

**LIVING WITH A SIBLING DIAGNOSED WITH AUTISM SPECTRUM DISORDER:
AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS**

BY

EDZANI ONICA DONGOLA

Submitted in accordance with the requirements for the degree of

MASTER OF ARTS IN PSYCHOLOGY: RESEARCH CONSULTATION

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: PROFESSOR ILSE FERNS

November 2018

DECLARATION

I Edzani Onica Dongola (student no 61439312) hereby declare that the dissertation entitled *Living with a sibling diagnosed with autism spectrum disorder: An interpretative phenomenological analysis* is my own work, and that I have acknowledged all the sources quoted by means of a complete list of references. I further declare that I have not submitted this work or part of it thereof for examination for another qualification.

SIGNATURE:

Ms Edzani Onica Dongola

DATE:

ACKNOWLEDGEMENTS

I am mostly grateful to God, for bestowing good health and overall wellbeing unto me during this journey.

I would like to express my deepest gratitude to my supervisor Prof Ilse Ferns. Thank you very much for your continuous support, motivation, patience and enthusiasm.

A big “thank you” to my father, Mr T.E Dongola, who has always supported my academic journey. Without you daddy, this would not have come close to completion. I appreciate your words of encouragement, full support and love. To my two mothers: Mma Vho-Avheani, I know if you were here, you would be proud of me, “Mama I made it.” Mma Vho-Muongwa, thank you for all your love and support. I would also like to thank and acknowledge my grandmother, Vho-Nyamukmadi: *ndo livhuwa thikhedzo yavho na ngeletshedzo dzavho*. To my aunt, Mme muhulu Vho-Gile, *ndia livhuwa u dzula vhatshi nntutuwedza*

Hangwe, Rabe, Dzivhu, Fhulu, Adel, Khathu, Musa, Lusi, Mulalo, Todi and Livhu; you all have shown me love and support throughout this journey. Thank you very much. My two close friends – Lydia and Nyiko, thank you ladies, for the support you have given me. Although you are far away, I could always rely on you for strength and motivation. Esther, thank you for being a great mentor and friend.

I would also like to extend my deepest appreciation to Autism South Africa, who were the biggest help in connecting me with some of the participants. I am also grateful to everyone else who played a part in sharing information to make this study possible.

I am very grateful to the siblings of individuals with autism and their families, who welcomed me into their homes and into their spaces with open arms. Your welcoming hearts, your willingness to share and the ability to reflect, has humbled me. Without you, none of this would have happened.

Last, but definitely not least, I would love to thank the Marc team and the 2017 Marc Alumni, I am grateful for guidance and constructive criticism. A special “thank you” goes to Harold Ncongwane and Gadi Malatsi for their contribution and expertise.

ABSTRACT

This qualitative study explored the experiences of individuals living with a sibling diagnosed with Autism Spectrum Disorder (ASD) and how these individuals make meaning of this experience. The data for this study was collected from five (5) individuals between the ages of 12 and 19, who shared their experience of living with siblings diagnosed with ASD. The data was analysed using the interpretative phenomenological analysis method (IPA). I conclude that although living with a sibling diagnosed with ASD is a challenging experience, the way one makes meaning from the experience contributes greatly to their interpretation of their experience thereof; and therefore, making it a positive experience. The participants in this study showed great maturity and resilience. The findings of this study will be useful to parents, professionals and those who engage with individuals living with a sibling diagnosed with ASD.

Keywords: Autism Spectrum disorder, Siblings, Interpretative Phenomenological Analysis, Experiences, Normal functioning, Making meaning, Bio-ecological model, Family, Living with, DSM-5

TABLE OF CONTENTS

DECLARATION	i
ACKNOWLEDGEMENTS	ii
ABSTRACT	iii
CHAPTER 1: INTRODUCTION	1
1.1 Background	1
1.2 Research problem	2
1.3 Research aims	4
1.4 Research objectives	4
1.5 Significance of the study	7
1.6 Definition of key terms	8
Autism Spectrum Disorder	8
Siblings	8
Normal functioning	8
1.7 Chapter overview	8
CHAPTER 2: THEORY AND LITERATURE REVIEW	9
2.1 Introduction	9
2.2 Autism spectrum disorder: An overview	9
2.3 Autism Spectrum Disorder: Parents and caregivers	11
2.4 Siblings	15
2.4.1 Siblings in an African context	15
2.5 Autism Spectrum Disorder and siblings	20
2.5.1 Positive and negative influences	20
2.5.2 Psychological functioning	21

2.5.3	Attitudes and behaviour	23
2.5.4	Relationships.....	24
2.6	Theoretical framework.....	25
	Figure 2.1 Bronfenbrenner’s bio-ecological model.....	27
2.7	Chapter overview.....	28
CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY		30
3.1	Introduction.....	30
3.2	Research questions.....	30
3.3	Research paradigm.....	30
3.3.1	Qualitative approach/method	30
3.3.2	Interpretative phenomenology	31
3.4	Research methodology.....	32
3.4.1	Population	33
3.4.2	Sampling criteria.....	33
3.4.3	Inclusion and eligibility	33
3.5	Data collection	34
3.6	Data analysis.....	35
3.7	Measures to ensure trustworthiness.....	37
3.7.1	Credibility	37
3.7.2	Transferability.....	38
3.7.3	Dependability	38
3.7.4	Confirmability.....	39
3.8	Ethical considerations	39
3.8.1	Informed consent	40
3.8.2	The best interest or wellbeing	40
3.8.3	Respect for the participants.....	41

3.8.4	Stranger as the researcher	41
3.9	Chapter overview	41
CHAPTER 4: RESULTS		43
4.1	Introduction.....	43
4.2	Background of participants	43
	TABLE 4.1 Backgrounds of research participants	44
4.3	Presentation of themes	44
	TABLE 4.2 Summary of main themes and sub-themes	45
4.3.1	Main theme 1: Loss of the self.....	45
4.3.2	Main theme 2: Learned behaviour	50
4.3.3	Main theme 3: Available support.....	58
4.3.4	Main theme 4: Making meaning	67
4.4	Chapter Overview	71
CHAPTER 5: DISCUSSION.....		72
5.1	Introduction.....	72
5.2	Discussion of the research findings	72
5.2.1	Themes related to loss of the self:.....	72
5.2.2	Themes related to learned behaviour:	76
5.2.3	Themes related to available support:	81
5.2.4	Themes related to making meaning:	85
5.3	Clinical implications	87
5.4	Strengths of the study	88
5.5	Limitations of the study	89
5.6	Researcher reflections.....	89
5.7	Recommendations for future research	90

5.8 Conclusion	91
References.....	92
APPENDIX A	106
APPENDIX B	109
APPENDIX C	110
APPENDIX D.....	111
APPENDIX E	115
APPENDIX F.....	117

CHAPTER 1: INTRODUCTION

1.1 Background

The prevalence of the autism spectrum disorder (ASD) is on the rise. Previous studies conducted record that one in every 2000 children in the 1970s and 1980s was diagnosed with the disorder (Doheny, n.d.). In 2016 the incidence of children diagnosed with ASD has increased remarkably, with studies revealing that globally, one in 160 children was diagnosed with the disorder (World Health Organisation, 2016).

Therefore, one can argue that it is important for studies to investigate further this phenomenon by exploring the experiences of those who live with individuals diagnosed with the condition, notably, siblings.

An ASD diagnosis has ramifications for the affected individual, as well as the people who are involved in his/her life, on a daily basis – hence, the researcher became curious to explore the experiences and perceptions of people who live with such individuals. Moreover, from a developmental psychology perspective, and bearing in mind Urie Bronfenbrenner’s bio-ecological systems theory, a diagnosis of ASD has a bearing on the different facets of the diagnosed child’s life. How dire these ramifications are is compounded by the different systems in the child’s life (Gillibrand, Lam & O’Donnell, 2011).

In South Africa, institutions such as the University of Cape Town are dedicated to conducting autism specific research (UCT ACSEPT, 2017). Centres and schools, such as Autism South Africa, and schools that cater for individuals with ASD are dedicated to assisting families and individuals with ASD (Autism South Africa, 2017). Furthermore, many scholars have taken the time to conduct research on the various aspects of ASD across the world. Although ASD is slowly becoming a well-researched disorder in South Africa (Martins, Walker & Fouché, 2013), these studies did not explore the experiences of siblings living with individuals diagnosed with ASD.

Unlike the previous studies, the current study follows a new angle by exploring the experiences of children who live with a sibling diagnosed with ASD. Unlike many previous studies (e.g. Doody, Hastings, O’Neill & Grey, 2010; Giallo, Roberts, Emerson, Wood & Gavidia-Payne, 2014), this particular study looks specifically at the home environment,

where siblings live together. The purpose of conducting this research was to try to get an insight into the unique experiences of siblings of children with ASD.

According to De Caroli and Sagone (2013), siblings can be regarded as “surrogate parents, informal teachers and friends” (p. 1217). Siblings play a role in how each of them develop psychologically (Whiteman, McHale & Soli, 2011). In doing so, their bond can be strong, but can sometimes become complicated, due to certain circumstances at home, school or anywhere else. Complications of this nature can be caused, for example, by the differential treatment that parents give to their children. The birth order of all siblings in the family, among other factors, can also cause these similar complications in the household.

1.2 Research problem

The current researcher has worked with individuals diagnosed with ASD before. As a result, the experience she gained through working with individuals diagnosed with ASD has made it easier for her to interact with families, friends and caregivers of children with ASD. The researcher also comes from a big family and as such, knows what it is like to be part of a household with many siblings. This in turn, has created curiosity in the researcher in respect of the experiences of living with a sibling diagnosed with ASD, and the meaning making thereof. Moreover, having read about and having interacted with people diagnosed with ASD; has added to the researcher’s curiosity and enabled her to identify the underlying gaps in the research, in this regard.

A further review of literature exposed the researcher to more studies that explored ASD and how this can impact on the lives of individuals living with persons diagnosed with ASD.

The focus of these studies had been more on caregivers, parents and the experiences of siblings of children with ASD (Herlihy, Knoch, Vibert & Fein, 2015; Martins et al., 2013; Mbwilo, Smide & Aarts, 2010).

The gap was, however, identified on the experiences of children who live in the same household with their brothers or sisters diagnosed with ASD. Furthermore, it has been noted that many studies that focused on the experiences of siblings tended to look at these experiences from the perspectives of parents or teachers (Walton, 2016). Further studies in this regard focused on individuals in the older age group; for example, those between the

ages of 19 and 72 (Doody et al., 2010); while others looked at the relationship with their siblings with ASD (Rossetti & Hall, 2015).

Although such studies are necessary, and make a contribution to the existing body of knowledge, the researcher saw that it was equally important to consider the voices of individuals who live in the same household with their siblings with ASD, as this will provide a new perspective in this regard (Lovell & Wetherell, 2016).

Many families keep the ASD diagnosis and other child psychopathologies a secret, or shy away from talking about them (Mbwilo et al., 2010). In addition, there is still much uncertainty about ASD and other psychopathologies among parents, children, as well as communities (Mbwilo et al., 2010; Scorgie et al., 2014). It was, therefore, crucial for the researcher to explore further the phenomenon of ASD.

This was not the first study to explore the experiences of individuals living with a sibling diagnosed with ASD – few qualitative studies have been conducted in the past, in this regard. These studies tended to look at autism traits in siblings and parents (Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001; Ruzich et al., 2016). Although the findings of these studies seem to be valuable, a gap in knowledge still exists in respect of the core experiences of siblings of individuals who diagnosed with ASD. Studies such as this one contend with the fact that the diagnostic criteria for ASD have changed to a certain extent over the years. Currently, the focus is on the DSM-5. Previous researchers used the DSM-I through DSM IV TR. These versions are reviewed repeatedly, and one often finds thoroughly revised versions of the DSM.

According to Inam and Kausar (2016), when one child in the family has a disability, parents tend to focus all the attention on the child with a disability, while neglecting, though unintentionally, other children without disabilities. For this reason, studies that focus on the experiences of siblings living with a brother or sister diagnosed with ASD as related by parents cannot be considered as completely credible; as the parent speaks on behalf of the child he/she is supposedly paying less attention to (Giallo et al., 2014).

Although previous studies have made some valuable contribution to the knowledge of ASD, they did not explore in detail, the essence of being a sibling of an individual with ASD. As a result, it is important to explore the experiences of those children who are living with a sibling diagnosed with ASD. This was necessitated by an increasing number of children, who

are being diagnosed with ASD. The experiences of siblings of children with ASD are, however, not commonly explored in South Africa. The researcher deems it necessary to explore the experiences of these children, as this can assist in identifying current and future support systems for siblings who find themselves in this situation. Hence, the researcher conducted an in-depth study on what it is like to have a sibling with ASD.

There is a vast amount of literature that covers the perspectives of parents and caregivers in respect of taking care or raising an individual with ASD (Al-dujaili & Al-mossawy, 2017; Ozturk, Riccadonna & Venuti, 2014; Scorgie, 2017). However, little is known about the actual experiences of the siblings themselves, who live at home with individuals with ASD.

Therefore, this study sought to fill this gap by exploring the experiences of the siblings themselves, from their own perspective. It is important to report on the siblings' own perspectives as this gives more credibility to the findings (Lovell & Wetherell, 2016).

1.3 Research aims

The current study aimed at exploring the experiences of children who live with their siblings with ASD. The main aim of this study was to ascertain and gain insight into the extent to which these children experience having a sibling with ASD. The researcher followed an interpretative phenomenological approach in analysing the data. The researcher paid special attention to the experiences of children in their immediate home environment, also known as the micro system, according to Bronfenbrenner's (2005) bio-ecological theory in order to contribute to the existing support systems for these children and more like them.

1.4 Research objectives

The main objective of this study was to explore the experiences of children living with siblings diagnosed with ASD, by paying special attention to the home environment. Certain factors contribute to these children's experiences, as well as how they make meaning of these experiences. Hence, this research paid particular attention to these factors, while looking at these children's experiences, and how they make meaning thereof. The following is a brief overview of the factors that the study explored:

- Birth order

The order in which siblings are born comes with certain responsibilities and roles that the siblings play (Meltzer & Kramer, 2016). These responsibilities and roles are almost automatic and not necessarily agreed upon or negotiated. Thus, being an older sibling can automatically make one an assistant parent, in some ways (Gilmore, 2016). While the younger siblings are known to be the 'babies' and the spoilt ones in the family, older siblings seem to play the role of a parent, as the parents tend to have confidence in their ability to make decisions, including the decisions involving their younger siblings (Iturralde, Margolin, Lauren & Shapiro, 2013).

When there is a child with a disability in the family, the so-called birth order roles are often reversed. These changing roles may contribute to the manner in which a child experiences their sibling with ASD, and how they make meaning thereof.

- Gender of the child and their sibling

Society has specific gender roles and gender responsibilities prescribed for males and females respectively. When growing up, children are usually socialised to perform certain gender-specific roles – such as when girls are dressed in pink; and boys in blue. As girls grow up, they are given dolls as toys and kitchen sets – thus, they are being groomed to be mothers and nurturers in the process. Girls are also encouraged to sit and walk in a certain way, considered proper. On the other hand, growing up; boys are given toy cars and toy guns. They are discouraged from crying, as suggested by the adage, **men are tigers, they don't cry**' as crying, it is said, is associated with girls and suggests that as a man, one is strong (Mwamwenda, 2013).

These gender-specific roles, which girls and boys are socialised into from a young age shape their behaviour as they grow up. These gender roles thus, determine a child's experiences of living in the house with other family members. The manner in which gender roles are emphasised in a household shapes how a child relates to their sibling(s), and ultimately their experiences (Ozturk et al., 2014).

In households where one or more children are living with their sibling/s who has/have a physical and/or mental disorder, such children may have to assume more varied responsibilities that may not be seen as “traditional” for their gender. This may influence how they experience the home environment, and how they make meaning from the experiences thereof.

- Severity of ASD

Autism is a spectrum disorder that ranges from low functioning to high functioning. The difference lies in the spectrum of difficulties, where one child, on the one end of the spectrum may have difficulties that the other child on the other end of the spectrum may not necessarily have (Smith, Elder, Storch & Rowe, 2015; Victoria, 2013).

The severity of ASD may contribute to the manner in which siblings experience the home environment. This is because no one child with ASD is the same as another, and therefore, the experiences may or may not be different.

- Parent-child interaction

Children develop some type of attachment style from birth, based on how parents interact with them (Whiteman et al., 2011). The interaction between parent and child contributes to how they make sense of the behaviour of their sibling with ASD, and how they experience the home environment. The possible shift in parental attention, when there is a child diagnosed with ASD in the family, can inform the extent to which the interaction between parents and children occur (Cridland, Jones, Stoyles, Caputi & Magee, 2016).

Therefore, it is important to investigate the extent to which children make sense of their interaction with their mother and/or father, when they have a sibling with ASD in the family.

- Sibling relationships

Similarly to parent-child interaction, the relationship between siblings may contribute in shaping their experiences and meaning making (Diener, Anderson, Wright & Dunn, 2015). It is safe to say that the relationship between an individual with ASD and their sibling is not the same as the relationship between two siblings who are both typically developing (Smith et al., 2015).

- Support from other family members

As mentioned earlier, living with a sibling diagnosed with ASD can be a challenging experience for everyone involved (Lovell & Wetherell, 2016). While growing up, siblings typically depend on each other for support, as well as the support of their parents to cope with situations. At some stage, they are also, expected to take care of their other siblings,

especially younger ones, during hardships. The extent to which this support is given has a bearing on the manner in which they experience having a sibling with ASD, as well as the way in which they make meaning of it (Chan & Goh, 2014).

- Friends and peer relationship

Similarly, the support that the child gets from other family members and peers has a bearing on how they will experience living with someone diagnosed with ASD. The relationship with friends and peers, other than the sibling with ASD also has a bearing on how the child experiences the home environment. This is because when a child experiences more positive peer relationships, they become more fulfilled, and have confidence in how they go about living their lives, and are thus, better able to cope with the difficulties of life and display better self-worth (Chan & Lai, 2016)

- Sibling perspective on ASD

Although the perceptions that outsiders have of a child diagnosed with ASD contributes to how the other siblings make meaning of the situation, it is ultimately the knowledge that the siblings themselves have about ASD that determines how they will experience living with their siblings with ASD. Given that families deal with challenges differently, parents are also selective of what they share with their children in relation to the challenges or struggles with which they may be contending. The perspective of children whose siblings have been diagnosed with ASD is based on their understanding of what they think is happening to their siblings, and this would differ from sibling to sibling (Connell, Halloran & Doody, 2016).

1.5 Significance of the study

This study sought to gain an in-depth understanding of how siblings make sense and construct meaning from their experiences of living with a brother/sister diagnosed with ASD. Additionally, the study aimed to develop an in-depth understanding of siblings' experiences of living with a brother or sister with ASD, as well as their understanding of ASD.

Because many of the studies on ASD conducted previously were done outside South Africa, it became important for the researcher to conduct research in South Africa that will contribute to the body of knowledge here at home and worldwide. Furthermore, considering that South Africa is a diverse country in terms of race composition, and therefore cultural

background and the fact that it is a developing country, studies on ASD are vital. Furthermore, this study will make a positive contribution to the existing support systems for siblings of individuals with ASD and pave the way for more research in this area, in order to shed some understanding on the experiences of children whose siblings have ASD.

1.6 Definition of key terms

- **Autism Spectrum Disorder**

The Diagnostic Statistical Manual of Mental Disorders Fifth Edition (DSM-5) explains that individuals with autism spectrum disorder (ASD) have difficulty with social and emotional interaction or exchange. According to DSM-5, people with ASD struggle with back and forth conversation, sharing of interests, as well as verbalise emotions and affect. People with ASD also have difficulty initiating and responding to various forms of social interaction (American Psychiatric Association, 2013).

- **Siblings**

For the purposes of this study, the researcher describes siblings as individuals who share at least one common individual they refer to as a parent. This may be owing to blood relation, adoption or remarriage. This aspect is dealt with in chapters that follow.

- **Normal functioning**

In this study, the researcher refers to individuals not diagnosed with ASD or any other mental disorder as normal functioning.

1.7 Chapter overview

This chapter introduced the reader to the study. The chapter began by outlining the background of the study, and its relevance. The chapter further outlined the research problem, drawing from the existing literature. The chapter also outlined the aim of the study, as well as important definitions and key terms employed in this study.

The rest of the dissertation is divided into four chapters. Chapter 2 presents the literature review, while chapter 3 discusses the research methodology. Chapter 4 presents the findings, while the final chapter draws conclusions and make recommendations for future studies.

CHAPTER 2: THEORY AND LITERATURE REVIEW

2.1 Introduction

As there is growing interest in research around ASD, more research is now focusing on parental/caregiver interaction, as well as the concerns of caring for an individual with ASD (Cridland et al., 2016; Cuzzocrea, Larcana, Costa & Gazzano, 2014; Herlihy et al., 2015; Scorgie, 2017). Previous studies have focused primarily on relationships and the adjustment of siblings of individuals diagnosed with ASD (Chan & Lai, 2016; Inam & Kausar, 2016; Rossetti & Hall, 2015). While only a few scholars have conducted studies on normal functioning siblings of individuals with ASD (Chan & Goh, 2014; Davys, Mitchell & Haigh, 2016; Kovshoff, Cebula, Tsai & Hastings, 2017), some of the research was done on siblings who do not live together in the same household as their sibling diagnosed with ASD. Of the studies conducted on siblings living in the same household with individuals diagnosed with ASD, many have produced inconsistent findings; which then puts forward the need to conduct further studies in this regard. This chapter reviews the literature on previous studies on ASD.

2.2 Autism spectrum disorder: An overview

Previous editions of the DSM included specific subcategories of autism, which included Autistic Disorders, Asperger's Syndrome, as well as Pervasive Developmental Disorders, otherwise not specified. The most recent version of the DSM, which is the DSM-5, has a single diagnostic criterion for Autism Spectrum Disorder.

According to this version of the DSM, ASD is characterised by difficulty in social interaction, unusual interest in objects, inflexibility, under or over reaction of one or more of their senses, repeated actions of bodily movements, as well prolonged and intense emotional reactions (American Psychiatric Association, 2013).

Additionally, people diagnosed with ASD have difficulty communicating in a nonverbal manner during social interaction. Examples of these difficulties include poor eye contact, difficulties displaying and understanding body language, difficulty in understanding and displaying gestures, as well difficulty expressing appropriate facial expressions (American Psychiatric Association, 2013).

Individuals diagnosed with ASD show deficits with developing, maintaining and comprehending relationships with others. This includes difficulties adjusting their behaviour to suit different social contexts, sharing imaginative play or making friends, as well as a lack of interest in peers (American Psychiatric Association, 2013). Individuals with ASD present restricted, repetitive patterns of behaviour, interests, or activities. This can be repetitive motor movements and the repetitive use of objects or speech. These individuals may also engage in echolalia (engaging in repetitions of vocalisations made by another person). Furthermore, individuals with ASD engage in repetitive behaviour such as lining up of toys or other simple motor repetitive such as the flapping of hands or looking at objects from the corner of their eyes (American Psychiatric Association, 2013).

They may show inflexible commitment to routine or ritualised patterns of behaviour. This can include, but is not limited to, extreme distress when there are small changes in their routine, difficulties with transitioning, greeting rituals, their need to take the same route or eat the same type of food every day (American Psychiatric Association, 2013).

Individuals diagnosed with ASD present highly restricted, fixated interests that are abnormal in intensity or focus. For instance, they could have a strong attachment to something or a preoccupation with unusual parts of an object, or objects as a whole, such as the wheel of a car, fixated over a drawing in a book or the back of a spoon (American Psychiatric Association, 2013).

Finally, individuals with ASD may present hyper or hypo reactivity to sensory input. Likewise, they may present unusual interests in sensory aspects of the environment. For example, they may show unusual or strange responses to pain/temperature, specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement (American Psychiatric Association, 2013).

Living together with an individual with these qualities can present different challenges to parents/caregivers and siblings. As one parent said: “one child with ASD needs the same attention as six typical children” (Bateman, 2013, p. 1). For many people, having an individual with ASD in the family can be a very unusual circumstance. It is said that a child with ASD can uneven the parental attention (Inam & Kausar, 2016) which is caused by the differences in development the children may have. Previously, ASD only seemed to be prevalent in well-resourced countries that have high technological development. There has

always been a huge gap about what is known about ASD, in particular, very little seems to be known about ASD in Africa (Thomas, Badoe, Akua & Owusu, 2009).

This lack of awareness is not only evident among ordinary people, but also among health professionals. As Ruparelia et al. (2016) state, health professionals were asked in a presentation what they thought ASD was, and most of them indicated that ASD was a spiritual case. These professionals also mentioned that when someone has a pervasive developmental disorder, a traditional healer treats them. Therefore, very often, children with ASD access support services only later in life, as compared to children with other forms of disabilities. The major gap, however, is in terms of what is known about ASD globally, as well as families' experiences of living with an individual who has this condition (Franz, Chambers, von Isenburg & de Vries, 2017).

A diagnosis of ASD not only affects those who have been diagnosed with the condition, but also those living with them in the same household, as well as those who care for them (McVicker, 2013). In many cases, families care for their own members who have disabilities, including ASD. It is, therefore, not uncommon in many instances; for parents, siblings, grandparents or other relatives to care for individuals with ASD (Mbwilo et al., 2010).

2.3 Autism Spectrum Disorder: Parents and caregivers

As children grow older and become adults, parents tend to be less involved in their lives. The child becomes more independent and sometimes even becomes the one caring for the parents in their old age (Statistics South Africa, 2014). This assertion has been supported by Hole, Stainton, and Wilson (2013), who also posit that it is not uncommon for children to care for their parents as they get older. However, this is not the case for parents of individuals with ASD, who are faced with the challenge of caring and providing long-term, if not lifelong care, for their child with ASD (Cuzzocrea et al., 2014).

The findings of a study by Ozturk et al. (2014), have also shown that parents often contend with feelings of anxiety about the future of a child with ASD, who may never be able to do all of these, but instead, a child who may need care for the rest of their life. Although the relationship between parent and child is a hierarchical one (Hesse, Danko & Budd, 2013), parents expect their children to grow up, become independent, care for themselves, and have their own children (Martins et al., 2013).

From the moment a child is diagnosed with ASD, parents often experience some disappointment and confusion about the well-being of their child (Herlihy et al., 2015). This disappointment and confusion may emanate from the feeling that parents have, that they are somehow responsible for their child's condition – in the sense that the child may have inherited their genes (Martins et al., 2013). This produces more anxiety as the child grows because parents are constantly worried about their child's struggles in terms of social skills, academic work and self-care (Tsai, Cebula, & Fletcher-Watson, 2016).

Furthermore, parents of children with ASD experience ASD as a stressor in their lives in the sense that it puts a strain on their spousal relationships, and have a bearing on family dynamics. These family dynamics also include the parents' awareness of the role they are playing as parents, including 'double standard parenting', where parents have different parenting styles towards their children with ASD and their normal functioning children (Chan & Goh, 2014). What often adds to the parents' anxiety is that they are aware of their inconsistent parenting style, and are also aware that their other child/children are aware of this (Cuzzocrea et al., 2014).

Herlihy et al. (2015) examined parents' first concerns about their normal functioning toddlers being born into a family where they find a sibling with ASD. The researchers predicted that parents of toddlers who have no siblings, or have typically developing siblings, would express less concern with ASD, compared to those who already have children with ASD. This prediction was largely unconfirmed, as there seemed to be an insignificant difference in parental concern. The findings of this study support those of other studies that have shown that parents are concerned about their children's health, including those with ASD (Hesse et al., 2013).

A second prediction from the same study was that parents in the Sibs-ASD (siblings with ASD) group would have the earliest concerns, followed by Sibs-TD (typically developing siblings), with the least concerns being in the No-Sibs (no siblings) group. These findings then confirmed that parents who have older children with ASD are concerned about their younger children's development on average, before their first birthday, while parents in the other two groups were likely to have concerns later than the other groups, even though these children have significantly greater developmental delays (Herlihy et al., 2015)

This kind of concern and anxiety about their children can bring a psychological burden in the parents' lives. It has also been found that when a child has ASD, caregivers of these affected children who are not parents, also experience anxiety and depression (Al-dujaili & Al-mossawy, 2017). These caregivers have expressed feeling overwhelmed by the demands of taking care of a child with ASD, due to the challenges that come with caring for such children. This burden is referred to as caregiver strain (Shivers, Krizova & Lee, 2017). This strain occurs when the act of caring for the individual with ASD affects the caregiver's life in roles and routines including their finances, work schedule or their emotional wellbeing, among other things (Al-dujaili & Al-mossawy, 2017). These may result in a compromised mental health and high levels of stress, compared to families of individuals with intellectual and developmental disabilities (Khanna et al., 2011).

Additionally, it was found that the quality of life of a mother was higher if her child was developing normally, as compared to instances where the child has special needs (Mckechanie, Moffat, Johnstone & Fletcher-Watson, 2017). Therefore, a diagnosis of ASD contributes a great deal to the quality of life of family members, as Mckechanie et al. (2017) assert, when he indicates that families of typically developing children showed a higher measure in the quality of life, compared to families with children who have special needs, such as ASD. This difference in the quality of life was also influenced by the type of special needs children with ASD require; these include services from various medical professionals, to the extra effort put into looking for an appropriate school for their child with ASD, and finding the right food for the child with ASD (Shivers et al., 2017).

The quality of life referred to above is also defined from the parents' perspective, as well as their assumption on how their normal functioning children feel about having a sibling with ASD. Raising other children while raising a child with ASD often causes parents to worry about their relationship with the normal functioning children (Cuzzocrea et al., 2014). This may be due to the complex needs of an autistic child, which again, affects the interaction between parents and their normal functioning children (Inclendon et al., 2015). Some parents may cope with the stress of having a child with ASD in the family by reserving some time or a few times a month to spend with their normal functioning children, or together as parents (Cuzzocrea et al., 2014).

In the same way as parents of children with ASD experience stress, families, caregivers and communities of individuals with certain disabilities, including autism, tend to

feel uncertain about disabilities in general. According to Mbwilo et al. (2010), caregivers of children and adolescents with a mental disability expressed that they were uncertain about how they should care for children and adolescents with mental disabilities. These uncertainties have been attributed to the lack of information on the disability, where it came from, and how to care for the affected person. Furthermore, the stress is worsened by the level of stigma associated with mental disabilities, and the stereotyping of people with disabilities, as well as those in their social circles (Someki, Torii, Brooks, Koeda & Gillespie-Lynch, 2018).

Although families that have a member with ASD contend with feelings of uncertainty and the resultant stress, the stress and anxiety are sometimes aggravated by the economic status of the family. People with autism need special care, and may require a special diet (Eklund et al., 2018; Elias & White, 2018). Basic needs such as food that the individual is allowed to eat and, specialised health care are big concerns, especially in families that do not have sufficient resources (Tilahun et al., 2016).

Moreover, caregivers of individuals with ASD may experience challenges as far as relating with members of the community is concerned. They indicated that there was often miscommunication and misinterpretation of certain cues and gestures from family to family in their communities. A lot of this miscommunication was between caregivers and the individual with ASD, due to the fact that many of them do not have the ability to use appropriate verbal communication (Mbwilo et al., 2010). With all that in mind, caregivers are anxious about the future of their loved ones with psychopathologies (Davys et al., 2016) – for instance, what would happen to them in future, how they will survive and whether or not they will be able to sustain themselves (Mbwilo et al., 2010).

One study that is significant was conducted by Wolfe, Song, Greenberg and Mailick (2014). The aim of the study was to compare typical normal functioning people whose siblings and/or children were either diagnosed with a developmental disability or a mental illness. An interesting part of this study was that many aspects, including genetics were taken into consideration. Genetics was an important aspect to consider in this study because the researchers wanted to make sure that they were indeed measuring the influence of having a sibling with ASD, and not just shared genetic makeup.

The study found that parents who grew up in rural areas were less likely to have a child with a developmental disability, as compared to those who grew up in urban areas. Thus, mental illness was more prevalent among parents who had higher IQs and among fathers who had attained higher levels of education (Wolfe et al., 2014). Without arguing on the validity of the findings, one can simply argue though that these findings were obtained out of convenience. People with higher IQs and higher levels of education are more likely to have the resources to have their children assessed and treated, and are thus, more informed in terms of the real issue at hand that affect their children.

A diagnosis of mental illness should be done by a professional in the field; and as such, many children go undiagnosed; because their parents lack the required financial resources and the knowledge to obtain such a diagnosis. The lack of diagnosis is more prevalent in poorer communities with parents who are less educated and have lower IQs – because that is where resources and information are lacking.

In a study by Walton (2016) involving the risk factors and emotional difficulties experienced by siblings of children with ASD, parental and teacher reports on the same individuals indicated a few things that contribute to the behavioural problems of the siblings of those with ASD. These are factors such as lower family income, the typical child having fewer siblings than their peers, and their sibling with ASD being male (Walton, 2016).

Studies have demonstrated clearly that parents of children with ASD report more problems, as compared to parents of children with normal developing children. This impact on the parents therefore, has a secondary impact on children who do not have ASD (Mwamwenda, 2013).

2.4 Siblings

2.4.1 Siblings in an African context

It is said that sibling relationships are some of the longest lasting relationships individuals can enjoy (Connell et al., 2016). In such a long-lasting relationship, and through growing up together, siblings are said to play a role in facilitating each other's growth (Giallo et al., 2014).

Even though siblings are not of the same age, their relationship tends to be a peer relationship, as compared to a parent-child relationships, which is usually hierarchical (Whiteman et al., 2011). With this in mind, one can conclude that siblings play multiple roles in each other's development, as the saying goes, "siblings are surrogate parents, informal teachers and friends" (De Caroli & Sagone, 2013, p. 1).

Although researchers have stated that a sibling is a brother or a sister that is born from at least one common parent (Whiteman et al., 2011), due to the fact that South Africa is a culturally and religiously diverse country, the researcher has adopted a suitable definition of what a sibling is as mentioned in Section 1.6.

As far as the growth and development of a child is concerned, the family is regarded as a cornerstone. The child's family serves as the backbone of their development (Rosa & Tudge, 2013).

One cannot speak of siblings without first looking at families and family composition, because as mentioned earlier, siblings are part of a specific family, and the two cannot be separated – hence in this literature review, these terms are not being discussed in isolation.

Although the scope of this research does not cover families per se, that is what it means to be a family and a family member, the researcher saw a need to discuss family dynamics, as this is what shapes the behaviour of siblings, and determine what a sibling is.

In the same manner as problematic as defining a sibling is, it is equally tricky to define a family, including the composition thereof. The different roles and functions that people play in each other's lives have changed over the years, because of eras and evolving cultures (Okon, 2012). This in turn, makes it difficult to provide a simple definition of what a family is.

Over the years, the organisation and composition of families in South Africa have changed. The living arrangements have changed, not only for local people, but for settlers as well (Okon, 2012). This change is a result of the expropriation of the African land, as well as the change in work and educational arrangements that happened in South Africa prior to 1994. The change in government in 1994 brought about a change in living arrangements for the South African family. This type of change included the forceful removals of people from

their homes into other townships, forcing fathers to live far from their wives and children and therefore, changing the family structure (Amoateng, Heaton & Kalule-Sabiti, 2007).

Based on the lack of clarity, the definition of what a family is or should be, remains open. Scholars such as Amoateng et al. (2007) have studied living arrangements, which were based on blood relations and adoptive households. Furthermore, the increased death rate due to illness such as HIV/AIDS, and the increase in the rate of divorce in South Africa meant that people are more likely to remarry – therefore, making the family structures more complex (Amoateng et al., 2007).

In the African culture, there are aspects such as polygamy, and this too can make family composition more complex (Rabe & Naidoo, 2015). The family structure in South Africa also became complex because of the increase in the number of orphans due to parental death from violent crimes, HIV/AIDS, or other causes of mortality (Makoae et al., 2015). On the other end of the scale, there are child-headed households, as well as unmarried couples living together (Okon, 2012). This complexity in family structure could determine the kind of relationships among children who live in the same household. This in turn, means that defining a sibling can be somewhat problematic (Okon, 2012).

For centuries, family sociologists have written about different types of families. They spoke about the two main broad family systems, namely the extended family system, and the nuclear family system. The extended family system is mainly characteristic of rural societies, while the nuclear family is usually characteristic of modern complex societies (Okon, 2012).

As years went by, nuclear family systems started to evolve into extended families. Amoateng et al. (2007) noted that the biggest family system in South Africa is the extended family. This, however, does not mean that other types of families are not recognised.

Due to the changes sweeping our country (South Africa) such as political, economic, and cultural changes in family circumstances, the family structure has also changed. This change has brought about a change in family relationships as well. Also, one cannot ignore the influence of socio economic factors, and how they shape families and living arrangements in South Africa (Amoateng et al., 2007).

Another challenge associated with defining a family is that only a nuclear family is considered a normal family. This notion then, disregards all other types of families,

including those formed as a result of remarriage, extended families, adoptions, same sex parents, as well as child-headed households (Okon, 2012). This way of thinking therefore, becomes problematic in the African context, and especially in a country such South Africa, where people are so diverse, as they come from equally diverse families. Moreover, belonging to these diverse families could mean that the definition of a sibling is not as common or normal as one may think (Okon, 2012).

From the discussion above, one can easily conclude that being a sibling is often much more complex than just sharing at least one parent. Although traditionally, siblings were individuals related by blood, and by virtue of sharing at least one parent, the complexity of the family structure in South Africa has changed all of that.

In the African context, being a sibling goes beyond the bloodline. As mentioned earlier, for the purposes of this study, the researcher adopted her own definition of what a sibling is – that is, siblings include individuals who share at least one common individual they refer to as a parent. This could be as determined by blood, adoption or remarriage.

Siblings are usually very close to each other. It has been said that the relationship between siblings is the longest lasting relationship in a person's life – much longer than the relationship one has with parents, friends or romantic partners (Connell et al., 2016). While growing up together, siblings learn from one another and sponge off from one another. Moreover, they become more than just blood – being a sibling means one is in a relationship with someone, and that the relationship was established over time – by either growing up together, parental agreement, or blood ties.

The contribution made by siblings to each other's lives is illustrated by the research done by White and Hughes (2018), where they explained that siblings are like playmates and social tutors. Growing up together, siblings are likely to spend a lot of time together. This means that they play together and learn from one another as far as social interaction is concerned (Nowell, Brewton & Goin-Kochel, 2014).

Observers have indicated that the quality and quantity of play between siblings is more meaningful, as compared to children playing with their friends (White & Hughes, 2018). This says a lot about the nature of sibling relationship.

The extent of the relationship between siblings can influence them in more ways than just learning from one another in relation to playing nicely with other people. The role siblings play in each other's lives can be likened to being one another's role model. Since siblings model behaviour to one another, they often mimic what the other is doing (Bandura, 1977).

It is important to note that this role modelling is not always intentional. The mimicking and looking up to one's sibling does not only happen with positive attributes that sibling possess, but can be anything from good academic achievements to drug use (White & Hughes, 2018). This is evident from the social learning theory, which holds that learning takes place from one sibling to another in a social context. Bandura (1977) asserts that siblings can learn a whole lot of things from one another, such as violence, aggressive or even antisocial behaviour. This kind of learning can extend to learning positive behaviour; such as taking responsibility, showing empathy, or even good social interaction.

Having a sibling does not necessarily mean that there will be clearly-defined roles and positive outcomes from the interaction. Sometimes siblings can be rivals and sparring partners all at the same time. Research indicates that most parents decide to have a second or third child or even more, because they think it will benefit the children (White & Hughes, 2018). Having another child, however, does not always benefit the child in question. Siblings can be rivals for many different reasons that include competing for parental attention. The level of this rivalry between siblings can be minimal, and can be witnessed for instance, as just an innocent argument, or as a serious brawl with serious ramifications, like in the biblical story of Joseph and his brothers, where the latter decided to sell him because of jealousy (Genesis 37:27).

Considering the sibling roles discussed above, the researcher was motivated to find out from the siblings of individuals diagnosed with ASD what their experiences are of living with a brother or sister with ASD, and the nature of the interaction, as well as how they make meaning out of the experience.

2.5 Autism Spectrum Disorder and siblings

While going through various sources in reviewing the literature, various themes emerged, which the researcher extracted to formulate the following subtitles:

2.5.1 Positive and negative influences

The actions and behaviour of individuals with ASD affect their siblings' lives, much as the behaviour of family members affects the lives of one another in a positive or negative way. Researchers such as Ward, Tanner, and Mandleco (2016) state that positive influences in this regard, may include the fact that the normal functioning siblings, who grow up as mature and responsible people, and who have a positive self-concept, quarrel less and are driven less by competition, and admire their sibling who has ASD. On the other hand, a negative effect that a sibling with ASD may have on their normal functioning sibling is that they can arouse feelings of fear, sparked by the violent behaviour they display, decreased or less sibling intimacy, as well as social and emotional difficulties displayed by the normal functioning siblings.

Some of the negative and positive effects that children with ASD have on their typically developing siblings include the manner in which normal functioning siblings seem to empathise with their parents. Typically, developing siblings seem to understand that their parents are going through a lot in taking care of their autistic brother/sister. This empathy is evidenced by the siblings' willingness to go an extra mile to help care for their siblings with ASD (Chan & Goh, 2014). Assuming the role of a caregiver, while still having to play the role of a brother or sister to their sibling, seems not to have a negative effect on them. These siblings mentioned that they understood that they have to do this because this is the situation they find themselves in, and that they just have to accept it (Incedon et al., 2015). This resonates with the sentiments by Cuzzocrea et al. (2014), who assert that when there is a disabled child in the family, the relationship between siblings changes, and the non-disabled siblings begin to play more significant roles – that is, some of the roles usually played by parents.

Some studies suggest that there is a lack of evidence in relation to whether there are positive or negative effects of living with a brother or sister with ASD (Hastings & Petalas, 2014). A further study suggested that there was an over assumption that having a sibling with ASD impacts negatively on the normal functioning children (Shivers, Deisenroth, &

Taylor, 2013). It has been observed that studies that assume having a child with ASD affects the lives of normal functioning siblings in a negative way are those that gathered the data from parents of children with ASD, while sibling self-reports tend to be full of positive accounts (Shivers et al., 2013; Tudor et al., 2013).

Furthermore, Rossiter and Sharpe (2001), found that parents mostly report lower psychological adjustment in their children with ASD, as compared to siblings self-reports. Furthermore, normal functioning siblings reported that their relationships with their brother or sister with intellectual disabilities were more positive as compared to those who have typically developing siblings.

2.5.2 Psychological functioning

In order for siblings of children with ASD to cope and adjust to the negative experiences, they often engaged in distractive activities, problem solving, wishful thinking, and attempt to control their emotions when hurt. Furthermore, these normal functioning siblings seek ways to broaden their personal boundaries by obtaining formal and informal support. “Normal developing” siblings report that the techniques they learn from their parents help them cope with their siblings with ASD (Gorjy, Fielding & Falkmer, 2017).

Siblings of disabled individuals not only have empathy, but also display a high level of understanding and tolerance for other people outside their families (McVicker, 2013). “Normal” developing siblings have also reported that they are somewhat embarrassed when they are in public places with their brothers or sisters with ASD. This embarrassment and shame is sparked by the negative reactions of members of the public, as well as the prejudice and misjudgement directed at their siblings with ASD (Franz et al., 2017). Although this misjudgement and prejudice is from people who know about the person’s condition, they somehow, stigmatise them. Siblings of children with ASD reported that the lack of knowledge concerning ASD by the wider community adds to their sense of embarrassment. Furthermore, the looks and questions they get from strangers add to their feelings of shame (Meltzer & Kramer, 2016).

Typically developing siblings seem not to mind about the extra work that they have to put in while taking care of their brother or sister with ASD. However, they seem to experience high levels of anxiety, conflicts between themselves and their siblings with ASD, as well as jealousy, sparked by the fact that their parents seem to give more attention to their

siblings with ASD (McAdams, 2016). Similarly, Ross and Cuskelly (2006) state that siblings of children with autism have higher levels of depression and seemed to internalise and externalise more behavioural problems.

Although it is clear from previous research that having a sibling with ASD contributes to feelings of anxiety and depression in the normal functioning siblings, it seems that family functioning also has an effect on their anxiety levels. The time spent with each child, the level of attention that parents pay to each child, combined, play a significant role in the manner in which the sibling experiences life at home. Therefore, not only does an ASD diagnosis of the sibling contribute to their experience at home, but also to the family dynamics (Bitsika, Sharpley & Mailli, 2015; Welch et al., 2012).

Furthermore, having a sibling with ASD shapes the behaviour of normal functioning siblings to a certain extent. This indicates that the home environment of a child also influences how normal functioning children grow up. An example drawn from a study, which explored social attitudes of children towards their disabled brother or sister suggests that siblings of individuals with ASD expressed that they concur, to a large extent, that their siblings are unfortunate, marginalised by other people, and that this puts a strain on them (their siblings) (Caroli & Sagone, 2013). The findings of this study also indicated that people with autism are considered to impose limitations to the family in certain ways, and that they do not seem to lead normal lives, due to their disabilities.

Siblings of individuals with ASD are regarded as helpless; because they have little or no control of what happens in their own lives. For example, they may not be able to do the things they wish to do because their sibling with ASD may be having a meltdown, or being unable to go to certain places because their sibling with ASD will not like it (Woodgate, Edwards, Ripat, Rempel & Johnson, 2016).

Having a sibling with a disability, and more specifically, ASD, affects the wellbeing of a typically functioning child to a certain extent. A two-year study conducted on children between the ages of 4 and 7 years found that children who have siblings with a disability scored lower on wellbeing indicators (Emerson & Giallo, 2014). The findings of the study also revealed that these children's wellbeing, however, does not necessarily deteriorate over time – and that having a sibling with a disability does not just affect one's general wellbeing, but also their psychological functioning. When one has a sibling with ASD, it can impact on

their wellbeing and psychological functioning, in the sense that for most children; having a sibling with ASD can be embarrassing and frustrating. At times, these children may feel jealous, but at the same time, they may be concerned about their brother or sister, and sometimes even feel scared for them (Buist, Dekovic & Prinzie, 2013; Diener et al., 2015; Mchale, Updegraff & Feinberg, 2017).

2.5.3 Attitudes and behaviour

Many studies looked at the attitudes, behaviour and relationships of children and adults in relation to their sibling with autism (Angell, Meadan & Stoner, 2012; De Caroli & Sagone, 2013; Emerson & Giallo, 2014; Huinker, 2012; Verte, Roeyers & Buysse, 2003).

A child with ASD lacks social skills (Victoria, 2013). An interesting discovery is that children who have a sibling diagnosed with ASD credited themselves as possessing better social skills. This is from a study done by Verte et al., (2003) on behavioural problems, social competence and self-concept, which reported that siblings of children with ASD has credited themselves as having better social skills, as compared to siblings of typically developing children. This could be because the Matson Evaluation of Social Skills with Youngsters (MESSY) is a self-report questionnaire; and that these siblings could have used a frame of reference that made it seem like they possessed better social skills than their own siblings. These children's primary frame of reference is their family, with the closest peer, being the sibling (Spino, 2015).

When children who have siblings with ASD look at themselves in relation to their siblings, they could conclude that they have better social skills – whereas children with typically developing siblings may not necessarily do a comparison in respect of who have better social skills.

In a similar study by Verte et al. (2003), parents of children with autism reported that children whose siblings have ASD displayed more behavioural problems as compared to what parents of typically developing children reported, which was the opposite (Verte et al., 2003). The findings also indicated that the younger children (6 to 11 years) in the sample displayed more behavioural problems than the older children (12 to 16 years).

2.5.4 Relationships

Studies suggest that the sibling relationship becomes more complicated when one of the siblings has a disability, specifically ASD (Mchale et al., 2017). This complication is a result of the characteristics of ASD, which, as mentioned before, include difficulty with social interaction, communicating, displaying aggressive behaviour, as well as repetitive behaviour (American Psychiatric Association, 2013). Siblings prioritise the relationship they have with their brother or sister with ASD, as was evident in the study conducted by Woodgate et al. (2016), where the researchers noted that the participants had their siblings in mind when participating. Their participation required that they engage in certain activities (Woodgate et al., 2016).

Furthermore, studies revealed that children also assumed a responsibility when it comes to their siblings with ASD. This included being involved in their siblings' education, identifying themselves as their siblings' source of entertainment, caring for their siblings, and being their parents' helpers and relievers (Gorjy et al., 2017). Some siblings also indicated that they were more capable of caring for their sibling with ASD than their parents were (Gorjy et al., 2017).

Previously, very little was known about the caring roles older siblings normally assume in relation to their younger siblings with autism. As more research on autism was conducted, scholars started to look more into the issue. For instance, Atkin and Tozer (2014) explored siblings' perspectives of their relationships with their brothers or sisters with ASD. That is, the study involved the interpretation of these siblings of the situation; and how they gave meaning to their relationship, while caring for their siblings with ASD. Atkin and Tozer found that the relationship where one sibling has ASD is not the same as a relationship between typically developing siblings. A sibling relationship is regarded as a lifelong reciprocal relationship (Tozer, Atkin & Wenham, 2013). The exception is when one child has ASD, because having a sibling with ASD brings in a different dynamic as the reciprocal relationship associated with the sibling's disability affects their lives in a different way. Siblings in this study reported that they remember family life revolving around their sibling with ASD. Even though parents put in efforts to ensure that this does not happen, these siblings recall their family life as chaotic and as a struggle. In the midst of all these, these siblings had to find ways to contribute to the wellbeing of the family in order to make a meaningful impact (Tozer et al., 2013). Atkin and Tozer (2014) found that siblings paid more

attention to the wellbeing of their siblings with ASD compared to their own, all in an effort to minimise the said chaos and the struggles their parents are facing.

Individuals with ASD tend to be aggressive towards people around them. This happens when they do not get their way, or when they do not like something or even when they are just upset. Many siblings who participated in a study by Ross and Cuskelly (2006), when asked about their challenges in relation to dealing with their siblings with ASD, mentioned that the aggression directed at them by their siblings was the main stressor that also affects their interaction with their siblings (Ferraioli & Harris, 2009; Hicks, 2014). Although contributing meaningfully to the quality of life at home seemed like a good way of attaining responsible adulthood, their actions were driven by sadness (Inclendon et al., 2015). On the one hand, these siblings expressed the fact that they were anxious of the fact that they would forever be caring for their brother or sister with ASD. On the other hand, some siblings saw this as an opportunity to contribute positively to their brother or sister's life (Atkin & Tozer, 2014).

2.6 Theoretical framework

This study employed Urie Bronfenbrenner's bio-ecological theory of human development, which evolved from his ecological theory, as a theoretical framework. The bio-ecological theory of human development was known initially as the ecological model. The original model by Bronfenbrenner explains how human development occurs and pays special attention to the influence of the context in which the individual exists in their development (Rosa & Tudge, 2013). Bronfenbrenner's bio-ecological model provides a broader perspective when it comes to human development (Bronfenbrenner, 2005).

Subsequently, Bronfenbrenner reformulated his original ideas and began to put more emphasis on what he termed the proximal process. The proximal process according to Bronfenbrenner (2005) is the mutual interaction between the individual and other individuals in their systems. Not only does it involve interaction between two individuals, but also the interaction between people, objects, and symbols that they come across (Rosa & Tudge, 2013).

This theory is appropriate for this study as the researcher paid special attention to the individual and their experiences within this proximal process, which made it relevant when investigating the lived experiences of sharing a home with their siblings diagnosed with ASD.

It is important to note that according to Bronfenbrenner, the proximal process is the centre of the bio-ecological theory. The proximal process is viewed as the driving force of human development (Bronfenbrenner, 2005). That is, the child's development starts within this proximal process (Griffore & Phenice, 2016).

While Bronfenbrenner (2005) describes the ecological theory as a theory of human development, from the start the developing individual is seen as influencing, and being influenced by the environment. Children do not grow up in isolation. Their surrounding environment shapes their development. This environmental shaping can be either direct or indirect. The more direct shaping is from the child's immediate environment, be it their family, friends, school or caregivers (Gillibrand et al., 2011). According to the bio-ecological theory, the family is thus, seen as playing a key role in the child's development (Bronfenbrenner & Evans, 2000). It does so in terms of the personal characteristics of all individuals in the family, and most importantly, it does so in terms of the interactions among family members as part of proximal processes (Griffore & Phenice, 2016).

This, in turn, reveals another importance of this theory in relation to this study, as this study's main focus was on the immediate connections the research participants have, the home environment, which according to Bronfenbrenner and Evans, is called the microsystem (Bronfenbrenner & Evans, 2000).

In this regard, it is important to study the settings in which the developing individual spends time, and the relations they form with others in the same settings (Rosa & Tudge, 2013). Hence, the researcher paid a special attention to the participants' home experiences, where they are living with their siblings diagnosed with ASD.

The researcher looked at the experiences in the context of the participants' families, as well as the environmental factors, such as the extended family and friends – because all of these have the potential to determine the manner in which the research participants relate to their siblings diagnosed with ASD.

The following diagram explains Bronfenbrenner's bio-ecological model:

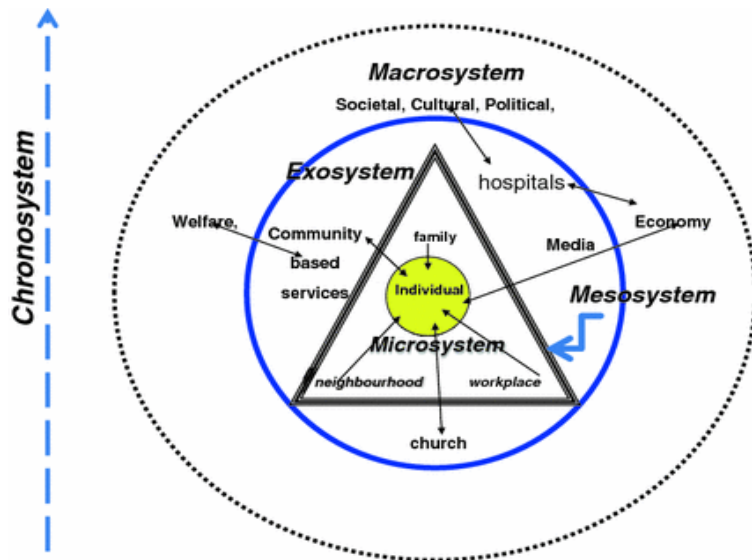


Figure 2.1 Bronfenbrenner's bio-ecological model (Boon, Cottrell, King, Stevenson & Millar, 2012, p. 390)

Based on the above diagram that explains Bronfenbrenner's bio-ecological model, the individual is at the centre of his or her own life. Immediately close to them is their microsystem, which according to Bronfenbrenner and Evans (2000), is the person's most immediate environment. This is where the child first learns about the world. This is the child's first point of reference. It is in this microsystem where the child starts learning, among other things, about trust and how to live with other people (Bronfenbrenner, 2005)

The manner in which the microsystem is structured has a bearing on how children experience the world outside their immediate family. The microsystem consists of the family; including caregivers and parents, as well as siblings. This part of the child's life determines their first experiences of life and living with people. Stressors experienced during this stage in the child's life determine the manner in which they handle other aspects of their life, and how they cope with stressors in their life (Bronfenbrenner, 2005). Some children have more than one microsystem – for example, the microsystem of the family and that of the school or day-care centre.

The next element of the model is the exosystem. The exosystem is not always a physical system, but often a psychological one; such as a social network of friends who provide advice, help and support, which creates a buffer between relations. The exosystem

also refers to social settings that the child may not experience directly, but which still influences the child's development, such as the parents' work environment, the media and religious institutions. The exosystem is a context that an individual experience vicariously. However, it has a direct impact on the individual. According to Bronfenbrenner (2005), the exosystem is a source of stress for most families; because it is not as well attended to as it should be – for example, most children experience stressors as a result of their parents' workplace; even though they are not physically part of the workplace.

The macrosystem is the larger system in the individual's life, in which the microsystem and exosystem are imbedded. This is the cultural beliefs, religion, political trends or the community. This influences the manner in which an individual live their life, their meaning making, how they relate with others, and with whom they form those relations (Rosa & Tudge, 2013).

The mesosystem represents the reciprocal interactions between various microsystems – for example the home, the school and the neighbourhood, which functions to connect two or more of the microsystems, to which an individual belongs. The mesosystem is about being in community with one another, while sharing and interchanging responsibilities (Gillibrand et al., 2011).

A final element of the model is the chronosystem, which refers to the framing of all the dynamics within the context in which they occur. An example of this can be the historical context of the systems; such as the family history or socio-cultural occurrences and changes (Bronfenbrenner, 2005).

It is clear from the above that according to Bronfenbrenner (2005) human development extends beyond the direct observation of behaviour; as the interaction of multi-person systems and aspects outside the direct environment of a child have a bearing on his or her development.

2.7 Chapter overview

There is scarcity of published literature on siblings of children with ASD that focuses on the self-report of these children's psychological adjustment, or any other type of experience. The findings of a few studies that are available are inconsistent. However, the

majority of these give a rather positive account of the siblings' experiences. This is, however, not to say that siblings are unaffected by the behaviour of their brothers or sisters with ASD.

This chapter has critically evaluated the findings of past research, conducted on siblings and families of individuals with autism or other disabilities. Furthermore, this chapter also examined the theoretical model relevant to this study. The researcher also conducted a critical evaluation of what it means to be a sibling in the African context. The researcher also made some remarks on the studies conducted on the phenomenon, while supporting them with other existing literature. The next chapter provides an overview of the methodological approach to the study.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This chapter highlights the process and method followed in order to fill the gaps identified in the literature mentioned in the previous two chapters in order to answer the research questions. The next section states in a clear manner the research questions, followed by the research design, information about the sample, data collection, trustworthiness of data, data analysis, as well as ethical considerations.

3.2 Research questions

This study explored the experiences of siblings of individuals with ASD in Gauteng Province, South Africa. The questions this research attempted to answer are as follows:

- a. How do children living with a sibling diagnosed with ASD experience it?
- b. How do children living with a sibling diagnosed with ASD make meaning of their experiences?

3.3 Research paradigm

3.3.1 Qualitative approach/method

The research design is a plan outlining how the researcher will conduct the research. The research design is necessary to direct responses to the research questions. Thus, the researcher chose the qualitative research design as the most appropriate method for answering the research questions for the current study (Willig, 2013). More specifically, the researcher adopted an interpretative phenomenological analysis design.

Qualitative research focuses on the subjective views and personal experiences of the research participants. With qualitative studies, researcher makes an effort to understand the world from the participants' point of view. Attempts are also made to unfold the meanings that research participants attach to their lived experiences (Willig, 2013). Qualitative research often results in rich data (Creswell 2014). Therefore, it was deemed a suitable design to adopt for the current study, as it provides an opportunity for the researcher to address the research questions in a suitable manner.

In addition, IPA is the study of the essence of experiences of a particular phenomenon – in this case, the essence of living with a sibling diagnosed with ASD. IPA further aims at exploring how human beings make sense of a particular phenomenon. This was the most suitable approach for this study, as the aim was to thoroughly understand what it is like to live with a sibling diagnosed with ASD, as well as understand how these individuals make meaning of their experiences of living with siblings diagnosed with ASD (Smith & Osborn, 2008).

IPA does this by carefully and thoroughly capturing and describing how these individuals experience living with a sibling diagnosed with ASD. This includes, how they perceive ASD, their definition thereof, and their experience, their feeling about ASD, as well as their experiences, and how they make sense of ASD, and whether they talk about it with others (Smith & Osborn, 2008).

3.3.2 Interpretative phenomenology

The study adopted an Interpretative Phenomenological Analysis (IPA), which takes into account the fact that participants' experiences and perceptions are unique (Smith, Jarman & Osborn, 1999). It is believed that these experiences and perceptions constitutes participants' own reality. This is particularly important, because IPA looks at how different people experience an event or phenomenon (Saunders & Tosey, 2013). In respect of the aims of this study, which was to explore the experiences of children living with a sibling diagnosed with ASD, and what meaning they attach to their experiences, the researcher found IPA to be a suitable approach.

What sets IPA apart as a valuable approach is that it recognises the central role the researcher plays in making sense of the participants' meaning making of their personal experiences. Further, IPA acknowledges that the research exercise is a dynamic process, with the researcher playing an active role, however, keeping in mind that research participants are the experts (Smith & Osborn, 2008).

IPA is thus, strongly connected to the interpretative or hermeneutic tradition. As elaborated by Smith and Osborn (2008), human research involves a double hermeneutics; since during the process, the participant tries to make sense of their experiences, while the researcher tries to make sense of what the participant is saying.

The ontological perspective of IPA is that there is not just one true reality, but that multiple realities exist. IPA sees reality as specifically constructed. There is no true reality, but one that is informed by one's experiences. Some theorists go on to describe the IPA paradigm as an attitude about knowledge (Bradbury-Jones, Sambrook & Irvine, 2009). Furthermore, this knowledge is in relation with what has been gathered at a certain point – and what is known up to that particular point – but not what is absolutely true, for as long as the research is still being conducted and new information discovered (Bradbury-Jones et al., 2009).

IPA seeks to understand and reconstruct the experiences of the research participants. Moreover, IPA is concerned with making meaning of these experiences, based on how the individual interprets his or her experience; and further, the researcher's interpretation of these interpretations (Smith, 2008). The chapter discusses further the detailed analysis of IPA to expand on issues of trustworthiness and credibility.

Furthermore, IPA is a study of the lived experiences or the life world of an individual and emphasises a person's lived experiences. IPA does not separate the person from their world or their reality (Bradbury-Jones et al., 2009). Thus, IPA asks, *what is this experience like?* IPA attempts to make meaning, as lived by the individual in their day-to-day life – and, therefore, try to understand the meaning from the experiences as lived by an individual.

IPA holds that we do not develop understanding from our knowledge of the world, but rather, from how we are. A person's life journey determines how they understand the world (Bradbury-Jones et al., 2009) – that is, from birth throughout their life, a person becomes acquainted with some aspects in the family, as well as in their lives. These may be aspects of culture, history, social background, and socio economic status (Boon et al., 2012). All these could contribute to shaping how one understands their reality. From this, one can deduce that a person will determine what is real. Interpretation is seen as critical to this process of understanding (Smith et al., 1999).

3.4 Research methodology

Sampling and recruitment of participants took place between January 2018 and July 2018. During this time, the researcher had two participants withdrawing after they have been

interviewed. The below section explains how the researcher chose the participants for the study.

3.4.1 Population

The population in this study is comprised of individuals who have and are living with at least one sibling diagnosed with ASD.

3.4.2 Sampling criteria

The researcher chose participants for this study through purposive sampling and snowball sampling. She employed these techniques because she was interested in studying selected and very specific individuals. Here the researcher only included participants who met the selection criteria (Struwig & Stead, 2004).

Participants for this study were recruited by emails to known individuals and organisations that are dealing with parents of individuals diagnosed with ASD. The researcher contacted Autism South Africa by email to explain the purpose of the study. Autism South Africa shared the details of the study to everyone on their database. Following this, some of the parents made contact with the researcher, because their children were interested in participating. This was successful in the case of three of the participants. Another participant was recruited by means of a reference. A colleague referred the mother of the participant to the researcher because her daughter was interested in participating. Finally, another participant was identified when the researcher communicated with another colleague about the study and she mentioned that her daughter was interested in participating.

The parents of all the participants were requested to pass the message about the study on. However, this attempt was unsuccessful as no participants volunteered.

3.4.3 Inclusion and eligibility

The sample in this study consisted of five individuals who have at least one brother or sister diagnosed with ASD; and with whom they are living in the same household. Data were collected until the point of saturation. Moreover, phenomenological studies generally use smaller samples, because analysing large amounts of data is time consuming. The participants were aged between 12 and 19; four of them were female and one of them was male. The criteria were that participants should have lived, in the past three months, with their brother

or sister with ASD. This is because the study required participants to reflect on the experiences of living with siblings with ASD. Reflecting on their experiences was an important part of this study, as this would enable them to answer the research questions appropriately.

The researcher excluded individuals who had more than one sibling diagnosed with ASD, as well as those who lived with another family member diagnosed with any psychopathological condition. As mentioned, children with a psychopathological condition require more attention than normal functioning children, and therefore, if there is more than one individual in the household who was a psychopathological case, chances are that the parents/s' attention is already split (Cridlan et al., 2016).

3.5 Data collection

To obtain rich data, the researcher conducted semi-structured interviews with participants. The researcher compiled an interview guide beforehand. Questions in the interview guide were used to guide the interview as it progressed (Willig, 2013). The questions included a few pre-set, open-ended questions that assisted and guided the researcher during the interview and the conversations.

This interview guide was developed from a combination of the selected theory of Urie Bronfenbrenner's bio ecological model as well as the literature review that was conducted. The interview guide used can be found on Appendix F.

The researcher informed the participants and their parents about the nature of the data collection method beforehand. In order to promote the richness of the data, the researcher compiled follow-up questions, based on the answers of the research participants. This attests to the value of semi-structured interviews, as they help the researcher to obtain rich data, while still confining him/herself to the questions to the interview guide (Kvale, 2006).

The interviews were conducted in the English language as this was the language the participants expressed themselves best in. The length of the interviews ranged from 32 minutes to an hour and 13 minutes.

The flexibility of the interviews was made possible by the fact that the interview process allowed the research participants to express themselves freely, and the researcher was

able to direct the session anywhere participants' responses lead. This helped the researcher to obtain in-depth, rich information from the participants. Additionally, semi-structured interviews enabled the researcher to dig deep into the experiences of the research participants (Creswell, 2014). This in turn, helped shed some light on the experiences of individuals living with a sibling diagnosed with ASD.

In qualitative research, it is important to keep a comprehensive record of the participants' words and actions to ensure that as little as possible information is lost "in translation." As a result, qualitative data tend to be voluminous and hard to manage (Creswell, 2014). To prevent this from happening, the interviews were tape-recorded, and notes made during the interview in order to recall important nonverbal communication that was evident during the interviews. The researcher also kept a diary with short reflections about the participants and the experience of collecting data before and after the interview.

The researcher was aware of the limitations of interviewing children and expecting them to make meaning out of their experiences. To minimise the risk involved, the researcher planned to ensure that the interview took the direction of what Sargeant and Harcourt) (2012) call, "conversations with a purpose" (p. 51). Thus, the researcher had intended the interview to be informal, communicating in a way that participants identify with. This did not entirely change. The researcher was pleasantly surprised by the unexpected turn of the interviews. The participants were able to articulate reflections and communicate without aids or prompts of other factors such as play. The researcher then went with the direction of the interview. The researcher met two of the participants at a coffee shop – this was also unexpected. This, however, did not in any way, affect the quality of the data. The participants were still comfortable and excited about taking part. The participants themselves chose the setting for the interviews.

3.6 Data analysis

The data collected were analysed using Interpretative Phenomenological Analysis (IPA). The main currency for IPA is the meaning the particular experiences holds for the participants. IPA is a method of data analysis concerned with exploring in detail what it feels like to have experienced a phenomenon. Therefore, this analysis was done in order to get an idea of what the participants' experiences were, and the meaning they attached to their experiences of living with a sibling diagnosed with ASD (Smith et al., 1999).

This, therefore, means that IPA as a method of analysis is appropriate for bringing an understanding of the personal world in relation to the experiences of the participants. IPA also looks at the individual's interpretations of their experience of a phenomenon and the researcher's interpretation of those interpretations, also known as a double hermeneutic (Smith & Osborn, 2008)

When using IPA, the data analysis process begins as early as during the interviewing stage. At this stage, the researcher is already making an interpretation of the participants' experiences. The researcher kept this in mind during the interviews and this in turn, prompted the journal entries that the researcher kept during and after the interviews. Furthermore, the researcher manually transcribed the interviews. This was also a part of the continuation of the early stages of interpretation to make ongoing analysis and theme generation possible.

Although IPA does not follow universal steps of data analysis – there is, however, a generic outline set out by Smith et al., (1999), which the researcher chose to follow in the present research.

Once the researcher was done with transcriptions, she began with the case-by-case analysis, firstly immersing herself in the data (Willig, 2013). The researcher read the transcripts repeatedly. Using the Atlas ti. qualitative analysis programme, the researcher made comments and notes related to aspects in the transcripts (Smith et al., 1999).

After the researcher has read the transcripts repeatedly, he or she identifies the codes, based on each section of the transcript. These codes are from the initial notes made from the first reading of the transcript (Smith et al., 1999).

As was the case before, the researcher had already started interpreting the data, as she labelled the transcripts and made initial notes. At the time, the researcher had already begun identifying the nature and meaning of the participants' experiences (Smith & Osborn, 2008).

Following this, the researcher attempted to introduce some kind of structure into the analysis by listing the codes that she had identified, and listed them in relation to one another (Willig, 2013). For example, transcripts with similar codes need to be identified and put together into a bigger theme. In this case, the researcher identified transcripts with similar codes and grouped them together into one theme (Smith & Osborn, 2008). The researcher kept on revisiting the transcripts to ensure that she has not misinterpreted the data.

The researcher then summarised the themes in table format (see Table 4.2) in a manner that would be easier to understand. Themes to include in this table were selected carefully to ensure that only the relevant, appropriate information was included (Willig, 2013). Further arrangements of the themes included combining the themes that seemed to have the same meaning or drew from each other. These themes were grouped together into what was referred to as superordinate themes (Smith et al., 1999). This table included the themes as well as brief quotations to support their relevance.

After the researcher had followed the interpretative process mentioned above for each participant's transcript, she attempted to integrate the participants' superordinate themes into a list of main themes. The superordinate themes that may produce the same meanings from different transcripts were grouped together to form master themes, accompanied by their relevant quotations (Smith & Osborn, 2008). The integration at this stage produced a list of master themes that captured the quality of living with a sibling diagnosed with ASD. This is referred to as the essence (Willig, 2013).

These steps that were followed, namely (a) immersion in data, (b) identifying and labelling emergent themes, (c) combining codes from initial themes, (d) summarising the themes and finally (e) integrating the themes across all cases will be discussed in detail in the chapter that presents the results.

3.7 Measures to ensure trustworthiness

According to Guba and Lincoln (1985), four measures, namely credibility, transferability, dependability and confirmability can be used to ensure trustworthiness. The researcher adopted the following measures in the current study.

3.7.1 Credibility

Credibility is the act of adopting truth-value. This refers to the researcher's efforts to ensure that the information received from participants is true. Because this research followed a qualitative approach, it was not possible to measure the absolute truth or test any hypothesis as this would require absolute knowledge of what the real world is like. As mentioned before, participants' reality differs from person to person (Guba & Lincoln, 1985).

In order to ensure that the data collected were credible, the researcher engaged with the participants for a reasonably long time. The researcher continuously reflected on what the participants were saying to ensure that she understood what they were articulating – a process referred to as member checking. Furthermore, the researcher collected data from different participants until the point of saturation.

In order to ensure honesty among participants, the researcher afforded each participant an opportunity to choose if they wanted to participate in the study. This is because if participants participate voluntarily chances are that they will be honest as opposed to when they have been forced to participate. Encouraging participants to be free from the beginning of each session and establishing a good relationship with them from the onset creates an environment where participants can freely express themselves in an honest way (Guba, 1981).

3.7.2 Transferability

Transferability is the extent to which the information obtained through the study is applicable to other contexts or respondents (Guba, 1981). According to Guba and Lincoln (1985), it is important for the researcher to ensure that the data is applicable to other contexts. This shows that the information gathered can be trusted.

Due to the nature of this study, it was not possible to generalise the findings to other contexts (Guba, 1981). The researcher provided background information in order to establish the context of study, and the participants' responses, as well as a detailed description of the phenomenon under study in order to ensure comparisons with other studies conducted on children living with siblings with ASD.

3.7.3 Dependability

When a study is conducted, it is important to ensure that there will be consistency in the event that another researcher conducts the same study, using the same sample or similar participants (Guba, 1981). To ensure dependability of the findings, the researcher provided a detailed description of the research design and the implementation thereof. The researcher also made use of an independent co-coder. The co-coder used in this case was an independent consultant at *Recomart* which is a research consultancy. The co-coder holds a Master's

degree in Psychology Research Consultation is trained and also trains others with the Atlas ti software and finally, he has experience working within the IPA framework.

3.7.4 Confirmability

The researcher ensured confirmability by using an independent co-coder during data analysis. Furthermore, the researcher made use of a journal in order to reflect on any ideas that she may have had from previous research. In the previous chapter, the researcher also mentioned that she has worked with individuals with ASD. Thus, going into the participants' environment to collect the data the researcher was aware of their own ideas and reflected on these in a diary (Guba, 1981).

3.8 Ethical considerations

When conducting this study, the researcher was aware of the ethical concerns involved. Thus, the researcher received ethical approval from the ethics committee at the University of South Africa (UNISA) on 5 October 2017, the UNISA policy that requires approval be granted by the ethics committee for all academic research to be conducted in the institute (see Appendix A). This ethics committee promotes certain generic moral principles, which all researchers need to adhere to. The researcher adhered to the following principles (UNISA, 2016):

- **Autonomy:** The UNISA policy indicates that research should respect the independence, rights and dignity of research participants (UNISA, 2016).
- **Beneficence:** This means that research should make a positive contribution to the welfare of the people (UNISA, 2016).
- **Non-maleficence:** This principle indicates that research should not cause any harm to the research participants (UNISA, 2016).
- **Justice:** In the context of research, the term justice refers to the principle of equality in the research context. This means that no segment of the population should be burdened by the harms of research or be denied the benefits of knowledge derived from the research (UNISA, 2016).

There were specific ethical considerations that the researcher needed to adhere to during the course of the study, which are pertinent, when considering the research participants, as well as the data gathered from them.

3.8.1 Informed consent

Informed consent is different from just mere consent. Informed consent involves the involvement and participation of both the participants and the researcher in decision-making. When this happens, participants are fully informed about the details of the study (Allan, 2011).

During recruitment, the parents of the research participants received a document explaining in detail the purpose of the study (see Appendix B). This document explained everything about the study, including the purpose of the study, what is required of participants, the right to withdraw from the study at any time, potential benefits of participating, risks involved, confidentiality, data security, further information, as well as contact details of the researcher's supervisor and those of the ethics committee at UNISA.

Participants were informed in writing (see Appendices C and D) that they could withdraw from the study at any time before the data are captured without any consequences (Health Professions Council of South Africa, 2008). The researcher had some participants withdrawing and had to exclude them from the analysis of the information collected. The information they provided was therefore, not transcribed. The researcher made it clear to participants that there were, however, limits to confidentiality, by informing them that the data can, by law, be requested and be made accessible to bodies such as the HPCSA (Health Professions Council of South Africa, 2008).

3.8.2 The best interest or wellbeing

The research participants' best interests and well-being are of utmost importance. Therefore, the researcher has to ensure that no intentional harm is done to participants (Health Professions Council of South Africa, 2008). The researcher had made provision for participants to speak to a counsellor or psychologist in cases of potential harm (Health Professions Council of South Africa, 2008). This, however, was not necessary, because the participants did not indicate that they needed to speak to a counsellor or psychologist; instead, participants saw the study as providing an opportunity for them to vent out, and were excited to share their experiences. To ensure the wellbeing of participants, they were also informed that should they feel uneasy and unable to continue with the interview they were more than welcome to take a break during the interview (Health Professions Council of South Africa, 2008). This also was also not the case, since the interviews went swiftly.

3.8.3 Respect for the participants

The researcher accorded full respect to participants, by ensuring their confidentiality and autonomy (Health Professions Council of South Africa, 2008). In this regard, the privacy of the participants was respected – in the sense that they remained anonymous and the information they shared was kept confidential as well (Allan, 2011).

Details of the information they shared in the study was stored and locked in a secure place, where only the researcher had access. Electronic versions of the information were kept in a secure device that is encrypted with a password (Allan, 2011). The co-coder who needed to see the transcripts signed a non-disclosure agreement which is attached on appendix E.

Autonomy means independence or freedom; however, the participants in this particular study were somewhat dependent when it comes to consent. However, this does not mean that these participants had no say regarding their involvement in the study; instead, they were given autonomy to decide whether they would like to support their parent's decision for them to participate in the study. The participants also signed a consent form to show that they agreed to participate, and were given freedom to choose the location of the interview as well (Allan, 2011).

3.8.4 Stranger as the researcher

In the beginning the researcher had anticipated that she may be treated as a stranger in participants' homes, and that her presence may influence the extent to which participants would be willing to share the information, as well as the kind of information they would be willing to share (Sargeant & Harcourt, 2012). This, however, was not the case. The participants welcomed the researcher warmly. This warm welcome was attributed to her ability to go down to the level of the participants, irrespective of their age.

3.9 Chapter overview

This chapter outlined the research questions, described the paradigm, research design, sampling methods, data collection techniques, data analysis, measures to ensure trustworthiness, as well as ethical considerations for the study. It is important to ensure that there is a paradigm to guide the focus of the research. It is also important to use a research design that seeks to answer the research questions in the best ways possible. In this regard,

the researcher employed IPA as it captures the essence and the participants' voices, to ensure that they are well represented. The next chapter presents the findings of the study, using individualised stories shared by the research participants.

CHAPTER 4: RESULTS

4.1 Introduction

This study focused on individuals living with a sibling diagnosed with ASD. This chapter presents the information obtained from the five research participants on their lived experiences of sharing a home with a sibling diagnosed with ASD. The information is presented in main themes and sub-themes. The researcher aimed to explore the experience of individuals who lived with their sibling diagnosed with ASD.

As mentioned in chapter 3, this study employed a qualitative research method; and each interview was, therefore, carefully analysed, using Interpretative Phenomenological Analysis (IPA) to organise the information obtained from the research participants into main themes and sub-themes. The aim was to make sense of the participants' experiences of living with a sibling diagnosed with ASD.

Key concepts used by the research participants in the interviews became the main themes; within which relevant sub-themes were identified. Each of the main themes have been presented individually in this chapter, and within each main theme, sub-themes have also been presented. Definitions of the themes and supporting excerpts of the actual comments and statements have been included in the themes. Several of the sub-themes have a common occurrence within the data, while some sub-themes relate only to some participants; but yet capture a fascinating experience that provides additional depth to the information.

4.2 Background of participants

Table 4.1 shows the biographical information of the participants as well as that of their siblings with ASD, and their family structure. This helps in providing a context for the reader of these findings. To ensure confidentiality, the names of all participants have been changed and replaced by pseudonyms. The researcher has given the participants pseudonyms, with the exception of one participant, who opted to choose her own pseudonym. The pseudonyms are Miss D, Susan, Mr T, Miss N and Miss Z.

TABLE 4.1 Backgrounds of research participants

Participant	Gender	Age	Ethnicity	Number of sibling(s)	Age of sibling with ASD	Gender of sibling with ASD	Birth position of research participant	Family structure
Miss D	Female	17	White	1	21	Male	Youngest	2 parents
Susan	Female	14	White	1	12	Male	Oldest	2 parents
Mr T	Male	18	White	2	21	Male	Youngest	2 parents
Miss N	Female	19	Black	1	9	Male	Oldest	1 parent (mom)
Miss Z	Female	12	Black	3	6	Male	Second	2 parents

The table above shows the background information of the five research participants. The table also shows that the age of participants ranged from 12 to 19. Four of the five participants were female. As ASD is more prevalent in boys than in girls, all the participants' siblings were male. Of the five participants, two were the oldest in the family, two the youngest, while one was the second born child.

4.3 Presentation of themes

As mentioned previously, the IPA method of data analysis was used in this study. In order to make this clearer, the main themes of the research have been outlined with supporting quotations in order to answer the research questions. The discussion of the main themes, including the applicable sub-themes follows in the next chapter.

Table 4.2 below presents an overview of the main themes and sub-themes identified.

TABLE 4.2 Summary of main themes and sub-themes

Main theme	Sub-themes
1. Loss of the self	<ul style="list-style-type: none">• Negative feelings• Being neglected• A sense of helplessness for sibling with ASD• Dealing with other people's perceptions of the sibling with ASD
2. Learned Behaviour	<ul style="list-style-type: none">• Learning to deal with the sibling's characteristics of ASD• Resilience and maturity• Sense of responsibility• Negotiation of the sibling relationship• Understanding of ASD
3. Available support	<ul style="list-style-type: none">• Support from friends• Support from relatives• Support from school• Support from a support group• Support from parents
4. Making meaning	<ul style="list-style-type: none">• Acceptance of the sibling• Appreciation of the sibling• Disconnectedness• Normal versus abnormal• Hope for the future

4.3.1 Main theme 1: Loss of the self

This main theme relates to the fact that participants seemed to lose themselves when living with their siblings diagnosed with ASD. Although the loss of the self; seemed to be

raising negative feelings about living with a sibling diagnosed with ASD, participants' meaning making of this situation had them expressing their experience in a positive manner.

4.3.1.1 Negative feelings

Participants expressed negative feelings when relating their experiences of having a sibling with autism. The negative feelings the participants have, were about their siblings and the manner in which the siblings led their own lives. These experiences also contributed to this negative feeling.

Here Miss D talks about how she feels when they have to go out as a family:

Miss D: "Sometimes it's a little bit annoying but uhm other times it can be good, uhm ya sometimes he really he hates waiting for anything, he has very little patience, like if you go somewhere where there is traffic he can get angry and its horrible, so it always depends on the circumstances. He is not always very keen on going places he doesn't know so that can also be a bit nerve wrecking. Uhm ya. Places that he is familiar with he is fine. He quite often if he doesn't know where we are going he will complain about going and then it's a bit like urg you know, annoying. Because you like a normal child would go wherever we wanted to go but we can't always, so ya."

In the quote below Miss Z expresses her frustration when her brother does not want to do things expected of him:

Miss Z: "Well, sometimes it's really frustrating cause he doesn't want to, so I just leave him a bit and try to relax and calm down."

4.3.1.2 Being neglected

In losing themselves, participants mentioned that they felt that their needs were being disregarded because parents give more attention to their siblings with ASD. At times this neglect also brings about feelings of jealousy. Although feeling neglected seemed to be justified, participants mentioned that they understood why it is important for their parents to pay more attention to their siblings with ASD. The researcher identified this as a form of meaning making from participants. Participants also seemed to make meaning from the reassurance they receive from their parents, when they explain to them that they do love and care for them. This reassurance can also be evident when parents ask them about their day, or

sharing information during meals. Here Miss D talks about the fact that her parents seem to be doing much for her brother; and how this makes her feel. She also talks about the relationship she has with her parents, and how that relates to neglect:

Miss D: *“You know like when we go to church my mom will pack a little lunch or snack for him so he can eat if he gets hungry, sometimes it's a bit like ugh they do so much for him than it seems for me, but I guess they do do more but then he needs more help. So sometimes it's like urg you kind of feel a bit neglected but it's not like that all the time definitely, I mean they, I have a very good relationship with them and I think generally we function quite well as a family, but it is generally [my brother] in everything I mean even going out to visit people [my brother] is not that keen on uhm we're we all like that.”*

When Susan spoke about the kind of attention that her parents give to her brother with ASD, she refers to herself as the “black sheep” of the family. It is also important to notice, however, that like other participants, Susan also mentions quickly that the reassurance she gets from her mother makes her feel better, and she therefore, attach meaning to living with her brother with ASD:

Susan: *“Sometimes I feel jealous. I feel like they pay too much attention to him and I'm just sitting there on a couch and be like the black sheep. I feel like the black sheep most of the time. But then my mom explains that she loves me I don't have to worry and just tries to balance both of us.”*

Mr T also mentions that getting attention from his parents is weird because they usually give it to his brother with ASD. Mr T makes meaning from this experience of being neglected by reminding himself that his brother does need more attention than he does:

Mr T: *“Well it uhm, it's nice to know that I'm appreciated, uhm it's uhm so it's a bit weird like going, not going through what [my brother] goes through but getting like almost equal amounts of attention, it's a bit weird getting that so then again it also makes you understand how much attention [my brother] really needs.”*

4.3.1.3 A sense of helplessness for sibling with ASD

The research participants also related the experience of feeling helpless for their siblings with ASD. This feeling is sparked by the knowledge that their siblings will probably, never be able to lead a normal life, because of their condition.

Here, Miss D talks about the fact that she feels sorry for her brother; because she is learning to how drive, while her brother will never learn how to drive.

Miss D: *“It’s almost kind of sad like I’m learning to drive now, and he never learned to drive. Ja you feel just sorry for him that he doesn’t get to do things that ordinary people do, but other times it’s like fine.”*

Miss Z also talks about contending with feelings of helplessness and gives an example to the effect that she is unable to relate to the emotional difficulties her brother experiences:

Miss Z: *“So you know moes on shows they show you like oh my gosh this person is paralysed, but you don’t know how that feels and think you know, you see people crying and like why is he crying sometimes you know like oh my gosh my baby brother is like this like this and then I cry, and like moes it’s not the end of the world wont he learn, ja he will learn but it just hurts. Some people don’t understand what it’s like on the person that is helping the child cause the child doesn’t really, like [my brother] understands emotion and he learns about it, but he really doesn’t understand it in general, like what is.”* Susan: *“Feel sorry for him. You know sometimes he can’t handle it. It’s just a reflex and then later he realises what he did and he is full of regret and he is unsure about himself and that’s just sad, uhm I also feel like he doesn’t deserve to be like this he deserves better.”*

4.3.1.4 Dealing with other people’s perceptions of a sibling with ASD

The research participants mentioned that they contend with other people’s reactions towards their siblings with autism. In some cases, this experience would seem embarrassing to them; especially because outsiders are not well informed as far as ASD is concerned, and are unable to make sense of the related behaviours. The behaviour that is typical of individuals with ASD is common when participants go out with their siblings in public, with or without parental supervision:

Miss D: *“Sometimes I mean I guess it is a little bit embarrassing in a way that you know sort of he does strange things like he will say strange things to you or one thing he does a lot of if we are at church he will be like [Miss D Miss D] who are you talking to.”*

In the below except Miss N talks about her experiences of going out in public with her brother, and how she handles him:

Miss N: *“Some people generally they understand, some people. They really do understand, and then there are those ones that don't want to understand at all, and it's more like they wouldn't be bothered also to find out what's going on, they just have a reaction, like you know they have that type of reaction like why is your child doing this it's very unnecessary. Whereas like someone else who maybe knows about this condition is like but I understand or like I, ya like I get why he is doing what he is doing. So it's more like that. There are people who want to learn stuff and there are those that don't so obviously the ones that learn about this stuff are more immune to whatever, ya, whatever happens.”*

Miss N: *“Ya, because now it doesn't really matter, like whatever he does, if we go to the shop then he is just shouting on his own, we just go because of we know that this is him there is nothing we can do to change how he is. So what is the point of us being like no keep quite but like but like, no it's not going to, ya.”*

Susan relates how her brother behaves in public places and how that makes her feel:

Susan: *“The first meeting is always the most nervous moment for them because they don't know how to work with him. It's something new to them and you know it takes time for them to get used to him then [my brother] always accepts my friends as family.”*

Susan: *“It happened once. We ordered something and the waiter got the wrong meal and he gave [my brother] the wrong dish and the [my brother] is like freaking out he is like NO NO and everyone was looking at us and I don't know what to do and I was like I wouldn't say I felt ashamed, I felt scared and my mom tried to calm [my brother] down my dad explain to the waiter this is not the meal he wanted and then he is like oh*

sorry sorry. uhm that was the last experience we had with the wrong menu order and stuff.”

In the excerpt below Mr T explains how he has also accepted his brother for who he is, and how he deals with observers:

Mr T: “well uhm, so I’ve sort of just I know that’s what [my brother] is like, uhm its just what I have to do, uhm well first thing would be making sure that they understand that he is not uhm dangerous at all cause some people, in his tantrum he will jump up and down and stamp his feet on the ground some people will get intimidated by that, so we just gotta make sure he is not gonna hurt you or anything like that, he is autistic he is just having a little tantrum he will be fine, and then uhm ya.”

Miss Z also talks about how difficult it is to be in the midst of a sibling with ASD, but that one has to gather the courage to be strong and deal with any situation. She also mentions how she wishes she could explain her sibling’s condition to everyone, because often, one finds that there is a “broken telephone” effect when she tells one person what is happening, and that one person has to tell someone else:

Miss Z: “It’s hard because people are watching and you don’t really know how to like explain to them because it’s a lot of people and if you explain one at a time it takes too much time and you can’t really tell them correctly.”

Miss Z: “Sometimes I really wish I could explain to them, like deeply what I feel is going on and sometimes you know you can’t, sometimes I try to explain to them if I get the chance to, but they don’t really understand and then I get, sometimes I get like angry like oh why can’t they understand, what’s going on. Sometimes I hate it when I explain to one person and then he tells the other person totally different.”

4.3.2 Main theme 2: Learned behaviour

This theme speaks to the learning and teaching experience that comes with living with a sibling diagnosed with ASD. Living with a sibling with ASD teaches the ‘normal’ siblings various aspects about themselves and others. This learning is also in terms of behaviour and dealing with certain aspects associated with living with someone diagnosed with ASD.

4.3.2.1 Learning to deal with the sibling's characteristics of ASD

The research participants related how they deal with their siblings with ASD. Characteristics typical of individuals with ASD include tantrums, or being picky regarding what to eat; as well as other aspects such as social interaction and preferences. At times this behaviour seems to take its toll on the research participants; who showed concern for their siblings. However, their attitude towards the behaviour of their siblings is a rather positive. They continue to make meaning of this experience by accepting how their siblings are:

Miss N: *“Yoooh! He breaks stuff, he hits people, he shouts he cries, ya. That’s what he basically does, ya..... When I was young it was still a bit odd, because, like you know when you are growing up then you see other siblings then in your head you like ya they are normal and it was hard for me to, to sort of understand. Especially when we are in public and he will have these tantrums, it was a bit hard for me to understand but then as I grew up it was more like you know it is what it is.”*

Susan: *“... Impatient. He like to fight with people if he is waiting too long, he once fought with my mom. My mom was late with the one patient then my mom was going to get him and he was like rararara, crying and screaming, my mom says sorry, then he says okay. Just stop crying then he says okay....He usually would scream, he would hit you, uhm he would cry and later he will cry harder cause he realise he did something wrong cause he is like mumbling sorry and while he crying and you know it’s just very sad. Uhm cause he know he did something wrong he went too far with being mad.”*

Mr T talks about his brother's behaviour and how he has learnt to deal with it:

Mr T: *“Then uhm one or two times he does have uhm temper tantrums and that’s if he is in a situation he doesn’t wanna be in and you can’t like do anything about it. So if there is a really loud place that’s uhm and we can’t really find a quiet place for him he might end up having a temper tantrum, but uhm it varies so sometimes he could go in a loud place and have the best time of his life and other times he would hate it.... well uhm, so I’ve sort of just I know that’s what [my brother] is like, uhm it’s just what I have to do, uhm well first thing would be making sure that they understand that he is not uhm dangerous at all cause some people, in his tantrum he will jump up and down and stamp his feet on the ground some people will get intimidated by that, so we just*

got to make sure he is not gonna hurt you or anything like that, he is autistic he is just having a little tantrum he will be fine, and then uhm ya.”

Miss Z expresses that she understands why her brother would behave in the manner that he does, and gets upset when others, especially her parents complain about it:

Miss Z: “Don’t like it when they really complain cause we all know his situation and sometimes my dad does have moods where he is like urgh why is he doing this, but he tries to calm down and then he starts all over again and tries again you know... sometimes it’s really a challenge cause he wants, maybe he wants to sleep or he wants to go outside or he wants to do something he is not supposed to do and then he is making a fuss and then we all get stressed and then it’s like ooh we wanna go to bed that time ... we do, oh we do go to the park a lot and he finds it very fun, uhm we don’t even we do go to restaurants but he is not very calm there cause when he is at a new place like here he has never actually been here in this restaurant... I wonder if he overthinks things you know like he gets so concerned about something that he will throw a tantrum or something like that, ya sometimes it does concern me in that way.”

4.3.2.2 Resilience and maturity

In their experiences of living with their siblings with ASD, research participants showed resilience and personal growth. They mentioned that these experiences have provided them with an opportunity to reflect on their own behaviours, relationships, and attitudes towards their sibling. Furthermore, it seems as if these experiences enhanced their personal growth in various ways; such as being patient, empathic and putting the needs of the siblings first. Some of the research participants also mentioned that they seem to have attained more maturity than their peers, and that observers are often stunned by the level of their maturity:

Susan: “Uhm, how do I explain that, okay uhm, there are times that I self-feel like I’m letting people down and stuff then sometimes I think to myself what if [my brother] feels like that. I don’t want him to think that thoughts. Then it’s like [my brother], hey do you know you make me smile today, you saved my life today, you make me live another day. So keep doing what you do, ya people feels insecure, but you make them smile. You make people happy..... I learned how to be more mature. I learnt how to be more responsible. And my mom herself said uhm, she needs to apologise because I didn’t have those years to be a child because I have years of you know uhm acting like

a mom basically and I didn't have time to have fun, stuff and you know I don't mind, because as long as I can spend time with him as long as he knows I'm there for him, everything is okay. It's just, uhm actually at this time, I first have to experience how to child. Like I know how to have fun, how to hang out with friends... and so, being able to, living in the house in the same house as [my brother] has sort of made you grow up faster and become this mature at an early age."

Mr T: *"Well I think where I am now most of it has evened out, with the exception of one or two there is always gonna be that so I think everyone has gotten to sort of technically adulthood level of responsibility, So I've been, it's been a good experience for me I think, it showed me that the world isn't this stereotypical thing that it is there are different people out there but because they really different it doesn't mean they are bad they just different people... Ya and because of [my brother] [my brother] I have experienced the kind of things that most people wouldn't have been able to experience and that has helped grow me as a person."*

Miss Z further describes her brother as a teacher:

Miss Z *"Sometimes it really teaches us lessons and it teaches us new stuff like you know we never really knew anything about autism until my brother and now we are doing all these activities and going out and telling people about autism, with my parents of course and you now fun stuff like that... well, I learnt that like sometimes you know I am a bit selfish if I do say so, and I think about myself more than I think of other, and sometimes I learnt like okay he is here now, I need to like leave myself alone and try like take care of him for once and then it teaches me how to like listen to other people and you know like understand what other people need and stuff like that... And he teaches us self-confidence cause we have to have courage to go up to that person and tell them."*

4.3.2.3 Sense of responsibility

The research participants mentioned that they often felt like they were forced to assume responsibility in their respective home. Although this can be overwhelming, they expressed it as good; because it only means that their parents trust them, and that they have grown up. Although this is a positive thing, sometimes it may not be – as one of the research participants mentions that it takes a toll on her social life.

Miss D: *“So when I’m making breakfast or baking I sort of like monitor what he is doing and like I will be, well he will read the recipe then I’ll make sure he is putting the right amount in, I will help him , so I guess I generally do more... but somehow I try to make it seem like he is doing it, like uhm the other day I said I didn’t know what the date was, and then I asked him so then he was like ill check the diary on my phone, so I waited for him to check and in that time I worked out what the date was, but then I waited for him to tell me ya, cause I think it’s nice to let him feel like he is doing stuff... Ya so probably I think because of the general capability I do more, but ya I mean, when making breakfast you know we crack eggs and I mainly just make sure what he is doing fine.”*

Susan: *“It is, it’s actually cool because we drop him off first, so then we can see uhm he is alright at school, he is doing fine, he loves going to school so it’s not a huge problem. Uhm, yeah then I go to school at peace knowing that he is safe at school nothing to worry about.”*

Susan: *“But also on a negative side, I feel like autism is like holding me back in everything, like sometimes I feel scared to hang out with my friends and I WhatsApp my mom saying how is [my brother], how are you guys and my friends do get mad at me if I’m too much on the phone talking to my mom and stuff. I did have a huge argument with one of my friends about it, uhm it’s just I feel too overprotective around [my brother] and also other autistic children don’t go after him.”*

Susan: *“In my old house [my brother] room was across from mine, now he is like on the side so its different cause usually I walk out the room and just by standing at the door I can see how he is, so I don’t have to worry and then my mom’s room was like across, and then the bathroom was where [my brother’s] room now is. So that was not a huge deal, but now it’s like there is a wall now there, I can’t see him, now I make lots of noise walking down the hall.”*

Mr T: *“So we have to brush his teeth, shave him, eating then we have to pick out his clothes and then hand them out to him, we have to bath him, every now and again you have to go and tell him to go to the bathroom, uhm what else, we have to put his music on for him, then we have to uhm if we can see that he is getting agitated inside we can*

open the door so that we can put him on his swing, Well it's uhm, I think it's forced me both me and my brother to have a lot, get a lot of responsibility from a young age."

4.3.2.4 Negotiation of the sibling relationship

This sub-theme refers to how research participants manage their relationship with their siblings with ASD, regardless of the challenges they have in relating. The excerpts in this theme include scenarios of play and interaction between siblings. This theme was named "negotiated", since it taps into how siblings negotiate expectations and demands among themselves to maintain peace – this includes being able to maintain the sibling relationship, while still playing the role of the "adult" carer to one's disabled sibling:

Miss D: "Sometimes it's hard. And sometimes I don't pretend I'm like arg goodness and it annoys him... I think we just kind of accept like that's our relationship like its ya, ... it's really difficult because the stuff he does I don't uhm, and sometimes I don't really make a big effort to do things that have, uhm but yeah.... So uhm he is quite good at asking me about my day uhm if I had any tests and uhm if I failed the test. ... One big thing back to spiders. I am terrified of spiders and [my brother] did not, so whenever there is a spider in the shower or in my bedroom I call him to come catch it for me... And he loves doing that, then there is a whole lot of questions about did you see the spider, then did you come call me, so that's quite a lot of a big part of what we do together, we catch spiders. well obviously I love him he is my brother and some days Um like I love you so much you so nice then other days he is just like in your hair being annoying, but ya so it's a whole lot of different things and some days he makes you laugh it's so funny and ya just really good mood and some days it's a bad mood and not so good, ya some days he is just like not having it or anything and he is obnoxious and disagrees with everything you say, ua he like he looks for things to complain about, ya."

Miss N: "A conversation but mostly when I do stuff he goes with me or he sits while I am doing the stuff or he does his own thing... how can I describe it, hmm, okay, this is something I didn't think of, uhm it's okay, I think it's any normal, it's like any normal brother and sister relationship were there are those days that he just he is not interested in me like he is not feeling me and whatever I say, he is just like you know its

fine, and then there are those days were we just get along, so it's a normal sibling relationship other than the fact that he has autism, but its fine."

Susan: "Uhm, we act out movie scenes, we play swordfights, gunfights, uhm tickle each other, we watch TV, we play games together... laughing. We watch movies. A lot. There is times when we play a song and then we sing the song very loud sometimes I worry about the neighbours though, uhm yeah that's it, and also we play a lot with uhm, fake guns, fake uhm, light savers, we also run around the house chasing each other then we scare the cats.... actually I like, I feel happier when I spend time with the family, but uhm I also feel happy when I'm near him... I feel like I am happier, like all the stress I feel, all the pain I feel from school and stuff, I feel actually better when I spend time with him, I feel like I a happier person."

Mr T: "Well, I enjoy it cause I know that it's the most orthodox way to spend time with a brother it's the one of the better ways that we can do it, so and it's also, I I'm like working too hard or stressing myself, I just go and do that and just relax.... so we usually go out for dinner on a Sunday night, so then we take him with us, and uhm, sorry just one more thing that my mom and dad do for [my brother], so if we go out he has trouble eating with a plate cause he drags his fork with the food across the edge to get it out, so we usually have to get him a bowl so he can drag it up like that, ya. So then we usually go out for dinner on the weekends and then if there is a movie that we all wanna see we will go and take him with and then if it is a movie since uhm he doesn't like wearing glasses at all so we can't, if we take him we try not to go to any 3D movies or anything like that so he can enjoy it better."

4.3.2.5 Understanding of ASD

This sub-theme relates to the research participants' understanding of autism. It appears that most participants have a good understanding of autism, and the practical behavioural pattern associated with the disorder, based on their experiences of living with their siblings with ASD. This goes well with the notion of learning behavioural patterns of their siblings with ASD, because it relates to specific ways in which they handle behavioural patterns displayed by their siblings. Their understanding of ASD contributes to their experiences of living with siblings diagnosed with ASD, and their meaning making thereof.

Miss D: *“So uhm like it's a brain disorder, uhm but I think the main issues are social interaction and uhm that like lots of different symptoms, so just think it's a very wide spectrum, you know like people who can't even talk, like [my brother] who can talk fine and everything that is like generally delayed and not ya just mentally disabled and not able to do uhm things that a normal person would be able to, and not communicating that effectively. Uhm and I think another like a key symptom of autism is sort of like not being able to express your emotions and like express them in like if you can say the wrong way, like overexpressing them like getting way too angry over something little or ya, so ya. I mean it like varies a lot from person to person.”*

Miss N *“Ya okay. For me I think autism is a, I wouldn't say mental, because mental disability makes it sound like you know the person is not really functional, but more of, okay this is not correct, but slow person. Ya, and that's in my head basically that's how I try to put it, especially when I try to explain it to someone, because I don't really, ya. So basically in my head I just say ya, someone that is really slow, they might be fully functional in other areas of life, but mentally ya.”*

Susan: *“My friends don't know a lot of autism uhm they usually ask me what is autism. I don't know how to explain it, cause I don't know what's the cause of Autism I just know how autism acts, how they eat how they, let's say attitude. It's like I don't know the definition of Autism so it's very hard to explain.... uhm there was one friend who lived in the same street with a family with an autistic girl nonverbal she can't talk, she only screams and usually they help the family out with food and everything. They will support and stuff and the father is workless uhm the mother uhm needs to work extra hard to keep the family together, so it's very stressful for that family so my friend and her family supports them as well.”*

Mr T: *“So what I have always been told is autism is when you have a in colloquial terms brain damage that affects a certain area of the brain, well a certain area of the brain doesn't function as it should so either your speech area or your motor skills area there is something in your brain that isn't working as it should then people end up with mental disabilities because of it, so then uhm then I've been told there are varying degrees of autism so you can get high functioning autism which is people who are able to speak performs minimal labour maybe survive in the road own but would still uhm have a certain amount of brain damage and then you get uhm low functioning autism*

which is like my brother were they wouldn't be able to survive on their own most of them can't perform certain tasks of minimal labour and they don't speak they are dependent on other people to survive... So uhm in my mind it's something that is perfectly normal, so it's just a small defect that has occurred, it doesn't mean that you can't live a happy life or anything like that it's just a disability it's like say someone being born without one leg, it's a bit more severe than that but it's the same principle, you can still have a meaningful and happy life with it."

Miss Z: *"Well, I know that it's a mental condition and it can't be cured and it mostly affects boys, like my mom told me out of 64 children 1 of them is autistic, so it's a rare kind of a rare disease... and my mom likes saying this to me, like autism is not a disability, it's a different ability. so she tells me that even though my brother is autism it's not like he can't do this, he will learn eventually, so I don't have to do a lot of things with him, ya, and you get to learn different things. and I like hanging out like with the other children who are autism who have autism and it's like learning new stuff from the children that you didn't really learn from your brother or sister and it's just like different and you start understanding like other people's personalities and you know some people will just, you know if you ask them to explain their own personality they will just explain it like a normal person would, but sometimes its nicer to like find out by yourself."*

4.3.3 Main theme 3: Available support

This main theme relates to how participants access the available support. This also seems to contribute meaningfully to the way in which they made meaning from their experiences.

4.3.3.1 Support from friends

The research participants mentioned that friends provide emotional support when needed. It seems that friendship is vital in helping research participants cope with, and deal with their siblings with ASD. This support is offered by friends of the family, friends of the siblings with ASD, as well as the research participants' own friends. This support also contributes to how participants make meaning of their experiences of living with siblings with ASD:

Miss D: *“Ya, so my close friends do, so uhm ya the both of them at school. The one in particular I sort of grew up with her and ya she is really good with [My brother] and close to him and ya, she is very like good with him and uhm, then the church one's as well I mean they see [my brother] at church every week and then it's quite funny I think girls tend to be more understanding and patient with him, so he loves all the girls they are so nice to him, so ya they generally do uhm as most of my friends. Ya they quite often ask about him like how he is doing, what he is doing, which is really nice, so they are like interested and also just like sometimes you know at church he also just hang around me the whole time so some of them will talk to him or whatever so that's like supportive, so people make an effort because it's not that easy to talk to him you have to go out of your way to think of questions to ask him so quite a lot of them make an effort talk to him...”*

Miss N: *“Uh, at school I don't know, but where we live he has friends but as I say he doesn't really, he doesn't, like he can play with them but he doesn't really play, he, he could go outside and they would be playing outside but he won't necessarily go to them. They could greet him or whatever but then he could do his own thing and he would come back into the house.... no when they do, he can like I said he had friends right, so if they come over sometimes, ya he will sit with them but he doesn't necessarily always show the need to go out and play with other people when he can be his own company if that makes sense, ya..... ya, like all of my friends actually.... uhm, what should I say, I think from what I, I think he intrigues them. Because he will, you know he is himself but for some of them they haven't really come into contact with someone that has autism so from what I also get from them and then what they say after he leaves it's like they are trying to figure out how he thinks and how he responds to people, so it's more of ya, like he intrigues them so.”*

Susan: *“His whole school actually is his friends, he doesn't have that specific one friend. Uhm he sees everyone as his friends... yes I have a lot of friends. Usually they are like when they see [my brother] they are kind of scared of what, if they do something wrong how I would handle it because they know I am a protective person. Then I tell them you know don't worry don't stress, he is only human, you are a human you make mistakes. They are like okay. Uhm, I have a boyfriend... We know each other since 2009. We grew up together so he also knows [my brother] for a very long time,*

uhm he accepts [my brother] the way he is.... [my brother] also wants to play with them. And sometimes they don't understand and I have to explain. When [my brother] is mumbling then I have to explain, what do you want [my brother], oh he wants a cookie. It's his bonding moment.... feel happy, I feel like there is hope for a better world. And sometimes I feel kinda jealous cause that person he is bonding with is not me, and it's like I want to be with my brother but I don't want to interrupt their friendship. Like I want them to be friends, but not that much guys (laughing)... that's not actually a problem, actually I feel happy for both of them, I'm actually happy. Well I have 5 friends with [my brother] then I'm happy with all 6 of them, uhm I'm happy.... uhm, my friends I usually get cool comments saying [my brother] is awesome. How did you become such a great sister? Just that they just say you know you're awesome because you know how to take care of [my brother], they usually give me you know inspiring words to keep me going knowing that I'm doing great. I myself have insecurities because I feel like sometimes I'm not doing great at what I do, then my friends will say don't worry you are doing awesome. Not great, you are AWSOME. So they support me by telling that I am awesome.... Uhm you can point out fake friends, fake family members, backstabbers and stuff uhm you also learn how to gain real friends and how to feel loved and know who is actually there for you."

Mr T: "So I know my best friend who I have known for about 12 years is used to him by now so it's just a normal thing for him because he had known him so much.... So there a quiet a few that come over, like my best friend who has known him long enough he has been around long enough to understand if certain thing feels things about him and then they can help with.... I think most of them don't really care about the fact that he has autism like in the fact that it doesn't bother them, not that they don't care about him. For most of them it's the small thing that I have it's just he is just another guy you know what I mean... Whenever I introduce them to [my brother] I do end up usually having to explain what autism is and then once they know what it is that it usually when they become more relaxed... So they like with the friends that have known him from a while they come around and they say hi [my brother] how you doing, even though he can't respond."

Miss Z: "sometimes when I am mad about autism, like if I tell them yoh I wish my brother didn't have autism case I will be doing all this stuff with him, she likes calming

me down and telling me that you have done a lot of things with her and it's really its heart-warming and just teaches me that sometimes its fine you know, you just need to calm down and gather yourself up and try again you know cause I know that one day he will get the hang of it... it's only because of my personality you know and I don't know how else to explain this, like my best friend, my best friend she knows all my secrets and everything so whenever I have a problem that I can't really explain to my parents I come to her and so she really explains to me like no Miss Z like all you need to do is just calm down ... yoh, it is really amazing cause sometimes I like sharing things with my parents, but I'd not feel comfortable sharing it with them and sometimes I can't tell a bit of things to my sister so she is there she is in between my parents and my sister..."

4.3.3.2 Support from relatives

The research participants mentioned that they have extended family or relatives who are supportive, and this makes it easy for them to handle their siblings with ASD. In most cases, the extended family or parents take the role of caretakers:

Miss D: "So my grandparents in Howick they quite often offer just to have him for a week so we can go on holiday there which is like a huge support for us, it means we can go on a break for a week or a week and a half we don't have to worry about him, so that's a big thing going they do. Then even we as a family go to visit them quite often and ya [my brother] really likes going there. He is generally happy there and ya, cause there it's sort of like the family together, you can do a log if things that include him, uhm and my cousin in Cape Town they are like I think what's nice with them is this sort of like they are so relaxed with him, I don't know if they are patient to be like a perfect family or whatever so they are just supportive and really happy to see him and they like spending time with him. And they all talk to him and engage with him and ya."

Miss N: "It's basically the same with ours. It's the same as ours because they love him as much as we do, so ya and basically that. I think everyone in our family has gotten used to him now at this point you know because for everyone it was a bit difficult also at the beginning when he was diagnosed with Autism but like now, like that's why I say that we, for us this is our normal because they can't also imagine him any other way because this is how he is, ya... usually sometimes, especially when my mom is uhm

when she knows that she wants to be alone and maybe work is gonna get hectic, she usually tells my uncle if he is going to my granny's house to pick him up and take him there, or he goes and he visits my granny's place... no he visits actually and he likes my granny's house more because it's more, he is alone there, so he likes it more because, and he has enough space to just roam around and just chill... she is good with him, you know because ya, she is. And my my little brother get along with my granny very well, so they are good when he is there they do stuff together and sometimes he helps out my granny sometimes he doesn't want to, but you know ya. So they have a good relationship."

Susan: "[my brother] and I usually go to my grandparents for a sleepover, it's usually on Friday nights cause my mom and dad also need a date night to themselves, you know having a break time from both of us, I'm a handful, I won't say [my brother] is a handful, uhm you don't actually sleep over with our aunts and uncles, because uhm its actually our family uhm have a weird relationship, they kind of you know ditched us because of [my brother]. We don't drink a lot, we don't party late and they kicked us out basically out of the family, because of that. We don't mind, we like we have us we are happy to have us, we are strong... I feel well for the other family members I feel sadness because they don't see the deeper the bigger picture because [my brother] he is different yes he is different but we have a time, we have our ways and they can't expect us to break it. I am happy for us that we respect our own rules but we kind of angry with them for being that way... uh, usually I, my grandmother she knows she is not the best at working with [my brother] the she always comes to me and says help me, I can't do it. Then I feel like wow, I can do this I need to help my grandma, then uhm, there are times that we have our issues were my grandma will say no, leave him and then I say I can't leave him I can't let him do that it's not acceptable in my book, uhm I do get support from my grandfather a lot. Like if my grandmother is feeling like she knows what she is doing then my grandfather will say no let Susan do the thing, she knows what she is doing. The fact that they know I know what I'm doing with [my brother]."*

Mr T: "Ya so uhm at my nan's house we have, we'll had Sunday lunch every Sunday and we always take him with and nana was absolutely incredible with [my brother], so she had this sort of instinctive thing that my parents had with him so she knows when

he is getting agitated and if we going somewhere and we can't take [my brother] with us we would be perfectly fine just leaving him with nana... So our family isn't that big, but everyone in our pretty much everyone that we visit in our family we go to with [my brother]. So my dad's cousins we go visit with [my brother], my grandparents we went with [my brother], my nana we went with [my brother], my cousins we went with [my brother] so whenever we go to family we go with [my brother]...All the people in the family are very helpful and very understanding of [my brother] uhm and all of them really know what they comfortable with doing with I'm so some of them know that they wouldn't be able to look after him for weekend and they know that so we can't and there are other ones that would be 100% fine with [my brother]... Well it's really uhm encouraging that everyone in the family has accepted him as part of the family because I know that uhm, I'm sure some people in some families the minority of people would, some people would reject someone with Autism, so it's really nice to know that everyone has fully accepted him as part of the family... So uhm, so it's it really does make me happy that he is part of the family and that really makes me happy that you can really see that everyone in the family is making an effort to spend time with him so that really makes me like appreciate all the family members for doing that for him."

Miss Z: "well, my dad is a bit rough and my brother really doesn't like that cause he is soft and you know sensitive and all of that, but he does like playing with my dad like you know sometimes they watch wrestling and then my brother will try to wrestle my dad (laughing) ya and do stuff like that. with my mom, yoh my baby brother loves my mother, like if we are at my grandmother's house just visiting or like my mom has to go somewhere and she lives at my baby brother uhm at my grandmother's house, he sometimes cries cause he really misses my mom and sometimes when he hears the car like starting, he will rung (laugh) like he actually knows like the pattern like she lives us at my grandmother and then she goes out the door really quite and then he notices that someone is missing and then he goes and checks outside and sees the car starting and sometimes it's really sad cause you know he wants to be with her, but she , he can't do anything...well, not much really cause my mom and dad, my mom went back to school and my dad is working and there is not really much we do. but when we get to my grandmother's house, I have a lot of cousins there who also like visiting and then after we do our daily chores we just go outside and he doesn't really like being trapped in one place so we just go, maybe we go to the shop like not the nearby shop, like that

far away shop so that he can get a bit of a walk and then maybe we like play something, or like throw the ball and you know he kicks it like just does stuff with the ball, like he tries to explore, like he just tries to figure out what to do with this one object and then we all find that fun cause it's something different that none of our cousins and friends ever do. ya, so that's fun about it."

4.3.3.3 Support from school

The research participants mentioned that they enjoy support from schools where both their siblings with autism and themselves attend. It seems that the school environment provides the core support for learning and interaction for their sibling with autism. It also appears that the school environment offers support for research participants, and this helps them to deal with the negative experiences of living with a sibling with ASD:

Miss D: "He goes to a place [school name] which is like for adults with autism.... He goes there they teach them life's skills and uhm, he has to get up and go do that so he generally needs to be hurried along."

Susan: "His whole school actually is his friends; he doesn't have that specific one friend. Uhm he sees everyone as his friends."

Miss Z: "And I don't know, we sometimes try to research on it and sometimes when we have like assignments to do and like they say choose your own topic, we also like choosing autism as a topic and telling people about it and sometimes my teachers also I like telling them and there is this one teacher who also has a niece who is autistic and so she tells me sometimes like tell your mother this and ask her if she does this and then my friends sometimes they think like oh wow she can do this because of autism, like she can she has the bravery to like confront people and tell them because of her little brother and now I like teaching them what I learn from my baby brother because it feels like it really impacts me and if it impacts me it can impact others in the same way... it's because of my mother she was like okay you know how to talk to people about autism why don't you talk to people at your school."

Miss Z: "Ya but the nice thing is that there are teachers there and there is 2 teachers in each class... so it's easy to ya ya, to just keep track of them and then the teacher will

just call my mom or WhatsApp her and say okay [my brother] was being bullied by another autistic child but I think it's because this happened and this happened."

4.3.3.4 Support offered by support groups

One of the research participants mentioned that she and her parents have a support group:

Miss D: "We have been going to churches and telling them about autism, what we know about autism and my mother has this autism support group were there is different women who all have the same situation and they teach each other new stuff like how to not like, how to take care of the child in new different ways than you normally do with an ordinary child and like stuff like that, like and then sometimes they involve us and we go to fun places and try new things and we see what stuff they like and you know we test them a bit and see what they learn what they learning and ya different stuff like that and ... and sometimes its nice cause we also get to come along and help and ya it's fun cause we also learn stuff there like how other children behave as well like not only our child, but if it happens that he starts acting like this other child, then we know how to handle it."

4.3.3.5 Support offered by parents

All the research participants mentioned that they have immediate support in their parents. This support is expressed in the form of observing the attitude and behaviour the parents have with the sibling with ASD, as well as how the parents are with the participants:

Miss D: "My mom is really patient with him; she is probably the best out of us three. Uhm she is really good a like getting down on his level and talking to him and answering his annoying questions and things like that and, yeah. My dad is also really good with trying to do stuff with his., he is really good. Uhm he quite often if he needs to fix something he I will ask him to come help fix it and ya, ... Obviously sometimes they also get really frustrated by him, uhm but ya I think really especially my mom is pretty good, uhm ya and I think she sometimes does get quite tired you know he loses things a lot like a phone or whatever and he gets upset and it's annoying and tiring, but she us r really patient with him actually so is my dad.... Probably my mom, just because she is around the most. We'll miss dad works all the time, so ya she is generally the one who would be like okay [my brother] can feed the dogs or go do this

uhm, I mean my dad also does I kind of don't really cause uhm, he tends to get annoyed if I tell him to do things because I'm the little sister."

Susan: "Uhm, [my brother], I won't say [my brother] has something against my dad, it's just sometimes my dad and he is found arguing ad stuff and when you see [my brother] wants to spend time with him, then my dad is like why do you wanna spend time with me when you are fighting with me then you wanna spend time with me. Then there times when my mom helps a lot, so like he parents, I won't say that parents works too much that one works too little, actually they have their parts."

Mr T "So ya, they have been with [my brother] for 24 years so I guess they know all his little insights so if he gets, agitated he gets uhm waving his hand up and down and motion or spinning around in circles, so then they are very good at picking up when he is not comfortable in a certain situation and they will make sure to get him from that situation and then calm him pretty quickly. So one thing he really likes is just sitting in the car, doesn't have to be driving anywhere I think he likes the silence inside it and he has got, if we are out somewhere and he is not coping well and is finding the situation a bit stressful they will go and put him in the car and then uhm they have a it took them quite a while but they have told him how to eat with a knife and fork so they actually uhm very good with him in my opinion. So uhm they we try to take him everywhere we go so they make sure that he is fine and then pretty much everywhere we go. ... so obviously they have to prepare his food and uhm make his bed and after that what they have to do is that they have to get out his clothes with him and uhm just gives him to as he dresses himself and uhm bath, he doesn't do that on his own and then they also have to give him his uhm medication uhm they always make sure that he has got something to do, so if he is not listening to music they will out him on the swing and if he doesn't wanna go on the swing they give him an asterisks book, so they try to keep him entertained."

Miss Z "Well, my dad is a bit rough and my brother really doesn't like that cause he is soft and you know sensitive and all of that, but he does like playing with my dad like you know sometimes they watch wrestling and then my brother will try to wrestle my dad (laughing) ya and do stuff like that. with my mom, yoh my baby brother loves my mother, like if we are at my grandmother's house just visiting or like my mom has to go somewhere and she lives at my baby brother uhm at my grandmother's house, he

sometimes cries cause he really misses my mom and sometimes when he hears the car like starting, he will rung (laugh) like he actually knows like the pattern like she lives us at my grandmother and then she goes out the door really quite and then he notices that someone is missing and then he goes and checks outside and sees the car starting and sometimes it's really sad cause you know he wants to be with her, but she , he can't do anything."

4.3.4 Main theme 4: Making meaning

This theme relates to how the research participants make meaning from living with their siblings with ASD.

4.3.4.1 Acceptance of the sibling

Although there are some challenges associated with living with a sibling diagnosed with ASD, the research participants mentioned that they have accepted that their sibling has autism:

Miss D: "So what it means to me I guess uhm like uhm like it's kind of you know like uhm ya like he is just it's I think like I uhm, like I need to like to accept it you know like that, he is my brother and uhm it's, ya I mean ya not to think what it could be like, you know he is autistic and lets go from there. You know uhm, I hope that answers your question."

Miss N: "For me it just means he is a little bit different from the next person, but he is still my brother". "Ya, like you know it's very hard for me to think of it any other way when it's just like that. The only difference between us another siblings is that he doesn't actually formulate a whole sentence when we have conversations, but basically we talk and we sit together we watch stuff together we do stuff together, we like the same things when it comes to food and like, so its ya."

Mr T: "So I've always known that he is autistic and I've accepted that so it's just a normal for me and I can't imagine him any other way, I enjoy spending my time with him cause there are very few ways that I can do it with him". "Well it's really uhm encouraging that everyone in the family has accepted him as part of the family because I know that uhm, I'm sure some people in some families the minority of people would,

some people would reject someone with Autism, so it's really nice to know that everyone has fully accepted him as part of the family.”

4.3.4.2 Siblings as blessings

The research participants indicated that they appreciate their siblings. It appears that in spite of the challenges associated with living with a sibling with ASD, they regard their siblings as blessings; because there is none else in the world that is like them. Participants further described their sibling as different and interesting. They mentioned that no one else in the world goes through what they (research participants) go through, and that this is a blessing:

Mr T: *“So uhm what I've...I've thought about it this way I've been blessed in the fact that I've got a brother who is different and interesting, cause you can get up with a brother who is like a million other people or a thousand or billion other people, but I've been blessed with a brother that's unique and different and interesting and isn't the norm.”*

Miss Z: *“Well it actually means a lot of things. it means like I have my own personal teacher cause he teaches me a lot of things and he teaches me like things that I will not learn from a normal brother, and then it's nice having him as a brother cause I don't, like he is my first brother and like my last brother (laugh).”*

Susan: *“It feels like a blessing. It means like yes, uhm now it's gonna sound weird uhm. He is like a gift from God telling me you know there is always something good coming your way, don't give up. [My brother] is someone who makes me feel better when I have a tough day. He is, like I said, the light to my darkest days.”*

4.3.4.3 Disconnectedness

Even though they regard having a sibling with ASD as a blessing, the research participants also acknowledged that they have to live in two different worlds:

Miss D: *“And sometimes it is like hard because you can't just like connect with him like you would with a normal person, uhm but other times, yeah I guess it's depending on his mood and my mood and, ya it's interesting. Like every day is really different.”*

Miss Z: *“I’m happy, but he doesn’t really understand emotion itself and sometimes when you overthink things like that it sometimes gets to you and then you just act out and you cry or you and then people are like but why are you crying cause you know kuthi yoh this child is like this and I can’t do anything to change it I’m not a doctor I’m not a magician I can’t do anything and then people still don’t understand because they are not living with this person and they don’t understand the things he does and like the things he can’t do like even opening a banana so they don’t understand how a banana was closed so how do you open it.”*

4.3.4.4 Normal versus abnormal

This sub-theme relates to the concept of normality versus abnormality. Although the research participants understand that being diagnosed with ASD is not the typical or normal way, this is what they know and this is their “normal”. The fact that they regard this as normal helps them make meaning in relation to living with a sibling diagnosed with ASD:

Miss N: *“No I didn’t think it was normal because from the people that like I was with for example and their siblings, they had in my head that was normal, so for me now this is normal, like it’s I can’t imagine it being another way.”*

Susan even explains how society expects you to act and is wondering if normal is a concept that actually exists:

Susan: *“It’s like people expect you, you look like a normal person, uhm there is nothing wrong with you on the outside, you know on this inside you have, I wouldn’t say a problem it’s just different. Eish man the words I want to use sound like a bad thing. Like you look normal on the outside but you are actually different on the inside. It’s like uhm, it doesn’t matter what’s on the outside it matters what’s on the inside. That’s a good example. So yeah it just means that different isn’t, different it can be different in a weird way and that normal doesn’t actually exist.”*

Mr T explains his “normal” as that which he has ever known:

Mr T: *“it’s actually a bit weird cause from my experience is normal because that’s all I’ve ever known.... So uhm I in my mind it’s something that is perfectly normal, so it’s just a small defect that has occurred, it doesn’t mean that you can’t live a happy life or anything like that it’s just a disability it’s like say someone being born without one leg,*

it's a bit more severe than that but it's the same principle, you can still have a meaningful and happy life with it... So uhm in my mind I have sort of just made it that Autism is just a normal thing so it doesn't really mean anything special that I have an autistic brother it's just the normal.... Yeah, someone might have red hair someone might have white hair, one person's brother might be high functioning, one might be low functioning."

Miss Z: *"Well, as a brother he is really like one of those normal brothers you know, that sometimes play with your stuff and you know get naughty and then sometimes it's fun cause he wants to play with you like a normal sibling or a friend or like how he understands what you are."*

4.3.4.5 Hope for the future

The research participants express a sense of hope for their own future and that of their siblings with ASD, in spite of the challenges of having and living with a sibling with ASD. These participants express hope in terms of the ASD prognosis as well:

Miss N: *"I guess now it feels pretty good, because for me I take it as a sense that he is growing up. You know, and I take it as he is becoming his own, more and more of his own person and he doesn't need to depend on us and as he gets older and as his autism will eventually get better and he will start talking then he won't need us much, you know, so I guess for me it's just a thing where it makes me happy because I know that he is growing, ya."*

Susan: *"For me it means the world isn't all darkness, there is also always that one light you need to find, he is the light in my dark days. Wow I'm so deep today, wow. (laughing). Like uhm, there is always someone you can lean on, you don't have to worry, that someone is always there. You just need to look deeper into the picture.... I feel happy, I feel like there is hope for a better world. ...uhm, it's special. It's like meeting people that like helping me through this experience and tell me you know everything will be okay. Maybe not now, but eventually everything will go great. Keep your head up or your crown will fall down."*

4.4 Chapter Overview

This chapter presented in themes and sub-themes the information obtained from the research participants, using the Interpretative Phenomenological Analysis. The four main themes and 19 sub-themes were presented with supporting direct quotations from the interviews with the research participants. Chapter 5 discusses the main themes and sub-themes, and integrates literature and theory. The chapter also outlines the strengths and limitations of the study and make recommendations for future research on the phenomenon under study.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter reflects on the information obtained from the research participants. The main themes and sub-themes that emerged from the research participants' accounts of living with a sibling with ASD are discussed in relation to the relevant literature and theory. In so doing the researcher was able to review the research aims and research questions, using IPA and Bronfenbrenner's bio-ecological model to interpret the information obtained. The chapter concludes by highlighting the strengths and limitations of the study and making recommendations for future research.

5.2 Discussion of the research findings

The researcher outlines the main aims of the study and the research questions before discussing the research findings.

Research aims:

- To explore the experiences of individuals living with siblings diagnosed with ASD;
- To gain an understanding of how individuals experience living with a sibling diagnosed with ASD, and how they make meaning from this experience.

Research questions:

- How do individuals living with siblings diagnosed with ASD experience it?
- How do individuals living with siblings diagnosed with ASD make meaning from their experiences?

5.2.1 Themes related to loss of the self:

Negative feelings, neglect, helplessness, dealing with the public

The research participants indicated that they contend with negative feelings associated with living with a sibling with ASD – which spark feelings of self-loss; as they have to focus more on their siblings with ASD than themselves. Spending time with their autistic siblings at

home and outside the home environment seems to contribute to these negative feelings. This, according to the research participants, is often annoying, nerve wrecking, and frustrating.

The research participants also indicated that they felt helpless because individuals with ASD are not always, due to their disability, able to engage in everyday activities that “normal” developing children engage in. As a result, the other family members may be limited in the kind of activity or activities they can engage in. This, therefore, fuels negative feelings in these participants.

It is interesting to note that although the research participants expressed being annoyed, frustrated, and having nerve-wrecking feelings, they make meaning by being positive about their experiences. The participants also indicated that they exercise patience on their siblings with ASD as a way of making meaning of this negative experience.

Miss Z: “...so I just leave him a bit and try to relax and calm down.”

The research participants also indicated that at times they feel neglected by their parents. Although most participants expressed feelings of being neglected, it was however, evident that they could still maintain a positive attitude and make meaning of their experiences. They make meaning from this by showing understanding that their siblings essentially do need the extra attention paid to them. Participants also make meaning of these experiences by remembering that their parents do care and love them. This parental support will be discussed later in the chapter.

The research participants indicated that they sometimes feel that they are being neglected in as far as receiving parental care is concerned. The time and attention their parents give to their siblings with ASD seem to trigger in them feelings of being left out, or being neglected at times, as they also want and need special attention from their parents.

Although the research participants indicated the need for their parents to attend to them, they however, understand that they do not need much of the assistance or attention as their sibling. The research participants were all aware that individuals with ASD usually require more help with engaging in day-to-day activities, which may mean that their parents and the rest of the family should work together to assist the individual with ASD – although they may feel jealous about the amount of help and time that their siblings with ASD are enjoying, they do understand the plight of their siblings.

One of the research participants mentioned that it feels strange, when their parents eventually give them the extra attention, because that is when they realise that they actually do not need it as much as their siblings with ASD does.

This ability to think for others and being able to accept situations is shown to be common in individuals who have siblings with ASD. The literature reviewed shows that these children seem to be more understanding when compared to their peers, whose siblings do not have ASD (Carvalho, 2017). Individuals with siblings who have ASD tend to contend with feelings of neglect, but in this study the research participants indicated clearly that they understand that they do not need more attention as their siblings with ASD. Their ability to understand was one of the things that surprised the researcher because, based on a study by Falk, Norris, and Quinn (2014), it is expected that they will feel sad and show signs of struggle, as a result of this neglect. As in line with the findings of the study by Atkin and Tozer (2014), participants in this study did not seem to struggle with the fact that they get less attention from their parents than their siblings with ASD – instead they expressed that they do understand why their siblings with ASD need to be given more attention than them, and tend to be empathetic towards their siblings with ASD.

Siblings of individuals with ASD tend to show empathy and care for them. They seem to have an increased tolerance for others, especially those with disabilities, when compared to their peers and people in general (Dansby, Turns, Whiting & Crane, 2017). Siblings of individuals with ASD are reported to have more empathy for those who are different to them, and are also, more aware of other people's needs, compared to their own.

This deep sense of empathy and understanding was evident in the research participants in the current study because, instead of them feeling helpless, they felt helpless on behalf of their siblings with ASD. They indicated that they almost, intentionally lose themselves in the situation in order to accommodate their siblings with ASD. This was evident in all cases, where the research participants assume their siblings with ASD are helpless, and they therefore, feel sorry for them. They perceive that their siblings will not lead the kind of life that they themselves will lead, and that their siblings will not have the opportunities that they themselves have – and this sparks feelings of helplessness in them. Examples of how these research participants feel relate to the day- to-day activities, such as the fact that their siblings with ASD will never learn to drive a car, are unable to engage in a conversation that involves discussing emotional issues, or share their emotional difficulties. These research

participants further expressed a sense of helplessness on behalf of their siblings with ASD in relation to the fact that their siblings are unable to control their urges or emotions.

While experiencing feelings of being neglected and feeling helpless for their sibling with ASD, research participants in this study also shared the experience of having to deal with observers' perceptions of their sibling with ASD.

In the African context being disabled in general carries a lot of stigma. There is evidence that people with disabilities are being treated badly. When one has a family member with a disability, most people in Africa tend to stigmatise them as well. Those who care for individuals with disabilities are also seen differently, and are ridiculed by many people in society, as compared to those who do not care for such people (Someki et al. 2018).

Therefore, much still needs to be done in terms of making society understand what a disability is, and what it implies. Although a person with ASD is not visually different to normal developing individuals, the behaviours they display cannot be hidden from the public eye. This often results in people watching an ASD person as their behaviour is very prominent (Dorozenko, Roberts & Bishop, 2015).

Siblings of individuals with ASD engage in activities with them outside the home environment, and because one cannot always tell when their ASD sibling will have an outburst, they usually have to deal with the watchful eye of the judgemental and uninformed public.

For normal developing people, dealing with the peculiar behaviour of an ASD person may be a devastating and frustrating experience. The research participants in this study, however, seemed to have it all under control. They indicated that although the behaviour of their siblings is sometimes, somewhat embarrassing, they however, do not take it personally when people give them funny looks, because there is nothing they can do to change their siblings, especially because many of the general public "*wouldn't be bothered to find out what is going on*"; according to Miss N.

The research participants mentioned that it becomes easier to handle their siblings with ASD when onlookers understand what ASD is all about. Again, when there is more than one child with ASD in the vicinity, onlookers can relate and better understand what is happening when an ASD-diagnosed person acts in a peculiar manner.

There are, however, some contradictions in respect of how the research participants make sense of the attitude of onlookers in this regard. Although it was clear that the research participants do not care about what people think about their siblings with ASD, it was also, clearly evident that they feel they need to share the knowledge they possess on autism, and always explain that their siblings have ASD. This includes sharing with people that their siblings are not at all dangerous, and that they are just having a meltdown. One of the participants also mentioned that she regards her sibling's condition as providing a teaching opportunity and a way to share information about ASD.

5.2.2 Themes related to learned behaviour:

Dealing with behaviour, resilience, maturity, responsibility, relationship, ASD knowledge

Learning to deal with the behaviour typical of individuals with ASD sparks negative feelings that the research participants contend with, as highlighted in the previous theme. These behavioural characteristics can be difficult to deal with, especially for the people close to the individual diagnosed with ASD. As Miss Z mentioned, it is harder for people who care for a person with ASD than for people who are looking at the situation from outside.

While some individuals who have siblings with ASD experience the demands that come with dealing with the characteristics of ASD as emotionally or intellectually draining – according to Hughes (2017), the research participants in the current study have learnt how to respond to their sibling's demands.

The research participants indicated that they often contend with frustration, sparked by their siblings' inability to understand and manage certain aspects of life, which are clear – for example, when they are unable to do something that normal people take for granted, such as peeling a banana, as mentioned by Miss Z. Her brother cannot peel a banana; he does not understand why it is closed, why he can't eat it as it is; and why he must peel it in the first place. This is, however, accompanied by feelings of helplessness as mentioned before, for the siblings with ASD, which leads to the realisation by the research participants that they may entertain the sibling's unawareness and use that as an opportunity to teach others and also derive some lessons.

Another aspect of ASD, which complicates the relationships between siblings, involves the difficult behaviour typical of individual with ASD, which their siblings display. This includes aspects such as the type of food the siblings insist on eating, their play style, as well as their temper tantrums.

The research participants mentioned that it is upsetting when their siblings engage in certain types of behaviour. The participants reckoned that it is difficult to deal with the behaviour associated with ASD, such as siblings playing loud music or having a temper tantrum during exam times. The research participants also mentioned that it was difficult for them to make sense of this behaviour when they were still younger and growing up with their siblings. However, as they grew up they came to understand that most of the times their siblings were just having a tantrum and that they would be fine. The research participants, therefore, seemed to have developed more insight of autism and what it entails. Furthermore, the research participants tended to have empathy for their siblings, and asserted that the fact that they have autism is explanation enough – there is, therefore, no need to get upset over their siblings' temper tantrums.

According to the findings of a study by Tudor et al. (2013), ASD affects the way in which siblings bond and grow close together. The behaviour of children with ASD, such as difficulty engaging in social interactions, as well as repetitive stereotypical behaviour may affect the manner in which siblings bond and the kind of relationships that siblings normally enjoy (Tudor et al., 2013).

But, because the research participants know the source of the behaviour, this may reduce the distress they experience in relation to dealing with them. As asserted by Mitchell (2016) and Safran (2017), social behaviour that is embarrassing, temper tantrums, aggression, destructiveness, screaming, running away, and self-injury are often associated with ASD. In actual fact, this kind of behaviour is often a reaction to the environment, or a desperate attempt to communicate (Koudstaal, 2011), and doesn't mean anything less or more.

As a result, living with siblings with ASD inculcates maturity and resilience in participants – hence all of them mentioned that the experience of living with their siblings has contributed to their levels of growth and maturity, as compared to their peers. Furthermore, the research participants showed the ability to reflect on their own behaviour, relationships, and their attitudes towards their siblings with ASD. Again, the experience of living with

siblings diagnosed with ASD has made them see the importance living in the present, and to be conscious of what is happening in their lives, and in the lives of others.

Resilience is defined as the ability to bounce back after dealing with a difficult situation. This happens when an individual becomes even stronger, as a result of having faced a difficult situation (Bitsika et al., 2015). The findings of a study by Bayat (2007) on resilience and children with autism indicated that what makes families to remain strong even after experiencing difficulties is determined by how they make meaning from the adversity – in this case the disability – and how they become closer as a family, and being more appreciative of each other and life in general. Furthermore, the findings indicated that in order to handle individuals with ASD, and for siblings of individuals with ASD to develop resilience, they need to have support from their families. Moreover, the environment that one lives in, their relationship with others, as well as their routine, contributes to their degree of resilience. This relates to the support systems that one enjoys, as asserted by Bronfenbrenner (2005), that each system, either on its own or playing together, contributes to building the individual.

Thus, family relationships and the marital status of parents may contribute to the resilience of individuals who are living with siblings with ASD. This is evident in the research participants' lives, who confirmed during the interviews that they enjoy good relations with their family members, which also include some extended family members. The research participants seemed to be able to reflect on their experiences of living with siblings who have ASD, and make meaning thereof.

According to Tudor et al. (2013), there are several advantages to promoting resilience in children and adolescents who experience the daily stressors of living with a sibling with ASD. These qualities of being resilient include the potential to develop a positive self-esteem, a strong temperament, and a pro-social behaviour; increased opportunities to build a supportive family environment; and learning skills to develop wider sources of social support through the extended family, friends, and peers (Kovshoff et al., 2017).

A recent report by Yacoub, Dowd, McCann and Burke (2018) revealed that siblings of individuals with disabilities normally develop a strategy to deal with their disabled siblings by taking responsibility for them. Research participants in this study seemed to have

learned how to deal with the behaviour of their siblings with ASD. The research participants displayed some commonalities in respect of how they deal with their siblings.

The research participants also reported a sense of responsibility for their siblings with ASD. They mentioned that being responsible for their sibling gives them joy, as they feel that their parents trust them with their siblings. This further shows that they are being regarded as independent and worthy to be trusted. The research participants expressed sentiments similar to those expressed by Mitchell (2016), that individuals feel a sense of responsibility towards their disabled siblings – and this brings them closer and help build their relationship. In contrast, the findings of the same study also reported that siblings revealed that they sometimes try to abdicate the responsibility, and get away from their families in order to enjoy their freedom. This is in contrast to what the research participants in this study indicated, as they mentioned that taking the responsibility of caring for their siblings shows that they are trusted (especially by parents), but that they are also being given their independence.

Taking on responsibility for one's disabled sibling predisposes one to parentification – this refers to a situation where a child cares for another/others – thus taking over the duties that are usually performed by parents. In the process, such a child sacrifices his or her own needs (Tomeny, Barry, Fair & Riley, 1992). Parentification was noticeable in some of the research participants. One participant showed signs of parentification when she mentioned that she wakes up in the night to check on her sibling, who will be sleeping. This is usually done by a parent. The research participants do not seem to worry about taking on responsibility for their ASD siblings at all. In actual fact, they seem to be happy to care for their siblings and knowing that they are comfortable. This makes the research participants to feel good about themselves.

Parentification is, however, not always a positive thing, as shown by the case of another research participant, who mentioned that she had a fight with her friends, because when she is out with them she is always checking up on her brother with ASD, who would be at home the entire time. This shows that although cases differ, taking on the responsibility may in some instances, affect siblings' social lives in a negative way.

For the research participants, negotiating the relationships entails seeking to find a good balance between entertaining their siblings with ASD, and the manner in which they

interact, as well as staying sane and not getting frustrated by the fact that their interaction is not typical of persons their age. The research participants seemed to negotiate the relationship between themselves and their siblings with ASD by showing the ability to blend in well with their siblings' characteristics and their lifestyles.

Although their relationship is "*not the most orthodox one*", according to Mr T, the research participants seemed to have accepted that it is how it should be. Instead of getting impatient with their siblings, because of to their peculiar way of interacting, these research participants displayed some maturity in as far as negotiating a good relationship with their siblings with ASD is concerned. This is also associated with a sense of responsibility the research participants seem to have towards their siblings. According to Meltzer and Kramer (2016), the nature of sibling relationships is mostly shaped by the individual characteristics of the siblings during childhood such as age, birth order, gender, and temperament, as well as the relationships within the sibling system, and the larger family context.

Within the sibling relationship, older and younger siblings are likely to have different perceptions of their relationship, as well as varying abilities, social skills, and knowledge (Bontinck, Warreyn, Van Der Paelt, Demurie & Roeyers, 2018). Age is said to play a role in sibling relationships, specifically when younger siblings learn from and model the behaviour of older siblings. This, however, is not the case when it comes to the siblings of individuals with ASD. There is however, evidence that siblings play roles that are age-specific. However, the situation is different when the sibling with ASD is older. Then the younger, normal sibling has to negotiate space for growing up quickly in order to have a good and meaningful relationship with their older sibling with ASD.

Furthermore, it is said that older siblings often assume the role of teachers, while younger siblings are likely to assume the role of followers – that is, learners (Howe & Recchia, 2014). This is clearly not the case when it comes to the siblings of individuals with ASD, because as seen from the research participants' responses, there is a difference in learning and teaching in a relationship between siblings when one of them is diagnosed with ASD. The research participants, therefore, seemed to be the main teacher and age did not play much of a role in this regard. Although it was evident that the research participants learned more about themselves and others, due to the fact that their siblings have ASD, some of the research participants even described their siblings as the teachers; and that they learned a lot from them.

In relation to learned behaviour, the research participants' understanding of ASD contributes to how they experience living with their siblings, and how they make meaning thereof. More knowledge about ASD can, therefore, help foster resilience in siblings of individuals who have been diagnosed with ASD. This also speaks of such siblings' ability to accept and understand other people in society, who are differently abled (Hughes, 2017). It was clear from the responses of the participants that not only do they have an idea of what ASD is, and what the characteristics are of individuals with ASD; but are continuously seeking more information about it. They went further to share information about ASD in order to create public awareness of ASD. Information on ASD is shared with peers, teachers, extended family members, and even strangers.

There seemed to be commonalities among the participants in relation to the fact that they have some knowledge about ASD; and are willing to share this knowledge. The findings of this study corroborate the findings of the study by Hughes (2017), who asserts that siblings of individual with ASD have the ability to engage with others, due to their understanding of others, and being more aware of other people, evidenced by the fact that they are able to empathise more with people with disabilities.

5.2.3 Themes related to available support:

Friends, relatives, school, support groups, parents

For the siblings of individuals with ASD, good peer relationships or good friendships have been said to boost their self-worth and healthy coping skills. Moreover, good friendships also seem to contribute to reducing psychosocial risk and vulnerability of individuals who are living with a sibling with ASD. This, furthermore, contributes to building resilience and the ability to cope with the stressors of living with a sibling diagnosed with ASD (Shivers, McGregor & Hough, 2017). The accounts from the research participants in the current study support the assertion by the above authors. When asked about their friends and their relationship with friends, the research participants mentioned that they have friends, and that they have good, supportive relationships with their friends. These relationships and the kind of support they get from their friends help them make meaning from their experiences of living with siblings with ASD.

Although it is important for siblings of individuals with ASD to get support from peers, the participants in this study are enjoying such support, having a sibling with ASD can

make it tricky for one to navigate in relationships. It seems that living with a sibling diagnosed with ASD can make relationships untenable. When asked if their friends visit them at home, some of the participants answered in the affirmative. However, they also mentioned that these visits can be somewhat awkward, especially because they worry about what their friends would think of their sibling with ASD. Another research participant also mentioned that her sibling with ASD contributes to conflict in her friendships, because she does not always have a chance to be completely free – for example, constantly checking on their sibling when they are out with their friends, or having to consider her sibling’s wellbeing before going out to spend time with friends or inviting her friends over. This is in contrast with the findings of a study by Dansby et al. (2017), which revealed that friendships can be extremely tricky to navigate when one’s sibling has ASD. In their study, they found that fear of being embarrassed, associated with how their siblings with ASD would behave in public was the reason why they had few friends. In this current study, however, the participants seemed more concerned about their sibling’s wellbeing, and what impressions will the public have of their siblings.

Living with siblings diagnosed with ASD has also contributed to the level of maturity of the participants, as mentioned in a previous section. One of the research participants even mentioned that if she reckons that someone wouldn’t get along with her sibling, she would not choose them as friends. This was evident in all the cases, as the participants described their relationship with their friends and the kind of support they get from them. They mentioned that they have friends who encourage them when they are upset or feeling discouraged. They seemed to have someone to talk to, who is a voice of reason at all times. Their friends have become close to the point where they feel comfortable spending time with them, as well as their siblings with ASD. For the research participants, this is also an opportunity to share information on ASD, and when they do this with their friends they often receive positive feedback. Their friends are often intrigued and seem to want to know more about autism. This, again, is contradictory to the findings of a study by Dansby et al. (2017), who asserts that half of the participants in their study were not able to explain ASD to their peers; and did not explain why their siblings were different from other people.

According to Bronfenbrenner’s bio-ecological model (Boon et al., 2012), an individual’s life is also influenced by extended family members. The participants in the study indicated that they do have extended family members such as cousins, aunts, uncles and

grandparents, who offer support to families, to help them deal with children with ASD. Many a times, grandparents are seen as the immediate support structure among extended family members and are the ones who usually have to assume babysitting roles for individuals with ASD; so that the parents can have time alone or engage in their own activities, and also, to allow the typical developing sibling a break. The support from extended family members makes it possible for individuals living with siblings diagnosed with ASD to cope better (Vanhoutteghem, Van Hove, D'haene & Soyez, 2014). The participants in the current study also mentioned that they were happy knowing that their sibling were with people who care about them.

Most of the participants in the study seemed to get good support from their relatives. This is, however, not the case for all the participants. One of the participants mentioned that she does not get sufficient support from all her relatives. She mentioned that this is why she regards her brother's diagnosis of ASD as a blessing, because she gets to see people for who they really are. This is worth mentioning; because of the information that is shared by the participant, and how this participant makes meaning from the experience of being excluded by some of their relatives.

Susan: *"We don't drink a lot, we don't party late and they kicked us out basically out of the family, because of that. We don't mind, we like, we have us we are happy to have us, we are strong..."*

Susan also mentioned that the good thing about living with a sibling with ASD is that it makes it easier to identify *"fake friends, fake family members, backstabbers and stuff uhm you also learn how to gain real friends and how to feel loved and know who is actually there for you."*

Like any form of support, support from school seems to be an integral part of the siblings' lives. This support is coming from the schools of the research participants, or from the schools of these siblings themselves. The participants spoke about how they are allowed to share information on ASD with their teachers and other students at school. They see this as an opportunity to be heard and to share information and teach others about ASD. This is usually done in the form of public speaking, or with assignments they write for the schools.

Individuals with ASD usually attend some form of educational facilities. While some of the siblings of the research participants with ASD attend adult education, others are still

young and attend schools for autism that cater for children. These schools provide the support structure for the participants; because they offer a safe place where children with ASD can learn, spend their day and engage with other individuals like them. The research participants also mentioned that their siblings enjoy attending these schools. The teachers at these schools offer good support in terms of educating these individuals and update the parents about their progress on a regular basis.

There is, however, a challenge in terms of schools for individuals with ASD in South Africa. The research participants indicated that finding a placement for a person with ASD is a struggle – it is more of a struggle when these individuals are grown up (21 years and older). One of the research participants even mentioned that his mother started a centre for adults with ASD, because she could not find a suitable institution for her son at his age.

Only one of the participants is part of an ASD support group. She mentioned that her mother started this support group because of the lack of available support and facilities in the Mpumalanga Province. Although this support group is primarily for mothers of children diagnosed with ASD, the participant and her family get to engage with families who also care for their children with ASD.

Even though this type of support is only available to one of the participants, it is worth mentioning. During the interviews, all the participants indicated that there is a need for them to communicate with someone about their experiences of living with a sibling with ASD. They even mentioned that having the researcher conducting the interviews was a positive experience, and that it feels good to share their experiences with someone.

The participant who is part of the support group also mentioned that one would not know what it is like to live with someone diagnosed with ASD until it happens to them. She mentioned that sometimes she wish she can let people be in the company of her brother for a day, so that they can know exactly what it feels like to live with an individual who has autism. In mentioning this, she also indicated that it is worthwhile to be part of a group that experiences the same thing, like she and her family sharing information about her children with ASD, with other individuals who also have a similar experience.

The findings of a study by Dansby et al. (2017) revealed that being part of a support group helps reduce feelings of guilt, loneliness and depression. Although these feelings were not necessarily evident in all the participants, being part of a support group, however,

contributes in reducing negative experiences, and the loss of self that is often associated with living with a sibling with ASD.

In a previous study done by Chan and Goh (2014) on siblings of individuals with ASD, it was found that siblings describe their relationship with their parents in a negative manner. It was found that these siblings felt unloved and their relationship with their parents was filled with negative feelings and a lack of communication. These findings are different from the findings of this study. The participants in the study reported having a good relationship with their parents. They experienced their parents as a good support structure and get supported optimally in what they want to do at the moment, and in the future.

Although participants in the study reported that their parents gave more attention to their siblings with ASD, the research participants, however, seemed to understand that their siblings need more attention than they do. They further indicated that their parents communicate with them on a regular basis and are sensitive to their needs. Parental support is evidenced by the fact that the parents give them the freedom to follow their own dreams and have a social life outside the home environment. Some of the research participants also mentioned that their parents often explain to them that they are doing their best to find a balance between caring for the siblings with ASD and them. One of the research participants even indicated that her mother apologised to her for paying more attention to her brother with ASD.

5.2.4 Themes related to making meaning:

Acceptance, blessing, normalcy, disconnectedness, future hope

The findings of a study conducted by Mitchell (2016) indicated that siblings of individuals with ASD have accepted their siblings' condition – this is evidenced by the fact that they are able to share information about their siblings with other people. They do not only share information about their siblings, but about the behaviour typical of individuals with ASD as well. These findings have been corroborated by the findings of the current study. The research participants explained that they make meaning of their experience of living with a sibling with ASD.

Challenging as it is to live with a sibling diagnosed with ASD, the research participants indicated that they have fully accepted their siblings just as they are. They further

indicated that they cannot imagine their lives any other way. They asserted that their siblings are unique in the sense that not all people experience what they experience, and that is why they see their siblings as a blessing.

Even though having and living with a sibling with ASD may be challenging, the research participants seemed to be positive and able to make meaning from his experience by regarding it as a blessing. They indicated that they are blessed with a “teacher”, someone who provides unconditional love, someone who is different and unique to other. They seemed to regard themselves as been blessed with someone who also helps them see the world for what it is. It seems like when one has a sibling with ASD, they can truly see who their real friends are, who is in their life for the right reasons, and who is in for something. One of the participants mentioned that they are happy not to have a brother who is like a million other people, and even though there are only a few things they can do together, they are really happy to do those things with him. Another research participant mentioned that her brother’s condition is God’s way of saying good things are coming her way. One participant described her autistic sibling as the light in their dark days.

Although the research participants are able to make meaning from their experiences, by regarding it as a blessing, it is evident, however, that in contrast; they sometimes feel disconnected from their siblings. The participants indicated that sometimes it feels like they are in a different world than their sibling with ASD. This is said to be because of the fact that they cannot always identify with their sibling (Conn & Drew, 2017). Whether or not their siblings are older or younger, siblings are closer and often mimic one another’s behaviour, play, interaction, and also share information, which sometimes includes deep emotional conversations. The fact that the participants cannot have this type of conversation with their siblings may contribute to their feelings of disconnectedness and being in separate worlds.

This relates to the participants’ internal conflict regarding what is normal and what is abnormal. The participants indicated that they experience their siblings with ASD as normal. However, they often have self-debates about whether or not their siblings are normal in comparison to their peers. This internal debate mostly seems to flourish into acceptance, as mentioned before, and the belief that, as one of the research participant indicated “*normal doesn’t exist*”. Another research participant compared ASD to something different; like having a brother with blue eyes or blonde hair. Although the participants understand that ASD is not a typical way to develop, they seem to have decided to accept this for what it is –

they also mentioned that it is okay to be different. Whether one has albinism, is born with an extra finger, is diagnosed with ASD, is born with blue eyes or even having blonde hair, it does not matter. For them, their siblings with ASD are just as normal; and can function normally as anything else.

This is in line with the findings of a study by Petalas, Hastings, Nash, Dowey and Reilly (2009), who suggest that although siblings are aware of society's perception of what constitutes "normal" and "abnormal", as a family, they seem to have passed a stage where a sibling's disability is often "invisible" and part of everyday life. Even though the participants can see what is happening and are aware of their siblings' disability, they consciously choose to look past that and see their siblings as normal people like any of their other siblings – and "*not my brother with ASD, but just my brother*". Through the descriptions of their siblings, the research participants seemed to maintain a sense of normalcy.

This talks about the hope the research participants have for the future. They seemed to remain positive about the future of their sibling with ASD. They also remain hopeful about the prognosis – as one of the participants also mentioned "*his autism will get better*". The participants seem to believe that the future ahead is bright for themselves as well as for their siblings with ASD. Another participant mentioned that "*there is always someone you can lean on*".

5.3 Clinical implications

The findings of the study revealed that living with a sibling with ASD presents one with a complex situation that affects various aspects of a person's life both positive and negative ways. As indicated in the Bronfenbrenner's bio-ecological model, different aspects of a person's life contribute to how they experience life (Bronfenbrenner, 2005). For example, when a child is diagnosed with ASD, a shift occurs in the family structure, which may affect the roles of the family members, specifically siblings.

The findings of this study offer a relatively in-depth explanation of how individuals experience living with siblings with ASD, which may guide parents in their efforts to increase the support they offer to typically developing children, through interaction in the home environment, which would in turn, contribute to reducing stressors for both the parents and the children, where a family member has been diagnosed with ASD.

The parents of the participants were the first contact for the researcher. They were willing to step aside and let the researcher interview their children in their absence. These parents were also open in sharing their thoughts in conversation. The willingness of the parents to participate and give their children an opportunity to participate in this study speaks volumes about the support they give their children. This also speaks to the possibilities of exploring interventions to assist the participants to adjust and cope better.

It is important for families to work together with teachers and mental health professionals to improve siblings' experiences when one child in the family is diagnosed with ASD. This can also include more education about ASD to the affected families and their relatives. Furthermore, sharing information and connecting those who are close to one another, families with individuals who have ASD can engage with one another in a way that is easier. This will create space for the children in a household where one sibling is diagnosed with ASD to connect with other typically developing peers in order to share experiences away from the parents. These groups can be organised in a manner that foster engagement with other people outside their home environment – therefore, making friends and experiencing something similar so as to be able to support one another even from a distance.

Furthermore, it is important for interventions to be made available, by providing more places for families to have their members diagnosed. When conversing with one of the parents, she mentioned that they had to travel all the way from Mpumalanga to Pretoria to get a diagnosis for their child. This shows that there is a shortage of professional services in this regard. Diagnosis and misdiagnosis is also an issue of concern for teachers at special schools. When looking for participants, the researcher contacted a few special schools that cater for children with autism. Principals of these schools mentioned that although they can often see that a child displays characteristics of ASD, they cannot confirm it because the children they work with have not had an accurate diagnosis. This shows how important it is to have accurate and timely diagnosis, paying attention to the children who are in special schools. This may help to make interventions more effective.

5.4 Strengths of the study

It was indicated earlier on that there is limited research conducted on siblings of individuals with ASD. The current study, therefore, focused on the gap identified, even more so in the context of South Africa.

The research participants were given an opportunity to share their lived experiences and, therefore, their voices were heard, which is something that does not often happen. Secondly, parents and relevant professionals can be better informed about the experiences of a person who has to live with a sibling diagnosed with ASD. Therefore, the findings of this study can be used in developing suitable interventions for siblings of individuals diagnosed with ASD, and improve on the existing interventions. Finally, the findings from this study may also contribute to more available literature about sibling research.

5.5 Limitations of the study

The findings of this study are considered to add a valuable contribution to the literature on individuals living with siblings diagnosed with ASD. However, the study has a number of limitations.

The research sample was drawn from Gauteng and Mpumalanga Provinces, South Africa. The research participants were either found from existing organisations dealing with people with ASD, or individuals in the field of psychology. This excluded people from extremely low-income backgrounds, who do not have access to the internet or psychological services. Furthermore, the participants were all from a middle socio-economic class and as such, were not representative of all socio-economic classes in South Africa. Therefore, the findings of the study cannot be generalised across all similar cases, even though the qualitative research design allows for rich and detailed accounts from the research participants. The researcher also had time constraints. If there was more time, the researcher would have liked to conduct follow up interviews with the participants.

5.6 Researcher reflections

Before conducting the interviews, the researcher expected to hear sad stories about the experiences the research participants have of living with siblings diagnosed with ASD. The researcher expected tears and distress, but the opposite was the case. The researcher was received by the research participants with a warm welcome and warm embraces. The participants were excited to share their stories and experiences of living with siblings diagnosed with ASD. They seem to regard this as an opportunity to speak and engage with someone about themselves and their lived experiences of being in a household where one of the siblings has been diagnosed with ASD.

The researcher expected to engage and play, especially with the younger participants, but was pleasantly surprised by the participants' willingness to engage and have a conversation with her on the topic. They were willing to talk and continued talking. The conversations were an enjoyable experience for both the researcher and the participants.

This experience was also very insightful because the researcher got to hear about the participants' experiences. Although they are positive people full of hope, it should not be forgotten that they are children growing up in a home with a real stressor. Their ability to cope does not come automatically, but is enhanced by the support of various structures.

Going into this journey and conducting the research with these participants, the researcher was surprised by the wisdom and maturity of these participants. They communicated in an open and genuine manner. The level of their wisdom was amazing, and so was their ability to articulate, communicate, reflect and do some introspection. The researcher also found their ability to understand and empathise to be amazing.

Such strength displayed by the participants needs to be acknowledged. One must also, not forget that these participants have all round support, and this needs to be promoted across all cases in families where someone has been diagnosed with ASD.

5.7 Recommendations for future research

This study aimed to explore how individuals experience living with their siblings diagnosed with ASD, as well as how they make meaning from their experiences. Nevertheless, some recommendations can be made for future research on the phenomenon under study. As such, more qualitative research needs to be conducted in order to explore further the phenomenon of living with a sibling diagnosed with ASD, as it brings about rich and detailed information. This will afford researchers an opportunity to gather the experiences of people from different cultural groups, socio economic classes, and people living in different locations than the research participants in this study.

It is important to engage with the people living with a sibling diagnosed with ASD on a long-term basis. A suggestion is to conduct an ethnographic research on the phenomenon or another form of longitudinal study to explore this phenomenon further, and to report on the experiences of such siblings over time, especially in cases where a parent passed away or

grew older, and can no longer take care of the individual with ASD. A similar study can also be done on a larger sample across the country.

5.8 Conclusion

The current study provided an interpretative phenomenological analysis of living with a sibling diagnosed with Autism Spectrum Disorder from the perspective of five individuals. Even though the participants did not necessarily regard their experiences as a negative one, it must not be forgotten that the experience can be overwhelming. The strength and maturity of the research participants should, therefore, not be taken for granted. Such a level of maturity at a young age should be applauded.

Often in life, people deal with stressful situations by remaining positive and finding meaning from them. With sufficient support from different people in the person's life, these individuals can handle the stressor of having a sibling with ASD better. This will help reduce the anxiety or any kind of distress that they may feel.

Providing more information to society and families affected by the ADS diagnosis is also important. This may help reduce the stigma, improve access to services, and therefore, improve the available interventions. Services for individuals with ASD, including education, also need to be tailor made to cater for low income earners in South Africa.

References

- Al-dujaili, A. H., & Al-mossawy, D. A. J. (2017). Psychosocial burden among caregivers of children with autism spectrum disorder in Najaf province. *Current Pediatric Research*, 21(2), 272–282.
- Allan, A. (2011). *Law and ethics in psychology an international perspective* (2nd ed.). Somerset West: Inter-Ed Publishers.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed). Arlington VA: American Psychiatric Publishing.
- Amoateng, A. y., Heaton, T. B., & Kalule-Sabiti, I. (2007). Living arrangements in South Africa. In Amoateng, A.Y. & Heaton, T.B. (eds) *-apartheid South Africa: ...* (pp. 43–60). Human Sciences Research Council. Retrieved from <http://www.docs.hsrc.ac.za/uploads/pageContent/1653/FamiliesandhouseholdsinpostapartheidSouthAfrica.pdf#page=53>
- Angell, M. E., Meadan, H., & Stoner, J. B. (2012). Experiences of siblings of individuals with Autism Spectrum Disorders. *Autism Research and Treatment*, 1–11. <https://doi.org/10.1155/2012/949586>
- Atkin, K., & Tozer, R. (2014). Personalisation, family relationships and autism: Conceptualising the role of adult siblings. *Journal of Social Work*, 14(3), 225–242. <https://doi.org/10.1177/1468017313476453>
- Autism South Africa. (2017). Retrieved from <http://aut2know.co.za/>
- Bandura, A. (1977). *Social Learning Theory*. Engelwood Cliffs: Prentice Hall.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/High-Functioning Autism, Males and Females, Scientists and Mathematicians. *Journal of Autism and Developmental Disorders*, 31(1), 5–17. <https://doi.org/10.1023/A:1005653411471>
- Bateman, C. (2013). Autism- mitigating a global epidemic. *The South African Medical Journal*, 103(5). Retrieved from [h:%5Cnew%5CAutism – mitigating a global epidemic Bateman South African Medical Journal.mht](http://www.sciencedirect.com/science/article/pii/S0950268813000500)

- Bayat, M. (2007). Evidence of Resilience in families of children with autisms. *Journal of Interlectual Disability Research*, 5(9), 702–714. <https://doi.org/doi:10.1111/j.1365-2788.2007.00960.x>.
- Bitsika, V., Sharpley, C. F., & Mailli, R. (2015). The influence of gender, age, Psychological resilience and family interaction factors upon anxiety and depression in non-autism spectrum disorder siblings of children with an autism spectrum disorder. *British Journal of Guidance & Counselling*, 43(2), 216–228. <https://doi.org/10.1080/03069885.2014.950944>
- Bontinck, C., Warreyn, P., Van Der Paelt, S., Demurie, E. & Roeyers, H. (2018). The early development of infant siblings of children with autism spectrum disorder: Characteristics of sibling interactions. *PLoS ONE*, 13(3), 1–19. <https://doi.org/10.1371/journal.pone.0193367>.
- Boon, H. J., Cottrell, A., King, D., Stevenson, R. B., & Millar, J. (2012). Bronfenbrenner's bioecological theory for modelling community resilience to natural disasters. *Natural Hazards*, 60(2), 381–408. <https://doi.org/10.1007/s11069-011-0021-4>
- Bradbury-Jones, C., Sambrook, S., & Irvine, F. (2009). The phenomenological focus group: An oxymoron? *Journal of Advanced Nursing*, 65(3), 663–671. <https://doi.org/10.1111/j.1365-2648.2008.04922.x>
- Bronfenbrenner, U., & Evans, G. W. (2000). Developmental Science in the 21 [sup st] century: Emerging questions, theoretical models, research designs and empirical findings. *Social Development*, 9(1), 115–125. <https://doi.org/10.1111/1467-9507.00114>
- Bronfenbrenner, U. (2005). *Making human beings human : Bioecological perspectives on human development*. London: Sage Publications.
- Buist, K. L., Dekovic, M., & Prinzie, P. (2013). Sibling relationship quality and psychopathology of children and adolescents: A meta-analysis. *Clinical Psychology Review*, 33(1), 97–106. <https://doi.org/10.1016/j.cpr.2012.10.007>
- Caroli, M. E. De., & Sagone, E. (2013). Siblings and disability : A study on social attitudes toward disabled brothers and sisters. *Procedia - Social and Behavioral Sciences*, 93(1993), 1217–1223. <https://doi.org/10.1016/j.sbspro.2013.10.018>

- Carvalho, M. J. (2017). *Living with a sibling who has autism spectrum disorder*. Sadbury. Laurentian University
- Chan, G. W. L., & Goh, E. C. L. (2014). “My Parents told us that they will always Treat my Brother Differently Because he is Autistic” - Are Siblings of Autistic Children the Forgotten Ones? *Journal of Social Work Practice*, 28(2), 155-171. <https://doi.org/10.1080/02650533.2013.844114>
- Chan, J. Y. N., & Lai, K. Y. C. (2016). Psychological adjustment of siblings of children with Autism Spectrum Disorder in Hong Kong. *East Asian Arch Psychiatry*, 26(4), 141–147.
- Conn, C., & Drew, S. (2017). Sibling narratives of autistic play culture. *Disability and Society*, 32(6), 853–867. <https://doi.org/10.1080/09687599.2017.1321526>
- Connell, Z. O., Halloran, M. O., & Doody, O. (2016). Living with a brother who has an Autism Spectrum Disorder: A sister’s perspective. *British Journal of Learning Disabilities*, 44(1), 49–55. <https://doi.org/10.1111/bld.12109>
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches*. (4th ed.), *Research design Qualitative quantitative and mixed methods approaches*. Carlifornia: Sage Publications Inc. <https://doi.org/10.1007/s13398-014-0173-7.2>
- Cridland, E. K., Jones, S. C., Stoyles, G., Caputi, P., & Magee, C. A. (2016). Families living with Autism Spectrum Disorder : Roles and responsibilities of adolescent sisters. *Hammill Institute of Disabilities*, 31(3), 196–207. <https://doi.org/10.1177/1088357615583466>
- Cuzzocrea, F., Larcan, R., Costa, S., & Gazzano, C. (2014). Parents’ competence and social skills in siblings of disabled children. *Social Behavior and Personality: An International Journal*, 42(1), 45–57. <https://doi.org/10.2224/sbp.2014.42.1.45>
- Dansby, R. A., Turns, B., Whiting, J. B., & Crane, J. (2017). A phenomenological content analysis of online support seeking by siblings of people with autism. *Journal of Family Psychotherapy*, 29(3), 1–20. <https://doi.org/10.1080/08975353.2017.1395256>.
- Davys, D., Mitchell, D., & Haigh, C. (2016). Adult siblings consider the future: Emergent

- themes. *Journal of Applied Research in Intellectual Disabilities*, 29(3), 220-230. <https://doi.org/10.1111/jar.12172>
- De Caroli, M. E., & Sagone, E. (2013). Science direct siblings and disability: A study on social attitudes toward disabled brothers and sisters. *Procedia -Social and Behavioral Sciences*, 93, 1217–1223. <https://doi.org/10.1016/j.sbspro.2013.10.018>
- Diener, M. L., Anderson, L., Wright, C. A., & Dunn, M. L. (2015). Sibling Relationships of Children with Autism Spectrum Disorder in the Context of Everyday Life and a Strength-Based Program. *Journal of child and family studies*, 24 (4) 1060–1072. <https://doi.org/10.1007/s10826-014-9915-6>
- Doheny, K. (n.d.). *Autism Cases on the Rise; Reason for Increase a Mystery*. Retrieved March 22, 2017, from <http://www.webmd.com/brain/autism/searching-for-answers/autism-rise?page=2>
- Doody, M. A., Hastings, R. P., O'Neill, S., & Grey, I. M. (2010). Sibling relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities*, 31, 224–231. <https://doi.org/10.1016/j.ridd.2009.09.007>
- Dorozenko, K. P., Roberts, L. D., & Bishop, B. (2015). The identities and social roles of people with an intellectual disability: challenging dominant cultural worldviews, values and mythologies. *Disability and Society*, 30(9), 1345–1364. <https://doi.org/10.1080/09687599.2015.1093461>.
- Eklund, H., Findon, J., Cadman, T., Hayward, H., Murphy, D., Asherson, P., ... Xenitidis, K. (2018). Needs of adolescents and young adults with neurodevelopmental disorders: Comparisons of young people and parent perspectives. *Journal of Autism and Developmental Disorders*, 48(1), 83–91. <https://doi.org/10.1007/s10803-017-3295-x>
- Elias, R., & White, S. W. (2018). Autism goes to college: Understanding the needs of a student population on the rise. *Journal of Autism and Developmental Disorders*, 48(3), 732–746. <https://doi.org/10.1007/s10803-017-3075-7>
- Emerson, E., & Giallo, R. (2014). Research in developmental disabilities The wellbeing of siblings of children with disabilities. *Research in Developmental Disabilities*, 35(9), 2085–2092. <https://doi.org/10.1016/j.ridd.2014.05.001>

- Falk, N. H., Norris, K. & Quinn, M. G. (2014). The Factors Predicting Stress, Anxiety and Depression in the Parents of Children with Autism. *Journal of Autism and Developmental Disorders*, 44(12), 3185–3203. <https://doi.org/10.1007/s10803-014-2189-4>.
- Ferraioli, S. J., & Harris, S. L. (2009). The impact of Autism on siblings. *Social Work in Mental Health*, 8(1), 41–53. <https://doi.org/10.1080/15332980902932409>
- Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism Spectrum Disorder in sub-Saharan Africa: A comprehensive scoping review. *Autism Research*, 10(5), 723–749. <https://doi.org/10.1002/aur.1766>
- Genesis 37:27, New King James Version. (n.d.). In *Holy Bible*.
- Giallo, R., Roberts, R., Emerson, E., Wood, C., & Gavidia-Payne, S. (2014). The emotional and behavioural functioning of siblings of children with special health care needs across childhood. *Research in Developmental Disabilities*, 35, 815–825. <https://doi.org/10.1016/j.ridd.2014.01.017>
- Gillibrand, R., Lam, V., & O'Donnell, V. L. (2011). *Developmental Psychology*. Harlow: Pearson Prentice Hall.
- Gilmore, G. (2016). Understanding birth order : A within-family analysis of birth order effects. *Undergraduate Journal of Humanistic Studies*, 3, 1–8.
- Gorjy, R. S., Fielding, A., & Falkmer, M. (2017). “It’s better than it used to be”: Perspectives of adolescent siblings of children with an autism spectrum condition. *Child and Family Social Work*, 22(4), 1488–1496. <https://doi.org/10.1111/cfs.12371>
- Griffore, R. J., & Phenice, L. A. (2016). Proximal process and causality in human development. *European Journal of Education and Development Psychology*, 4(1), 10–16.
- Guba, E. G. (1981). Criteria for Assessing the Trustworthiness of Naturalistic Inquiries. *Association for Educational Communications and Technology*, 29, 75. <https://doi.org/10.1007/BF02766777>
- Guba, E. G., & Lincoln, Y. S. (1985). *Understanding and doing naturalistic enquiry*. Bervely

Hills: Sage Publications.

- Hastings, R. P., & Petalas, M. A. (2014). Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder. *Child: Care, Health and Development*, 40(6), 833–839. <https://doi.org/10.1111/cch.12131>
- Health Professions Council of South Africa. (2008). *General ethical guidelines for health researchers: Booklet 6*. Pretoria: Health Professions Council of South Africa. Retrieved from http://www.hpcsa.co.za/Uploads/editor/UserFiles/downloads/conduct_ethics/rules/generic_ethical_rules/booklet_6_gen_ethical_guidelines_for_researchers.pdf
- Herlihy, L., Knoch, K., Vibert, B., & Fein, D. (2015). Parents' first concerns about toddlers with autism spectrum disorder: Effect of sibling status. 19(1), 20-28 <https://doi.org/10.1177/1362361313509731>
- Hesse, T. L., Danko, C. M., & Budd, K. S. (2013). Siblings of children with autism: Predictors of adjustment. *Research in Autism Spectrum Disorders*, 7(11), 1323–1331. <https://doi.org/10.1016/j.rasd.2013.07.024>
- Hicks, U. (2014). *An Interpretative Phenomenological Analysis of adolescent siblings' experiences of aggression by a brother with Autism Spectrum Disorder, and their perceptions of their coping processes*. Cardiff. Cardiff University.
- Hole, R. D., Stainton, T., & Wilson, L. (2013). Ageing adults with intellectual disabilities: Self-advocates' and family members' perspectives about the future. *Australian Social Work*, 66(4), 571–589. <https://doi.org/10.1080/0312407X.2012.689307>
- Howe, N., & Recchia, H. (2014). Sibling relationships as a context for learning and development. *Early Education and Development*, 25(2), 155–159. <http://dx.doi.org/10.1080/10409289.2014.857562>
- Hughes, T. (2017). *Sibling relationships in families of children with autism spectrum disorder, down syndrome, and fetal alcohol spectrum*. Laurentian University.
- Huinker, H. (2012). *The Experiences of Individuals with a Sibling Diagnosed with an Autism Spectrum Disorder*. Minnesota. St Catherine University.

- Inam, A., & Kausar, R. (2016). Psychological Adjustment of Typical Siblings of Children with Autism in The Context of Family Environment. *Isra Medical Journal*, 8(3), 176–181.
- Incedon, E., Williams, L., Hazell, T., Heard, T. R., Flowers, A., & Hiscock, H. (2015). A review of factors associated with mental health in siblings of children with chronic illness. *Journal of Child Health Care*, 19(2), 182–194. <https://doi.org/10.1177/1367493513503584>
- Iturralde, E., Margolin, G., Lauren, A., & Shapiro, S. (2013). Positive and negative interactions observed between siblings: Moderating effects for children exposed to parents' conflict. *Journal of Research on Adolescence*, 23(4), 716-729. <https://doi.org/10.1111/jora.12020>
- Khanna, R., Madhavan, S.S., Smith, M.J., Patrick, J.H., Tworek, C., Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 41(9), 1214-1227. <https://doi.org/10.1007/s10803-010-1140-6>
- Koudstaal, C. (2011). Autism Spectrum disorder. In E. Landsberg, D. Kruger, & E. Swart (Eds.), *Addressing barriers to learning* (2nd ed., pp. 341–362). Pretoria: Van Schaik.
- Kovshoff, H., Cebula, K., Tsai, H.-W. J., & Hastings, R. P. (2017). Siblings of children with Autism: The siblings embedded systems framework. *Current Developmental Disorders Reports*, 4(2), 37–45. <https://doi.org/10.1007/s40474-017-0110-5>
- Kvale, S. (2006). Dominance through interviews and dialogues. *Qualitative Inquiry*, 12(3), 480–500. <https://doi.org/10.1177/1077800406286235>
- Lovell, B., & Wetherell, M. A. (2016). The psychophysiological impact of childhood autism spectrum disorder on siblings. *Research in Developmental Disabilities*, 49–50, 226–234. <https://doi.org/10.1016/j.ridd.2015.11.023>
- Makoae, M., Roberts, H., Ward, C. L., Dsd, Dwcpd, Unicef, ... Lombard, C. (2015). Family AIDS, poverty and child abuse victimisation: Findings from South Africa's first prospective study, 49 *Child Abuse & Neglect* § (2015). <https://doi.org/10.1002/car.1180>

- Martins, C. D., Walker, S. P., & Fouché, P. (2013). Fathering a child with Autism Spectrum Disorder : An Interpretative Phenomenological Analysis. *Indo-Pacific Journal of Phenomenology*, 13(1), 1–20. <https://doi.org/10.2989/IPJP.2013.13.1.5.1171>
- Mbwilo, G. S. K., Smide, B., & Aarts, C. (2010). Family perceptions in caring for children and adolescents with mental disabilities : A qualitative study from Tanzania. *Tanzania Journal of Health Research*, 12(2), 1–12. <https://doi.org/10.4314/thrb.v12i2.56400>
- McAdams, A. (2016). *The experiences of siblings of individuals with disabilities : A holistic view*. Orange. Chapman University.
- Mchale, S. M., Updegraff, K. A., & Feinberg, M. E. (2017). Siblings of youth with Autism Spectrum Disorders.: *Theoretical Perspectives on Sibling Relationships and Individual Adjustment*, 46(2), 589–602. <https://doi.org/10.1007/s10803-015-2611-6>
- Mckechnie, A. G., Moffat, V. J., Johnstone, E. C., & Fletcher-Watson, S. (2017). Links between Autism Spectrum Disorder Diagnostic status and family quality of life. *Children*, 4(23), 1–11. <https://doi.org/10.3390/children4040023>
- McVicker, M. L. (2013). *The sisters' experience of having a sibling with an Autistic Spectrum Disorder*. New England: Antioch University. <https://doi.org/10.1017/CBO9781107415324.004>
- Meltzer, A., & Kramer, J. (2016). Siblinghood through disability studies perspectives: diversifying discourse and knowledge about siblings with and without disabilities. *Disability and Society*, 31(1), 17–32. <https://doi.org/10.1080/09687599.2015.1127212>
- Mitchell, D. K. (2016). *We Band of Sisters and Brothers : Sibling Relationships and Autism Spectrum Disorder in Military Families*. Chicago. Chicago school of professional psychology.
- Mwamwenda, T. (2013). Adolescents ' gender stereotypes , differences and other aspects of behaviour in the Eastern Cape Province, South Africa. *The Independent Journal of Teaching and Learning*, 8, 54–70.
- Nowell, K. P., Brewton, C. M., & Goin-Kochel, R. P. (2014). A Multi-rater study on being teased among children/adolescents with Autism Spectrum Disorder (ASD) and their

- typically developing siblings: Associations with ASD symptoms. *Focus on Autism and Other Developmental Disabilities*, 29(4), 195–205.
<https://doi.org/10.1177/1088357614522292>
- Okon, E. (2012). Towards defining the ‘ right to a family ’ for the African child. *African Human Rights Law Journal*, 12(2), 373–393.
- Ozturk, Y., Riccadonna, S., & Venuti, P. (2014). Parenting dimensions in mothers and fathers of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 8(10), 1295–1306. <https://doi.org/10.1016/j.rasd.2014.07.001>
- Petalas, M. A., Hastings, R. P., Nash, S., Dowey, A. & Reilly, D. (2009). “I like that he always shows who he is”: The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, Development and Education*, 56(4), 381–399. <https://doi.org/10.1080/10349120903306715>.
- Rabe, M., & Naidoo, K. (2015). Families in south africa. *South African Review of Sociology*, 46(4), 1–4. <https://doi.org/10.1080/21528586.2015.1116873>
- Rosa, E. M., & Tudge, J. (2013). Urie Bronfenbrenner’s Theory of Human Development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review*, 5(4), 243–258. <https://doi.org/10.1111/jftr.12022>
- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability*, 31(2), 77–86. <https://doi.org/10.1080/13668250600710864>
- Rossetti, Z., & Hall, S. (2015). Adult sibling relationships with brothers and sisters with Severe Disabilities. *Research and Practice for Persons with Severe Disabilities*, 40(2), 120–137. <https://doi.org/10.1177/1540796915592829>
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation : A quantitative integration of the literature. *Journal of Child and Family Studies*, 10(1), 6584. <https://doi.org/10.1023/A:1016629500708>
- Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., ... Newton, C. R. (2016). Autism Spectrum Disorders in Africa: Current challenges in identification,

- assessment, and treatment. *Journal of Child Neurology*, 31(8), 1018–1026. <https://doi.org/10.1177/0883073816635748>
- Ruzich, E., Allison, C., Smith, P., Ring, H., Auyeung, B., & Baron-Cohen, S. (2016). The Autism-Spectrum Quotient in siblings of people with Autism. *Autism Research*, 10(2), 289–297. <https://doi.org/10.1002/aur.1651>
- Safran, S. (2017). *Relationships between Typically Developing Individuals and their Siblings with Autism Spectrum Disorder: A Qualitative Analysis*. Bloomington. Indiana University.
- Sargeant, J., & Harcourt, D. (2012). *Doing ethical research with children*. Berkshire: Open University Press.
- Saunders, M., & Tosey, P. (2013). The layers of research design. *Rapport*, 14(4), 58–59. <https://doi.org/08 jun 2015>
- Scorgie, K. (2017). Broadening family perspectives: The experiences of fathers and siblings when a child has chronic illness or disability, 97–113. <https://doi.org/10.1108/S1479-363620170000010012>
- Scorgie, K., Latta, A., Rampton, T., Rosemann, J., Peterson, M., Mandleco, B., ... Van Der Merwe, C. (2014). Continuity, commitment and context: Adult siblings of people with autism plus learning disability. *Health and Social Care in the Community*, 29(4), 97–113. <https://doi.org/10.1080/08856257.2014.922811>
- Shivers, C. M., Deisenroth, L. K., & Taylor, J. L. (2013). Patterns and predictors of anxiety among siblings of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(6), 1336–1346. <https://doi.org/10.1007/s10803-012-16857>
- Shivers, C. M., Krizova, K., & Lee, G. K. (2017). Types of strain among family members of individuals with autism spectrum disorder across the lifespan. *Research in Developmental Disabilities*, 68, 42–51. <https://doi.org/10.1016/j.ridd.2017.07.003>
- Shivers, C.M., McGregor, C., Hough, A. (2017). Self-reported stress among adolescent siblings of individuals with autism spectrum disorder and Down syndrome. *Sage journal*, 23(1), 112-122. <https://doi.org/10.1177/1362361317722432>

- Smith, J. A. (2008). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research Psychology, 1*(1), 39–54.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. *Qualitative Psychology A Practical Guide to Research Methods, 21*(2), 53–80. <https://doi.org/10.1002/9780470776278.ch10>
- Smith, J. A., Jarman M., & Osborn, M (Eds.). (1999). *Doing interpretative phenomenological analysis: Qualitative Health Psychology*. London: Sage
- Smith, L. O., Elder, J. H., Storch, E. A., & Rowe, M. A. (2015). Predictors of sense of coherence in typically developing adolescent siblings of individuals with autism spectrum disorder. *Journal of Intellectual Disability Research, 59*(1), 26–38. <https://doi.org/10.1111/jir.12124>
- Someki, F., Torii, M., Brooks, P. J., Koeda, T., & Gillespie-Lynch, K. (2018). Stigma associated with autism among college students in Japan and the United States: An online training study. *Research in Developmental Disabilities, 76*, 88–98. <https://doi.org/10.1016/j.ridd.2018.02.016>
- Spino, D. (2015). *The psychological impact of living in a family with an autistic sibling*. Carpinteria. Pacifica Graduate Institute.
- Statistics South Africa. (2014). *Profile of older persons in South Africa*. Pretoria. Statistics South Africa.
- Struwig, F. W., & Stead, G. B. (2004). *Planning, designing and reporting research*. Cape Town: Pearson education.
- Thomas, P. D., Badoe, E. V, Akua, N., & Owusu, V. (2009). Family perspective of Autism Spectrum Disorder in urban Ghana. *Journal of the International Child Neurology Association, 15*, 1–7.
- Tomeny, T. S., Barry, T. D., Fair, E. C. & Riley, R. (1992). Parentification of Adult Siblings of Individuals with Autism Spectrum Disorder. *Journal of Child and Family Studies, 1*(26)(2012), 1–11. <https://doi.org/10.1080/02701960.2012.718008>.

- Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey. *BMC Health Services Research*, *16*(1), 1–12. <https://doi.org/10.1186/s12913-016-1383-9>
- Tozer, R., Atkin, K., & Wenham, A. (2013). Continuity, commitment and context: Adult siblings of people with autism plus learning disability. *Health and Social Care in the Community*, *21*(5), 480–488. <https://doi.org/10.1111/hsc.12034>
- Tsai, H.-W. J., Cebula, K., & Fletcher-Watson, S. (2016). Influences on the psychosocial adjustment of siblings of children with autism spectrum disorder in Taiwan and the United Kingdom. *Research in Autism Spectrum Disorders*, *32*, 15–129. <https://doi.org/10.1016/j.rasd.2016.09.007>
- Tudor, M. E., Lerner, M. D., Bowman, S., Alvarez-Jimenez, M., Wade, D., Mcgorry, P., ... Clubley, E. (2013). Children’s experiences of having a younger sibling with severe and complex special educational needs An interpretative phenomenological analysis. *Research in Developmental Disabilities*, *4*(1), 1–213. <https://doi.org/10.1002/9780470776278.ch10>
- UCT ACSEPT. (2017). Retrieved February 17, 2017, from <https://uctautism.com/>
- UNISA. (2016). *Policy on Research Ethics*. Pretoria: University of South Africa.
- Vanhoutteghem, I., Van Hove, G., D’haene, G. & Soye, V. (2014). “I never thought I would have to do this”: Narrative study with siblings-in-law who live together with a family member with a disability. *British Journal of Learning Disabilities*, *42*(4), 315–322. <https://doi.org/10.1111/bld.12077>.
- Verte, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health and Development*, *29*(3), 193–205. <https://doi.org/10.1046/j.1365-2214.2003.00331.x>
- Victoria, A. (2013). The new Autism Spectrum Disorder (ASD) Diagnostic Criteria as defined by the DSM-5, 00 (working paper) retrieved from <https://www.autismspectrum.org.au/sites/default/files/Vic/The%20DSM%205%20Autis>

m%20Spectrum%20Disorder%20criteria.pdf

- Walton, K. M. (2016). Risk factors for behavioral and emotional difficulties in siblings of children with Autism Spectrum Disorder. *Am J Intellect Dev Disabil*, *121*(6), 533–549. <https://doi.org/10.1352/1944-7558-121.6.533>
- Ward, B., Tanner, B. S., & Mandleco, B. (2016). Sibling experiences : Living with young persons with Autism Spectrum Disorders, *42*(2), 69-76.
- Welch, V., Hatton, C., Emerson, E., Robertson, J., Collins, M., Langer, S., & Wells, E. (2012). Do short break and respite services for families with a disabled child in England make a difference to siblings? A qualitative analysis of sibling and parent responses. *Children and Youth Services Review*, *34*, 451–459. <https://doi.org/10.1016/j.chilyouth.2011.12.002>
- White, N., & Hughes, C. (2018). *Why siblings Matter*. Abingdon: Routledge.
- Whiteman, S. D., McHale, S. M., & Soli, A. (2011). Theoretical perspectives on sibling relationships. *Journal of Family Theory & Review*, *3*(2), 124–139. <https://doi.org/10.1111/j.1756-2589.2011.00087.x>
- Willig, C. (2013). *Introducing Qualitative Research in Psychology* (3rd ed). New York: McGraw-Hill. <https://doi.org/10.1017/CBO9781107415324.004>
- Wolfe, B., Song, J., Greenberg, J. S., & Mailick, M. R. (2014). Social Science & Medicine Ripple effects of developmental disabilities and mental illness on nondisabled adult siblings. *Social Science & Medicine*, *108*, 1–9. <https://doi.org/10.1016/j.socscimed.2014.01.021>
- Woodgate, R. L., Edwards, M., Ripat, J. D., Rempel, G., & Johnson, S. F. (2016). Siblings of children with complex care needs: their perspectives and experiences of participating in everyday life. *Child: Care, Health and Development*, *42*(4), 504–512. <https://doi.org/10.1111/cch.12345>
- World Health Organisation. (2016). *Autism Spectrum Disorder Fact Sheet*. Retrieved March 22, 2017, from <http://www.who.int/mediacentre/factsheets/autism-spectrum-disorders/en/>

Yacoub, E., Dowd, M., McCann, L. & Burke, L. (2018). *Impact of Challenging Behaviour on Siblings of People with Autism. Advances in Mental Health and Intellectual Disabilities.* 12(5), 145-152, <https://doi.org/10.1108/AMHID-01-2018-0001>.

APPENDIX A

Ref. No: PERC-17031



Ethical Clearance for M/D students: Research on human participants

The Ethics Committee of the Department of Psychology at Unisa has evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA and the Unisa Policy on Research Ethics.

Student Name: Edzani Onica Dongola

Student no.: 61439312

Supervisor: Prof. Ilse Ferns

Affiliation: Department of Psychology, Unisa

Title of project:

Living with a sibling diagnosed with Autism Spectrum Disorder: An Interpretative Phenomenological Analysis

The application was approved by the departmental Ethics Committee on the understanding that –

Consent is to be obtained from the parents or guardians of all minor children involved directly or indirectly in the study;

All ethical conditions related to voluntary participation, informed consent, anonymity, confidentiality of the information and the right to withdraw from the research must be explained to parents/guardians of the participants in a way that will be clearly understood;

The researcher should make reasonably sure that children do not feel pressured to participate or made to feel disloyal (to other members of the family system). This implies that consent should also be given by the participating child (this may however be verbal and implicit);

The rights of children diagnosed as 'autistic' who are indirectly involved in the study should also be protected and reasonable care should be taken not to disclose information by which they may be identified.

Signed:

A handwritten signature in brown ink, appearing to read 'P Kruger', with a long horizontal stroke extending to the right.

Prof P Kruger

Date: 5 October 2017

[For the Ethics Committee]

[Department of Psychology, Unisa]

The proposed research may now commence with the proviso that:

- 1) *The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*

- 2) *Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Psychology Department Ethics Review Committee.*

- 3) *An amended application should be submitted if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*

- 4) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

Please note that research where participants are drawn from Unisa staff, students or data bases requires permission from the Senate Research and Innovation Committee (SENRIC) before the research commences.

APPENDIX B

Title: living with a sibling diagnosed with Autism Spectrum Disorder: an interpretative phenomenological analysis.

My name is Edzani Onica Dongola and I study at the University of South Africa.

I am asking you to take part in this research because I am trying to find out what it is like to live with a sibling who has Autism. I want to learn more about you and the things you like to do with your brother or sister.

If you agree, I will play with you while you tell me all about it. I will come to your house and we can do things you like while we talk.

You do not have to be in this research, no one will be mad if you don't want to be in the research. Even if you start, you can stop later if you want. I won't ask you why. You may ask any question about the research that you want.

If you decide to be in the research, I will not tell anyone else what you say or do.

Signing here means that you have read this form or someone has read it for you and that you are willing to be in the research.

Your name please: _____

Your signature please: _____

My signature: _____

Today's date: _____

APPENDIX C

Title: Living with a sibling diagnosed with Autism Spectrum disorder: an Interpretative phenomenological analysis

I, _____ (parent/guardian name), confirm that I give permission for my child to take part in this research.

I have been told about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to give permission for my child to participate in the research. I understand that my agreement is voluntary.

I am aware that the findings of this research will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential

I agree to the audio recording of the interview.

I have received a signed copy of the information sheet.

Parent/guardian full names

Parent/guardian Signature Date

Researcher's Full names

Researcher's signature Date.....

APPENDIX D

PARTICIPANT INFORMATION SHEET

Ethics clearance reference number: Ref. No: PERC-1703

Title: Living with a sibling diagnosed with Autism Spectrum disorder

Dear Parent/guardian of Prospective Participant

My name is Edzani Onica Dongola and I am doing research with Prof Ilse Ferns a professor in the Department of Psychology towards a Masters degree in psychology research consultation at the University of South Africa. We are inviting your son/daughter to participate in a study entitled Living with a sibling diagnosed with Autism Spectrum Disorder: An interpretative Phenomenological Analysis.

WHAT IS THE PURPOSE OF THE STUDY?

I am conducting this research to find out what it is like living with a sibling who has been diagnosed with Autism. This study will be looking at children who have a sibling with Autism in order to gain more information about their experiences. This research will benefit in terms of bringing a better understanding of what these children's experiences are. Furthermore, this research will also benefit in terms of assisting the existing support systems for siblings of children diagnosed with Autism.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

The study involves a conversation with your son/daughter doing activities they like. The conversation will be audio recorded. The interview will be at your home at a time convenient for your son/daughter.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is voluntary and you are not obligated to participate. If you do decide to agree for your son/daughter to take part, you will be given this information sheet to keep and be asked to sign a written consent form. Your son/daughter will also be given theirs to sign if they agree to participate. Your son/daughter is free to withdraw at any time before the data has been captured and without giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

There are no direct benefits to taking part in this research; however the information provided by your son/daughter will be beneficial in terms of contribution to the larger scope of research. This information will also help other professionals in terms of supporting siblings of people with Autism.

ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

There will be no intentional harm on your son/daughter. If at the end of the interview they do feel sad, provision will be made for them to speak with someone.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

No identifying information will be recorded on the report. Your information and that of your son/daughter will be kept a secret and the only people who will have access to it are the two researchers mentioned above.

You and your son/daughter have the right insist that your name will not be recorded anywhere and that no one, apart from the researchers will know about your involvement in this research. Your answers will be given a code number or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard where only the researchers have access to, this is for future research or academic purposes; electronic information will be stored on a password protected computer. At the end of the five years, hard copies will be shredded and destroyed in water while soft copies will be permanently deleted.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

There will be no payment or incentives for allowing your son/daughter to participate in the research. Your son/daughter will also not receive any payment or incentives for participating in the research.

HAS THE STUDY RECEIVED ETHICS APPROVAL

This study has received written approval from the Research Ethics Review Committee of the department of psychology UNISA. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Edzani Onica Dongola on 072 865 6742 or email edzidee@gmail.com.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact Edzani Onica Dongola on 072 865 6742 or email edzidee@gmail.com. Should you have concerns about the way in which the research has been conducted, you may contact Prof Ilse Ferns on 012 429 8210 or email fernsi@unisa.ac.za. Contact the research ethics chairperson of the Department of Psychology UNISA Prof Piet Kruger 012 429 6235 or email krugep@unisa.ac.za if you have any ethical concerns.

Thank you for taking time to read this information sheet and for allowing your son/daughter to participate in this study.

Thank you.

Edzani Onica Dongola

APPENDIX E

NON-DISCLOSURE AGREEMENT

BETWEEN:

1. EDZANI ONICA DONGOLA, (THE "DISCLOSING PARTY")

AND

2. HAROLD NCONGWANE, (THE "RECEIVING PARTY")

Title of Research Project: Living with a sibling diagnosed with autism spectrum disorder: an interpretative phenomenological analysis.

By: Edzani Onica Dongola

Local Principal Investigator:

As a co-coder consulting on the abovementioned research topic, I Harold Ncongwane, understand that as the receiving party, I have access to confidential information about the study participants. By signing this statement, I am indicating my understanding of my responsibilities to maintain confidentiality and agree to the following:

- I understand that names and any other identifying information about study sites and participants are completely confidential.
- I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained from the participants with exception of sharing with the disclosing party the information agreed on.
- I understand that all information about study sites or participants obtained or accessed by me in the course of my work is confidential. I agree not to divulge or otherwise make known to unauthorized persons any of this information, unless specifically authorized to do so by the disclosing party

- I understand that I am not to read information about study sites or participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.
- I agree to notify the disclosing party immediately should I become aware of an actual breach of confidentiality or a situation which could potentially result in a breach, whether this be on my part or on the part of another person.
- Upon completion of the contracted work, I understand that I will send all the necessary information to the disclosing party and as soon as I receive confirmation I will permanently destroy all the information on my part.

Signature

Date

Print name

Signature of disclosing party

Date

Print name

APPENDIX F

Interview guide

BIOGRAPHY

Name:

Interview date:

Age:

Parents:

Sibling:

Introduction

What do you want to do while we talk?

Before we start is there anything you would like to ask me?

Tell me about yourself: what do you like to do.

Position in the family

Who is in your family?

What do they like to do? What are they like?

Tell me about [brother/sister with ASD].

Do you do any chores together?

How do you feel about that?

Parent child interaction

- How is mom/dad towards your brother/sister?
- How does that make you feel?
- What is it like when you are together as a family?
- How is mom/dad towards you?
- How does that make you feel?

Sibling relationship

- What do you like to do together?
- What is that like?
- What other things do you do together?
- How do you feel about your brother?
- Does your brother/sister need help with a lot of thing?
- What kind of things does he/she need help with?
- Who helps with him/her
- What is that like?

Support from other family members

- Do you get support from your family?
- What kind of support do you get?
- How does that make you feel?

Friends and peer relationships

- Do you get support from other people who are not your family?
- Who gives you support?
- What kind of support do you have?
- How does that make you feel?
- Do your friends know about your brother/sister's ASD?
- What do they think about it?
- How do you feel about the other people in your life and the way they are to your brother/ sister?
- How does that make you feel?
- What does that mean to you?

Sibling perspective of ASD

- What do you think about ASD?
- What do you know about ASD?
- What do you understand about ASD?
- What does ASD mean to you?

Severity of ASD

- What kind of things does brother/sister do?

Main research questions

- ✓ What is it like growing up with your brother/sister?
- ✓ What does it mean to you to have a brother/sister who has ASD?

Is there anything you want to ask me?