification of siblings with a child with ASD (Orsmond & Fulford, 2018; Tomeny et al., 2017a), there was a noticeable shift for some participants in the roles they occupied within adulthood. Evidently, a move away from parenting for some, a move towards parenting for others, and an establishment of an equal sibling relationship for others:

> *These days, it feels like the gap has narrowed, actually, like, it's less the older younger brother relationship more just brothers, almost like we're on kind of equal footing like, I don't feel as protective of him anymore because I feel like my, I don't know, he's developed to a stage where he's, he's still very vulnerable but he's a lot less vulnerable than he used to be more so than I ever really expected of him* ***(Timothy)****.*
>
> *Less motherly, now we have a brother sister relationship* ***(Amy)****.*
>
> *I don't feel like a deputy mom anymore, I just feel like a sister* ***(Khani)****.*

> *So, [my role] did [change] because of a situation of my family. So, my mom had passed away when I was 20 and that changed everything… I ended up having to be the person that had it covered, and it did end up turning to be a more mother sibling relationship… like my brother's my child like in terms of a responsibility. So yeah, there definitely was a switch but I think it was situational* ***(Samantha)****.*

This dynamic nature of evolving roles throughout the sibling relationship not only stresses how such a sibling relationship is akin to able-bodied sibling relationships in that such dynamics shift and change across one's relationship, but it also challenges findings that postulate childhood as the primary determinate of future sibling dynamics (Johnson et al., 2020; Nordone, 2014). Whilst a shift in roles occurred for some in adulthood, participants expressed dividing views on the role in which their sibling with ASD played within their adult life, stressing the complexity of this sibling dynamic:

> *Most recently, probably not much hey. I think this kind of ties back to guilt… There's a big feeling of separation between me and him, almost that I am independent of him. So yeah, I don't think he plays a huge role on my decisions and needs. I mean, I'd love to consider him my friend, but I guess our relationship just isn't there* ***(Timothy)****.*
>
> *Wow, my brain is going immediately to like my second child… Yeah, it's like having another, yeah kid… a lot of the things he does, you know, he's very much like a child* ***(Kim)****.*
>
> *I think he is more than just my brother. He's also my support… a teacher, a friend, mentor* ***(Terri)****.*
>
> *I do actually bounce ideas off of him. If I know that I want to study something further I do chat to him about it first and see what he thinks of it, because I know that's the stuff that he's into, and he's almost like, a reminder of what's important to me* ***(Samantha)****.*

4.3.2 Responsibility

Participants' narratives about the roles they embodied, indicate how such roles intertwined with their feelings about their responsibilities as a sibling of an individual with ASD, both in childhood and adolescence. Just as they embodied parentified roles, so too did they enact parentified responsibilities, consistent with literature acknowledging that siblings of individuals with ASD undertake adult responsibilities at a young age (Benderix & Sivberg, 2007). Whilst some participants acknowledged the necessity of such responsibilities to aid members in the family but also out of love for their sibling on the spectrum, they simultaneously expressed feelings of such responsibility being complex, tiresome, and constituting a different sibling experience:

> *I feel like it (increased responsibility) kind of sped up my own maturity. I had to take on a lot more responsibility than maybe someone of my age would have* ***(Timothy)****.*
>
> *It was a bigger responsibility on me, I don't know, for a 16-year-old to do that and there was like changing, bathing, giving medication, you know, we would take turns in our house, but that was our lived reality, and it was a different reality for someone who would like I don't know, on the weekend go hang out with friends… I just knew it was different. Like, yeah, so there was just a lot more responsibility on self. I didn't see it in a bad way with my brother, our relationship remained the same, but it was different and there were times I guess, when I felt, just wished I could hang out, or, you know, just chill with friends, and not worry about having to do something, or… needing to be there for someone. I felt like I'm having a very different experience in comparison to other people, where I just had a little more responsibility than others and that was not necessarily bad, just different and I guess at times, it was hard* ***(Terri)****.*

These anecdotes are consistent with research which found that siblings of brother or sister on the spectrum not only experience stress and frustration due to the responsibilities they assume but also largely viewed increased responsibility negatively (Mandleco & Webb, 2015; Rossetti & Hall, 2015). Likewise, research stressed how such increased responsibility may result in siblings maturing prematurely and displaying a need for relief and freedom from their caregiving duties (Abrams, 2009; Benderix & Sivberg, 2007), corroborating the accounts of some of the participants in the current study (Khani, Terri, and Timothy). Thus, participants' reports highlight how the undertaking of responsibility for care can lead to negative effects for the parentified sibling, such as constraints on social life and heightened internalised symptoms (Braconnier et al., 2018). Consequently, responsibility places excess tension on the sibling relationship (Sharpe & Rossiter, 2002).

Additionally, the findings of this study indicate that this inherent responsibility extends beyond childhood and adolescence into adulthood, echoing findings that neurotypical siblings take on responsibility for their sibling with ASD across their sibling relationship (Heller & Arnold, 2010; Orsmond & Seltzer, 2007a; Tomeny et al., 2017a). Accordingly, the participants expressed awareness of the intergenerational nature of responsibility that is not only enacted by siblings but also transferred onto them throughout their siblinghood. The participants' reflections on their sibling relationships stressed ambivalence, sensitivity, and complexity around confronting and engaging with their lifelong responsibility towards their sibling with ASD. Accounts varied from reports of such responsibility being assumed but not warranting a conversation, to such unspoken responsibility not being addressed at all. Whereas some participants (Peter and Nishka) actively sought out engagement with the responsibility imposed on them. Others (Kim and Terri) only confronted it later in life when they and their sibling were older and when there was an indication of their sibling's capabilities. Peter captured this ambivalence and sensitivity:

> *There's a sense of responsibility that's, it's like an elephant in the room. My parents have done very well to support for him and do all that kind of stuff, but you kind of get to realise that responsibility pretty young, without anyone really saying anything... and keeping that in the back of your mind.*

Responsibility within the sibling relationship within adulthood was largely compounded with future care of their ASD sibling. This anticipation of taking over greater responsibility in their sibling's life, especially as the primary caregiver in the future, is consistent with various literature (Heller & Kramer, 2009; Nuttall et al., 2018; Rossetti & Hall, 2015):

> *So eventually, I know she will be mine and my brother's responsibility and I'm prepared for that, which is why like right now I'm trying to work as hard as possible so that I can set myself up so that when it comes to that my brother and I will be able to take care of her* ***(Nishka)****.*

> *There's definitely a sense of responsibility and a look to the future on how we're going to best be able to still you know, have him for our Christmas's, and you know, still do all the family things together that we did before I moved overseas… There's definitely a more later life responsibility that we are kind of starting to feel the weight of* ***(Kim)****.*

Furthermore, detailing their experience of siblinghood in adulthood, participants depicted diverging views around the responsibility of future care and the possible impact this would have on their adult lives and future sibling relationship:

> *When I'm thinking about the future of my life, it's not only me, it's other people too. I think it is what it is. I don't see it materially affecting my life outcomes negatively. So,*

> *I really do think you know I can live a happy life and it's not going to bring me down, you know, yeah* ***(Peter)****.*
>
> *We're gonna be the ones looking after our brother later in our lives. It's a different responsibility and then you go in, in some ways, a little bit like a parent role as well, it just naturally will change as we grow, and we learn and mature. I don't see it in a bad way, as well. It's something we can navigate... I'm not saying that it's not going to be hard but it's also just being realistic you know, this is the way it is, you know, you want him to be safe, you want him to be loved and cared for… I have a partner who understands my family dynamic and understands that whatever happens my brother is a part of my life, that's just the way it is* ***(Terri)****.*

Although other participants recognised the normative practice of future care within their sibling relationship, they nonetheless stressed the weight and atypicalness of such responsibility. Subsequently, expressing difficulty, sadness, stress, and self-imposed pressure around such responsibility:

> *It's extremely tough. With every decision in my life, I have to consider my brother at every point. So, it's whatever future decision I make… every single step I have to consider him, and I think that's not normal for siblings* ***(Samantha)****.*
>
> *It's not a normal sibling relationship where you know that one day, you're going to live in your own house and things like that, very much one day you're going to be responsible for them on some level. I think it's really hard. It's quite scary actually* ***(Amy)****.*
>
> *I said to my husband before we got married, I said, just know that when you marry me you also marrying this responsibility that we'll be taking on… There's also that sense of responsibility to my mother as well, who worked so tirelessly to make sure you know that, that he was never going to be just left, and that he's going to live a normal life as possible… and I'll you know, make sure that that is taken care of* ***(Kim)****.*

These varying accounts within adulthood stress the complex and nuanced feelings around enacting and maintaining future care responsibilities towards one's sibling on the spectrum. These accounts are in line with findings that indicate the psychological impact (anger, anxiety, fear, stress) on adult neurotypical siblings who are expected to take on greater caring roles within their sibling relationship (Jones et al., 2019; Moss et al., 2019; Tozer & Atkin, 2015). Thus, responsibility for future care poses implications for the sibling relationship.

4.3.3 Support

Reflecting on their roles and responsibilities across their sibling relationship participants stressed the necessity and importance of support for an individual with a sibling on the spectrum. The significance of support within such a sibling dynamic is consistent with findings of Chan and Goh (2014) who stress that the amount of support offered is related to the way in which individuals experience having a sibling with ASD and the way in which they make meaning of it. Likewise, research postulates that individuals with a sibling with ASD convey more positive affect in their sibling relationship when they have emotional and tangible support from parents (Jones et al., 2019). The current study found that parental and familial support was emphasised as invaluable in some of the participants' accounts of their upbringing in supporting, educating, and aiding their experience of siblinghood:

> *I had like extremely, extremely supportive parents, and my mom was always the one who just got it* ***(Samantha)****.*

> *My immediate family, my parents, and then both my grandparents and my cousins we are quite… tight knit and very close, which has been extremely helpful, and I think we had a very nice supportive network of family who really, you know, all sympathetic to [my brother's] situation* ***(Peter)****.*

Participants' narratives depicted the benefits of supportive networks in combating feelings of being overwhelmed and confused when their siblings engaged in ASD behaviour, as well as loneliness and anger associated with public perceptions and reactions towards their sibling with ASD. These accounts concur with research which found that support networks aid sibling adjustment (Jones et al., 2019; Vanhoutteghem et al., 2014). One participant provided an account of the necessity of support when he was younger, especially in relation to managing the emotions resultant from public perception of his sibling:

> *I'm sure my parents were keeping a close eye on me but just keeping a close eye on the kid in terms of I think it's just so overwhelming, you know [when] the one child [is] having a tantrum, it's like just chaos. I understand how difficult it was and it's not like I have any resentment but maybe just focusing on the kids and trying to build courage and understanding and resilience in them in terms of public perception and why it's not*

> *a big thing. I think I was very fortunate to have a lot of that I think it probably did help, you know, so say from my parents, and then also just like I had really great cousins, and I think it's support, because it's like, you're very by yourself when everyone's looking at you and kind of in your own head, but if you say, have other people around you kind of with you saying no don't think about it, like having people to kind of break the stigma that you place on it for yourself... mechanisms and ways to kind of break it for the child, I think would be big and highly influential* ***(Peter)***.

However, some expressed that whilst having loving parents who ensured they had the best, they felt that they could not approach their parents as they were *"preoccupied" (Nishka)* with their sibling on the spectrum. Parental preoccupation led to resentment for some participants, whilst others expressed how it had become normalised across their siblinghood resulting in increased independence and resilience. Coupled with this, some expressed lack of support from extended family members, ensuing judgement towards the participant's immediate family, mistreatment towards their sibling, and ignorance due to lack of understanding:

> *The outside family never got it like they will always give me [and] my parents lectures about you must just send him to like a military school or something… no one got it but my immediate family* ***(Samantha)***.

> *You still going to have family that struggle to navigate it. Like, I have some family members that have come, and they won't even like pull out a board and talk to [my brother], you know, or like really try to build a relationship with him and you can't change other people, that's just the way they are* ***(Terri)***.

Subsequently, some participants turned to friends for support:

> *I do have a friend that has a brother that has Down's syndrome, so she understands having to look after a sibling on some level. So sometimes, I think it is best just to have someone to talk to if you need to* ***(Amy)***.

> *My close friends… love my sister, and they you know, they are very supportive and very loving towards her because they understand how important she is to me* ***(Nishka)***.

Furthermore, in reflecting on support, Nishka stressed the interaction between culture, community, and support:

> *[My grandmother] kind of has this opinion of my parents, she's like, but they didn't do the right prayers, you know if they did the right prayers then she would be different, and she'd be normal… Then like in the broader community, where people who would like go out of their way to come and speak to me or greet me, you know, because I'm an attorney, or because, you know, they feel like I can engage with them on a certain level, but then they will completely ignore my sister. So those things I think, are the most difficult thing for me personally.*

Moreover, Dansby et al. (2018) highlight the value of therapeutic support in providing and enhancing adaptive coping skills for individuals with siblings with ASD. Some participants expressed that they sought therapeutic support in adulthood, a valuable outlet for their feelings and expression of their lived experiences. Despite some participants not seeking support, some participants conveyed an interest to obtain support outside of the home, especially now in adulthood, primarily with other siblings of autistic people:

> *I think that would have been really helpful when I was a teenager and even now, I think it would be extremely helpful* ***(Samantha)****.*

> *I would like to connect with people who've had a similar experience to me, because I'm quite interested to hear like, what they've gone through maybe what the similarities are between us… It would be nice to talk about it with other people* ***(Timothy)****.*

Accounts of how essential support groups would have been in their upbringing to make sense of their experience, combat feelings of anger, sadness, confusion, and loneliness, but also valuable in adulthood due to a shared experience and understanding of siblinghood are sentiments supported by literature. Angell et al. (2012) found participants' appreciation for communicating with someone of a shared, similar experience of their sibling relationship. Additionally, research regarding the effectiveness of support groups for siblings has indicated improvements in self-esteem, knowledge of the sibling's ASD, and interactions between siblings (Evans et al., 2001). Thus, it can be postulated that engaging in support groups with other siblings of autistic people could enable a space for togetherness, support, honest expression of feelings, improved insights, joint learning, and shared understandings of the sibling experience.

Apart from support for themselves, some participants recounted complex processes of accessing appropriate support for their siblings in South Africa (Kim, Nishka, Samantha, and Terri). Such difficulties resulted in three participants' parents (Kim, Nishka, and Terri) starting schools or autism organisations to aid their siblings with ASD. The difficulty of accessing support resulted in participants stressing the importance for inclusivity and equal access to resources and support for individuals on the spectrum and their families.

4.4 Theme Three: Balancing the Self

Participants' accounts of their lived experiences across their sibling relationship illustrated a navigation of self. Responsibilities and roles enacted as means to meet familial needs for some led to a loss of self – a feeling of being unseen. However, some participants acknowledged a changed, positive self attributed to their sibling on the spectrum. These retrospective accounts stressed a process of discovering a self that enabled a more balanced sense of self.

4.4.1 Being Unseen

As previously mentioned, some participants (Khani, Nishka and Timothy) expressed that family members greatly focused on their sibling with ASD, resulting in some not feeling seen. Whilst participants stressed their parents' strengths and love for them, they were not impervious to feeling unseen from their parents, with some expressing how such invisibility was normalised due to the greater needs of their siblings:

> *My mom said: "I'm sorry, if like, you feel like [your brother] is getting more attention, but he actually does require more attention because he's not neurotypical"* ***(Timothy)***.

However, for some participants this notion of being unseen extended to their sense of self. The boundaries between their collective self and their individual self were blurred and ill-defined. This is consistent with the findings of Dickey (2008) who indicates that through siblings' attempts to aid their families, by enacting various roles and responsibilities, they become detached from their own wants and needs. Likewise, identity has been found to be significantly based on the relationships and roles one embodies (MacCall & Simmons, 1978). Consequently, the participants' main source of identity becomes that of 'sibling', and they experience difficulty being seen and seeing themselves as an individual. This loss of self was captured by Terri in adulthood:

> *I attached a lot of my identity and self-worth to that kind of nurture role… If I look back and only when I started working and having to kind of go out of the space a lot more, did I see, I think it really shaped my self-awareness, awareness of self-identity of self,*

> *kind of finding myself, you know, I had to find my voice by myself, that wasn't just all of me. Because I think when I was in school, a lot of my life was attached to you know, family and caring.*

This awareness that participants' selves were more than one's roles, responsibilities, and autism, was shared by other participants (Peter, Nishka, and Amy), who depicted a discovery of self, alongside their sibling relationship. It is postulated that such self-discovery is aided through self-awareness about one's experience of growing up with a sibling with ASD, as increased self-awareness can potentially enable the formation of a secure sense of self (Dickey, 2008). This is supported by the findings of the current study in that participants reflected on loss of self in adulthood whilst simultaneously engaging in increased meaning making and exploration of their sibling relationship.

4.4.2 Seeing the Self

There was a predominant perception that participants grew intrapsychically from participating in their relationship with their sibling on the spectrum, a change to self that was largely apparent in adulthood. This resembles a core aspect within the literature that having a sibling with ASD results in individuals demonstrating improved psychosocial development and interpersonal perspectives (Macks & Reeve, 2007). This was succinctly captured by Terri who stated:

> *Your life gets shaped so much by that experience, and the lived experience with all the ups and downs and chaos. It's really shaped my way I think, the way I feel, the way I look at the world. I'm really grateful for that.*

Similarly, when reflecting on the impact their siblings have had on their personal development and sense of self, some participants identified being more compassionate, empathetic, and emotionally stronger:

> *It made me a lot more compassionate to other people and what people go through* ***(Nishka)****.*
>
> *It fostered a greater sense of empathy in me* ***(Peter)****.*
>
> *It's made me more resilient. It's made me more courageous* ***(Terri)****.*
>
> *He's made me a much kinder person that I might have ordinarily been* ***(Kim)****.*

These accounts of enhanced emotional development reflect a dominant discourse in the literature on acknowledging the positive aspects of growing up with a sibling on the spectrum (Latta et al., 2014; Petalas et al., 2015; Ward et al., 2016). Participants made a noticeable effort to recognise the positive impact their sibling had on them, perhaps to balance out the more challenging retrospective accounts and take stock of the positive aspects across their siblinghood. Furthermore, an additional positive aspect of having a sibling on the spectrum that has been reported in the literature is that one may become more accepting and empathetic towards others compared to individuals who do not live with a sibling with ASD (Benderix & Sivberg, 2007; Dansby et al., 2018; Nielsen et al., 2012). This was noticeable when Timothy expressed how such an impact on self resulted in a greater sense of understanding of disabled individuals:

> *I find that I'm very accepting and understanding of people with disabilities, because of my own experience with [my brother].*

Moreover, Walton and Ingersoll (2015) indicate that siblings of autistic people display increased tendencies to help others. This finding concurs with the current study as some participants expressed how an increased understanding of their sibling on the spectrum resulted in the development of a life goal of helping others:

> *[In] adulthood, [there is] a real appreciation for the impact that he has had on me as a person in terms of the way that I look at other people. I feel a real sense of needing to defend people a lot, that wouldn't ordinarily necessarily defend themselves* ***(Kim)****.*

> *I saw how like a lot of people like misunderstood everything that had to do with [my brother], that made me like want to push more in getting the information out there, learning more, and just being sort of like an advocate for people on the spectrum* ***(Khani)****.*

> *It gave me a sense of purpose and wanting to give back* ***(Terri)****.*

Terri went on to give an account of how her brother impacted her professional life:

> *He taught me a lot… a quieter leadership style, a listening leadership style, a you don't have to have all the answers style and that it's okay to fail, and royally fail and then dust yourself off and pick up the pieces and carry on and piece it together.*

Whilst reflecting on the personal developments their siblings have had on their sense of self, appreciation for such impact was noticeably evident in Kim's account of how having a brother on the spectrum impacted her mothering:

> *My son was diagnosed with autism and if it weren't for [my brother], I might not be the mother that I am today. I know, for a fact that I wouldn't, I probably wouldn't know half of what I was doing when it came to my son and, you know, I would just be doing what I read on the internet but [my brother] kind of fully prepared me and I will be honest, I don't think my son would be, you know, half as okay as he is if I didn't have that previous knowledge, and I also wouldn't have gotten the support as early as I did… but I was under no illusion because of my knowledge and my experience with [my brother]… Luckily I have the tools you know already to support him and the experience to support him already and also luckily a family who all understand already… What I've learned through autism, and him, that's been amazing… I love him deeply because he's given me all these wonderful gifts and ways of seeing the world.*

Whilst participants expressed positive impacts on their personal development and sense of self, some expressed negative implications across their sibling relationship:

> *[My brother's behaviour growing up] caused me to be a bit introverted **(Peter)**.*

> *Growing up I was very hard on myself and put an enormous amount of pressure on myself, which I believe is to overcompensate for [my brother's] inability to do things. It's lessened today but it's still something that's quite deeply ingrained in me **(Timothy)**.*

> *Having to be very self-sufficient [as a child] is still something I carry to this day [in adulthood] and it has created a barrier in terms of me asking for help **(Terri)**.*

Although only three participants noted negative impacts on their personal development as a result of having a sibling on the spectrum, such accounts depicted the polarities on personal development, highlighting the dichotomous experiences of such sibling accounts evident in the literature exploring siblings' experiences of having a sibling on the spectrum (Benderix & Sivberg, 2007; Coffman et al., 2021; Corsano et al., 2017; Dansby et al., 2018; Diener et al., 2015; Johnson et al., 2020; Latta et al., 2014; Mandleco & Webb, 2015; Nielsen et al., 2012; Nordone, 2014; Petalas et al., 2015; Walton & Ingersoll, 2015; Ward et al., 2016).

4.5 Theme Four: Making Meaning

Understanding and making sense of their lived experiences central to their sibling relationships was a core aspect of the participants' accounts. Apart from aspects previously mentioned such as awareness of typical and atypical aspects of their sibling relationships and acceptance, and compassion for their siblings, three aspects emerged as vital components of participants' continuous meaning making. These include understanding ASD and the implication of changed understanding as a result, exploring the connection between ASD and disability and what this means for the sibling relationship, and retrospective advice based on their experiences of growing up with a sibling on the spectrum that they felt would have aided earlier meaning making processes.

4.5.1 Understanding ASD

Participants' accounts reflected a changed understanding of ASD across their sibling relationship, an understanding that facilitated a meaning making process and aided the sibling relationship. During childhood and adolescence when participants' siblings were diagnosed, some participants expressed unfamiliarity with ASD, as illustrated by Timothy:

> *[I knew] pretty much nothing. I just knew that my brother was different, that he couldn't talk… my perception of it was always, like quite a rudimentary one, that he would have the mental age of someone much younger than his actual like physical age… I don't think I really understood really anything around autism until I was probably in my mid-teens and that was just from picking up from what my parents had like told me about and researched.*

Timothy's lack of knowledge which echoed that of many of the participants' earlier experiences with autism (Kim, Nishka, and Samantha), is consistent with research around childhood perceptions of ASD siblings. The literature stresses that such early understandings are possibly based off visible difference between the sibling dyad, as well as current mannerisms and actions enacted by the sibling with ASD (Coffman et al., 2021; Petalas et al., 2009). This finding was evident in this study as some participants' understandings of autism were encapsulated by their sibling's presentation:

> *So, when I was younger, I just thought that what my brother was, was autism… I had your very generic view of what autism was, but I'd say I only really learned about it in*

> *high school. When I was younger, I knew it was autism but all I could really do was like oh he's like 'Rain Man' (a movie)* ***(Kim)****.*

> *I would just explain to [my friends] not exactly what autism was, but I would explain what [my brother] does. I would say, he might just shout for no reason, please don't bump his cars on the floor, he will scream they're in a straight line, so don't move them. You know, I would have to explain it like that to them* ***(Amy)****.*

However, all participants expressed a changed understanding as they grew up, a growth in understanding that has been found to be largely facilitated by parents or primary caregivers (Coffman et al., 2021). Whilst some participants still described ASD to others based on their sibling's presentation, they expressed an awareness of the diversity of ASD, that whilst some autistic individuals may share similar presentations they are unique to each individual. Additionally, they stressed how a greater understanding of ASD enabled meaning making and enhanced their sibling relationship. This finding is supported by Coffman et al. (2021) who indicate that an increased understanding of a sibling's diagnosis can possibly encourage empathy, mitigating any potentially negative impacts of ASD-related stressors within the sibling relationship. Thus, the greater the knowledge about ASD, the more positive the sibling relationship (Jones et al., 2019). This association was succinctly captured by Samantha:

> *It (improved understanding) impacted the sibling relationship because I think at that point… I wasn't trying to find out why it was, this is the situation and I know how it is. It enabled me to have a better understanding of my brother and his personality, which improved our relationship and my engagement in it.*

Likewise, Kim expressed how although she thought she had sufficient knowledge about autism, having a son on the spectrum led to an increased understanding of ASD and an understanding of how this could aid her brother:

> *It's funny, I thought I knew everything there was to know about autism, but now that my son is presenting with characteristics, I've realised that I had no idea, none whatsoever. My brother is, you know, had serious sensory issues, completely nonverbal as a child, you know, extreme stimming, prone to extreme meltdowns, would run and hide as he couldn't handle noises, hands over the ears, everything that you could think of in terms of presenting as culture's idea of autism. Whereas my son is hyperlexic, so he's three years old and you know, he knows the alphabet, he can count to 100, he can write his name, he can read, he is verbal, but it's all echolalia and scripting, he makes eye*

> *contact, he was very, very, very social up until 18 months, and then he had a regression and so his kind of autism is very different to what my brothers was... So, I'm learning that it's all very different now compared to what it was then… It's incredible how different it is and how far it's come because at a certain point we stopped you know, [my brother] was, and he is the way he is, and he was an adult, so we just kind of settled in what suited him and what we were used to, and never really went further than that. But now, obviously, we're learning all these new things and it's been really good to kind of incorporate the things that we are doing with my son with him [brother] and see if that helps support [my brother] now, because those are things, we never knew a few years ago... So yeah, it's been interesting.*

4.5.2 ASD and Disability

Part of the participants' meaning making involved exploring the relationship between ASD and disability. Although participants alluded to a possible connection between ASD and disability throughout their accounts, which is consistent with the literature, exploring such connection directly was met with discomfort. This feeling towards engaging with disability was perhaps largely attributed to the commonly held nuances related to having a disability as negative in nature (Coleman et al., 2015). Having to explore the relationship between disability and their autistic siblings, someone central to their lived experience, is perhaps difficult as the word 'disability' has largely been used to characterise individuals who are lacking or incomplete (Meltzer, 2018). What might it mean for how participants view their sibling with ASD in recognising such association between ASD and disability? The sensitivity of exploring such connection was evident when majority of the participants expressed a view of ASD as a disability but did so with caution:

> *I want to say the politically correct thing would be that no, it's not a disability, and people with autism can do everything that anybody else can do, but in reality, yes, it is a disability because it's something that, whereas I might be able to do this easily, a person with autism will struggle to do it and they may need extra assistance from us **(Nishka)**.*
>
> *If I was answering for [my brother] specifically, I would say yes **(Peter)**.*
>
> *I mean, my brother's case very much so. Like, I don't like the stigma around the word disability, but I would still consider it a disability **(Timothy)**.*

> *I would say it is, but I don't, I don't want to like, I feel bad for saying it is* ***(Khani)****.*
>
> *So, I don't see it as deficit, certainly not, right, I do see it as someone requiring support. So, to deny and say that it's not a disability is also wrong* ***(Terri)****.*

These accounts depict the ambivalence and agony for some in labelling ASD as a disability, due to the possible implication this may have for their view of their sibling. Goffman (1963) notes that having a stigmatised quality, like a disability, diminishes an individual from their whole self as people only concentrate on their difference. Thus, disability stigma hinders complete social acceptance, supported by subjective negative predispositions which are easily established yet hard to evade (Gomes, 2020). This association with disability stigma was apparent in the current study as majority of the participants' accounts emphasised the awareness and distain of such stigma directly or indirectly. Many participants (Amy, Nishka, Peter, Samantha, Terri, and Timothy) attempted to justify a reason for a view of ASD not being a disability, perhaps out of a protective sense towards their siblings, a role that is ingrained in all aspects of their sibling relationship even in their own perceptions of their siblings. Whereas others (Khani and Kim) expressed guilt for having admitted their viewpoint, possibly displaying sadness and fear for what such connotations mean for their sibling but also perhaps stressing a feeling of having let their sibling down by adopting a view of ASD as a disability. Uneasiness with exploring such interaction highlights the complexity of meaning making undertaken by an individual with a sibling with ASD.

Whilst disability studies literature is saturated with diverging views, the participants' hesitancy in exploring the relationship between ASD and disability due to fear, guilt, and irreconcilable implications align with a dominant viewpoint that situates disability in the individual postulating an interpretation of disability resultant of substantial deficits in functioning (Nario-Redmond et al., 2013). This interpretation of disability consequently implies a negative experience and understanding of disability, fuelling stigma and discomfort. Contrasting this delineation is a view of disability as a contextual phenomenon, subjected to societal associations, attitudes, and responses around one's deficits (Harvey, 2019). This understanding was prominent within some of the participants' narratives which support and champion the thoughts put forward by Albrecht et al. (2001) in that societal oppression and ignorance are a cornerstone for the experience of disability. Subsequently, some participants expressed how viewing ASD as a disability was socially constructed, as captured by Kim:

> *In terms of societal expectation, yes. In terms of the difficulties that they face because of what is normal and because of the lack of knowledge, it does give them a disability within society because they are not accommodated… but not by the perspective of you know, a neurodiverse person being disabled.*

Consequently, research stresses how individuals will express diverse and contradictory views of disability, whether due to social stigmas, individual preferences, or insufficient knowledge (Gomes, 2020). However, it is also noted in the literature that individuals with a disabled sibling, such as ASD, sustain a specific relationship with, and understanding of, disability (Friedman, 2019). This can be deduced due to conflictual feelings of admiration for the sibling on the spectrum and the dominantly negative assumptions and perceptions of disability potentially evident in their different life domains. This nuanced and complex interaction between disability and the sibling relationship was evident in the study, when some participants had trouble stating whether they view themselves as having a disabled sibling. This was succinctly captured by Kim:

> *Gosh that's a tough one, because I immediately thought of my son and now when you first asked that question, interesting, very clever, hmm. [My brother], yeah, oh, G-d, it's hard… it's hard because there is parts of it that yes would be a disability because that person would need full time care for the rest of their life and you know, wouldn't be able to have a family or not that that Oh, g-d, its society, isn't it? Yeah, I think in terms of [my brother] potentially but I'm very scared of stepping on toes because of semantics these days… in terms of [my brother], I would say disability, in terms of my son I would say if society was more accommodating and there was more understanding and more knowledge on it, then potentially not, however there isn't so because there isn't, I would have to say yes, I do have a disabled sibling.*

Perhaps participants’ difficulty stating whether they had a disabled sibling, despite indicating their views on ASD as a disability, could be attributed to their identity of being an individual with a sibling who is viewed as disabled and the personal and social stigmas they may encounter as a result. This deduction concurs with literature which postulates that despite the degree of involvement in their sibling’s lives, the challenges and stigma of disability are prone to reach individuals of disabled siblings through association (Meltzer & Kramer, 2016). Thus, postulating that siblings of a disabled individual are likely to be recipients of society’s negatively tinged prejudices about disability. Furthermore, apart from receiving negativity and the weight of judgment themselves, such difficulty of stating a view of whether they have a disabled sibling may also be a result of internal processes. Gomes (2020) indicates that such processes involve reflecting upon and questioning one's own ideas of, and relationality with, disability if one is to assume the identity of a sibling of a disabled individual. Subsequently, all dimensions of identity are interdependent and complement or contradict one another (Jung & Hecht, 2004). Thus, making meaning about ASD and disability may involve negotiation of one's identity.

4.5.3 Sibling to Sibling

Reflecting on their sibling relationships, participants expressed advice that they would provide other individuals who have a sibling on the spectrum. This retrospective advice would have aided their meaning making earlier on in their sibling relationships but has nonetheless enhanced their meaning making and sibling relationship in adulthood. Exploring their experience of living with a sibling on the spectrum, some participants expressed the importance of boundaries in a dynamic accustomed to parentification of neurotypical siblings because of their autistic sibling as captured by Nishka:

> *Understand your boundaries, to understand that you're not a parent, and that you have to respect the decisions that your parents take, and that you have to do the best that you can in supporting them, but you are in a supporting role, and I think that would be the greatest perspective change from my 20s.*

Defining boundaries can be viewed as an imperative to maintain homeostasis in the family but also within and between subsystems such as parent-neurotypical child and sibling-ASD sibling. Research has noted that parent-child relationships can be impacted when having a sibling on the spectrum (Ward et al., 2016). However, perhaps the above account postulates an alternative reasoning for such impact, apart from associating blame on the sibling with ASD needing more parental time and attention to that of the over-parentification of the parentified sibling. Thus, acknowledging the purview of one's role enacted in the sibling relationship is essential to prevent the emergence of an additional barrier to the sibling relationship.

Additionally, attempts to understand their sibling's world, enabled empathy and awareness of their sibling's experiences:

> *Try and empathise with what they're going through, and it will make you a lot more patient, a lot more understanding of them* ***(Timothy)****.*

> *Be very aware of how terrifying everything is for them and it's so hard to, to place yourself in their shoes, but everything is scary and if you think of how you feel when you're scared of something, just like, put that to everyday situations and then that's how you can kind of understand them a little bit better* ***(Samantha)****.*

Although the implications of attempting an understanding of one's ASD sibling's experience has been discussed, this retrospective advice posits that such attempts are perhaps easier to obtain when one is older, as earlier sibling experience may cloud the need to understand the other's perspective. Nonetheless, the benefits of perspective taking are valuable in enhancing one's meaning making within their sibling relationship as it demonstrates consideration and empathy towards the other and allows one's sibling to be seen, and to an extent understood.

Likewise, participants expressed the necessity of a neurotypical sibling enhancing their understanding of ASD, a finding that has proven to enhance sibling relationships (Coffman et al., 2021):

> *Know about autism and understand symptoms* ***(Terri)****.*

> *If you can learn more about autism, learn more about like what options are available for helping with the development for someone with autism* ***(Timothy)****.*

Similarly, participants stressed their role as advocates for autism:

> *Be willing and open to discuss it. The more people know, the more we're going to get to a place where it becomes a normality… be open to discussing it and be open to letting people ask questions. My biggest thing now with my little one is that, the thing that most hurts me is silence, people being too shy or awkward or don't want to say the wrong things… I'm happy to talk about it, I want to talk about it in any opportunity. I would want people to ask questions, show interest, because the lack of interest and silence yeah, it's lonely* ***(Kim)****.*

> *Be your sibling's greatest advocate, I would say that, you know, give them voice when they might not have, educate other people at school and in new environments* ***(Terri)****.*

> *Don't hide the fact that [your sibling] is on the spectrum from other people, but rather make people understand that okay, my sibling is on the spectrum this is what it means, this is how you can interact with him* ***(Khani)****.*

Advocacy for ASD is a prominent theme in the literature to combat stigma, prejudice, and misconceptions around ASD (Hall & Rossetti, 2018). For some participants (Nishka, Khani, Kim and Terri), representing and protecting their sibling on the spectrum, both within and outside the family, was inherent to their role as a sibling of a person with ASD. Additionally, these accounts stress the importance of not being ashamed or embarrassed about having a sibling on the spectrum. Rather talking about it and educating others can reduce feelings of loneliness and the impact of inaccurate predispositions on self and the sibling relationship, facilitating an improved understanding of their lived experience.

Furthermore, most participants stressed the importance of obtaining support for themselves and the wish that they had done so in the past. This was captured by Terri:

> *Get support if you are not okay and ask your parents for support as well, you don't have to have it all together or do it on your own.*

This advice resonated with other participants (Peter and Samantha) who often felt alone in their experience throughout their siblinghood, imposed intense pressure on themselves for having to know how *"it all works"* (*Samantha*) and needing to maintain a façade of control to prevent further stress and difficulty within the home. Support is vital for the management of stressors apparent in any sibling relationship (Chan & Goh, 2014). Support may alleviate difficulties, enable insight and understanding about ASD and its related challenges, offer solutions to relational barriers, an awareness of togetherness counteracting feelings of isolation, an outlet for emotions, and encourage connection and improvements within the sibling relationship. Consequently, the availability and absence of such support has been found to influence one's meaning making of experience of having a sibling on the spectrum (Chan & Goh, 2014).

Moreover, participants expressed the importance of finding a means to connect with their siblings, a way to make the sibling relationship meaningful:

> *Try and build a connection with them because ultimately you'll find that a lot more meaningful than just trying to distance yourself from them* ***(Timothy)***.

> *I would tell siblings to get to know their siblings, find something, you know, whatever that is, to get to know your sibling. If your sibling doesn't talk, find a way to communicate and engage, find that connection and there's so much you can learn*

> *together. You know, it's not an either or, it's not you teaching your sibling, [but] it is what your sibling can also teach you, so finding that connection where you can grow together and learn together and not seeing your sibling as any less than you* ***(Terri)***.

Achieving a connection with one’s sibling was a desire shared by most of the participants. Whilst barriers to accomplishing sibling connection have been explored, the above accounts stress the poignance of not trying to connect with one’s sibling on the spectrum. Retrospective regret was evident in some of the participants processing and understanding of their lived experiences (Kim, Peter, Samanatha, and Timothy). Consequently, this finding emphasises the value of muddling through various difficulties, relational barriers, negative feelings, and experiences of rejection, to strive for some resemblance of a sibling bond. Further, the above postulates potential components for establishing meaningful sibling relations, namely the importance of becoming acquainted with one’s sibling, investing time and effort in finding means to communicate and connect, striving for shared experiences, and not viewing one’s sibling as less than.

Conclusively, one participant expressed how the value of being comfortable in the ambiguous space aids one’s understanding, view, and experience of the sibling relationship:

> *You can feel angry, that's okay, you can fight that's okay, it could be chaos, that's okay, you can feel lonely that's okay to feel those things… it is kind of living in this ambiguous space, but it's not either or and it's not supposed to be like fair and equal, it's not about all of that, it's just about this is the way it is and how do I celebrate and find joy within that, how do I find joy within all of this that's going on within the difference* ***(Terri)***.

This ambiguous space central to sibling relationships with a sibling on the spectrum is nuanced and dynamic. For participants of the current study, having a brother or sister on the spectrum entailed confronting mixed emotional and relational dynamics with themselves and others. Subsequently, perhaps part of one’s meaning making of their lived experience with a sibling on the spectrum is not only about embracing contradictory emotions but allowing oneself the space and capacity to embrace them. Experiencing and sitting in the complexity that is the making sense of one’s lived experience enveloped by difference, lies a task for siblings to find happiness and celebrate their lived reality, opposed to engaging in comparisons of others’ lived experience which is postulated to result in skewed understandings and impact the sibling relationship.

4.6 Summary of Findings

Exploring the relational ebb and flow enabled an opportunity to gain insight into the complex vacillations of the sibling relationship with a sibling on the spectrum across one's siblinghood. At times, adult siblings reflected on past and current moments of disconnection, feeling negative about their sibling relationship. These viewpoints stressed the negative impact on the sibling relationship due to inherent relational barriers of ASD, as well as depicted the effects on family and social life as a result of having a sibling on the spectrum. These accounts of disconnection and distance stressed findings of a loss of an imagined sibling relationship and the presence of a different sibling relationship characterised by distance. Interestingly, people with ASD are often distanced and othered (Berkovits et al., 2020; Humphrey & Lewis, 2008; Sasson et al., 2017) but within the sibling relationships in the current study it was the neurotypical siblings who felt distant and alienated at times. Whereas at other times, such narratives expressed positive views of their sibling relationship. Moments of genuine connection and warmth were recounted, depicting the presence of sibling connection and affinity experienced throughout one's siblinghood. These experiences highlight the unique means of achieving and establishing a closer sibling relationship, overcoming, and working with the various relational barriers, as well as postulated adulthood as a stage within siblinghood that could foster and enhance connection within the sibling dyad.

Longing for a sibling connection was a significant account expressed by majority of the participants. This ebb and flow, whilst characteristic of all sibling relationships, challenges the dominant absolute dichotomies in the literature (Beyer, 2009; Kaminsky & Dewey, 2001; Macks & Reeve, 2007; Mandleco & Webb, 2015; Petalas et al., 2009) of an either-or relationship with a sibling on the spectrum. Rather, this theme provides significant understandings of how individuals experience and view their sibling relationship across different life stages and how they behave and act when encountering barriers to, and opportunities for, relationality. These narratives of evolving perceptions and experiences of one's relationship with their brother or sister on the spectrum provide nuanced understandings of negotiations between moments of distance and closeness (an evolving dynamic) and the associated emotional and personal processes enacted between siblings within the sibling relationship.

Additionally, detailing the various neurotypical sibling functions of such a sibling relationship enabled awareness and insight of the magnitude of such sibling duties and the ramifications of these intensified functions on the sibling dyad. Participants' narratives detailed largely negative connotations about the roles and responsibilities they embodied and enacted for their sibling on the spectrum. Although there was an awareness of why such functions needed to be carried out and maintained, there was a prevailing sense of such roles and responsibilities being difficult, tiresome, overwhelming, intense, unnatural, and at moments impinging on one's own life. However, the retrospective accounts demonstrated a shift in sibling roles in adulthood. Roles evolved to resemble roles typical of brothers and sisters' relationships, where the dominant parentification characteristic of earlier sibling years was absent. Such shift afforded some participants opportunities to be on equal footing with their sibling, enabling the means to establish a friendship. Whereas, for one participant, they adopted a more parental role within their sibling relationship resultant from situational circumstances. This insight into shifting roles across the sibling relationship substantiates evidence (Coffman et al., 2021; Gorjy et al., 2017; Johnson et al., 2020; Noonan et al., 2018; O'Brien et al., 2020) challenging understandings of stagnant and fixed dynamics within ASD sibling relationships. Subsequently, accounts of enacting such roles and responsibilities stressed the value and importance of support for neurotypical siblings and the implications of reduced support. Support was shown to aid sibling's experiences with a sibling on the spectrum. Whist differential treatment and limited supportive networks impaired the neurotypical sibling and parental relationships, intensifying feelings of anger, resentment, and loneliness in the sibling dyad. A noteworthy finding was participants' desires to access sibling support groups as well as support outside the home environment.

Furthermore, the findings enabled greater awareness of the impact on the self with having a brother or sister on the spectrum. The self embarks on a journey of discovery for clarity and security within these sibling relationships. Whilst such exploration is usual in sibling relationships, the characteristics inherent in an ASD sibling relationship have bearing on the view, feel, and experience of the self of the neurotypical sibling. Consequently, embodying intense parental roles and attending to one's sibling through enacting various responsibilities has the potential to overpower one's sense of self. Carrying out one's sibling functions across the sibling relationship may concretise an aspect of the self as all-consuming, resulting in a loss or insecure sense of self when confronted with experiences outside of siblinghood. It can be understood that later adolescence and early adulthood provide a catalyst for such awareness of loss of self and opportunities to reclaim and redefine one's sense of self, a self not delineated by 'sibling'. Additionally, obtaining a clearer sense of the self enables one to fully see their sense of self, a self that is also enhanced by virtue of having a sibling on the spectrum. Awareness of the extent to which one’s sibling on the spectrum has influenced one across one’s life, strengthens the sibling relationship by allowing for connection and a greater appreciation and understanding of such a sibling dyad and relationality with ASD.

Moreover, the participants’ accounts uncovered the centrality of the complex and continuous meaning making of one’s sibling relationship with a sibling on the spectrum. Understandings and experiences of ASD influence one’s interpretation of their lived experience. Subsequently, parallel to changing life stages, was a growth in understanding of ASD. Shifts in understanding illustrate a dynamic lived experience where meaning of one’s reality is constantly altered and challenged. This is noteworthy as it disputes postulations of a definitive understanding of a relationship with a sibling on the spectrum that is fixed and not subject to possible change (Benderix & Sivberg, 2007; Heller & Arnold, 2010; Kaminsky & Dewey, 2001; Latta et al., 2014; Macks & Reeve, 2007; Mandleco & Webb, 2015). It can also be seen how individuals engage in various dimensions of making meaning, such as retrospective guidelines in adulthood and exploring the relationship between ASD and disability. The nuances of disability are apparent within the sensitivity and difficulty of navigating and engaging such a topic. Exploration of this interaction was approached with caution in relation to one’s sibling relationship due to possible implications for one’s view of their sibling, one’s relationality with disability, and the ingrained negative underpinnings and perceptions of disability. Interestingly, discomfort for such interaction was further complicated by exploring identification of a sibling as disabled resultant from disability association, identity reconfiguration, and contending with internal conceptions of disability. Overall, the findings provide succinct, nuanced, and insightful understandings of adult siblings’ retrospective and current accounts of growing up with a sibling on the spectrum.

CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS

A detailed exploration has been offered of the lived experiences of eight adult individuals growing up with a sibling with ASD. This chapter will discuss the conclusions reached, illustrate the study’s contributions and limitations, as well as provide recommendations for practice and future research.

5.1 Conclusion

The current research study aimed to explore the lived experiences of adult individuals growing up with a sibling on the spectrum. Adult psychological experiences of having a sibling on the spectrum have long been negated from the sibling literature, with heavy reliance on parental, child, and adolescent perspectives saturating the literature and informing understandings (Doody et al., 2010; Hall & Rossetti, 2018; Orsmond & Seltzer, 2007a). Whilst these perspectives have been significant and insightful in laying the groundwork for autism sibling studies, they have resulted in an often rigid and hypothesised understanding of the sibling relationship as it evolves over time, particularly in adulthood. Whilst recent studies (Coffman et al., 2021; Johnson et al., 2020; Moss et al., 2019; O'Brien et al., 2020) have begun to contribute to an understanding of the sibling relationship in adulthood and from adult perspectives, more research is still needed to elucidate adult siblinghood and adult lived experiences of growing up with a sibling on the spectrum. Subsequently, this study contributes towards such dearth of information by including adult voices in the sibling relationship discourse.

Through exploring retrospective and current lived experiences of siblinghood from adult individuals, this study enables valuable insights into the nuanced sibling dyad across time, and more specifically, insight into the sibling relationship in adulthood. A significant finding of this study is that siblinghood with a sibling on the spectrum is characterised by an ebb and flow relationality. Subsequently, siblings negotiate between moments of closeness and distance within their relationship across siblinghood, challenging the often rigid or predefined understandings, expectations, and images of autism sibling relationships. These retrospective and current relational negotiations provide significant insight into the multifaceted sibling dyad, where both negative and positive associations were recounted in the current study, further substantiating evidence against absolute dichotomies reported in the literature (Benderix & Sivberg, 2007; Beyer, 2009; Heller & Arnold, 2010; Kaminsky & Dewey, 2001; Latta et al., 2014; Macks & Reeve, 2007; Mandleco & Webb, 2015; Petalas et al., 2009). Negative accounts of the sibling relationship were commonly associated in the current study with the inherent relational barriers of ASD and the impact on familial and social settings. These aspects were found to heighten disconnection within the sibling bond. Consequently, moments of disconnection were found to elicit feelings of loss around an imagined sibling relationship and awareness of a different sibling relationship characterised by distance. Likewise, participants' reported sibling experiences were also characterised by positivity in terms of warmth and connection. Whilst some means of connection may be viewed as atypical to able-bodied sibling relationships, genuine connection and affinity was achieved and cultivated within the participants sibling dyads. This finding of moments and experiences of connection and closeness challenges the reported reduced intimacy and closeness particularly in adult sibling relationships often reported and hypothesised in the literature. The inherent change within this ebb and flow relationality stresses shifting sibling perceptions throughout siblinghood, perceptions that alter the sibling relationship in nuanced ways. This finding of an ebb and flow relationality across the relationship highlights an evolving sibling dynamic with a sibling on the spectrum, akin to able-bodied sibling dyads. Furthermore, this claim is substantiated by participants' differing accounts of their sibling relationship in adulthood, compared to their retrospective accounts.

Additionally, the narratives explored in the study stress the intensity of various sibling responsibilities and roles enacted by neurotypical siblings. These accounts provide insight into the ramifications of the often reported difficult, intense, and tiresome sibling duties on the sibling dyad. Whilst such duties were experienced as negative, some accounts stressed a shift of duties in adulthood, which subsequently changed the dynamics of the sibling relationship. This shift provides further corroboration for an evolving and dynamic sibling relationship across siblinghood. Furthermore, this study's findings enable greater insight into the interaction between the self and one's lived experience of siblinghood with a sibling on the spectrum. The self was expressed as potentially being impacted by the embodiment and enactment of various roles and responsibilities within the sibling relationship because of the presence of ASD. These acts of siblinghood may inadvertently overwhelm and, or blur one's sense of self, resulting in a self heavily delineated by one's sibling. Interestingly, this study found later adolescence and early adulthood to be moments of divergence, enabling opportunities to rediscover and redefine one's sense of self outside of the prevailing sibling self. Contrastingly, this study also found adulthood to be a moment of intersection, where retrospective and current influences on self can be acknowledged and seen as a whole. Subsequently, a moment of reflection on how having a sibling on the spectrum may have also enhanced one's sense of self up to, and including adulthood, aiding connection, and understanding within the sibling relationship.

Moreover, the study illustrates that meaning making of one's sibling relationship is not isolated to a specific life stage, but rather is a continuous, dynamic process across one's life. The findings stress the influential nature of such meaning making engagement, a complex and multifaceted process that alters the sibling relationship both positively and negatively, as one's understandings of their lived sibling experience and knowledge of ASD changes across siblinghood. Through exploring the lived experiences, participants acknowledged that improved understandings of ASD overtime altered their sibling relationship. Likewise, this study found that individuals with a sibling on the spectrum engage in one dominant meaning making process, namely the relationality between ASD and disability. The sensitivity and complexity around this relationality and various associations illuminated the nuanced implications such exploration and engagement could have on the sibling relationship due to perceptions of one's sibling, experiences with disability, disability association, and identification of a sibling as disabled. Overall, the Interpretive Phenomenological Analysis of eight adult individuals' current and retrospective lived experiences of growing up with a sibling on the spectrum illustrates an evolving, complex, nuanced sibling relationship across siblinghood.

5.2 Contributions of the Study

This study has a number of notable contributions. Most significantly, this study contributes to an underexplored area of research, that of adult perspectives of the sibling relationship with a sibling with ASD. Moreover, this study did not only explore siblinghood in adulthood, a common avenue taken with such a sample, but rather explored current and retrospective accounts of the sibling relationship across siblinghood from adult individuals perspectives. Therefore, this study contributes to the emerging literature creating space for adult voices about the past and current sibling relationship, opposed to child, adolescent, and parental voices which have largely saturated the literature (Doody et al., 2010; Hall & Rossetti, 2018; Latta et al., 2014; Orsmond & Seltzer, 2007a). Furthermore, the findings of this study contribute theoretically to the ASD sibling discourse which has been predominately reported as an either-or relationship (Benderix & Sivberg, 2007; Beyer, 2009; Heller & Arnold, 2010; Kaminsky & Dewey, 2001; Latta et al., 2014; Macks & Reeve, 2007; Mandleco & Webb, 2015). This study supports growing viewpoints that having a sibling on the spectrum does not automatically delineate such sibling dyad as negative or positive. Rather, this relationship is subject to typical relational ebbs and flows of moments of disconnection and connection. Thus, this relationship evolves overtime and is not fixed or determined by specific childhood or adolescent relational patterns or dynamics. Moreover, this study contributes methodologically to the limited qualitative studies exploring the sibling experience with a brother or sister on the spectrum. This scope of research frequently adopts a quantitative paradigm (Doody et al., 2010), negating the rich accounts derived from exploratory studies. Lastly, this study contributes to limited ASD research within South Africa (Malcom-Smith et al., 2013).

5.3 Clinical Implications

Exploring the current and retrospective accounts of adult individuals' experiences of growing up with a sibling on the spectrum resulted in several important implications for practice. The participants expressed contradictory emotions towards their parent-child relationships within the earlier years of their sibling relationship; namely feeling love for their parents yet also anger and resentment for differential treatment and assumption of parentification. Whilst there was an overarching understanding for differential treatment from their parents and a feeling of obligation to enact various sibling functions to ensure homeostasis, the participants were not impervious to feeling overwhelmed, angry, unseen, and unsupported by their parents. Coupled with a desire to offer parents respite, maintain the 'good' sibling role, and understanding that one's sibling on the spectrum needed more assistance, created a sense of inherent pressure to not complain, ask for help, or give an impression of not being able to perform the various sibling duties, especially within the earlier years of the sibling relationship. Subsequently, these findings stress significant implications for the parent-child relationship when one child in the family has ASD and offer valuable insight into areas of improvement for such a relationship. Thus, it is hoped that these findings can increase parents' awareness of the experience of their neurotypical child and guide them in their efforts to increase support they provide to this child within the home environment, as well as create an environment where the neurotypical child is empowered to voice difficulty, distress, and contradictory emotions. Likewise, psychoeducation on the implications of parents assuming or imposing responsibility onto neurotypical sibling(s) and implications of siblings enforcing boundaries around enacting their roles and responsibilities is necessary. This psychoeducation can further enhance the parent-neurotypical child relationship, as well as aid the neurotypical sibling's understanding of maintaining a balance between their sibling duties, being a sibling, and their own wants and needs, thus safeguarding the sibling relationship.

Additionally, the participants' accounts detailed experiences of confusion, frustration, and anger because of a lack of understanding of ASD and its characteristics, as well as tools to encounter and combat various relational barriers within the sibling relationship. This description stresses the imperative for health professionals, schools, and organisations offering services for individuals on the spectrum to include and work with the siblings of an individual with ASD throughout the stages of the intervention plan, instead of utilising a monomodal treatment intervention focused solely on the individual with ASD. Research has stressed how an ASD diagnosis does not only impact the individual diagnosed but also the entire family of that individual (Coffman et al., 2021; Leedham et al., 2020). Therefore, including siblings in intervention plans, and creating programs that foster sibling involvement and interaction may result in beneficial outcomes. Empowering siblings with knowledge and tools to aid their experience of their sibling with ASD, the expertise of how to engage and communicate with their sibling, as well as equip them with coping mechanisms, may enhance the sibling relationship. Subsequently, practitioners and educators should avail resources to siblings of their clients, that can in turn aid their meaning making and navigation of their sibling relationship. Interestingly, a diagnosis that strives for inclusivity is often exclusive in its treatment and management. Inclusivity has the potential to enhance the sibling relationship, as both members of the dyad are involved and supported in the continuous process of engaging in efforts to understand one another and improve and strengthen the partnership innate to siblings.

In addition to including siblings in the interventions, another implication of the present study's findings is the poignance of not trying to connect with one's sibling on the spectrum, despite strong desires for a sibling bond. Although oscillations of connection and distance characterised many participants' sibling relationships across their siblinghood, the findings of this study illustrate the benefits of muddling through various relational barriers, adverse feelings, and experiences of being rebuffed, to strive for some resemblance of a sibling connection. Although it is noted that it may be overwhelming and onerous to continue muddling through, the findings also assist in this regard by denoting various components for establishing potentially meaningful sibling relations. One should understand the importance of becoming acquainted with one's sibling – getting to know their sibling, their personality, and interests. Secondly, one should invest time and effort in finding means to communicate and connect, opposed to using conventional means that may not be optimal for one's sibling with ASD; or abandoning efforts when rejected or aggravated by no desired outcome. Thirdly, one should strive for shared experiences, as this may lead to shared growth and development, encouraging a more collaborative and relational sibling dyad. Lastly, one should not view one's ASD sibling as less than, since such disparity in perception can limit one's understanding of their ASD sibling, put them in a box, undermine their capabilities, cause the emergence of resentment, and impose feelings of inferiority onto one's brother or sister on the spectrum. Therefore, it is hoped that individuals with siblings on the spectrum will employ these findings as guidelines to achieve a sibling bond and to avoid future regret, as well as to understand the benefits of muddling through the difficulty to arrive at a place of closeness and connection.

Furthermore, a common trend amongst participants across their different lived experiences of their sibling relationship was the necessity of support. Whilst increased parental support is optimal for the improvement of the individual's lived experience and their sibling relationship, support outside the home environment as expressed by the participants is just as vital. Parents and healthcare practitioners should provide access to sibling support groups for individuals with a sibling on the spectrum, but such support groups should also be sought out by the siblings themselves. Sharing information and connecting with others with a sibling with ASD potentially enables support different from that given by a parent, friend, or extended family member. Connecting with others through shared experiences of siblinghood can reduce isolation of such experience and foster engagement, understanding, and companionship. Engaging in support groups with other siblings of autistic people may: alleviate difficulties; enable insight and understanding about ASD and its related challenges; allow for joint learning; offer solutions to relational barriers; encourage an awareness of togetherness; create an outlet for honest expression of emotions; allow for discussion about and access to resources to aid future care and responsibilities; encourage connection and improvements within the sibling relationship; and offer a space for shared understandings of the sibling experience. Essentially, support groups can offer a wealth of resources from individuals with a shared yet different experience that can aid the betterment of the sibling dyad across siblinghood. It is noteworthy to mention that the participants expressed a dearth in awareness of such sibling support groups, as such this postulates the need for the creation, access, and promotion of sibling support groups by practitioners working within the field of ASD in South Africa.

The findings of the study revealed that an ASD sibling relationship is nuanced and complex across the sibling lifespan. The emotional and personal accounts described by participants within their lived experiences of growing up with a sibling on the spectrum may need to be processed and explored to make sense of one's sibling relationship and continued lived experience. Thus, parents and / or healthcare practitioners should encourage therapeutic support for siblings of individuals with ASD, to facilitate the unpacking and understanding of their lived experience across their siblinghood as a postulated means to begin improving and enriching the sibling relationship. Additionally, public perception was reported as impacting the sibling dyad and one's sense of self. Subsequently, there is a need for the establishment of advocacy groups to raise awareness and improve public and professional knowledge of and around ASD.

A further implication for practice that emerged is with regards to the future of care for one’s sibling on the spectrum. Whilst participants expressed diverging views around taking on such responsibility, an underlying anxiety was evident. This was primarily as a result of no conversations being had, either until the siblings were older or until there was an awareness of the autistic siblings’ capabilities. Resources should be made available to educate parents on the necessity of addressing such a conversation and equip them with tools on approaching such conversations with their children. An awareness and space to converse about the unknown and weight of such responsibility may reduce inherent anxiety and fear of taking on this later life responsibility. Additionally, healthcare practitioners and various living facilities should also be vigilant in their roles of guiding and assisting individuals with the intricacies of embarking on this responsibility when the time comes. However, such guidance should not negate the sibling’s knowledge, experience, and involvement of previous care taking of their ASD sibling. Enacting such obligation with confidence and an understanding of resources and options available may facilitate a smoother transition for both the individual and their sibling with ASD.

A final implication for practice is with regards to resources for individuals with ASD. The participants recounted complex processes of accessing appropriate support for their siblings with ASD in South Africa. This difficulty was attributed to inaccessibility, unequal division of resources, financial strain, unjust enrolment criteria, and limited treatment options. This implication calls on policy makers to implement policies stipulating the development of diverse ASD service within South Africa, with stringent measures ensuring equal access of resources for all ASD individuals and their families, regardless of socio-economic standing. For such policies to adhere to their mandate they need to be accompanied by increased grant and scholarship opportunities, as well as medical aids or medical policies covering various therapies and services for individuals on the spectrum. In addition, the onus also lies with schools and organisations offering services for individuals on the spectrum to be more rigorous in their promotion and engagement with communities to ensure a wider reach of individuals, as well as maintain fair service fees and adequate enrollment criteria. These schools and organisations should also be subject to inspections and guidelines detailing appropriate services. An individual with ASD should not be denied support due to limited services, lack of awareness of available services, inadequate service delivery, and financial burden. In turn, siblings of those with ASD may be less likely to undertake significant responsibilities within the sibling relationship but at the same time may be better equipped to aid their sibling.

5.4 Limitations of the Study

The study drew valuable insights from adult siblings about their sibling relationship with their sibling on the spectrum. While the findings of this study are noteworthy, it is important to acknowledge their limitations. This study focused on the experiences of adult individuals with a sibling on the spectrum. Owing to this, when conducting the research, only the adult individuals' perceptions were considered. As a result, the voices of the siblings with ASD were not heard. Joint voices of both individuals within the sibling dyad may have enabled a more comprehensive understanding of the sibling relationship with a sibling on the spectrum.

Additionally, the small sample size reduces the ability to generalise the findings of this study. However, it was not the intention of this study to necessarily generalise findings to a wider population. Rather, the significance of the findings is apparent in the richness of information and nuanced understandings provided about adult perspectives on the sibling relationship with a brother or sister on the spectrum. In addition, only eight adult individuals were interviewed, and this small sample size may be deemed a limitation. However, given that this research is situated within a qualitative paradigm with a focus on in-depth inquiry, a larger sample was unfeasible. Thus, it can be reasoned that such sample size was suitable. This was further substantiated by the rich data collected; subsequently the sample was capped at eight participants.

Perhaps the characteristics of the sample may be considered a limitation in that an equal sample of differing ethnicities representative of South Africa's diverse population could make for a more representative collection of adult individuals' experiences of growing up with a sibling on the spectrum. Likewise, the gender imbalance within the sample (more females to males) and within the siblings with ASD (more males to females), may pose another limitation. The sibling gender imbalance is representative of the diagnostic gender bias, wherein females are at a disparate risk of not receiving an ASD diagnosis as symptomatology and presentation is postulated to manifest differently as reported in males with ASD (de Giambattista et al., 2021; Loomes et al., 2017; Zhang et al., 2020). Although this study did not explore gender as a determining factor for siblings' experiences, accommodating an equivalent representation of gendered participants and their siblings may enable for differing findings of the lived experiences of adult siblings with a sibling on the spectrum.

Moreover, the sample was obtained via an advert posted on the researcher's personal social media pages, as well as on various organisations and ASD support groups' social media pages. Subsequently, this sampling method excluded people from extremely low-income backgrounds who do not have access to the internet and or social media, thus findings are not necessarily representative of all socio-economic classes in South Africa.

5.5 Recommendations for Future Research

Given the under-exploration of adult perspectives, specifically in autism sibling research, it is recommended that future research continue to explore this narrative to add to the extant child, adolescent, and parental voices within the literature. Subsequently, there is room for expansion on this current topic, such as exploring adult perspectives with a targeted sibling sample (sibling pairs with equal age gaps or both in adulthood, individuals with older or younger ASD siblings, specific cultural, racial, or socio-economic groups) or exploring the determinants that mitigate or impact the sibling relationship from adult perspectives (gender, age-gap, birth order, having additional siblings or living situation). The benefits of current and retrospective accounts offered by an adult perspective are endless and enable a springboard to explore the multifaceted nuanced ASD sibling relationship across the lifespan. Further to this, future research could elucidate the current findings by including the adult perspectives of both the sibling and the sibling with ASD. A dyadic approach may yield differing findings and a dynamic understanding of the sibling relationship across siblinghood. Moreover, a possible suggestion is to conduct a longitudinal study to explore the sibling relationship with a sibling on the spectrum from an adult perspective, across the different phases of adulthood – early, middle, and late adulthood. Lastly, researchers need to be mindful of how they portray the experience of ASD sibling relationships, not avoiding the difficulties experienced and reported, yet also acknowledging and noting the positives of such a sibling dyad. ASD is a significantly under-researched field within South Africa, thus research exploring sibling relationships with a sibling on the spectrum will continue to contribute to the limited pool of ASD research.

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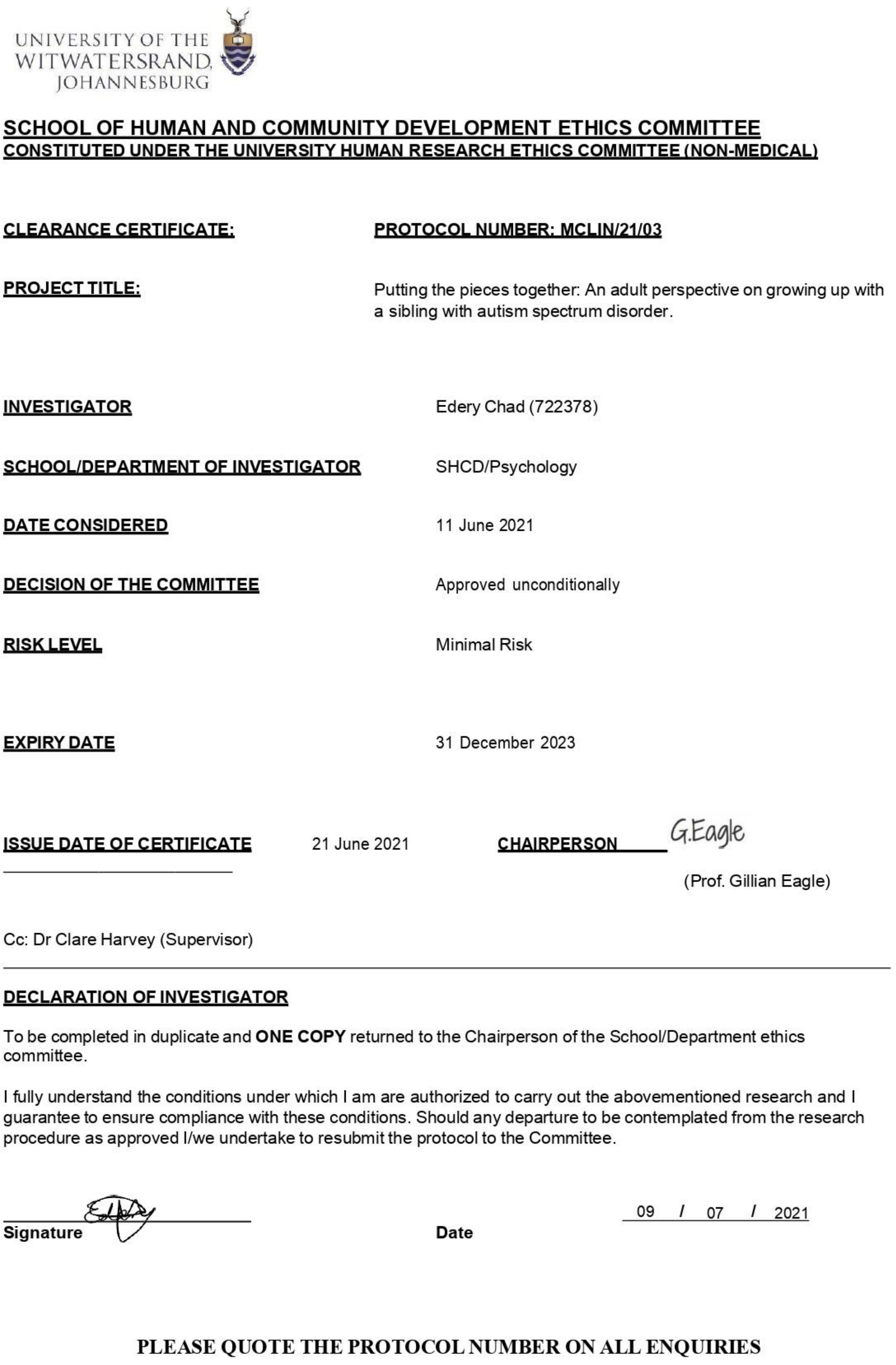
Appendices

Appendix A: Ethical Clearance Certificate



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE
CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

CLEARANCE CERTIFICATE:	**PROTOCOL NUMBER: MCLIN/21/03**
PROJECT TITLE:	Putting the pieces together: An adult perspective on growing up with a sibling with autism spectrum disorder.
INVESTIGATOR	Edery Chad (722378)
SCHOOL/DEPARTMENT OF INVESTIGATOR	SHCD/Psychology
DATE CONSIDERED	11 June 2021
DECISION OF THE COMMITTEE	Approved unconditionally
RISK LEVEL	Minimal Risk
EXPIRY DATE	31 December 2023

ISSUE DATE OF CERTIFICATE 21 June 2021 **CHAIRPERSON** G.Eagle

(Prof. Gillian Eagle)

Cc: Dr Clare Harvey (Supervisor)

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I fully understand the conditions under which I am are authorized to carry out the abovementioned research and I guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.

Signature **Date** 09 / 07 / 2021

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix B: Letter of Invitation

A Clinical Psychology
Masters Study

RESEARCH
PARTICIPATION NEEDED

AUTISM

An Adult Sibling Perspective

Are you 25-60 years old?

Do you have a sibling with autism spectrum disorder?

Have you lived with them for all or most of your childhood?

Share your story of growing up with a sibling on the spectrum, in a 60 - 90 minute online Zoom interview.

Contact Chad Edery (the researcher) at
chad.edery@gmail.com

Appendix C: Interview Schedule

INTERVIEW SCHEDULE

Demographic questions:

1. How old are you?
2. What is your gender?
3. What is your race?
4. How old is your ASD sibling?
5. What gender is your ASD sibling?
6. Do you have any other siblings? (gender? birth order?)
7. Do you still live with your ASD sibling?
8. How long did you live in the same household as your ASD sibling?
9. When did you learn that your sibling had ASD (if applicable)?
10. What level of severity is your siblings ASD?

Interview guide:

1. What comes to mind who you think about your **childhood** growing up with a sibling on the autism spectrum?
    a. Elaborate – can you tell me something about what it was like to have a sibling with ASD?
    b. What feelings, reactions come to mind when you think about your upbringing?
    c. Looking back, how did you perceive or make sense of your sibling's behaviour?
    d. How would you describe your relationship with your ASD sibling when you were growing up?

    e. What did you know about ASD when you were younger? How did you learn this?
    f. Was your sibling’s disorder talked about? If so, with whom?
    g. Do you feel that your sibling’s ASD influenced your development in any way? If so, how?

2. Was there anything difficult about your experience of growing up with a sibling on the spectrum?
    a. Follow up – so what are some negative aspects of your relationship when you were younger?
3. Was there anything easy about your experience of growing up with a sibling on the spectrum?
    a. Follow up – so what are some positive aspects of your relationship when you were younger?
4. Can you recall any happy or unhappy times in particular?
5. Did growing up with a sibling on the spectrum influence your family and social life? If so, how? And if not, why?
    a. Follow up – how much time did you spend together / what activities did you do together?
    b. How would you describe your interactions?
    c. Do you think age or family life played a factor in your relationship?
6. What role/roles do you think you played in your sibling relationship?
    a. What did you like about this role?
    b. What do you not like about this role?
7. In what ways is your relationship similar to other relationships?
8. In what ways do you imagine your relationship is different to other relationships?

9. There is something called the broader autism phenotype, would you say you were ever concerned about being diagnosed with ASD yourself/ of showing ASD symptoms?
10. Is there anything you would change about your childhood and or adolescence of growing up with your sibling?
11. When you were younger how would you describe autism to someone who had never heard about it?
12. How would you describe autism now to someone who has never heard about it?
13. Do you consider ASD to be a disability? Why?
14. Do you view yourself as having a sibling with a disability? Why?
15. What feelings or thoughts do you have (if any) with regards to difference and or otherness?
16. How would you describe your relationship with your sibling today, as an **adult**?
    a. How do you think your relationship will change as you get older?
17. Looking back, how has your relationship with your sibling changed from when you were younger?
18. What is rewarding about your relationship today?
19. Is there anything difficult about your relationship today?
20. Is there anything easier about your relationship today compared to when you were both children and/or teenagers?
21. Has having a sibling with ASD influenced your adult life? If so, in what ways?
22. Has your role in your sibling relationship changed as you have gotten older?
    a. What do you like about this role?
    b. What do you not like about this role?
23. What role does your sibling play in your adult life?
24. Has your perception of your sibling changed overtime? If so, how?

25. Do you feel that ASD impacted your sibling relationship in any way?
26. What advice would you give to other siblings who have a brother or sister on the spectrum?
27. Thank you for answering these questions. Is there anything that I have not asked about your experience that you would like me to know, or feel is important for people to understand one's experience of growing up with an ASD sibling?

Debrief questions:

1. How did you experience the interview in terms of talking about your sibling relationship?
2. Were you surprised at anything that arose?
3. Did the interview bring up any emotions you would like to discuss?
4. Is there anything in particular that you would like to discuss?
5. Are you feeling alright to finish the interview now?

Appendix D: The Participant Information Sheet

School of Human and Community Development
Private Bag 3, Wits 2050,
Johannesburg,
South Africa
TEL: 011 717 4500 **FAX:** 011 717 4559

Participant Information Sheet

PUTTING THE PIECES TOGETHER:
AN ADULT PERSPECTIVE ON GROWING UP WITH A SIBLING WITH AUTISM SPECTRUM DISORDER

Dear Sir / Madame,

My name is Chad Edery, and I am a Masters student in Clinical Psychology at the University of the Witwatersrand, Johannesburg. As part of my Degree, I am conducting a research project under the Supervision of Dr Clare Harvey, exploring adults' perspectives of growing up with a sibling on the autism spectrum.

I would like to formally invite you to take part in my research study. Participation will involve an individual online interview via Zoom (alternatively WhatsApp video call), to accommodate for the necessary COVID-19 social distancing protocols. The interviews will be between 60 to 90 minutes long and involves answering questions around your experience of having a sibling on the spectrum. Participation is completely voluntary, as such, you are free to withdraw from the study at any time prior to the data analysis, without facing any negative repercussions. Participating in the interview will not disadvantage or advantage you or others in any way and if there are any particular questions during the interview that you feel are difficult to answer, you may refrain from answering them.

Moreover, for analysis purposes and with your consent, the interview will be audio recorded (the Zoom platform enables one to save an audio only recording), of which confidentiality will be ensured by storing the recordings and transcripts in a password-protected computer folder that will only be accessible to myself and my supervisor. This will be maintained following the completion of this thesis for potential future publications. Further, interviews will take place in a secured Zoom meeting, using a specific meeting ID and password, only accessible to a specific participant and myself or alternatively a WhatsApp video call will be used. Additionally, the researcher will conduct interviews in a private setting to ensure no one is able to overhear the information shared and to avoid interruptions. Although, complete anonymity will not be guaranteed as face-to-face interviews will take place, no identifying information will be used, and participants will be given pseudonyms (a false name) such as John, Adam, or Jaimie, to aid anonymity in the case of direct quotes potentially being included in the final report. Thus, final anonymity in the research report can be assured.

Due to this study requiring participants to express and divulge their lived experiences of siblinghood, it may potentially elicit sensitive and complex emotions. Consequently, if you feel unduly stressed or wish to explore a topic further, please make use of the free counselling services at the Emthonjeni Community Centre at the University of the Witwatersrand:

- Emthonjeni Community Centre:
    - Ms. Paballo Lepota
    - Tel: 011 717 4513
    - Email: paballo.lepota@wits.ac.za

Lastly, before you take part in the interview, I ask that you please read through and sign a consent form. This form will confirm that you understand what is required by participating in the study.

Should you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact Shaun Schoeman at the University Human Research Ethics Committee (Non-Medical), telephone 011 717 1408, email Shaun.Schoeman@wits.ac.za. Additionally, should you have any questions or concerns regarding any aspect of this study, please free to contact myself or my supervisor.

Kind Regards

Chad Edery (Researcher)	Dr Clare Harvey (Supervisor)
0828842831 chad.edery@gmail.com	0117179999 clare.harvey@wits.ac.za

Appendix E: Consent Form

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

School of Human and Community Development
Private Bag 3, Wits 2050,
Johannesburg,
South Africa
TEL: 011 717 4500 **FAX:** 011 717 4559

Consent Form

PUTTING THE PIECES TOGETHER:

AN ADULT PERSPECTIVE ON GROWING UP WITH A SIBLING WITH AUTISM SPECTRUM DISORDER

I... consent to taking part in the interview conducted by Chad Edery, for his Master’s Degree in Clinical Psychology study, that will be exploring adult perspectives of growing up with a sibling on the autism spectrum. The research has been explained to me and I understand what my participation will involve.

As a participant in his study, I understand that (please tick yes/no accordingly):

	YES	NO
My participation is voluntary.		
I am able to withdraw from the study at any time prior to data analysis.		
I do not have to answer any question(s) I do not wish to.		
All my personal details and information will remain confidential and anonymous, although I may be quoted in the final report. However, if I am quoted, it will be under a pseudonym.		
Participation involves the audio recording of the interview.		
The recordings and transcripts from the interview discussion will remain confidential and stored in a password-protected file accessible to only Chad and his supervisor.		
The results of the study will be used in the research report that is required for the completion of the Masters in Clinical Psychology Degree.		
I give permission for my data to be used in future research.		

Signed.. Date..

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by Chad Edery

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