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FACULTY OF SOCIAL SCIENCES

DEPARTMENT OF PSYCHOLOGY

A STUDY ON THE EXPERIENCES OF INDIVIDUALS WHO HAVE SIBLINGS WITH AUTISTIC CHALLENGES. THE CASE OF PATHWAYS AUTISM TRUST.

BY

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DEDICATION

I dedicate this research to all the siblings of autistic individuals and most particularly those who went out of their way so as to partake in this study, siblings of the autistic individuals at Pathways Autism Trust I dearly appreciate you unwavering support this is for you.

ABSTRACT

This study sought to explore the experiences of siblings with a brother or sister with autistic challenges, for the presence of such a challenge in one child can affect the sibling experiences perhaps bringing them close together or pushing them further apart. The researcher observed that little is known when it comes to the sibling's experiences when one has autism though it is of heightened importance, so this dissertation sought to bridge this gap. This is a qualitative study using a phenomenological research design; the 7 participants of this study were purposefully selected using the heterogeneous sampling and they were 16 years of age and above. Data was analysed by the content analysis, which is a procedure of verbal categorization of verbal behavioural data for purposes of classification, summarization and tabulation. Several themes and subthemes emerged from this study the negative challenges faced by the siblings being embarrassment, being a young carer and future caregiver and lack of attention. The positive experiences included an improvement in their leadership skills, personal enrichment and psychological growth. The coping strategies they used were support groups, therapy sessions and avoiding unnecessary physical and emotional pressure. Conclusively, the researcher brought out both the negative and positive experiences faced by siblings of autistic individuals and how they cope. The researcher recommended a further enlightment on autism so as to lessen the challenges that are faced by the siblings of autistic individuals.

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

The chapter serves as the fundamental principle of the whole research, it contains the background of the study, statement of the problem, significance of the study, purpose of the study, research questions, delimitations, limitations, assumptions, definition of key terms and the chapter summary.

1.2 Background of the study

Autism is increasingly becoming an area of concern and interest for mental health professionals, educators and researchers (Rivers & Stoneman, 2008). Autistic children face discrimination not as a result of the inherent nature of their incapacity, but rather as a consequence of lack of understanding and knowledge of its causes and implications, fear of contamination or religious and cultural views of autism. This lack of understanding shows the need for a further research on autism which motivated the researcher to do the study so that the experiences of siblings of autistic individuals would be more positive.

Studies have shown that researches have been carried out on children with autism in relation to a number of factors such as diagnosis and responses to treatment (Brunner, 2009), early intervention (Towle, 2009), intelligence and mother child relationships. However there has been little attention given to the typically developing siblings of children with autism. The sibling bond can be a unique and powerful influence on mental, emotional and physical elements of an individual's life (Wolf, 2008). As such, the presence of an illness in one child can affect individuals in the sibling experiences perhaps bringing them closer together or pushing them further apart.

The sibling subsystem is of heightened importance since the sibling relationship can be the first and most intense peer relationship. Typical sibling relationships change over time and provide the siblings opportunities to experience sharing, companionship, rivalry and other outcomes (Angell et al, 2012). Some sibling's pairs experience warm, supportive relationships whereas

others experience conflicts and isolation and therefore the experiences of siblings of autistic individuals' shows the need for more research which therefore motivated the researcher.

There has been an increase in the diagnosis of autism over a short period of time. Approximately eleven years ago, the cases of autism ranged from 5 per 10000, (American Psychiatric Association, 2000) and increased to 60 per 10000, (Altiere & Kluge, 2009). Autism is becoming more and more prevalent in today's society with males being affected 4.5 times higher than females,(Rice & Centers for Disease Control Prevention ,2009).Typically diagnosed autistic individuals in early childhood, from recent prevalence suggests that 1 in 68 individuals in the USA and approximately 1 in 100 individuals in U.K have autism. Global prevalence of autism and other pervasive developmental disorders is 62/10000 (Elsabbagh, 2012).It is no longer considered as a rare condition even in Zimbabwe where its prevalence is also seen to be increasing. Prevalence of autism from a hospital based population study in Nigeria found autism to be 0.08 % (Bakare et.al,2011),most likely influenced by low help seeking behaviours for Childhood Neuro-developmental Disorders. However in Zimbabwe there is no current statistics of children with autism the country relies on the statistics of the centre of disease control that is 1 in 88 individuals is autistic in every population. Basing on these statistics it shows that there are quite a number of children with autism which therefore shows the need to study the experiences of individuals who have autistic siblings.

Psychological stress is one of the negative consequences of having an autistic sibling for it is reported to be the most frequent challenge faced by the siblings of the autistic individuals (Meadan & Halle, 2010). Siblings may feel the need to over- achieve or make up for the limitations of the impaired child. The non- autistic siblings may feel under pressure to provide extra emotional support to their parents or to provide for the physical needs of their siblings as parents grow older. Such demands whether there are real or imaginary can result in an at least transitory feelings of resentment or hostility on the part of the siblings. Feelings of shame and embarrassment or problems of teasing do not seem to be particularly severe on the whole of the children's social contacts which are not unduly affected (Mc Hale et al, 2014). In addition sibling's self-reports of their feelings, parents frequently confirm that the impaired child is loved and accepted within the family and that most of the negative consequences that develop are resolvable (Simeonson & Mc Hale ,2008).

Goehner (2007) noted that, another negative consequence of having an autistic sibling is that of having difficulties in social interactions. This is so because of the social impairment in the individuals with autism, they are unable to reciprocate and communicate as effectively as possible. To a young child this may seem undoubtedly difficult to understand especially during playtime. These siblings may also become the target of aggressive behaviors, pushing them away for wanting to engage and play with their autistic siblings (Autism Society, 2011). A study reported that in siblings aged 8- 15 years, 84% reported that aggressive behavior produced by their siblings with autism in trying to interact with them (Orsmond & Seltzer ,2007).

The worldwide perspective on autism have improved with the improvement of technology also for now an early diagnosis can be made therefore resulting in autism being identified in the early stages of development in childhood mostly in the more developed countries (Atkin & Tozer, 2015). This results in positive experiences between the autistic and non-autistic siblings for the early awareness helps to build their relationship in a good and positive manner. Thus one can say that due to the improved technology in today's world the experiences of the autistic individuals and their siblings appear to be more positive from a global perspective.

Many of the African countries are a bit primitive which will therefore lead to the lack or less knowledge about autism. This lack of sufficient knowledge will lead to the siblings of the autistic individuals to have negative experiences with their siblings for they will not be well acquainted about their sibling's conditions and the ways to cope and so on. On the other hand the situation is different when it comes to developed countries in Africa where the autism is diagnosed early and the siblings are aware of their autistic sibling's condition and therefore they will know the right ways to cope with them, thereby leading to positive experiences (Barr et al, 2010). Thus one can say that from an African perspective the experiences of individuals who have autistic siblings are determined by how primitive or developed the country is.

In Zimbabwe autism is becoming known by the day, most autistic children were mostly wrongly thought to have a mental disorder as they are unable to make sense of the world and end up acting out of their frustration. This lack of knowledge therefore often troubles the siblings thereby resulting in negative experiences amongst them. From a Zimbabwean setting with the lack of knowledge these autistic children can be isolated and can even be seen as wasting resources when trying to support them with educational needs. This kind of treatment will

therefore make the non-autistic siblings to have negative experiences with them for they lack the full knowledge about their sibling. With technology coming in there is also a slight improvement for some children receive early diagnosis and this will therefore lead to the siblings becoming aware of their siblings condition and try to cope thereby leading to positive experiences (Begum et al, 2011).

The researcher observed that little is known when it comes to autism in Zimbabwe which even leads to a few schools which can accommodate individuals with this special need. This lack of knowledge on autism results in negative experiences between the autistic and non-autistic siblings for there will not be aware of their sibling's shortcomings and therefore needs help from them (Cairn, 2013). But on the other hand the researcher observed that those who had their autistic children early diagnosed results in positive experiences with their siblings for they will know how to cope with their autistic siblings in a proper way.

1.3 Statement of the problem

The researcher observed that siblings of autistic individuals face a number of negative experiences due to the lack of understanding and knowledge of the causes and implications of autism and also fear of contagion on the part of the siblings. Previous studies have found out that siblings of individuals with autism share most of the experiences that parents usually describe for instance, isolation, a need for information, guilt, concerns about the future, care giving demands (Doherty et al ,2008). It is through these findings that the researcher saw the need to conduct a study specifically on the siblings of autistic individuals so as to enlighten them and those who surround them so as to lessen the negative experiences that they face.

1.4 Purpose of the study

The overarching goal of this study is to represent a group of voices that has commonalities as well as variations thereby providing a rare opportunity for siblings of children with autism to share their experiences. This research also sought to provide an understanding of what it is like to be a non- autistic sibling to an autistic individual. The researcher attempts to illuminate how these siblings make meaning of their lived experiences. To do this subsidiary research questions are to be addressed for instance in trying to observe the responsibilities of the non- autistic siblings and weighing if these responsibilities add extra pressure on the siblings. Understanding the points of strengths and areas of need (Care Alliance Ireland, 2015), in developing positive

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sibling experiences within a population which can therefore offer an important insight for clinical application which is the aim of this study.

1.5 Significance of the study

There are various groups which are going to benefit from this study on the experiences of siblings of autistic individuals, as the researcher will bring more enlightment on autism so as to improve the experiences of these siblings. These various groups include:

The research will provide a rare opportunity for these siblings to tell their stories and acknowledge both positive and negative aspects of their sibling relationship. It will help to raise awareness on the lives of these siblings and the challenges there are facing in their lived experiences with their autistic siblings. If awareness is raised the siblings can therefore receive the help and support they need from their parents for instance. While autism cannot be cured, it should not be viewed as an enemy, (William, 1996). The siblings will be of benefit for they will be enlightened more on how to take their platform and also on how to deal with negative experiences and this will be significant to them for they will be given an adequate opportunity to express their feelings.

This study will create awareness on the lives of siblings and challenges they might be experiencing if there are any. This information can be used by parents to guide themselves in addressing specific needs of siblings and providing support. The parents will acquire more knowledge from the emphasis on the needed attention on the sibling coping systems aimed at adding richness and data in the words of the individuals who have autistic siblings honoring their unique perspectives which to date in Zimbabwe have been left unheard.

The field of Psychology will also find this study significant for it will add more to the already existing knowledge on the experiences of the siblings of autistic individuals and would also provide baseline knowledge for further studies under this area of study. To add on, having exposed such a research other psychologists could then come up with ways to alleviate the negative experiences between autistic and non- autistic siblings.

This study will also be vital to the community and the public as they will be equipped more on the experiences of autistic and non- autistic siblings. They would then offer help to their

colleagues and other family members who have autistic individuals whom they know with the knowledge that they would have acquired from this research.

1.6 Research Questions

1. What are the challenges faced by individuals who have autistic siblings?
2. What are the positive experiences of having an autistic sibling?
3. How do individuals with autistic siblings cope with their situation?

1.7 Delimitations

The research is to be conducted at Pathways Autism Trust in capital city of Zimbabwe, Harare. Focusing on the siblings of the autistic individuals with an age range of 16 years and above regardless of their gender.

1.8 Limitations

Coolican (2009) defined limitations as shortcomings of the research or challenges faced by researchers during their research. The topic or area of study may be sensitive and some of the participants might take it as their privacy which will lead them to be unable to disclose all or some of the information. The researcher will therefore shed more light on the ethical issues of the research which also includes the importance of keeping the information they give out confidential. More so, the findings from the study will be limited to a sample size chosen which might not perfectly provide true and accurate information about all of the experiences of individuals and their autistic siblings.

1.9 Assumptions

For this research to be valid it is assumed that there are both positive and negative experiences which are faced by siblings of autistic individuals. To add on, it is also of the assumption that the siblings to the autistic individuals will be willing to share information relating to their experiences with their autistic siblings. It is also expected from this research that it will provide accurate, valid and reliable information.

1.10 Definition of terms

1.10.1 Autism

Autism is one of the pervasive developmental disorders as classified by the Developmental and Statistical Manual of Mental Disorders Fourth Edition Text Revision (DSM-IV-TR), (American Psychiatric Association, 2000). This disorder is characterized by severe and pervasive

impairment in several areas of development, including reciprocal social interaction skills and communication skills or the presence of stereotyped behaviour, interests and activities (Carr et.al, 2007). Some decades ago people with autism would have been diagnosed with mental retardation or schizophrenia because the diagnosis of autism was unknown. Leo Kanner first identified and named Autism in 1943 (Grinker ,2007).

1.10.2 Siblings

A sibling is a brother or sister; siblings are therefore people who share at least one parent(http//en.wikipedia.org/wiki/siblings).Siblings usually grow together and spend a great deal of time together. These sibling relationships are unique because there are "ascribed rather than achieved" and they typically last longest of all human relationships (Ciarelli cited in Orsmond & Seltzer, 2007). Emotional bonds are formed, these bonds can however be complicated by factors such as parental treatment, developmental stages, personality and disability (Wait et.al, 2003).

1.10.3 Experiences

An experience is something that happens to an individual that affects how one feels either in a good or bad way, (Cambridge University Press, 2017). In this study, this is the process of personally observing or encountering or undergoing something which might be positive or negative.

1.10.4 Challenges

This involves stimulating tasks or problems (Webster, 2017). In this study, this is the situation of being faced with a problem or difficulty.

1.11 Chapter Summary

This chapter served as the bedrock of the whole study, as it focused on the background of the study, statement of the problem, significance of the study, purpose of the study, research questions, delimitations, limitations, assumptions and definitions of key terms in the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter will look into the literature review first which is an overview of the literature on sibling relationships of autistic and non- autistic individuals and previous studies on Autism also referring to the research questions of this study as subtopics. Followed by the Theoretical Framework which will include the Constructionist Theory, Eco- systematic Theory and the Social Learning Theory, these theories will back up the whole study. The knowledge gap will also be part of this chapter which simply refers to the issues that other researchers did not focus on concerning the experiences of autistic individuals and their siblings, and then finally the chapter summary.

2.2. Challenges faced by individuals who have autistic siblings.

Individuals with autism have a constellation of behaviours that might be expected to affect the sibling relationship, they have limited repertoire of play and social or affective behaviour, tends to have poor eye contact, show communication deficits, and may not be socially responsible. These factors can therefore add on to the negative experiences if they are not understood well by the non-autistic sibling. The limited research that exists regarding siblings indicates the neglect of siblings which can lead to damaging the sibling relationship throughout the lifetime (Tsao et al., 2012). Being the target of aggressive behaviour is one of the negative experiences in individuals who have autistic siblings.

There are more reports on how siblings have problems with their autistic sibling's destructive behaviours. Similarly (Ross et.al, 2006) reported that siblings of children with autism ages 8-15 reported more aggression in their sibling interactions. (Kaminsky & Dewey, 2009) also reported differences between 90 siblings of individuals with autism, other disabilities and typically developing individuals ages 8-18. That is, they found siblings of a brother or sister with autism reported on a Sibling Relationship Questioner (SRQ), less intimacy, pro-social behaviour, initiated play and nurturance with their siblings that siblings of individuals with Down syndrome and of typically developing individuals. (Knott et al, 2010) compared 30 sibling pairs of individuals with autism and siblings of individuals with Down syndrome and found that siblings

of individuals with autism spent less time with their sibling and lacked a close relationship and contact and were more concerned about their siblings' future which therefore led to their negative experiences with their autistic siblings.

Although there are many similarities between families of children with other disabilities and families of children with autism, autism can be distinguished from other disabilities because of its unique characteristics (Aksoy & Bercinyildirim, 2008). In comparison with siblings as children with mental disabilities, siblings of children with autism have expressed more negative views about siblings' relations, more loneliness and more concern for the future (Schunterman, 2007). Although findings with regard to gender differences in sibling's well-being are inconsistent some studies have found it that sisters of children with autism have more favourable psychological outcomes than brothers (Ferrari, 2009).

(Mascha & Boutcher, 2011) conducted a pilot study and interviewed 14 typically developing siblings of individuals with autistic challenges. These authors emphasized that their findings could be considered preliminary only. More reports of sibling's accounts of their experiences growing up in families with siblings with autism filling up the gap in the literature focused on the viewpoints and voices of siblings of children with autism in middle childhood and pre-adolescence.

The autism sibling literature is yet to consensus, however, (Macks &Reeve, 2007) succinctly conclude that having a sibling with autism may not be a risk factor in and of itself, and children with autism may even have positive influence on the life of the non-autistic siblings. However, when multiple risk factors are present, it becomes more difficult for the non-autistic sibling to deal with the child with autism both emotionally and psychologically. (Macks & Reeve ,2007) consider the contribution of this potentially makes to the inconsistency currently plaguing sibling research. If those studies reporting positive experiences of these siblings include samples of demographically stable families while those samples that exhibited negative impacts consisted of participants experiencing a higher number of demographic risk factors, the true experiences of growing up with a sibling with autism would be masked, justifying continued exploration.

A number of emotional reactions are identified within the sibling experience that is empathy, sympathy, fear, anxiety and social isolation. The sibling mostly feels obligated under a sense of precocious responsibility for protecting the individual with autism and helping the parents

(Bendrix, 2007). Also siblings might feel sorry for their autistic sibling; they are also exposed to frightening and abnormal behaviours which makes them hold emphatic feelings for their sibling with autistic challenges. The non-autistic siblings also hope and wish that their family and the individual with autism may have some relief with the individual in a group home. To add on, impulsive and uncontrolled physical violence which makes the siblings feel unsafe and anxious that their relationship with their peers can negatively be affected. Despite the positive emotions, the overwhelming feelings of the sibling's experience are negative because of all these stressful life conditions which therefore increase the negative experiences in individuals with autistic siblings.

Lack of attention or jealousy over the amount of time parents spend with the other sibling with autistic challenges is also amongst the negative experiences in non-autistic individuals. The sense that they come second to their parents, because so much of their time and energy is focused on the one with autism causes the sibling relation to be sour at times. Due to the significant needs of children with autism, the siblings may feel as though he or she is being ignored. It may be hard for some parents to balance time with their other children if their child with autism is in high need. A child with more high needs may require assistance with eating, toileting, personal cares and behaviour modification which can occupy the parents time more. In some cases, the typically developing child may act out in hopes to intercept some of the parental attention (Autism Society, 2011).

To add on, being a young carer and also the thought of being the future caregiver is also amongst the negative experiences faced by individuals with autistic siblings. Being expected to grow up so faster than you may want to, because you need to be the responsible one can be quite a hard task to some siblings and even trigger negative experiences in the non-autistic individual whilst others might even enjoy it which shows diversity. Also the concern over their role in future caregiving of the child diagnosed with autism can be stressful for the sibling and therefore result into negative experiences. A study indicated that siblings reported significant concern regarding the future of their brother or sister's autism (Orsmond and Seltzer, 2007). A sibling may feel obligated to take over for the parents when they are no longer able to take care of the child diagnosed with autism. The lack of consistent support services means that families became over reliant on sibling family members for help (Harries, 2008). There is a tendency for siblings to

take on extra responsibilities that can therefore lead to resentment (Sibs, 2008). This might lead to the negative experiences in individuals who have autistic siblings for it can be too much for them to handle for mostly they start this at a tender age when they also want the same care from the parents and guardians. On the other hand, a sibling may be persistent about taking over for the parent, however, fear that they will not be able to provide appropriate care and financial stability by the time the care is needed can hold them back and thereby result in the having a negative experience.

Unpredictable and sometimes violent tantrums and outbursts aimed at siblings which brings in embarrassment are also amongst the negative experiences in individuals with autistic siblings. In having a sibling with autism, they may say or do things that others find "weird" or exhibit aggressive behaviors. For instance, one siblings got a bite from her autistic sibling a night before her class photo shoot and had to lie to her classmates that it was cat which did it because she knew that they would find this kind of behavior as uncalled for (Stoneman, 2005). A sibling may feel awkward or nervous bringing friends around their autistic sibling with the fear of the unknown (Autism Society, 2011). A study indicated that siblings aged 7-20 years who have siblings diagnosed with autism mentioned feelings of embarrassment. Another study confirmed these results with siblings reporting the negative aspect of having a brother or sister with autism which are feelings of embarrassment (Orsmund and Seltzer, 2007).

2.3 Positive Experiences of having an autistic sibling.
Although a great deal of research has been dedicated towards understanding interparental relationships and their effects on the family unit, sibling experiences with other autistic children remains an underrepresented area of study. However, given the daily companionship and longevity of the sibling relationship, a growing number of researchers are beginning to document the developmental importance of this vital bond. A literature review by (Feinberg& McHale, 2012) delineates ample evidence that sibling relations impact individual development. The findings show the quality of sibling relationships influences internalizing and externalizing behaviours for all the siblings. Sibling's negative relationships are linked to increases in antisocial behaviours, substance abuse, depression and anxiety. Alternately, positive sibling relationships have been correlated with the increase in social competency and adaptive relationship skills. These manifestations have significant consequences for a child or adolescent in terms of school success, peer development and personal adjustment (Barnett & Hunter, 2012).

There is abundance on the literature on the unique characteristics of autism spectrum disorders, along with research on how having a sibling with autism affects the siblings. Research supports the idea that having a positive relationship plays an integral role on the development of pro-social behaviour, self-esteem, improved life satisfaction and reduces the risk for depression (Brody et.al, 2008). For with autism an individual will show some pervasive impairment in social interaction, communication with repetitive patterns of behaviour, interests and activities, obsessive interests (Johnson &Myers, 2007). For these effects to lessen they will need some social support from the family and a positive relationship with other siblings so as to lessen their difficulties and this shows the necessity of constant supervision from the family members especially the other siblings which can be very stressful to them therefore leads to negative experiences amongst the siblings with the one with autistic challenges.

Positive experiences faced by individuals who have autistic siblings can foster a better quality of life both in the present and in the future, such as once parents or guardians may be unable to take care of their child with autism. (Feider et al., 2006) reported that culture, traditions, interests and the environmental context all have an effect on sibling relationships. (Mascha and Bucher, 2006) concluded in their qualitative study that most siblings with autism ages 7-20 recalled positive experiences with their autistic siblings, stating that they played outside, watched TV and had fun with their siblings. Further, (Foden, 2007) reported that typically developing siblings of individuals with autism spoke of pride in teaching their siblings with autism. Siblings of individuals with autism were closer to their brother or sister with autism, used coping strategies, and when their sibling had higher levels of independence. Moreover, (Hodapp, 2007) reported more positive sibling relationships when they accepted their role as part of the family, perceived minimal parental favouritism, developed coping skills, understood their sibling disability and were not worried about the future of their sibling with ASD.

There are benefits or positive experiences which are encountered by individuals who have autistic siblings including the impact of sibling characteristics on the social- skill function of the diagnosed child. Such sibling characteristics have an increased empathetic ability, well rounded character and maturity (Brewton et al., 2012). Furthermore, results from qualitative studies that includes the perspective of the sibling without autism included themes of "Having a sibling with ASD has actually impacted my life for the better" and "It's a blessing and a curse" (Henderson,

2011) which shows that there are positive experiences which are also faced by the non- autistic individual. Research by Susan McHale and colleagues found that siblings without autism viewed their relationship with their siblings with autistic challenges as positive when they had an understanding of the sibling's disability, they had well developed coping abilities and they experienced positive responses from parents and peers toward the sibling with autism.

Despite the various stressful issues, most siblings cope well and growing up with a brother or sister with autism which can add more positive experiences and a unique bond to the relationship. Recent studies have also indicated that siblings may in fact benefit from growing up with a sibling with a disability (Belling et al., 2009) showing an increase in qualities such as optimistic self-esteem, assertiveness, empathy, affection, compassion and desire to protect. Every sibling relationship is unique, but having an autistic child in the family can impact the entire family dynamic. While much attention is paid to the challenges and difficulties faced by siblings of autistic individuals, growing up with an autistic sibling also offers many advantages and hidden treasures that can help shape an individual's life and character.

(Pike et.al,2015) conducted a study on sibling relationships and individual adjustment and proposed that siblings who spend more time playing together in a friendly manner may develop skills such as sharing, co-operation and empathy which in turn helps them develop more pro-social behaviours across a life span. These social exchanges can be reinforcement for both negative and positive behaviours but allow children the opportunity to learn about more acceptable social interactions through trial and error (Parke & Buriel, 2008).

Due to the social and communication deficits of autism, growing up with a sibling with autism can be dramatically different than growing up with a non-autistic sibling. Researchers are just beginning to understand the implications of having a sibling with autism on the non- autistic sibling. The purpose of this research is therefore to enlighten the non-autistic siblings further about autism so that their experiences with the autistic individuals will be better and therefore help the autistic siblings with their social and communication deficits for most of them will spend more time together and this interaction will help lessen some of the autistic sibling's deficits.

Sibling relationships in relation to the attachment theory suggest that siblings can become attachment figures during the early stages of individual life, (Whiteman et.al, 2011). The ability

to form secure attachment with sibling allows an individual to have a secure base in which to explore the world. The sibling provides emotional security and comfort in times of stress. As siblings age embark on adulthood, siblings that stay connected also provides each other with a sense of social support and assistance in the time of need. Siblings provide companionship, someone to confide in, serve as role models and are a source of support across the life span.

(Beyer, 2011) did a research related to sibling relationships when one sibling has autism and reported that researchers found both positive and negative factors in these sibling's relationships. Siblings claimed that they had minimal conflicts and warm relationships with their siblings with autism. They also stated that they had fun with their siblings with autism and were proud of teaching them. In contrast some siblings of children with autism reported that their brothers and sisters with autism were less close and warm compared to relationships with other siblings. In addition, few siblings reported greater feelings of embarrassment than siblings of typically developing children or children with other disabilities. (Beyer,2011) suggested that different research methods and comparison groups in addition to variation in other factors that is the family environment, severity of autism could explain the mixed results related to these sibling relationships.

One of the traits of positive experiences in individuals who have autistic siblings is seen from perception. Having an autistic sibling means growing up with someone who sees the world in a unique, personal or individual way, a way that is often unique from the mainstream population. The non- autistic sibling learns very early on that the world we live in is not black nor is white there not necessarily a right or wrong way to do all things. With solid guidance, siblings come to learn that individuality is not scary or wrong but valued and beneficial to the society (Davys et al, 2016). The neuro-typical siblings go into adult life with open minds and the ability to see the world from many views. Not only does this shape an individual with compassion, empathy and acceptance of differences, but also inspires innovation and creativity. The siblings can become real thinkers who see beyond face value, as well as diplomats who can navigate and reconcile conflicting points of view.

Growing up with an autistic sibling means watching your sibling face each day with more courage and strength than many of us can fathom, thus a better perspective. Whether facing ridicule and cruelty from others and simply trying to get by in a world that was not built to

accommodate their needs and their way of thinking, individuals with autism experience constant challenges. It's difficult to witness this on a daily basis and not grow up with a great perspective about what actually constitutes a problem. Granted, a pitfall of some siblings is to decide that their own real problems or feelings do not warrant attention or concern (Emerson & Giallo, 2014). However, with maturity and proper guidance from caring adults who can balance experiencing their feelings with not overreacting to trivialities or falling prey to self-pity. This is how perspective which is amongst the factors which causes positive experiences in individuals who have autistic siblings allows them to remain calm during difficult situations, and to be thoughtful rather than reactionary.

Another positive experience that is faced by individuals with autistic siblings is that of having leadership quality. Siblings of autistic children often have to mature very early- arguably, earlier than should be required. By necessity, siblings often must assist their parents in helping, providing care and teaching. These households can be chaotic, and siblings must develop real inner strength to deal with chaos, emotions and frequent uncertainty. Whether older or younger, the non-autistic siblings naturally gravitate to leadership roles in the sibling relationship. They learn to stand up for their sibling to others and advocate for their sibling's potential to be seen and met with proper challenges for growth and success. Whereas this can present difficulty for some, in the end, it shapes strong adults with tremendous potential for leadership. They can grow into leaders who are comfortable navigating uncertainty and still delivering results, they become comfortable leading and motivating others and learn to see and foster potential in those they lead. The siblings become strong, compassionate leaders who are natural innovators, protectors and advocates being the good fruits of having an autistic sibling (Weafer etal, 2012).

By necessity growing up with an autistic sibling teaches a child to have the courage to stand out. Venturing into society with someone who does not necessarily conform or have unfiltered reactions means there will be moments when the entire family stands out. For children and teenagers this sometimes can cause embarrassment. However, it is an important part of their development that will yield rewards their entire lives. It helps the siblings to learn to be themselves and express their ideas, and not to be swayed by the crowd. A lifetime of developing strength and compassion provides the courage and pride to face the world head on (Tozer et al, 2013).

Non-autistic siblings have a unique way of communicating with their autistic siblings, sometimes even developing shorthand or symbiotic relationship which shows creativity which is amongst the traits of positive experiences. Learning to communicate effectively with an autistic sibling takes a great deal of creativity. Autism manifests differently in a person and there is a broad spectrum. However, communication and social awareness are almost or always affected in some way. Siblings grow up learning how to organically communicate, reach or connect with their sibling. Because those with autism often have unique and varied ways of thinking, seeing the world, their neuro-typical siblings often benefit from a very creative point of view (Serdity, 2010).

Siblings of individuals with autism have been reported to conceptualize the self in a positive enhanced manner in comparison to the general population (Verte et al, 2013). Siblings of individuals with autism are more likely to develop positive perspectives towards their behavior, intelligence, academic ability and levels of anxiety. They also hold a more positive view of their overall personal characteristics than siblings of typically developing individuals (Macks & Reeve 2007). Furthermore, qualitative reports revealed empathetic feelings towards siblings with autism, showing an emotional maturity which is part of the positive experiences (Gray, 2009).

2.4 Coping with an Autistic Sibling

(Orsmond & Seltzer, 2007) reported that siblings of a brother or sister with autism who had developed effective coping skills reported more positive relationships. Thus typically developing siblings need effective coping skills in order to effectively deal with the challenges that come with having a sibling with a disability to develop more positive experiences with their autistic siblings. Coping strategies can be developed by first encouraging typically developing siblings to share how they are feeling and any concerns they have for their autistic sibling. That is by encouraging siblings to openly discuss their feelings unnecessary distress can be avoided and siblings can be reassured their feelings are natural. Secondly, siblings often lack information or are misinformed about their brother or sister's disability (Glasberg, 2010.). Approximately one of every five sibling's claim that they have never heard the sibling's diagnostic term (autism), thus proving them with accurate age appropriate information about autism can enable them to cope both interpersonally and intrapersonal by dealing more effectively with their own curiosity(Howlin et al., 2011). As siblings get older they should be provided with information concerning the disability, which can be found in books, magazines, and journal articles (Smith et

al., 2008). Further, siblings should be included in the education of their autistic siblings because they may often feel isolated (Fiedler et al., 2005).

There are two types of managing, one being the approach and problem- focused strategies and the other being avoidant and emotion focused strategies. Approach and problem- focused strategies define individuals who pay attention to a stressor and seek out a solution. Avoidant and emotion- focused strategies define individuals who ignore, minimize and deny their stressor (Meadan et.al, 2010). One study indicated that those who utilize approach and problem-focused strategies adjust better whereas those who utilize avoidant and emotion- focused strategies result in higher stress levels and mental health issues. Coping is an important aspect in the grieving process when presented with an autism diagnosis of a sibling. One way that siblings can cope with the stress of autism is by networking with other siblings who have been affected by the disorder. This provides siblings with comfort in finding others who are experiencing similar situations as well and receive advice that will be useful to them so as to have positive experiences with their autistic siblings (Autism Society, 2011).

To add on, formal support is also another coping mechanism for siblings. This includes support groups, health professional services and counselling. These services allow siblings to discuss their current issues or negative experiences and gain more knowledge of their sibling's autistic diagnosis. Another study explored the effectiveness of support groups for siblings of individuals with autism and this study indicated that siblings deepened their understanding and knowledge about autism (Banach et.al, 2011). Assessing social support could shield the harmful effects of stressors on the sibling relationship. Siblings use a variety of coping strategies in response to having an autistic sibling. One adaptive problem focused coping strategy being that of assessing social support (Lazarus & Folk man, 2010). Social support consists of informal social networks like extended family, friends, neighbours, church or more formal institutionalized support like education, healthcare. Access to social support has been related to positive family and sibling experiences in families with a variety of disabilities (Vanderberg, 2008). It was hypothesized that sibling's coping by accessing social support buffer the deleterious effects of negative experiences on the sibling's lives. When social support is high, the quality of sibling relationship is also expected to be similarly positive. Therefore, encouraging typically developing siblings to join

support groups can allow them to meet others who are going through similar experiences and realize that there are not alone.

In addition, the inclusion of siblings in support groups or family therapy in relation to the experienced stress and resilience in the family system. Hearing the unique experiences and insights of other siblings of children with autism can facilitate a greater understanding of interaction within the family thereby helping the siblings to the autistic individuals to cope with their situation. Additionally, the use of support groups, such as the ones proposed by (Conway & Meyer, 2008) and the additional provision of sibling interactive play therapy appeared to benefit these siblings as well.

Another coping strategy that can be used by individuals with autistic siblings is the redirecting technique. This is whereby the non- autistic siblings would redirect the attention of the autistic siblings and this can usually be used before a potential meltdown. This appears to be an effective use of the Premark principle which states that more probable or preferred behaviors will reinforce less probable behaviors (Premark, 2007). This strategy can be more effective if the non-autistic sibling pays more attention to the actions of the autistic individual so as to be more aware as to when and where to apply the redirecting technique.

More so, educating parents is also amongst the various ways that can help individuals with autistic siblings to cope with their situation. By educating parents and guardians about the children experience of the sibling relationship may increase the family's psychological resources and in turn, may increase positive sibling interactions and experiences (Guzman, 2009). The sibling bond can have a unique and powerful influence on the mental, physical, emotional and psychological aspects of a person's life. With a better understanding of this relationship parents, mental health professionals and supporting organizations can work together to create greater support and outcomes for the autistic and the non-autistic sibling thereby adding onto their coping strategies to their situation.

A survey of 60 individuals discerned that siblings of individuals with developmental disorders such as autism endorsed increased education and assistance from professionals in understanding autistic challenges. Results indicated that these individuals believed that this education resulted in providing more effective and willing care for their brother or sister (Hatfield et al.,2005). To add on, to education, provision of a social supports system may be integral in promoting the

sibling health and wellbeing therefore being a coping strategy. A study investigating the impact of applied behavioral analysis (ABA) found little significant changes across several areas of investigation, social support was demonstrated to evidence the largest impact on the quality of sibling relationship thereby being means of coping (Cebula,2012). Work by (Conway &Meyer,2008) emphasizes that the need for individual support for siblings of special needs children, they found international success through implementation of workshops designed to directly support siblings.

A recent literature review regarding coping strategies that can be useful to non-autistic siblings included the provision of parent support as well as sibling support to be the benefit to siblings of children with an ASD diagnosis (Tsao et al., 2012). Parent support, use of effective parent communication tools and establishing firm boundaries regarding equivalent treatment between siblings all yielded positive results for supporting siblings thereby being means of help in terms of coping with an autistic sibling.

Avoiding unnecessary emotional and physical pressure is also amongst the coping strategies that can be useful when having an autistic sibling. Siblings of individuals with a disability often become second parents in the areas of care and discipline (Smith et.al, 2008). Concerns about the future of the sibling with autism can lead to negative sibling relationships. Thus parents should be conscious of not putting too much responsibility on typically developing siblings for support for this puts unneeded stress upon them. More specifically, parents should plan for the possibly future residential placements of siblings with autism long before they become too old and typically developing siblings should not be involved in the process, but not feel obligated for future care.

(Tsao et al., 2012) lamented the lack of current literature surrounding sibling's coping strategies, and strongly proposed further investigation into this field so as to lessen the stress and negative experiences faced by the non-autistic individuals if they have more effective means of coping with their siblings with autistic challenges.

2.5 Theoretical Framework
A theoretical framework is like the lenses through which one views the world according to (Henning et.al, 2005). The researcher is going to be using two frameworks which are the Constructionist and Eco-systematic Perspectives.

2.5.1 Constructionist Theory

One of the frameworks that are going to guide this study is constructionism. The Constructionist perspective contends that through past and present interaction in the world people assign meaning to their experiences (Crotty, 2007). From this perspective objective knowledge is considered to not exist (Anderson, 2008). Different people may define truth in very different ways based on individual constructions. The experience of having a sibling diagnosed with autism may carry very different meanings from different children. From a constructionist point of view all individuals' interpretations should be considered valid.

To add on, the meanings that children assign to the experience of having a sibling diagnosed with autism may be influenced by many past and present circumstances including age of children in the family, the number of siblings in a family system, understanding of an autism diagnosis, available social support, parental interactions only to mention but a few. Under this theory, even when individuals' interpretations may vary considerably from each other, all should be considered valid. Guided by the constructionist perspective the research selected a methodology that would allow the voices of the participants to be heard while having the researcher become conscious of biases.

2.5.2 Eco- systematic Theory

In this study, the researcher will also use the eco-systematic perspective which originated from a blend of ecological and system theories. This perspective emphasizes the dynamic, interdependent and interacting relationships between individuals and groups at different levels of the society. The ecological theory is a holistic view of the interdependence of organisms of their environment depend on each other for survival and therefore, "that happens in one part of the system can affect the other parts" (Donald et.al.2006). (Donald et al, 2006) used the example of worker bees and flowers to explain this phenomenon. The bee needs the flowers to collect pollen and nectar to feed itself and if young, the flower needs the bee to spread its pollen so that new flowers can grow. Thus the flower and the bee are interdependent. However, if this system is disturbed by insect poisoning, both the flower and the bee will die. In other words, if there is a balance within the system, it can be sustained but a disturbance in one part of the system will threaten the whole system and the whole environment will struggle to recover its balance and sustain itself (Donald et.al, 2006). This concept has been adapted to the relationships between human beings and interactions between groups of people within their social context. Families

and schools are also interactive systems which function as a whole and are dependent on interaction between different parts. The systematic framework is based on the idea that people develop in isolation, but affect or are affected by multiple systems (Swart & Pettipher, 2011). Therefore if something happens to one member of the family affects everyone else in the family (Kaur,Scior, Wilson et al, 2009).

A diagnosis of autism therefore does not only affect the individual but the entire family. Usually when such a diagnosis is made all the emphasis is on the child with autism and some focus might be on the parents, but the needs of the siblings are overlooked (Conway & Meyer, 2008). If parents do not communicate the effects of the diagnoses of autism to the siblings of the autistic individuals, it can influence sibling's functioning and interaction with other subsystems. At times siblings of children with autism have contradictory roles within the family system; the siblings might have the role of a child, as well as of a caregiver for the child with autism. These contradictory roles may create problems for siblings with regard to how people in the system relate to them. For instance it might create problems in the relationship between siblings and parents, as siblings want to be treated as children but parents might treat them as co-carers (Donald, 2007).

2.6 Knowledge Gap
Little is known when it comes to the siblings of individuals with autism especially in Zimbabwe this lack of knowledge shows the need for a further study. The sibling subsystem is of heightened importance since the sibling relationship can be the first and most intense peer relationship. The researcher is going to focus mainly on the experiences of autistic and non-autistic siblings which have been an isolated area of study most researchers focused on the relationships of autistic children with their parents, peers and teachers but giving a blind eye to the siblings. So this study is going to breach this gap.

2.7 Chapter Summary
This chapter looked into the literature review first which is an overview of the literature on sibling relationships of autistic and non- autistic individuals and previous studies on Autism also referring to the research questions of this study as subtopics. It then highlighted more on the Theoretical Framework which included the Constructionist Theory and the Eco- systematic Theory, these theories backed up the whole study. Then finally the knowledge gap was also be

part of this chapter which simply referred to the issues that other researchers did not focus on concerning the experiences of autistic individuals and their sibling.

<h1 style="text-align:center">CHAPTER THREE</h1>

<h1 style="text-align:center">RESEARCH METHODOLOGY</h1>

3.1 Introduction

This chapter looked into the research methodology which is used by the researcher in this study. Research Approach is a collection of methods, practices, procedures and rules guiding the research in a study (Saunders, 2007). The researcher also focused on the research design, target population, population sample and the sampling procedure, research instrument, data collection procedure, data analysis and the ethical considerations that will be used by the researcher in this study.

3.2 Research Approach

For the purpose of this study, a qualitative method is to be utilized to investigate the lived experiences of siblings of autistic individuals. This topic has been largely neglected in the current literature, relying on quantitative measures that yield inconsistent results regarding sibling experiences. Through the use of participants' own views rather than reliance on outside observers, this topic is going to openly explore hopes of producing findings that can be used on greater scales in future studies. Additionally, a qualitative method was chosen so as to promote acknowledgement of autistic sibling challenges and successes from the participant themselves. The focus of qualitative research is meaning and understanding, hence the researcher aims to understand how people interpret their experiences, how they construct or make sense of their worlds and what meaning they attribute to their experiences (Henning, 2011).

Thus the researcher's interest is in uncovering meaning rather than determining the cause and effect or predicting the outcome (Merriem, 2009). In other words, the process of qualitative research is inductive which means that the researcher will first observe aspects of social life and then seek to discover patterns (Babbie, 2011). Central to the qualitative research is the assumption that individuals construct reality in interaction with their social worlds (Merriam, 2009). There the interpretive paradigm is often used in conjunction with social constructivism as it requires the researcher to see "through the eyes of the participant", (Nieuwenhuis, 2007). The purpose of an interpretive/ constructivist research study is to understand how people make sense of their lives and experiences (Merriem, 2009). The qualitative research approach is useful for studies at individual level and to find out in depth, the ways in which people think and feel for

example case studies that is the why the qualitative approach is more applicable to the study of experiences siblings of autistic individuals.

3.3 Research Design

The researcher is going to use the Phenomenological Research Design, which is defined by (Coolican, 2009) as mainly concerned with studying real events as they are on the actual ground. A research design is a plan or blueprint of how one intends to conduct the research (Mouton, 2001). Thus, the research design is needed to execute the plan and answer the research questions as suggested by (Terre Blanche et al, 2006). Phenomenology is used to identify phenomena and focus on subjective experiences and understanding the structure of those lived experiences. This research design was founded in the early 20th century by Edmund Husserl and Martin Heideggar and originated from philosophy. Phenomenology is used to describe, in depth, the common characteristics of the phenomena that have taken place. The aim of this research design is to describe experiences as they are lived and examine uniqueness of individual lived situations. Under this research design it supports the view that each person has his or her own reality that is reality is subjective.

The phenomenological research design best works in researches requiring descriptive answers like, "What is this experience like" or "What is the meaning of this experience or phenomena", such questions are referred to as phenomenological type questions. It is the ability of the phenomenological research design to give in- depth and reliable information on experiences and emotions of individuals concerning their real situations this therefore led the researcher to choose it as the study sought to explore the experiences of individuals who have siblings with autistic challenges at Pathways Autism Trust. This qualitative research design is an approach to understand the qualities of a phenomenon within a particular context (Brat linger et al, 2008) and (Whittinghill, 2011). To gain an understanding of the shared aspects of people's experiences, the sibling's perspective is represented as a group of voices, a shared experience that has commonalities as well as variation.

To add on, the phenomenology research design was selected by the researcher because of the interest and intent to understand the phenomenon from the participant's point of view through the collection of data. This type of research design is used to study areas in which there is little knowledge (Donalek, 2007). Phenomenology is a way of thinking about what life experiences

are like for people (Whittinghill, 2011). The reality is defined by the perceptions of the individual encountering the experiences according (Munhall, 2008). This research design inquires about the meaning of an experience, giving description of the experience as it is lived in everyday existence (Wilkerson, 2012). The purpose of this research procedure is to illuminate similar and divergent themes in descriptions of the sibling's experiences. It is therefore plausible to use this research design for it provides in-depth information regarding the lived experiences of the participants with respect to the sibling relationship.

3.4 Target Population

According to (Lucan, 2008) target population is the universe from which the subjects of research are drawn from, in short the people that the researcher purports to work with as participants in his or her study. The researcher's targeted populations are the siblings to the autistic individuals from Pathways Autism Trust from 16 years and above regardless of neither their gender nor race. This age range will ensure that participants are old enough to express themselves verbally and are also a bit mature to pass mostly accurate judgment. Adult siblings might also record different experiences when reflecting back on their situation when growing up as opposed to still being in the situation.

3.5 Population Sample and Sampling Procedure

Population sample is the actual number of participants that a researcher is going to work with (Baron Et.al, 2012). The goal of qualitative research is to provide in- depth understanding and therefore targets a specific population, type of individual, event or process. To accomplish this goal, qualitative research focuses on criterion-based sampling procedures to reach their target population. The study was conducted in Harare at Pathways Autism Trust and the population sample will comprised of 7 siblings of autistic individuals. Qualitative research does not seek to generalize results, thus a small sample size is sufficient to gain initial responses regarding research questions (Creswell et.al, 2009). However in attempt to gain answers from diverse perspectives, this study will gathered 7 adolescents for participation. In qualitative studies, sampling typically continues until information redundancy or saturation occurs. This is the point at which no new information is emerging in the data. Therefore in qualitative studies it is critical that data collection and analysis are occurring simultaneously so that the researcher will know when the saturation point is reached.

For the benefit of this research, participants were selected by the heterogeneous sampling which is one of the purposive sampling techniques whereby the researcher will select participants with a purpose in mind that means the participant is confined to specific demands that is age, sex only to mention a few. In this sampling procedure participants are sought based on pre-selected criteria based on the research questions.

3.6 Research Instrument

Research instruments are tools that are used to collect data or testing devices used to measure a particular phenomenon these include interviews, questionnaires, focus groups, observations only to mention but a few. For this specific study interviews are going to be used as the instrument. Interviews become necessary when researchers feel the need to meet face to face with the participants to interact and generate ideas in a discourse that borders on mutual interest. It is an interaction in which oral questions are posed by the interviewer that is the researcher to elicit oral response from the participants. Specifically with research interviews, the researcher has to identity a potential source of information from his or her respondent. The creation of a cordial atmosphere is therefore vital to the success of such an interaction. According to (Boyce and Neale, 2007), an interview seeks to unravel detail information from respondents on a particular phenomenon. The researcher will use a semi- structured interview in this format they will be an interview guide but it allows the conversation to flow naturally. This has an advantage for it will help the researcher and the study to gain greater detail from the responses of the participants. By means of a semi- structured conversation, the researcher learns more about the experiences of people and learns to understand people's perceptions. In interviews, however the researcher is the primary tool of inquiry and should be sensitive to the participant's feelings and capable of addressing interpersonal dynamics within the interview (Kvale, 2010). The use of open-ended questionnaires allows validation and authentication of participant experiences while providing an insider view of the life these siblings leads (Braddock et al, 2008).

A general interview guide was used for these semi- structured interviews. An interview guide serves as a checklist during the interview to ensure that key topic are addressed (Kvale cited in Bogdan, 1998), and still remain flexible so that the researcher can decide themes that will be discussed in further detail. This interview guide will be divided into four sections, the first section covering the demographic data of the participants and the other three sections having the major themes of the research which are the research questions. Also the subthemes will also be

under each major theme in these three sections which will be used in the interviews by the researcher.

3.7 Data Collection

The researcher got approval of the research topic from her supervisor. Then the researcher then applied to the executive board of Pathways Autism Trust for authority to conduct the research. The researcher the personally conducted the semi- structured interview and before interviewing the participants they were fully briefed about the study, for instance the purpose of the interview and that the research is solely for academic purposes. During these interviews the research took down the responses from these participants and also recorded what they were saying in case the researcher lives some points out.

3.8 Data Analysis and Presentation

The analysis of qualitative research involves aiming to uncover or understanding the bigger picture by using the data to describe the phenomenon. The form of data analysis and presentation that the researcher is going to use in this study is the qualitative content analysis, by which patterns and themes are identified by grouping data into units of meaning (Corbin and Strauss, 2008). Content analysis can be used when qualitative data has been collected through focus groups, interviews, observations, documentary analysis. Content analysis is a procedure for the categorization of verbal behavioural data for purposes of classification, summarization and tabulation. In the process of data analysis, a substantial amount of qualitative data is transformed into refined interpretation thereof (Gibbs, 2007). The aim of content analysis is to make sense of the data collected and to highlight important messages, features and findings.

 Content analysis takes into account the following elements when analysing issues that are the content of text components, latent structures of sense, distinctive individual cases, things that do appear in text (Kohlbacher, 2005). Content analysis in qualitative research is carried out by recording the communication between the researcher and its subjects. This method of analysis comprises of 8 steps having the preparation of data as the first step and in this study the researcher transcribed and recorded data from the participants. The second step is defining the theme of analysis which the researcher also did by classifying the content into themes which presented a major idea. The third step was developing categories and coding which is derived from three sources that are the primary data, theories on similar topic and empirical studies. The

4th step is pre-testing and coding scheme on sample so as to ensure consistency then code all the text. The 6th step was to assess the consistency of coding employed that is checking the validity and reliability of the findings. This leads to drawing inferences on the basis of coding or themes. Finally the last step was the presentation of results, where under each theme there were conclusions which were also supported by secondary data and quotes for the developed code.

3.9 Ethical Considerations

(Lahey, 2008) defines ethics as moral guidelines of what is good or bad in a research. In conducting this research the researcher is to be guided by the following ethical standards (McLeod, 2007).

3.9.1 Informed Consent

Before the study commences, all participants are to be given full information about the purpose of the study and they will voluntary agree to participate after taking note of the nature of the study and any risks regarding the study so as to ensure that participants make informed decisions.

3.9.2 Respect to privacy and confidentiality

Participants are to be assured that all information that they will provide for the purpose of this study will not be disclosed for non-academic reasons. Pseudonyms will be used so as to ensure confidentiality of the real identity or names of the participants. Information obtained in connection with this study that could reveal the identity of the participants will remain confidential and will be disclosed only with their permission.

3.9.3 The right to withdrawal

The participants will also be informed on their right to withdraw from the study at any point without any consequences of any kind. They can also refuse to answer any questions they do not want to answer and still remain in the study. The researcher could also withdraw the participants from this research if circumstances arise which warrant doing so.

3.9.4 Debriefing

At the end of the study the researcher will thoroughly debrief the participants. They will be given a general idea of what the researcher was researching on and why and their part in the research will be explained. This is done so as to eliminate the participants fear that the information they have disclosed will be abused.

3.10 Chapter Summary

This chapter looked on the methodology which is to be used in this study and this included the qualitative research approach, phenomenological research design, purposive sampling method and interviews in collecting data. Content analysis was used in analysing and presenting data and also ethical considerations were also discussed.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.1 Introduction

This chapter focused on the presentation, analysis and interpretation of the data that the researcher collected. The researcher started off by presenting the demographic characteristics of the participants and then presented the data in thematic form through the main themes and sub themes that emerged from the study. Although all the information obtained from the participants was all valuable, some themes came across more strongly in transcribed data. Major themes were the negative, positive experiences that are faced by siblings of autistic individuals and the coping strategies that they use to cope with their situation.

4.2 Characteristics of research participants

The study comprised of seven siblings to autistic individuals. Four being females and three being males. The minimum ages of the participants was 16 years and were all from the same race that's, African. In a bid to honor the right to participant's anonymity, the researcher did not use the actual names of the respondents; rather each participant had his or her own pseudonym and participant number. The table below summarizes the participants' demographic characteristics.

Table 4.1 Summary of Participants Demographic Information

Pseudonym	Age Range	Gender	Marital Status	Race	Birth Order	Participant Number
Sandra	22-24	Female	Single	African	2 out of 2	1
Bay	25-27	Female	Married	African	1 out of 3	2
Toby	25-27	Male	Single	African	2 out of 3	3
Chido	22-24	Female	Single	African	2 out of 3	4
Liberty	16-18	Male	Single	African	2 out of 2	5
Jabulani	Above 30	Male	Married	African	3 out of 4	6
Precious	22-24	Female	Single	African	1 out of 3	7

4.3 Theme one: Challenges faced by individuals who have autistic siblings

In having a sibling with autism was said by most of the participants as to be bringing negative consequences on their lives which therefore resulted in the negative experiences they face in their day to day lives. Embarrassment, anger, anxiety, jealousy, are also amongst the various emotions the participants said they experienced which will be briefed in the table below and further seen from their responses.

Table 4.2 Theme one and subthemes

Major Theme	Subthemes
Challenges faced by individuals who have autistic siblings.	-Embarrassment -Being a young carer and future caregiver -lack of attention and jealousy

4.3.2 Embarrassment

Most participants reported that from having an autistic sibling it comes with embarrassment at times especially around their peers and also other people who do not have an understanding on autism. Unpredictable and sometimes violent tantrums and outbursts aimed at the siblings made the siblings embarrassed for this can be a weird behaviour to someone who has little or no knowledge on autism. The following narratives show that embarrassment is one of the negative experiences faced by most of the participants:

> *She will say and do stuff that feels embarrassing to me and also awkward to others especially my friends. I always find myself shouting, sister stop it which is not really good for l do it with some rage in me constantly forgetting that l should not shout at her for it is not necessarily her fault for doing that awkward thing which mostly is socially unacceptable, for at times l understand that she is different and therefore social interaction is not easy for her.* (Participant 2)

This was further supported by Participant 3 who also complained that having an autistic sibling brings in embarrassment along with it:

She gets this tantrum thing you know, and it's not so nice because sometimes she goes on and on and she won't stop. She often starts crying, shouts at me and often punches me unnecessarily and suddenly walks away. This kind of behavior is kind of embarrassing especially when my friends are there when she outbursts even at my friends which is so uncool for they do not understand this as much as l personally do.

Similarly Participant 5 also shared that:

Having to see my brother whom l love so much acting all angry and stuff is not amusing at all, l would rather see him looking happy but instead he gets these mood swings and mostly l have to be the victim of most of my brother's tantrums which often makes me feel embarrassed in public for others won't easily grasp what is taking place. For instance this other day, he got this sudden outburst when we were at the local mall, he cracked and then screamed and started to cry whilst trying to hit me and also the people who were nearby which was unpleasant at all and also socially inappropriate which just left me feeling awkward and ashamed by my sibling's behaviour.

These narratives show that having an autistic sibling comes with bit of a load, embarrassment being one of them therefore resulting in the negative experiences they face. Thus, socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming, running away and self-injury are often associated with autism, but in actual fact, these behaviours are reactions to the environment which can also be interpreted as a desperate attempt to communicate. If siblings do not understand the causes of these behaviours and label them as embarrassing, it may cause distress or later adjustment problems in siblings therefore leading to a negative sibling relationship.

4.3.2 Being a young carer and future caregiver

Most siblings reported that having to be a caregiver to their autistic sibling at a tender age is quite a hustle and also the thought of being the future caregiver really made them more anxious. Their responses proved the present and future fear they had over the role they had to play:

My autistic brother will have to be taken care of his whole life meaning he will need to be supported emotionally, financially as a dependent for he is not independent to be capable

to look after himself because he will not be able to get a job and he is unable to cook, clean after or physically take care of himself. (Participant 6)

Participant 5 added on how his autistic sibling needed his care although he is way younger than him:

I have to attend to him almost every time considering the fact that he is also epileptic means that l should put more effort as a caregiver despite the fact that l am young than him.

More so, participant 2 also shared on how she also was a caregiver in her sibling's life:

l have been a caregiver at a very tender age as l was the only female child who was mature in my family and this was a hard phase for l knew little about my sibling's disability at that time. Also by being the oldest child it also means that l am also the provider financially to my autistic sibling since my parents are both late and this looks like it's going to be my role for the rest of my life though the concern that what if someday l can't provide for her what will be the outcome often hits me.

From the above narratives, the sibling's role of being a caregiver at a very tender age can be frustrating for sometimes they can be not be fully mature to tackle such a responsibility thereby resulting in the negative experiences they face. But as time goes on they get used and it then settles with them that they should accept and embrace this role for that is what it is. When siblings act as a carer, teacher and a protector which shows the resemblance of caregiving, this has a positive effect on both the sibling and the autistic individual (Jones & Robinson, 2007).

4.4.3 Lack of attention/Jealousy

The sense that the participants comes second to their parents, because so much time, energy is being focused on the one who has autism, portrayed another negative experience from the participants. This is further showed by their responses:

Sometimes when l am in my room, all of a sudden l hear the car starting and it goes and then later my sister and my parents comes back home carrying all these shopping bags and she always gets something and she also manages to go no one ever tells me what going on like l am not even there. So it's really annoying because sometimes it feels like

there are giving her more support and attention than me because sometimes it makes me a little bit jealous but l know that she needs it but l also think l should get that attention also.(Participant 4)

In addition, participant 1 also complained about the lack of attention from the parents though she is the youngest child seen from her response:

Although I know that he's got autism, but that does not make him a hundred times different than me. You know, in a sense that he deserves more attention than that of an average person. For even most of my accomplishments goes by least applauded for as compared to those of my autistic brother which is rather unfair.

Moreover, participant 6 also shared how she feels when her friends pay more attention to her sister than her. She said:

My friends laugh and then play with him which makes me feel jealousy for it looks like she tends to get more attention both at home and even with my own peers which is frustrating.

Caring for an individual with ASD is a full time job which frequently requires parent's undivided attention and crisis management. This explains more on why the cause of the participants jealousy or the need of attention over their autistic siblings.

4.4 Theme two: Positive Experiences faced by individuals who have autistic siblings

The participants reported more positive experiences as compared to the negative experiences between them and their autistic siblings and these included an improvement on being responsible, tolerant, patient, better communication and leadership skills which will be briefed in the table below and further elaborated by their responses.

Table 4.3 Theme two and subthemes

Major Theme	Subthemes
Positive experiences of having an autistic sibling	-Leadership skills -Personal Enrichment -Psychological growth

4.4.1 Leadership Skills

From the participants responses it was well brought out that non-autistic siblings were more identified with the role of a protector, advice give, and coach for their diagnosed siblings. This sense of responsibility was prevalent regardless of the participant's age and birth order. As siblings of the autistic children have to mature and take on more responsibility they also gain from it for they acquire a better quality of leading their autistic sibling which can even help or is even helping with their careers. This is observed from some of the participant's responses:

> *From being a young carer and also the present caregiver it has really improved my leadership qualities and I have learnt to be more responsible as my sibling looks upon me for everything so I have to do what I do extra consciously.* (Participant 2)

Participant 5 also highlighted that his leadership skills are now better and this is an outcome from taking care and being with his sibling most of the time as he said:

> *I have come to be a more responsible young man I have to take care of my sibling and this has also helped me on how to interact with other children with the same condition as l spend most of my time were they learn.*

This shows that there is more in having an autistic sibling as part of your life. From the responses of the participants they tend to gain a lot of insight which therefore helped them with their careers and even with their social life which shows a good impact from being the non-autistic sibling. Thus, it is plausible to say that there are also positive experiences which are also encountered by individuals who have autistic siblings with the attainment of leadership skills being part of them.

4.4.2 Personal Enrichment

Most of the participants reported feeling as if they had learned several lessons from interacting with their diagnosed sibling. The growth of personal traits such as being more calm or tolerant was frequently endorsed. At times the participants had difficulty in putting into words what exactly they have learned, because the experience of having an autistic sibling is so impactful seen from how they responded:

In all these years that I have lived with my autistic sister I have grown to be more patient, tolerant and loving. For I have got to know that her condition really needs a warm environment for her to improve for the better. (Participant 4)

Similarly Participant 6 showed by his response that he also learned something from having an autistic sibling which therefore shows the positive experiences by saying:

I feel like that having the most important thing that has happened in my life. I really do believe that. It's like, the most crucial aspect in my entire life from having him as a brother. My whole way of thinking is based off that patience that improved from having him as my brother.

Participants most often described personal enrichment experiences immediately following descriptions of difficult interactions with their diagnosed sibling. In this way, participants appeared to defend the behaviours of their siblings or made an allowance for their sibling's behaviour. Thus, though participants acknowledged the challenges that they have from having an autistic child as a sibling, they also stated that it also yielded personal growth within the participants.

4.4.3 Psychological Growth

Some subjects from the study posed some responses which showed an improvement psychologically in their lives. This is seen from how they said they were developing in terms of their cognitive, emotional, intellectual, social capabilities and functioning from the phase they have lived with their autistic siblings. The unique perspective, courage, perception that was stated by the participants showed traits of psychological growth as supported by their responses:

I am becoming better prepared to deal with a wide spectrum of psychological conditions that different people experience, hence I can function wider in the society. (Participant 6)

Participant 1 further added on that:

Growing up with an autistic brother means watching your sibling face each day with more courage and strength that many of us as non-autistic siblings cannot fathom. Individuals with autism experience constant challenges and it's difficult to witness this on

a daily basis and not grow psychologically with a great perspective about what actually constitutes a problem.

Participant 3 further concreted on the point that perception and a great perspective are part of the psychological growth traits which has improved in his life from having an autistic sibling by saying that:

From having an autistic sister my capacity for external accomplishment and inner fulfilment have increased. I have learnt to be myself and express any idea that comes into my mind without any hesitation or by not being swayed by what the crowd thinks or has to say about my idea.

The bunch of narratives all revealed how the participants have developed emotionally, intellectually and in terms of social capabilities by having an autistic sibling which shows the psychological growth experiences over the course of their lifespan together.

4.5 Theme three: Strategies used to cope by the siblings

Most participants seemed to make use of the avoidant and emotion focused strategies as means of coping that is the use of social support, engaging in therapy lessons, avoiding unnecessary emotional and physical pressure seeking help from parents and other family members. The table below shows the major theme and the subthemes that were brought out under this section:

Table 4.4 Theme three and subthemes

Major theme	Subthemes
Strategies used to cope by the siblings	-Support groups -Therapy sessions -Avoiding unnecessary physical and emotional pressure

4.5.1 Support groups

Participants shared their experiences from having joined various support groups with other siblings to autistic individuals reveling how effective it has been as a coping mechanism. They said that:

My relationship with my autistic brother has improved since I joined the sibling support group in my neighborhood. This is so because I get to hear the unique experiences and insights of other individuals with autistic siblings which facilitated a greater understanding of interaction between me and my brother. (Participant 7)

Again, participant 4 added on to the positive impact that support groups has as a coping strategy by echoing the following:

I joined an online support group as I was browsing some stuff, this group has helped me a lot in terms of coping with my sister for this move that I made shielded the harmful effects of stressors on my relationship with my sibling for I have heard the voices of others who are going through a similar or a much more challenging experience than mine and this has broadened my knowledge also on autism.

From the above narratives it can be seen that the use of support groups as a means of managing with an autistic sibling is really helpful for from the sharing's that takes place at the support groups the non-autistic siblings will therefore realize that they are not alone in that situation and thereby lessening the pressure and stress they will be loading on themselves.

4.5.2 Therapy Sessions

The subjects from the research also noted the use of therapy sessions as part of their coping strategies as they lessened the experienced stress and resiliency amongst the siblings. This is observed from the participant's responses:

From the sessions I got to know that my sibling's disability does not make her a lesser human thereby comforting my future concerns and worries over my sibling which had been causing some negative experiences with my autistic sibling because I was worried about the future she will live. (Participant 3)

More so, participant 2 stated that:

These therapy sessions have made me to see my sibling from a different and even brighter perspective than before I started the sessions. I have been further enlightened on the autism spectrum and also looking forward to get more sessions so as to acquire more

The responses of the participants show that engaging into therapy sessions is really of great help as a coping mechanism with their autistic siblings. This is so because they get to know more things there were previously unaware of thereby improving the experiences that they face with their autistic siblings.

4.5.3 Avoiding unnecessary physical and emotional pressure

Participants also raised this point as another coping mechanism though it needs more input of the parents and other family members for it to be more useful. This can be seen from the narratives below:

> *More enlightment and help from my parents lightens the situation for if they put their support also the work will be less and thereby improving my relationship with my sibling for if there is more pressure exerted on me I will just consciously or subconsciously exert the same or even more pressure on my sibling due to frustration thereby resulting in more negative experiences.* (Participant 1)

Furthermore, participant 5 also recapped that:

> *With the help of my other family members in trying to be caregivers to my sibling it has also lessened my duties that I have been doing despite the issue that I am way younger than my brother, so this strategy is working out just fine for me.*

The aforementioned narratives shows that avoiding unnecessary pressure on the non-autistic siblings helps as a means of coping with their situation so as to improve their sibling relationships by having more positive experiences.

4.6 Chapter Summary

The chapter focused on the presentation, analysis and interpretation of research findings from Pathways Autism Trust concerning the experiences of individuals who have siblings with autistic challenges. The chapter showed that there are both negative and positive experiences in individuals who have autistic siblings. The chapter also highlighted the coping mechanisms used by the non-autistic individuals which are under the avoidant and emotion focused strategies.

CHAPTER 5

DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

Following the presentation, interpretation and analysis of findings, this chapter looked at discussing the findings by comparing them with previous studies used in the literature review to see if they have a nexus or not so as to determine the validity of this research. Discussions were done following each research question that is the negative and positive experiences in individuals who have autistic siblings and the coping strategies that are used by siblings of autistic individuals so as to bring out the purpose of this study which is to see the experiences in individuals who have siblings with autistic challenges. Conclusions were drawn from this chapter and finally recommendations to help in lessening the negative experiences faced by siblings of autistic individuals. This chapter will also serve as a guideline for parents and professionals as it will give them an insight into the sibling's experiences and how they would like to be supported.

5.2 Challenges faced by individuals who have autistic siblings.

The development of the sibling relationship may differ from normal development of sibling interaction when a child in a family is diagnosed with a disability, such as autism (Guzman, 2009). Throughout the discussion, it is important to remember that each sibling's experience is unique. What they face as siblings is influenced by their personalities, age, their level of maturity, their context and the amount of support available to them. As mentioned under the theoretical framework of this study, the eco-systematic theory emphasizes that the interaction between an individual's development and the systems within the social context (Swart & Pettipher, 2011). Whilst one participant enjoyed being a young carer and probably a future caregiver to their autistic sibling another felt it placed inconsiderable pressure on her.

The study showed siblings expressing feelings of embarrassment, frustration and anger as did the siblings in Petalas (2009) study. In regards to sibling's feelings of embarrassment around their sibling's autism diagnosis, another study confirmed these results from this research with siblings reporting the negative aspect of having an autistic sibling (Orsmund & Seltzer, 2007). As described by many of the participants from this study, typically developing children in other

studies shared their experience of having to manage certain behaviours displayed by their autistic siblings including, temper tantrums, hyperactivity and aggression (Guzman, 2009). The researcher also found out in a previous study that siblings reported those same behaviours which express aggression as troublesome for them to handle (Mavropoulou &Baloyianni, 2009).

However, other researches such as that of (Bishop, 2012), its results contrasted with the result of this study. For the participants never mentioned that their autistic siblings embarrassed them as they expressed genuine love to them regardless of circumstances. Though the siblings who participated in this previous study were still young and the feelings of embarrassment may surface as they get older. Findings from (Hartmann, 2012) also showed no feelings of being embarrassed; the siblings who were interviewed felt comfortable bringing their autistic siblings around others. Thus socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming running away and self-injury are often associated with autism. But in actual fact, these behaviors are reactions to the environment which can also be interpreted as a desperate attempt to communicate (Koudstaal, 2011). If siblings do not understand the causes of these behaviors and label them as embarrassing, it may cause distress or later adjustment problems in siblings therefore leading into a negative sibling relationship (Aronson, 2009).

This finding links with the constructionist theory which is one of the two theories used by this study. For it has it that through past and present interaction in the world people assign meaning to their experiences (Crotty, 2007). So particularly with this finding it can be observed that having an autistic sibling carry very different meanings from different children that is why some participants felt embarrassed whilst in other studies did not. From a constructionist point of view all individuals' interpretations should be considered valid. Also the constructionist perspectives contends that the meanings that individuals assign to the experience of having a sibling diagnosed with autism may be influenced by many past and present circumstances including the age of children that is why they may be an inconsistence from findings of previous studies as compared to the findings of this research.

The role of being a young carer and a future caregiver was also mostly mentioned by most siblings as part of their negative experiences with their autistic siblings. This role of the "most involved sibling" was also described by (Heller & Arnold, 2010). Most participants are presently acting as the most involved carer for their sibling with autistic challenges. In most cases this duty

evolved from childhood and is frequently explained by reference to a close relationship with their sibling. Similar to this study, a previous research also brought out the role of being a future caregiver to their autistic sibling while most siblings do not feel obliged by their parents to assume responsibility for their sibling (Leane et al, 2016). Some expressed mixed emotions regarding the implications of such a role for other aspects of their lives. It became evident throughout the research that siblings took on caregiving roles with regard to their autistic siblings, even when the non-autistic sibling is younger similar also to (Bishop, 2012) findings.

Previous studies have also found that siblings often take on the parental role of caregiving. As it was pointed out in the literature review, that if it is done excessively could lead to those siblings maturing prematurely (Abrams & Aronson, 2009). The research findings also showed that siblings of individuals with autism usually maintain high levels of involvement with their siblings and demonstrate strong affective ties throughout the life course though it can be hard. Related to other research (Tozer & Atkin, 2015) found out that these ties are based on a shared history and a feeling by the participants that they have a unique understanding of their sibling and of their needs. When a sibling acts as a carer, teacher and a protector which shows resemblance of caregiving, this has a positive effect on the sibling and autistic individual (Jones & Robinson, 2007). This negative experience of siblings being young and future caregivers has a nexus with one of the theories of this study that is the eco-systematic theory. For it has it that is a sibling has contradictory roles in a family it might create problems for siblings with regard to how people in the system relate to them (Donald,2007).

Most participants from this study also reported that they felt as if they came second to their parents because most of the time; energy was being focused on the autistic individual. Due to the significant need of children with autism, the sibling may feel as though he or she is being ignored (Hartmann, 2012). It may be hard for some parents to balance time with their other children if their autistic child is in high need (Autism Society, 2011). From the literature as well as the other reports from the participants, it was clear that the daily lives of families are often planned around the needs of the child with autism (Tsibidaki & Tsamparli, 2009). This therefore leads to siblings experiencing treatment by parents as unfair. Siblings reported that they often feel left out; this in turn might influence sibling's relationships. Some siblings also felt excluded from peers and

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others feared the possibility of exclusion. These findings correlated with the eco-systematic perspective which emphasizes the interrelated between different systems (Donald et al, 2006).

Similar to the literature review of this study, the participants from a related study also shared feeling left out at times, or recognizing times when parental focus shifted to the autistic sibling (McVicker, 2013). This dynamics common in most sibling experiences as well as in families during a time a child receives diagnosis and the family attempts to meet the needs of the child to adapt new information. Findings from (Hartmann, 2012) contrasted from the findings of this research. For participants reported feeling as though their parents did an excellent job dividing their time between themselves and their sibling with autism. So they did not have any feelings related to lack of attention. Similarly, another previous study has also found out that children with disabilities including autism become the centre of attention (Tsibidaki &Tsamparli, 2009). This is the reason why sibling of the autistic individuals experiences the need for more attention and jealousness over their autistic siblings.

This finding on lack of attention raised by most participants it relates with the eco-systematic perspective under the theoretical framework of this study. For it has it that, people develop in isolation but affect or are affected by multiple systems (Swart & Pettipher, 2011). Therefore in this instance the siblings of the autistic individuals are affected with the diagnosis of their siblings for all the emphasis is mainly on the child with autism thereby resulting in the need of attention from the siblings of individuals with autistic challenges which is amongst the negative experience they face.

5.3 Positive experiences of having an autistic sibling.
The researcher found out three main positive experiences which were faced by the siblings of autistic individuals' personal enrichment being one of them. This finding from the research confirmed those of (Stalker & Conros, 2004) who found higher levels of empathy and patience in siblings of individuals with disabilities such as autism. Participants believed that they had learned much from their siblings and that they wanted to choose a meaningful career path as a reflection on these experiences. The participants experience with their sibling allowed them the opportunity to become more empathetic to other thus choosing a meaningful career path (Green, 2013). Similar to previous studies the researcher's findings showed that experiences assist the siblings in paying it forward in the community (Goehner, 2007), and are best reflected as

participants of this study say that their sibling taught them how to be patient, understanding and more empathetic when helping other people. The growths of personal traits such as being more calm or tolerant were more frequently endorsed by most participants. Such sibling characteristics have an increased empathetic ability, well-rounded character and maturity similar to (Belling et al, 2009). Showing an increase in qualities such as optimistic self- esteem, assertiveness, empathy, affection, compassion and the desire to protect which all shows traits of personal enrichment.

Furthermore in relation to this theme, there are also other previous reports which revealed empathetic feelings towards siblings of autistic individuals showing an emotional maturity (Gray, 2009).The constructionist perspective link with this finding for it has it that, different people may define truth in very different ways based on constructions. For instance in this study despite the negative experiences which are faced by siblings of autistic individuals there are also some good personal enrichment traits which they also face.

Leadership skills were also amongst the positive experiences which were voiced out by most of the participants from the study. These findings are similar to the study by (Weafer et al, 2012). Siblings of autistic children often have to mature very early arguably earlier than should be required. Most responses from the siblings showed that they engaged in more chores which mostly involved taking care of their autistic siblings which therefore brought in an improvement in these leadership skills. Whereas this can present a difficulty time for some individuals, in the end it shapes strong adults with tremendous potential for leadership. This finding shows that the siblings to the autistic individuals tend to gain a lot of insight which therefore helped some of them with their careers.

Most participants also mentioned traits which pointed to psychological growth as another positive experience they were encountering. The responses of some of the participants from the findings showed growth in their wellbeing that is emotionally, intellectually and also in terms of their social capabilities.

5.4 Strategies used to cope by the siblings
Most of the participants showed that one of the formal interventions which they used to cope was that of support groups or programs. Similarly to this research finding, another study suggested

that one of the most effective ways of promoting well-being and positive adjustment in siblings of children with autism is to involve them in a support group (O'brien et al, 2009). In the present review most of the participants revealed the need for a support group that can be viewed as an alternative or substitute system of help when there is no other (Mavopoulou & Baloyianni, 2009). The purpose of the support group is to provide an opportunity for the children to share common feelings and experiences, to learn about the disabilities, to practice some problem solving skills and coping strategies which others were using.

This finding, of the use of support groups as a coping technique also highlights the need for designing interventions targeted to develop problem solving and coping skills, so that siblings can effectively handle difficult and challenging situations with their sibling with autism (Thomas et al, 2014). In relation to this study, a previous study explored the effectiveness of support groups for siblings of individuals with autism and this study indicated that siblings deepened their understanding and knowledge about autism thereby improving their experiences (Banach et al, 2011). This coping strategy has a nexus to the eco-systematic perspective which contends that, the dynamic, interdependent and interacting relationships between individuals and groups at different levels of the society. So this therefore shows that the interaction of siblings in the support groups is of great help for they will be interdependence of organisms.

The subjects from the research also noted that the use of therapy as means of their coping as it lessened the experienced stress and resiliency amongst the siblings. In relation to this study, a previous survey of 60 individuals discerned that siblings of individuals with developmental disorders such as autism endorsed increased education and assistance from professionals in understanding autistic challenges. Results indicated that these individuals believed that education resulted in providing more effective and willing care for their autistic siblings (Hatfield et al, 2015). In contrast to the findings of this research, a study investigating the impact of applied behavioral analysis found little significant changes across several areas of investigation. Instead social support groups were demonstrated to evidence the largest impact on the quality of sibling relationship thereby being means of coping (Cebula, 2015). This finding links with the eco-systematic perspective for it has it that the interdepence of organisms to their environment depend on each other for survival that is therefore the dependence on therapy as a coping strategy is highly effective to the sibling relationship.

Most participants also voiced out that another coping strategy that helped in improving their negative experiences was avoiding unnecessary physical and emotional pressure. Siblings of individuals with a disability often become second parents in the areas of care and discipline (Smith et al, 2008). This naturally adds pressure on the sibling's wellbeing. So this mechanism of parents for instance and other family members helping also lessens the burden on the siblings of the autistic individuals.

5.5 Conclusions

In contrast with the tremendous increase in the prevalence of autism and the amount of research conducted on this topic, little is known about the experiences of siblings and of more importance, little support is currently available to these siblings. Having a sibling with a disability is not easy as there are often family disruptions, perceived inequality and emotional distress (Weiss, 2004). It is important that families ensure a safe and positive environment for one another, were communication is ongoing so that the sibling relationship can thrive in a positive and healthy manner. This study used a qualitative approach to better understand how the sibling relationship can change when one sibling is diagnosed with autism. The sibling relationship is important and is one of the longest lasting relationships one has (Heerwagen, 2013). It is also one relationship that evolves over time. For example during childhood the sibling relationship is often quite close, however, the sibling relationship will change once individuals move away from home (Tozer et al, 2013).

The participants who took part in the study were mature young adults with a positive outlook on their sibling relationship; they also provided great insight into their sibling relationships. Embarrassment, lack of attention that is the feeling of exclusion was mostly raised by participants and other negative aspects that they were facing. Though these experiences can be minimized if siblings and other family members become better informed about the intricacies of autism.

The researcher also noticed the positive experiences that are encountered by the siblings from having an autistic sibling which includes an improvement in their own personal traits, leadership skills, and psychological growth. Which therefore shows that there are also positive aspects from having an autistic sibling which should not be overlooked because of the negative aspects,

instead they should strive so as to improve these positive encounters for them to have more positive sibling relationships.

From being a sibling to an autistic individual is quite a big role on siblings for most of them have to partake in caregiving roles from a tender age. So for one to cope it was concluded from the findings of this study that the use of awareness of autism in support groups, therapy sessions and reduce the pressure on the siblings are all coping mechanisms that can be useful. A better understanding of the condition and the challenges that accompany it might have several positive outcomes. For a better sibling relationship with more positive experiences there coping strategies have proved to be helpful in helping the siblings.

5.6 Recommendations

- Having noticed that there both positive and negative experiences that are faced by siblings of autistic individuals it has been recommended that the government and the healthy institutions to make sure that there is an increase on the number of support groups and programs. In terms of formal interventions, one of the most effective ways of promoting well-being and positive adjustment in siblings of individuals with autism is to involve them in support groups (O'Brien et al, 2009). These help the siblings to learn more about their sibling's condition and discuss issues of personal concern and also that they express their feelings and experience peer support.

- Another long term goal of the researcher that evolved from this research is to identify therapeutic programs and family interventions that can encourage positive relationship experiences between the siblings and their autistic siblings. It is important to shed light on the experiences and create potential interventions that could optimize the strengths of the sibling relationship and positive outcomes for this population. Gaining a deeper understanding of the sibling relationship may have implications for therapeutic practice, as well as for education and research involving families with a child diagnosed with autism.

Recommendations for future studies:

- The experience of having a brother or sister with autism when living in a single-parent family, or a family with some degree of marital stress.

- Exploring the experiences of siblings of individuals with autistic challenges who have not received any form of intervention.
- A similar study which could be focused on a larger group of siblings.
- Explore the impact of socio- economic and cultural differences on siblings of autistic individuals.

5.7 Limitations

Coolican (2009) defined limitations as shortcomings of the research or challenges faced by researchers during their research. The topic or area of study was sensitive and some of the participants took it as their privacy which led them to be unable to disclose all or some of the information. The researcher therefore shed more light on the ethical issues of the research which also includes the importance of keeping the information they give out confidential. More so, the findings from the study were limited to a sample size chosen which could not perfectly provide true and accurate information about all of the experiences of individuals and their autistic siblings. Also the participants were not readily available so the researcher had to first find out where they were so as to interview them which was time consuming.

5.8 Chapter Summary

This chapter focused on the discussion of research findings, comparing them with previous studies from the literature review to see if there are similar which shows consistence and congruence of the study or if there are unique. Also the findings were also linked to the theories which guided this study that is the constructionist and the eco-systematic perspectives. Then went on to conclude the research findings and then offered recommendations so as to lessen the research problem and for future studies.

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APPENDICES

APPENDIX A- INTERVIEW GUIDE

TARGET POPULATION: INDIVIDUALS WHO HAVE SIBLINGS WITH AUTISTIC CHALLENGES.

My name is Ashley Mufambisi, and I am a student from the department of Psychology at Midlands State University studying for a Bachelor of Science Honours Degree in Psychology. I am carrying out a study on, *"The experiences faced by individuals who have siblings with autistic challenges at Pathways Autism Trust"*. I am kindly asking you to assist me in carrying out my research by taking a few minutes of your time to respond to the following questions as frankly as you can. Your responses will be treated as highly confidential as they will be used solely for educational purposes and full respondent anonymity is granted. I deeply appreciate your co-operation and support.

Date of Interview………………………………

SECTION A: DEMOGRAPHIC DATA

1. Age of participant

2.16-18 ☐ **19-21** ☐ **22-24** ☐ **25-27** ☐ **28-30** ☐ **Other** ☐

3. Gender: Male ☐ **Female** ☐

4. Marital status of participant: Married ☐ **Single** ☐ **Other (Specify)** ☐

5. Race: African ☐ **Caucasian (European Descent)** ☐ **Other (Specify)** ☐

6. **Birth Order:** The participant in the study is number ☐ of ☐ children.

7. Pseudonym ……………………………………..

SECTION B: CHALLENGES FACED BY INDIVIDUALS WHO HAVE AUTISTIC SIBLINGS.

1. How does having an autistic sibling impact your life negatively?

………

………

2. What factors trigger these negative experiences?

………

………

3. How do these negative experiences affect your social life?

………

………

4. Who causes most of the negative experiences between the autistic and non-autistic sibling and why?

………

………

SECTION C: POSITIVE EXPERIENCES OF HAVING AN AUTISTIC SIBLING.

1. How does having an autistic sibling impact your life positively?

………

………

2. Who contributes more for these positive experiences to occur?

………

………...

3. What are the psychological growth experiences of having an autistic sibling?

………

………

4. In what ways do you see your sibling's condition improving from these positive experiences?

………

………...

SECTION D: STRATEGIES USED TO COPE BY THE SIBLINGS

1. What are the coping strategies that you use as a sibling of an autistic individual?

…………………………………………………………………………………………………

…………………………………………………………………………………………………

2. How do these strategies work for you personally?

   …………………………………………………………………………………………………

   ………………………………………………………………………………………………...

3. How do you see these coping strategies improving your experiences with your autistic sibling?

   …………………………………………………………………………………………………

   …………………………………………………………………………………………………

4. How do these coping strategies affect your social life?

   …………………………………………………………………………………………………

   …………………………………………………………………………………………………

5. What support would you need for these strategies to work more efficiently?

   …………………………………………………………………………………………………

   …………………………………………………………………………………………………

6. How do you think these negative experiences can be lessened?

   …………………………………………………………………………………………………

   ………………………………………………………………………………………………...

7. What would you recommend to other siblings with a similar experience?

   …………………………………………………………………………………………………

   ……………………………………………………………………………………………......

8. How would you encourage others with a similar situation to have positive experiences with their autistic siblings?

   …………………………………………………………………………………………………

   ………………………………………………………………………………………………...

N.B: This marks the end of my research; I would like to thank you for your co-operation and devoting your time to take part on my research.

APPENDIX B- STAMPED LETTER FROM MSU AND ORGANISATION

Midlands State University

Established 2000

P BAG 9055
GWERU

Telephone: (263) 54 260404 ext 2156
Fax: (263) 54 260233/260311

FACULTY OF SOCIAL SCIENCES
DEPARTMENT OF PSYCHOLOGY

Date: 10 /11/ 17

To whom it may concern

Dear Sir/Madam

RE: REQUEST FOR ASSISTANCE WITH DISSERTATION INFORMATION
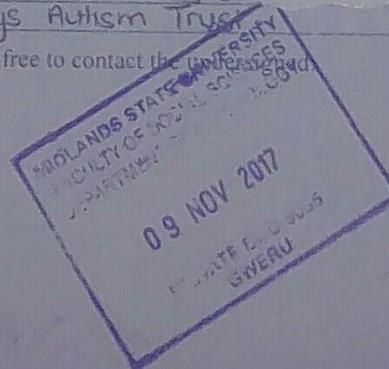FOR ASHLEY MUFAMBISI

BACHELOR OF PSYCHOLOGY HONOURS DEGREE

This letter serves to introduce to you the above-named student, who is studying for a Psychology Honours Degree and is in his/her 4th year. All Midlands State University students are required to do research in their 4th year of study. We therefore, kindly request your organisation to assist him/her with any information that she/he requires.

Topic: Experiences of individuals who are siblings to individuals who have autistic challenges. A case study of Pathways Autism Trust

For more information regarding the above, feel free to contact the undersigned

Yours faithfully

N. Ncube
A/Chairperson

APPENDIX C- AUDIT SHEET

Research Project

Supervisor-student audit sheet   **ASHLEY MUFAMBISI: R144516E**

DATE	ACTIVITY	COMMENT	SUPERVISOR'S SIGNATURE	STUDENT'S SIGNATURE
21/08/17	Topic discussion	Proceed		
06/09/17	Proposal submission	-		
12/09/17	Proposal discussion	Proceed		
05/10/17	Chapter 1-3 submission	-		
18/10/17	Chapter 1-3 discussion	Corrections and proceed		
22/10/17	Research instrument submission	-		
06/11/17	Research instrument discussion	Proceed		
12/03/18	Chapter 1-4 submission	-		
22/03/18	Chapter 1-4 discussion	Corrections		
30/03/18	Chapter 1-4	Proceed		
03/04/18	Chapter 1-5 submission	-		
09/04/18	Chapter 1-5 discussion	Corrections and proceed		
16/04/18	First draft submission	-		
17/04/18	First Draft discussion	Corrections and proceed		
23/04/18	Final Draft submission			

Supervisor's signature……………………………   Date………………………………….

APPENDIX D- TURNITIN SUMMARY REPORT

APPENDIX E- MARKING GUIDE

Name of student: Ashley Mufambisi   REG No: R144516E

	ITEM	Possible Score	Actual	Comment
A	RESEARCH TOPIC AND ABSTRACT clear and concise	5		
B	PRELIMINARY PAGES: Title page, approval form, release form, dedication, acknowledgements, appendices, table of contents.	5		
C	AUDIT SHEET PROGRESSION	5		
D	CHAPTER 1 Background, statement of problem, significance of the study, research questions, objectives, hypothesis, assumptions, purpose of the study, delimitations, limitations, definition of terms	10		
E	CHAPTER 2 Addresses major issues and concepts of the study. Findings from previous work, relevancy of the literature to the study, identifies knowledge gap, subtopics	15		
F	CHAPTER 3 Appropriateness of design, target population, population sample, research tools, data collection, procedure, presentation and analysis	15		
G	CHAPTER 4 Findings presented in a logical manner, tabular data properly summarized and not repeated in the text	15		

H	CHAPTER 5 Discussion (10)Must be a presentation of generalizations shown by results: how results and interpretations agree with existing and published literature, relates theory to practical, implications, conclusions (5)Ability to use findings to draw conclusions Recommendations (5)	20		
I	Overall presentation of dissertation	5		
J	References	5		
K	TOTAL	100		

Marker………………………….Signature ………………………………… Date……………

Moderator………………………..Signature………………………………… Date…………...