



**UNIVERSITY OF KWAZULU-NATAL**

**THE EXPERIENCES OF FAMILY CAREGIVERS OF CHILDREN LIVING  
WITH AUTISM SPECTRUM DISORDER**

**BY**

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Psychology Master's degree in the School of Applied Human Sciences.**

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## DECLARATION

I hereby declare that this research report is my own work. Wherever contributions of others are involved, every effort has been made to indicate this clearly, with due reference to the literature. This research report has not been submitted before for any other degree, part of degree, or examination, at this, or any other university.



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## ABSTRACT

A limited number of studies have explored and documented the daily challenges faced by the caregivers of children with autism spectrum disorder in Durban, Kwazulu-Natal, South Africa. The literature on the challenges of raising a child with autism spectrum disorder is mostly reported in northern American and European countries (Boyd, 2002). South Africa has little awareness of the ramifications associated with raising a child with this neuro-developmental disorder, irrespective of it being recognized as highly prevalent in South Africa (Stephens, 2012). The aim of this study was to document what family caregivers face in raising a child with autism spectrum disorder in Durban, South Africa. A qualitative approach was adopted by the researcher in order to gain insight into the experiences of family caregivers of children with autism spectrum disorder. Interviews were conducted with seven biological mothers (and according to race: five black, one white and one coloured) of children with autism spectrum disorder. Interviews were grouped using thematic analysis and the themes which were discovered included: (1) perceived daily challenging behaviour, (2) discipline and its effect on caregiving, (3) life style changes, (4) financial burden, (5) communication difficulties and caregiving, (6) emotional burden, and (7) support system. The results have suggested that family caregivers of children with autism spectrum disorder experience different degrees of stress, which stem either from difficulties in finding schools or not understanding what their child needs. They, however, showed some levels of optimism about their circumstances. The findings also emphasized on where family caregivers themselves believe they need additional support. Some family caregivers raised key coping strategies they found helpful in dealing with daily challenges.

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## **LIST OF TERMS**

**ASD:** Autism spectrum disorder

**SPM:** Stress process model

### **Primary Caregiver**

This term is used to refer to family members who are responsible for caring for a child with ASD, which include mothers, fathers, guardians and grandparents. However, only biological mothers of children with ASD formed part of the final sample.

### **Typically growing child**

This term is used to refer to a human being between the ages of infancy and puberty, or otherwise known as a person younger than the age of majority, who is developing within the boundaries of a norm, according to a particular society. This term is generally used when comparing a child with ASD with a child considered “normal”.

# CHAPTER ONE

## 1.1 Introduction

A universal concern about the prevalence of autism spectrum disorder (ASD), which is a collection of neuro-developmental disorders characterized by abnormalities in social interaction, impaired nonverbal and verbal communication, and restricted or repetitive patterns of interest and actions (American Psychiatric Association, 2013), has increased intensely over the past decade. Internationally, the prevalence of ASD is around 1%, placing it amongst common developmental disorders (Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum, & Charman, 2006; Fombonne, 2009; LoVullo & Matson, 2009; Schendel, Diguseppi, Croen, Fallin, Reed, Schieve, Wiggins, Daniels, Grether, Levy et al., 2012).

ASD has significant challenges both in terms of characterizing individuals with ASD, as well as identifying it accurately (Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). The accurate identification and management of the disorder are complicated by the complex process of diagnosing and finding evidenced-based individualized interventions for ASD. A research paper by Yates and Le-Couteur (2009) found a key diagnostic dilemma for ASD to be the absence of pathognomonic features; this means that ASD has no single particular feature or symptom whose presence or absence confirms or denies it. Impairment varies significantly across the spectrum, in terms of its nature and its severity, resulting in the complexity of the clinical picture. The clinical picture could also be complicated by comorbid disorders such as epilepsy, Attention Deficit Hyperactivity Disorder (ADHD), and Intellectual Disability (ID).

The amount of support an individual with ASD may need would also vary across the spectrum, depending on the presence of a comorbid disorder and the severity of the ASD (Knapp, Romeo, & Beecham, 2009). A number of interventions target specific features, such as the integration of senses, behaviour modification, anxiety, social skills and speech and language (Lord & Bishop, 2010).

Physicians mostly prescribe medication targeting symptoms of anxiety, externalizing problems as well as attention difficulties (Logan, Nicholas, Carpenter, King, Garrett-Mayer, & Charles, 2012; Memari, Ziaee, Beygi, Moshayedi, & Mirfazeli, 2012). It is no surprise then that Rahbar, Samms-Vaughan, Loveland, Pearson, Bressler, Chen, Ardjomand-Hessabi, Shakespear-Pellington, Grove, Beecher, Bloom and Boerwinkle (2012) found that ASD comes with a substantial and lifelong burden of cost, for both the government and the family.

A large body of research on the challenges of nurturing a child with autism is reported from European and North American countries (Boyd, 2002), and it has been discovered that some family caregivers have come to terms with the fact that they are living with a child who has been diagnosed with an enduring neurodevelopmental disorder (Gona, Newton, Rimba, Mapenzi, Kihara, Vijver, & Abubakar, 2016). However, these caregivers are still faced with a series of challenges irrespective of their acceptance of the diagnosed neurodevelopmental disorder (Gona, Newton, Rimba, Mapenzi, Kihara, Van de Vijver, & Abubakar, 2015). These challenges include the burden of caring, poor prognosis, stigma, financial burden, misconception of autism spectrum disorder, and low social support (Kim, Chang, Rose, & Kim, 2011).

Xiang and Carrie (2010) have stressed the impact that children with autism spectrum disorder have on their family caregivers, notably the level of stress that caregivers endure, as well

as the impact this has on their emotional wellbeing. This study aimed to explore and describe the experiences of family caregivers of children living with ASD, in Durban, KwaZulu-Natal.

ASD has been recognised as a highly prevalent disorder in South Africa (Stephens, 2012). This could be as a result of its broad criteria and the perceived occurrence in all classes, races, ethnic groups, and throughout the world (Sotgiu, Manzano, Gandione, Gomez, Romero, & Ridardetto, 2011). Autism spectrum disorder (ASD) is a complex, enduring neurodevelopmental disorder, marked by impairments in several areas of functioning, a persistent deficit in social communication and social interaction in several contexts, as well as repetitive patterns in behaviour, interests or activities (American Psychiatric Association, 2013). Family caregivers of children presenting with these symptoms experience difficulties accessing health care services (Brown, Uuellette-Kuntz, & Hunter, 2011).

## **1.2 Rationale**

The topic under discussion is of significant importance in the South African context. Firstly, it assists policy developers regarding several difficulties that family caregivers of children with autism experience. Caring for children with ASD is associated with a relatively high incidence of caregiver stress and depression, which adversely causes distress in family functionality and marital relations (Al-Towairqi, Alosaimi, Al-Zaidi, Helmy, & Al-Sherif, 2015). Secondly, the study brings about awareness of the ramifications associated with being a primary caregiver to a child living with this lifelong disorder. Al-Towairqi et al. (2015) confirmed that caregivers of children with ASD are more susceptible to depressive and related disorders than caregivers of children with Intellectual Disability without ASD. Al-Towairqi et al. (2015) further stated that even though there are many possible causes of depression, the main causative factor for caregivers

of children living with autism spectrum disorder appears to be related to the absence of a likelihood of remission of behaviours centred on it, leading to the misunderstanding in the community about the nature of this disorder.

### **1.3 Aim**

This study aimed to document events and encounters that family caregivers face in raising children living with autism spectrum disorder in Durban, KwaZulu-Natal.

### **1.4 Objectives**

The objectives of this study are:

- To understand the day-to-day experiences of family caregivers of children living with autism spectrum disorder.
- To document the available support for family caregivers of children living with autism spectrum disorder.
- To document the burden of care on family caregivers of people living with autism spectrum disorder.
- To document strategies that family caregivers employ in dealing with challenges that arise as a result of caring for children with autism spectrum disorder.
- To determine the demographic characteristics of family caregivers that are either highly, or least affected, by the stigma emanating from caring for children living with autism spectrum disorder.

## **1.5 Research Questions**

The study's research questions are:

- What are the day-to-day experiences of family caregivers of children living with autism spectrum disorder?
- What support is there for family caregivers of children living with autism spectrum disorder?
- What is the extent of the burden of care family caregivers of children living with autism spectrum disorder experience?
- What strategies do family caregivers employ in dealing with challenges that arise as a result of caring for children living with autism spectrum disorder?
- What are the demographic characteristics of family caregivers least affected, or highly affected, by the stigma emanating from caring for children living with autism spectrum disorder?

## **1.6 Ethical Consideration**

The researcher obtained ethical clearance from the University of KwaZulu-Natal before embarking on this research study. A gatekeeper's clearance letter was obtained from the chairperson of the Action in Autism organization.

Furthermore, the researcher was aware of the ethical principle of non-maleficence, which means to 'do no harm' (Allan, 2008; Allan, 2015). Therefore, certain ethical rules were followed. All participants were asked to give informed consent prior to participating in the study. This means



that each and every participant had to be duly informed about the study and also be protected (Allan, 2008; Allan, 2015). The researcher had to be versatile and culturally sensitive.

After the researcher had explained what the study entailed, a written consent form was made available for participants to sign and permission to record was obtained. Confidentiality and acknowledgment of participants' privacy were attended to.

## **1.7 Dissertation Layout**

The overall structure of this dissertation takes the form of six chapters.

**CHAPTER ONE:** Is the introductory section of the study, where the aim and objectives of the study are expounded upon.

**CHAPTER TWO:** The second chapter presents relevant and available body of knowledge regarding ASD, beginning with an overview of ASD.

**CHAPTER THREE:** This chapter discusses the methodology employed in this study, as well as the research design. This is followed by a detailed description of the process of recruiting the sample, along with the process of data collection. The chapter further explains the steps taken to analyse the data collected. Moreover, it explores ethical consideration relevant throughout this dissertation.

**CHAPTER FOUR:** The data collected are presented in this chapter and overarching themes are highlighted.

**CHAPTER FIVE:** The outcomes of the study are deliberated extensively in this chapter, discussing the important findings of the study.

**CHAPTER SIX:** Concluding remarks of the study are discussed in this chapter, as well as the implications of the study. In this chapter, the shortfalls of the study are further explored.

**REFERENCES:** The study's references will be listed in this chapter. The guide to APA referencing styles sixth edition is utilised.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

The previous chapter provided a synopsis, the rationale, aim, and motivation of this study. This chapter discusses the previous body of knowledge regarding the conception and understanding of autism spectrum disorder, as well as the challenges faced by those who care for individuals diagnosed with ASD.

### **2.2 Definition and Diagnosis of Autism Spectrum Disorder**

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder (Sadock, Sadock, & Ruiz, 2015) that was previously referred to as pervasive developmental disorder in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV). Currently, ASD is classified in the group of neurodevelopmental disorders in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). Autism spectrum disorder is conceptualized as a group of neurodevelopmental disorders. This group consists of five discrete disorders, namely: Autistic disorder, Asperger's disorder, childhood disintegrative disorder, Rett syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS) (Sadock et al., 2015).

The three most common forms of autism, which are mostly diagnosed in the pre-2013 classification system, are autistic disorder or classic autism, Asperger's syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS). These three disorders, as Smith and Hutman (2018) pointed out, share certain symptoms but differ with respect to severity on the

individual. Classic autism is the most severe of the three. The other two, namely Asperger's Syndrome, also known as high-functioning autism, and PDD\_NOS, or Atypical autism, are noted to be less severe. Some researchers have considered the Childhood Disintegrative Disorder and Rett syndrome as not truly belonging to the autism spectrum because both are extremely rare genetic diseases (Smith & Hutman, 2018). In large part, owing to inconsistencies and misdiagnosis, these disorders are grouped together to form a spectrum as they share a similar pattern of presenting symptoms marked by a persistent deficit in social communication and interaction.

As mentioned by Sadock et al. (2015), the behaviours of children with autism spectrum disorder may be characterised by nonconformity to expected norms of social reciprocity and natural non-verbal interplay. That single label moves the focus away from where a child falls in the spectrum to whether a child has autism, or not. Researchers stress that infants with autism spectrum disorder may not develop a social smile and that toddlers may lack the posture that sends a message that the child anticipates being picked up by a family caregiver (APA, 2013).

Moreover, children with ASD have restricted repetitive patterns of behaviours, interests, and activities (APA, 2013). In children presenting with ASD, the first year of exploratory play is restricted and muted. Communication deficit is evident in the early years of life. This deficit is pervasive in social communication and social interaction across multiple contexts (Leekam, Carrington, Kent, Gould, Wing, Maljaars, & Le-Couteur, 2014). A child with ASD exhibits an unusual social approach, as well as a failure to initiate or respond in social interactions (APA, 2013). Hence, communication is always one-sided; the child does not seek out comfort when in pain and, at times, may show limited, or absent, sharing of interests. A child with ASD may also exhibit poorly integrated verbal and non-verbal communication, for example, poor eye contact

when talking or using the caregiver as a mechanical aid (using the caregiver's hand as a tool to indicate the desired object rather than vocalizing) (Leekam et al., 2014). The symptoms are discussed according to the DSM-5, as shown in table 1.

**Table 1. DSM V Diagnostic Criteria for ASD**

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***Autism Spectrum Disorder Diagnostic Criteria 299.00 (F84.0)***

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***A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):***

- 1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.***
- 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.***
- 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to an absence of interest in peers.***

***Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.***

***B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):***

- 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).***
- 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat the same food every day).***
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).***
- 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).***

***Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.***

***C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).***

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*D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.*

*E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.*

**Note:** *Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder.*

*Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for a social (pragmatic) communication disorder.*

*Specify if:*

***With or without accompanying intellectual impairment***

***With or without accompanying language impairment***

***Associated with a known medical or genetic condition or environmental factor*** (Coding note: Use additional code to identify the associated medical or genetic condition.)

***Associated with another neurodevelopmental, mental, or behavioral disorder*** (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

***With catatonia*** (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)”

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*Note:* Adapted from “Neurodevelopmental Disorders” by American Psychiatric Association, *diagnostic and statistical manual of mental disorders* (5<sup>th</sup> Ed, p.50-51), 2013, Washington, DC. Copy right 2013 American Psychiatric Association.

Children with ASD also present with restricted, repetitive, stereotypical motor movements and a limited pool of interests (APA, 2013). They repetitively use the same objects, insisting on sameness in routines; they may also make use of idiosyncratic phrases and stereotyped speech. For example, they may line up toys when playing, make rocking movements or act out a role of an object or caregiver repetitively. Objects are often manipulated in a ritualistic manner rather than being used in a typical way (Sadock et al., 2015).

According to Ghanizadeh, Alishahi, and Ashkani (2009), children with ASD also exhibit sleep difficulties, most notably insomnia. Consequently, caregivers suffer greatly, more than those of typically developing children because of this sleep deficit. Caregivers’ sleep quality and

quantity are significantly lower than those of caregivers of children without autism spectrum disorder (Johnson & Malow, 2008).

Another notable symptom indicated by Lockner, Crowe, and Skipper (2008) is feeding difficulty; gastrointestinal disturbances are more common in children with ASD. A child with ASD may be a picky eater and also resist trying new foods since inflexibility is one of the major difficulties inherent in ASD. Sensory problems, such as taste, smell, visual and auditory processing, are essential symptoms (Ghanizadeh & Hyman, 2009; Ganizadeh et al., 2009; Rogers, Heburn, & Wehner, 2003). Oftentimes, these sensory impairments go undetected by clinicians but they are reported by caregivers.

These core symptoms make it hard for caregivers from disadvantaged communities to seek intervention (Tseng, 2005). The burden of care associated with having a child ASD is not only limited to interventions and dealing with comorbid conditions; caregivers face greater outlays of time and money (Sharpe & Baker, 2007).

### **2.3 ASD Comorbidity**

Matson and Nebel-Schwalm (2007) described the term comorbidity as the co-occurrence of two or more disorders in the same individual. The major difficulty in people with ASD is the high predicted rate of comorbid disorders. About 70% of people with ASD are likely to have one comorbid disorder, whereas about 40% are predicted to have two or more comorbid mental disorders (APA, 2013). Medical conditions, such as Cerebral palsy, Avoidant-restrictive food Intake Disorder or Epilepsy, are expected to co-occur in individuals with ASD (APA, 2013).

Matson and Goldin (2014) have found a high incidence of Intellectual Disability in individuals with ASD. Individuals with ASD who present with comorbid severe Intellectual Disability were found to present with stereotypical body movements, and speech and communication deficits. They further stressed the importance of continued development to broaden the expertise in the identification of ASD, as well as the ability to distinguish it from other mental disorders.

*ASD and Sleep Disorders* - children who are diagnosed with ASD are found to be more likely to have difficulties with sleep compared to children without neuro-developmental disorders. Researchers found that children with ASD have a shorter sleep duration in a 24-hour cycle (Mannix, 2016; Scott, Blair, Emond, Fleming, Humphreys, Henderson, & Gringras, 2013). Without enough sleep, a child's overall health is affected and this may in turn affect their behaviour. For example, a child might become hyperactive or show signs of aggression (Sikora, Johnson, Clemons, & Katz, 2012). Leitner (2014) reported that the prevalence of Attention Deficit Hyperactivity Disorder in children diagnosed with ASD is between 30%-50%.

## **2.4 Etiology of ASD**

ASD is one of the more complicated disorders and understanding the overall mechanisms that underlie this disorder becomes a thought-provoking exciting task for clinicians and researchers. A breakthrough and clear understanding of the main cause of ASD may lead to new horizons for interventions, such as prevention measures and management (Joshi, Percy, & Brown, 2002).



### **2.4.1 Genetic etiology**

It stills remains a mystery as to whether the real incidences of ASD have been augmented. Frith and Happé (2005) argued that if it has really increased it could have significant outcomes in understanding the cause of ASD. They further pointed out that ASD is among the most heritable of neurodevelopmental disorders. A number of family and twin studies have indicated that hereditary factors play a crucial role in autism spectrum disorder. These studies show a concordance in 60%-90% of identical twins compared to fraternal twins (Bailey, Palferman, Heavey, & Le Couteur, 1998; Le Couteur, Bailey, Goode, Pickles, Robertson, Gottesman, & Rutter, 1996).

This is supported by Colvert et al. (2015), who also reported that the concordance for ASD in monozygotic twin pairs is typically at least twice that of dizygotic twin pairs, resulting in high estimates of heritability (60%-90%). They also noted a loophole regarding genetic studies in ASD which included a lack of consistency in the diagnosis processes. Evidence suggests that ASD may not necessarily result from one gene abnormality but may result from abnormalities in two or more genetic loci interacting with the environment (Risch, et al., 1999).

A research paper by Dhillon, Hellings, and Butler (2011) reviewed a body of knowledge on chromosome abnormalities in individuals with autism. They found that the abnormalities were also implicated in sex chromosomes. A study conducted by Shao et al. (2003) indicated that there is a particular interest in genes possibly related to autism which lie on chromosome sets 2, 3, 7, 15 and X. The HOX family of genes is a subset of homeotic genes that control the body plan of an embryo. The HOX protein determines the type of vertebrate that will form on a particular segment after the embryo have formed and it is also responsible for turning on and off a number of genes

during the embryogenesis. This protein has also been implicated amongst the causes of autism (Li et al., 2002).

About 40% of individuals diagnosed with autism were noted to carry a muted HOXA1 on chromosome 7; this resulted in great interest but the studies which followed failed to prove this discovery (for example see, Ingram, Stodgell, Hyman, Figlewicz, Weitkamp, & Rodier, 2000; Li et al., 2002). Li et al. (2002) argued that this may be due to the fact that the sample was not drawn using the same guidelines, tools and/or criteria.

#### **2.4.2 Immune system deficiency**

Joshi, Percy, and Brown (2002) noted that a number of individuals with autism suffer from, inter alia, a deficiency of myeloperoxidase, IgA deficiency (an antibody that shields against infections of the mucous membrane lining of the mouth, digestive tract and airways) and impaired antibody production. These deficiencies may cause an inability to fight off virus infections for individuals with autism (Croonenberghs, Bosmans, Deboutte, Kenis, & Maes, 2002)

*Measles Mumps Rubella (MMR)* - There has been much research done surrounding the old and traditional practice of vaccinating infants with the measles-mumps-rubella (MMR) vaccine. Yet, concerns that this vaccine may cause autism were noted, irrespective of the benefits these vaccines may have worldwide in preventing child mortality and serious childhood diseases (Joshi, Perci & Brown, 2002). The Immunization Safety Review Committee (2001) compiled a report after reviewing a number of published and unpublished epidemiological studies and concluded that there is no evidence that supports a causal relationship between autism and the MMR vaccine. This is consistent with the study conducted a study by Farrington, Miller, and

Taylor (2001), which rejected the hypothesis that there is a causal relationship between MMR or measles-containing vaccines and autism. A clear cause of ASD continues to be a mystery researchers, irrespective of a number of hypotheses about the causes of ASD.

### **2.4.3 Environmental contributors – ASD**

Stress and environmental exposures are believed to have an impact on the development of the brain and its processes, development of organs and physiological processes (Herbert, 2010). A research paper by Rutgers, Van Ijzendoorn, Bakermans-Kranenburg, Swinkels, Van Daalen, Dietz, and van Engeland (2007) conceptualized the etiology of ASD from an attachment perspective paying particular attention to the affectionate bond that an infant with ASD develops with their attachment figure or significant other during infancy. Children with a more defined form of ASD were less securely attached and experienced to be less responsive in their relationship with their caregiver. This indicates that children with ASD are less securely attached to their caregivers, compared to typically growing children. This is believed to be as a result of an impaired reciprocal social ability (Maino, Viola, & Donati, 2009). These attachment differences between children without and with ASD were observed to disappear when the children were diagnosed with less complicated forms of ASD or when the child was diagnosed with higher functioning form of ASD (Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004).

Caregivers of more securely attached individuals were perceived to experience fewer daily difficulties and fewer psychological problems. It is noteworthy to mention that studies on attachment and ASD have mainly been conducted with pre-schoolers. During the preschool years (ages 3-5) many symptoms of ASD become apparent and easier to diagnose (Rogers, 2001)

A large body of literature attributed the pathogenesis of ASD to the gene-environmental interaction (Dietert & Dietert, 2008; Kinney, Munir, Crowley, & Miller, 2008; O'Donnell, O'Connor, & Glover, 2009). However, there are no definitive mechanisms explaining how environmental triggers can lead to ASD. A research paper by Theoharides, Doyle, Francis, Conti, and Kalogeromitros (2008) argued that substances originating from the brain and the gut can potentially trigger mast cells (a cell found in a number of connective tissues which releases histamine during an allergic reaction) to release mediators which could disrupt the gut-barrier and Blood Brain Barrier (BBB), thus contributing to the pathogenesis of ASD. This is in line with what Herbert (2010) argued regarding the disturbance of the BBB and gut barrier in causing deficits of the immune system in individuals with ASD.

Herbert (2010) further argued that diet should be considered as an environmental contributor to ASD. This was noted because of concerns raised about a reduction of omega 3 acids in lipid intake over the years and the potential risk of this deficiency on gastrointestinal disturbances of ASD cases. Bent, Bertoglio, and Hendren (2009) argued that this deficiency may give life to abnormal fatty acids that affect neural processing. The multifaceted nature of the etiology of ASD raises questions about the preferred and evidence-based treatment.

## **2.5 ASD Treatment Approaches**

In the last two decades, the incidences of ASD have increased and there is a critical need for effective evidence-based early interventions for individuals diagnosed with ASD and their families (Brentani, Bordini, Rolim, Sato, Portolese, & McCracken, 2013). However, literature has indicated that finding an effective intervention is challenging in the field of autism spectrum disorder (Joshi et al., 2002). The choice of treatment and adherence is mainly guided by parental

causal beliefs. For example, parents who hold strong beliefs on brain chemistry and genetic makeup as the cause of ASD are more likely to lean towards the medical route (Dardennes, Al Anbar, Prado-Netto, Kaye, Contejean, & Al Anbar, 2011). Black parents whose children are diagnosed with neurodevelopmental disorders commonly seek traditional medicine before exploring any Western alternative.

Decades ago, ASD was conceptualized and documented as a disorder that occurs mainly in developed countries with advanced technology (Ruparelia, Abubakar, Badoe, Bakare, Visser Chugani, & Skuse, 2016). However, this was not the case as incidences of ASD were also observed in developing countries. Ruparelia et al. (2016) argued that the use of technology in developed countries allowed for early detection and intervention of ASD and this could have created a perception that ASD mainly occurred in developed countries.

Once the child has been diagnosed, caregivers face the most challenging experience of adhering to the treatment plan. Caregivers of children with ASD are tasked to manage multiple treatment plans and therapies with different specialists. The array of treatment plans may range from diet plans, behavioural interventions, school-based interventions and pharmacological interventions (Mackintosh, Goin-Kochel, & Myers, 2012).

Adhering to the treatment plan, which may include specialised care, and transport to and from where a service is being offered, may prove costly for most caregivers. The preferred form of treatment may not be community-based, making access difficult or almost impossible (Mackintosh et al., 2012).

Individuals with ASD are not homogenous and hence treatment tends to be individualised. Thus, caregivers are exposed to multiple interventions in order to find one that works for the child. Early intervention and adherence on the part of the caregiver is hypothesised to yield improvement

on the child's behavioural and social skills, which includes language (Mackintosh et al., 2012). Currently, there is no cure for ASD; pharmacological interventions and behavioural therapies are the preferred form of intervention.

### **2.5.1 Behavioural therapies**

It is important to consider the context of a developing child for the effectiveness of any intervention, as research shows that behaviour is affected by numerous factors in an environment (Joshi et al., 2002). Applied Behavior Analysis (ABA) is a widely used behavioural technique in cases of ASD. ABA is considered a process of making use of behavioural principles in order to change targeted behaviours and at the same time evaluating the efficacy of the intervention (Lindgren & Doobay, 2011). Researchers and clinicians who use ABA pay attention to social skills and the environment, including the precursor of the behaviour and the consequences that attain and maintain behaviour.

The efficacy of ABA on ASD cases has been documented and literature suggests that early initiation of ABA, preferably prior to the age of 5, yields the best outcome (Brentani et al., 2013; Lindgren & Doobay, 2011)). However, there is insufficient evidence about the amount of ABA required for optimal results, as the only number of hours recommended range from 15-40 hours per week.

Lindgren and Doobay (2011) argued that providing sufficient training for family caregivers of children with ASD to enable them to provide ABA programmes in communities and at home is a crucial part of most ABA programmes. Training of as little as one hour per week is seen as crucial in eradicating undesired behaviour and building social communication in children with

ASD. The impact this therapeutic modality has on the family varies depending on the family's reception and enthusiasm.

There are a number of team players in this form of intervention, namely specialist doctors, occupational therapists, teachers and psychologists. Krynauw (2016) argued that such intensity could be overwhelming and potentially lead to high levels of stress on the part of the caregiver.

### **2.5.2 Pharmacological intervention**

Pharmaceuticals are considered as being widely used as an adjunctive intervention on individuals diagnosed with ASD (Brentani et al., 2013). The main established goal for pharmacological intervention is to regulate targeted symptoms of ASD such as irritability, impulsivity, anxiety, depression, temper tantrums, stereotyped behaviour, insomnia, and gastrointestinal problems. Pharmacological interventions are often highly recommended due to a high rate of comorbid conditions, which compound the clinical presentation of individuals with ASD, thus limiting the effectiveness or efficacy of non-pharmacological interventions (Brentani et al., 2013). Although pharmacological interventions have received empirical support, Bravaccio, Marino, Scicolone, and Riccio (2013) argued that it may not be the best option for long term treatment, due to side effects related to psychotropic medication, like weight gain.

Irrespective of the varying degrees of empirical support regarding pharmacological interventions, Brentani et al. (2013) posited that it is a common clinical practice for individuals with ASD to be put on psychotropic medication. In terms of frequency, the most commonly prescribed drugs are neuroleptics, anti-epileptics, stimulants, and antidepressants. Brentani et al. (2013) asserted that the problematic behaviours children with ASD exhibit may need a

pharmacological intervention in order for them to be regulated and easily managed by their caregivers.

The behaviours associated with ASD may differ across cultures or a multicultural society like South Africa. Thus, this pathology presents a responsibility to researchers and clinicians nationally to make an accurate diagnosis (Wilford, 2013).

## **2.6 South African Context and the Concept of Autism Spectrum Disorder**

Autism spectrum disorder, in the South African context, was first diagnosed 47 years ago, as pointed out by Venter, Op't Hof, Coetze, Walt, and Rietief (1984), that the first diagnosis was made in 1970. This diagnosis was made almost three decades after the discovery of the disorder by Leo Kanner in 1943. Simelane (2015) argued that not much has been done in South Africa in understanding the challenges that are coupled with caring for a child with autism spectrum disorder.

This deficit includes the shortage of professionals who are well equipped and qualified to make an informed diagnosis, the dearth of schools for children with autism spectrum disorder and insufficient general knowledge in the public concerning the disorder, particularly the challenges associated with it (Dabrowska & Pisula, 2010; Pillay & Lockhat, 2001; Roberts, 2007). Furthermore, there are no readily available statistics on ASD in the South African National autism Statistics. Research conducted by Mubaiwa (2008) argued that the prevalence of this disorder is somewhat similar to that of America and Europe, of 10-20 per 10 000.

Parents of children with autism want the issue of segregation to be addressed (Simelane, 2015). In South Africa, the majority of children with autism spectrum disorder attend segregated



schools which most parents cannot afford. Some of these schools are private and offer an array of treatments from specialists which could be costly for caregivers. Molteno, Molteno, Finchilescu, and Dawes (2001) expounded that there is no transition plan to integrate the segregated schools with mainstream schools. This is consistent with a study by Roberts (2007), which argued that authorities from the Department of Education in South Africa are not supportive of the idea of integration. It further argued that educators in mainstream schools receive limited, to no training, in special education and therefore feel less competent to teach children diagnosed with autism spectrum disorder.

It has been about five decades since the first diagnoses of ASD in South Africa; however, there are no known prevalence studies of ASD, even in sub-Saharan Africa, as a whole (Chambers, Wetherby, Stronach, Njongwe, Kauchali, & Grinker, 2017). This is believed to be due to a lack of standardised diagnostic tools for African populations and South Africa in particular. The development and implementation of accessible services depend largely on valid and reliable diagnostic tools for ASD in South Africa (Chambers et al., 2017). This could assist in understanding the genesis of ASD symptoms and its phenotype in the South African context.

Social interaction plays a crucial role in the conception of ASD symptoms and black South Africans' interactional style has raised a number of questions regarding its impact on the clinical presentation of ASD symptoms. Anecdotal knowledge asserts that isiZulu speaking individuals' interactional style is based, or shaped, by a hierarchical structure and gender systems of socialisation, whereby the care of a younger child is often in the hands of older siblings. An older sibling plays a crucial role in rearing, as primary caregivers are usually away due to work (Chambers et al., 2017).

Eye contact is a crucial part of interaction, but for IsiZulu speaking individuals, it is perceived as rude to make direct eye contact with adults. Similar conventions of direct eye contact are also seen in other parts of Africa. For example, children in rural Kenya are taught that it is bad mannered to make eye contact with adults in authority (Carter, Lees, Murira, Gona, Neville, & Newton, 2005).

Chambers et al. (2017) argued that it is still unknown whether the cultural styles of early socialisation between children and caregivers in a multicultural context like South Africa may impact the clinical presentation and early detection of ASD. These researchers further argued that these cultural variations put into question the use of the psychometric tools standardised in Europe.

A study conducted by Wilford (2013) on cultural variations in behaviours associated with ASD in the South African context argued that there are significant cultural differences mostly observed with black participants who tended to behave in various verbal and non-verbal gestures. Wilford (2013) further argued that variations across ethnic groups or cultures may account for variations seen in diagnosis. An acceptable form of communication in one culture may not be an acceptable form of communication in another. These forms of communication also affect the experience of caregiving.

## **2.7 Caregivers' Experiences**

### **2.7.1 Nature of caregivers' experiences – ASD**

Primary caregivers of individuals with a mental disorder are affected in many ways. Caregiving comes with a number of challenges, namely, a lack of social relations, stigma, and diminished support. All these factors are associated with the burden of caregiving (Sharpe &

Barker, 2007). Literature also indicates that the caregivers of individuals with autism are prone to a number of mental health issues, such as depression (Stuart & McGrew, 2009). The strain experienced by the caregivers of children with ASD is not only emotional, but also includes behavioural and cognitive components. This is believed to be as a result of the complexity of the clinical presentation of ASD (Ludlow, Skelly, & Rohleder, 2012; Seymour, Wood, Giallo, & Jellet, 2013). This is further supported by Gobrial (2018) who argued that the lived experiences of caregivers raising a child with ASD are complex and extremely challenging in almost all aspects of life.

Gobrial (2008) found that caregivers of children with ASD were also negatively affected, both socially and financially. The consequences of raising a child with ASD could be profound on the caregivers' life. Most children with ASD are not able to express themselves and may also become unhappy when their routines are changed.

The difficulties caregivers experience are sometimes complicated by the comorbid conditions such as Intellectual Disorder and/or Epilepsy (DePape & Lindsay, 2015). It comes as no surprise then that caregivers of children with ASD experience more stress than caregivers of typical children (Sivberg, 2002). Caregivers of children with ASD face multiple challenges in the community (e.g. church or a shopping mall), and at home (e.g. relationship problems or financial strain) (Sharpe & Barker, 2007). This means that they have to go through major lifestyle changes as they have to cut down on perhaps a once luxurious life and also limit their social life. These changes lead caregivers to experience poor mental and physical health (Stuart & McGrew, 2009). Literature also indicates that they tend to have a higher divorce rate (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, & Bolt, 2010).

### ***2.7.1.1 Financial aspect of the burden***

Interventions are an important aspect of the management of autism spectrum disorder. However, they require a lot of financial resources, which some family caregivers do not have. Sharpe and Barker (2007) argued that children with autism spectrum disorder need an intervention by a speech and language therapist in order to be assisted with the expressive and pragmatic language needed for social interplay. Moreover, biochemical interventions may also be needed for the treatment of food allergies and vitamin supplements.

The challenges experienced by primary caregivers do not only include practical aspects of the burden, but also extend to a loss of income and leisure time (Beecham, Knapp, & Romeo, 2007). Ghanizadeh et al. (2009) indicated that a high number of families of children with ASD usually have a lower level of income. Consequently, they often need additional income to cover the costs of their children's medical care. This is ironic since, according to Sharpe and Barker (2007), even those caregivers who enjoy steady employment are forced to reduce working hours in order to meet the needs of children with autism spectrum disorder. Sharpe and Barker (2007) further stated that those who are not working find it hard to get employment due to the challenges they face in caring for their children with ASD.

School services are another significant contributor to the high financial costs associated with raising a child with ASD, due to the increased use of a specialised education service. The use of special education was observed to range from 73 percent for children with mild ASD to 91 percent for children with a severe form of ASD (Lavelle, Weinstein, Newhouse, Munir, Kuhlthau, & Prosser, 2014).

Examining the South African context closely, the challenges linked to caring for children with autism spectrum disorder are often complicated by underprivileged socio-economic

backgrounds. A study conducted by Holborn and Eddy (2011) suggested that caregivers of children with ASD in single-parent households, receiving low financial and social support, and are consequently at an increased risk for experiencing psychological stress and relatively poor mental well-being. The challenges faced by family caregivers make them vulnerable to developing depression, which often goes unnoticed, or unattended to, due to a lack of support (Cairney, Boyle, Offord, & Racine, 2011).

### ***2.7.1.2 Social support***

Families of children living with autism spectrum disorder experience a number of challenges and significant levels of distress (Weiss, 2002). Research by Jack (2016) emphasised several challenges, including limited resources, obtaining a proper diagnosis from a professional, struggling with proper educational programmes, as well as financial burdens. Social support is considered central in coping with the afore-mentioned challenges (Lindblad, Holritz-Rasmussen, & Sandman, 2007).

According to Boyd (2002), social support entails physical and psychological information, as well as any material aid that is accessed formally and informally by caregivers of children living with ASD. Boyd (2002) also considered social support as central in reducing the negative effects of caring for a child with ASD, and other mental disorders. Informal support, as described by Boyd (2002), is a form of support one receives from friends, family, and social media platforms. It is viewed as effective in reducing stress among mothers of children with autism by a number of researchers (Boyd, 2002; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001).

The study conducted by Dunn et al. (2001) on moderators of stress in parents of children with ASD found that mothers who were perceived to be receiving higher levels of support, particularly from their spouses and close relatives, reported lower levels of depressive symptoms,

especially somatic ones, such as insomnia. Boyd (2002) made an important observation concerning informal social support, notably that there is no study stipulating that one source of informal support is more effective than another in dealing with the challenges.

### ***2.7.1.3 Stigma in general sense***

According to Broady, Stoyles, and Morse (2017), a stigma occurs when one is seen to possess an attribute that deviates from what society stereotypically considers as ‘normal’, thereby devaluing and reducing an individual from being perceived as whole and usual, to a tainted and discounted one. Researchers have argued that stigmas can be well understood through the differentiation between enacted stigmas and felt-stigmas (Scambler & Hopkins, 1986; Jacoby, 1994).

An enacted stigma is seen as reception of undesirable treatment as a result of a stigmatising condition. Simply put, enacted stigma is an external stigma emanating from the experience of being unfairly treated by others. In contrast, felt stigma refers to a feeling of humiliation or shame associated with such treatment and the fear of enacted stigma occurring (Braody et al., 2017). This means self-stigmatisation or internal stigma entails the expectations of ill treatment that prevents caregivers from talking about their experiences and in turn deters them from seeking help.

Felt stigmas were found by Scambler and Hopkins (1986) to be far more widespread compared to enacted stigmas and were also the cause of significant distress. Gray (2002) indicated that felt stigmas influences people’s perception of the world and how they see and interpret events around them. This often makes people go to extreme measures to appear as ‘normal’ as possible to society.

#### ***2.7.1.4 Stigma, caregivers and autism spectrum disorder***

Literature suggests that children with ASD and their families are more stigmatised than families of children with other disorders, for example, Down syndrome or cystic fibrosis (Broady et al., 2017; Gray, 2002, 2003; Gill & Liamputtong, 2013; Olsson & Hwang, 2001). Children with high functioning autism are less stigmatised than children with low functioning autism (Gill & Liamputtong, 2013). This is due to those children's limited communication ability and, at times, their physical appearance. This makes it likely to be a noticeable condition to the general public.

In contrast, children with higher functioning autism may display the socially unwanted behaviour associated with ASD in public spaces and have their behaviour perceived as disrespectful or resulting from poor parenting abilities (Gray, 2002).

Some researchers have noted that it is through such experiences that caregivers are found to show elevated emotional distress, as well as internalised feelings of shame, resentment and guilt (Green, 2003; Werner & Shulman, 2013). This makes caregivers prone to experiencing poor subjective wellbeing and self-concept. Moreover, when caregivers anticipate or fear the prospect of stigmas, they tend to withdraw from social situations and isolate themselves, thereby providing fewer opportunities for their children and themselves to receive support and interact positively with others in a social environment (Woodgate, Ateah, & Secco, 2008).

#### ***2.7.1.5 Caregivers coping styles – ASD***

A study by Folkman and Lazarus (1990) argued that general stress coping is a transitional process through which coping mechanisms vary across context and time in order to match the changing demands of the stressful environment. For example, a child's age, parent personality, symptom severity, and family functioning have been reported to affect caregiving stress levels (Lai

& Oei, 2014). Ganizadeh et al. (2009) argued that parental coping does not differ with the age of the child with ASD. However, the coping mechanisms of the caregiver change over time. As the caregiver ages, they cope better through reliance on service providers, social and withdrawal. Their coping mechanisms usually become religiously based and make use of emotion-focused mechanisms.

Folkman and Lazarus (1990) cautioned against the use of general coping constructs across dissimilar cultural groups. These researchers stressed the significance of considering the context-dependent nature of stress coping strategies, bearing in mind the collectivism-individualism (Triandis, 1988). Asian caregivers of children with autism value group gains and lean towards a collectivistic problem-focused coping mechanism, whereas the Western-European caregivers tend to focus on self-gain and identify better with the individualistic coping mechanism (Lai & Oei, 2014).

The cognitive and behavioural coping mechanism employed by caregivers of children with ASD affects the level of psychological distress they experience (Paynter, Riley, Beamish, Davies, & Milford, 2013). A study conducted by Hastings, Kovshoff, Brown, Ward, Espinosa, and Remington (2005), on coping mechanisms employed by primary caregivers of preschool and school-age children with ASD, found four reliable dimensions of coping: (1) problem-focused, for example, seeking help to mediate the situation, (2) avoidance coping, for example, making use of drugs/alcohol to get by, (3) religious coping, finding comfort in faith and, (4) positive coping, reframing in a positive manner. Adopting an avoidant coping strategy was found to be linked with increased vulnerability to depression, anxiety, and as well as having a negative impact on the family's quality of life (Hastings et al., 2005; Stuart & McGrew, 2009).



*Resilience* is viewed as the dynamic process of balancing protective factors and risk factors in the face of difficulty (Van Breda, 2001). Caring for a child with ASD has its own challenges and demands. Literature indicates that caring for children with ASD can be financially challenging, as well physically and emotionally draining (Altiere & Von Kluge, 2009; Gray, 2006). A number of studies show that caregivers of children with autism report poorer health and quality of life, depression, anger, feeling of loss, stigma, and anxiety, as earlier mentioned (Blacher & McIntyre, 2006; Hastings et al., 2005; Montes & Halterman, 2007). Yet, evidence suggests that some caregivers of children with ASD report that caring for these children brings a positive enhanced meaning of life and a positive sense of self (Bayat, 2007; Benderix, Nordstrom, & Sivberg, 2006). Caregivers like these were able to better handle any adversity (Woodgate, Aeah, & Secco, 2008). Van Breda (2001) found that resilience may not only assist caregivers to navigate their day-to-day difficulties, but may also create emotionally stronger, more flexible and healthier individuals.

### **2.7.2 Conceptualizing the nature of caregiver experiences (theoretical framework)**

The comprehensive model for understanding caregivers' experiences was proposed by Pearlin, Mullan, Semple, and Skaff (1990). The model was termed the Stress Process Model (SPM). This model focuses on four important dimensions: (1) background and context, e.g. caregivers' educational level, sex and/or ethnicity, (2) sources of stress/stressors such as eventful experiences of the child being diagnosed with autism spectrum disorder, (3) mediators of stress (coping strategies and social support) and (4) manifestation of stress/outcome (e.g. impact of stress related to caregiving experience).

*Background and context* were viewed as consisting of four underlying concepts: (1) socio-economic status (SES), (2) family and network composition, (3) caregiving history, and (4) programme availability (Bolden & Wicks, 2008). Pearlin et al. (1990) contended that these

attributes have a major effect on caregiving experiences and outcomes. Caregiver's characteristics (sex, level of education, age, and ethnicity) influence the nature and intensity of stress and the manner in which it is experienced. These characteristics also influence the ability to access and use personal and social resources (Bolden & Wicks, 2008). Thus, caregivers of children with ASD, who have limited to no personal resources, are most likely to experience increased stress.

Caregiving history, as noted by Bolden and Wicks (2008), pertains to the duration of caregiving, the severity of the condition and the quality of the caregiver-care-recipient relationship. The amount of time that the caregiver is required to be present, due to the severity of the condition, is a marker of the chronicity of the stressor that the caregiver endures. Family and other networks refer to the attachments and bonds that the caregiver has as a means of emotional and psychological support (Pearlin, 1985). The amount, availability, affordability and proximity of community-based resources/programmes can potentially affect the amount of stress that caregivers perceive and eventually experience.

*Sources of stress/stressors* were divided into two categories, namely, the primary stressors and secondary stressors. The former entails the high demands and needs of the care recipient (Bolden & Wicks, 2008). These demands and constant needs result from symptoms such as communication deficits, limited mobility, and memory loss experienced by the care recipients. Individuals with these, or similar symptoms, demand more time from the caregivers.

The secondary stressor is experienced as a result of the primary stressor. Pearlin et al. (1990) contended that this stressor consists of two components, namely, role strain and intrapsychic strain. The former is seen as arising out of circumstances whereby a caregiver has multiple roles which are not fully integrated in a mutually accommodating way, where the obligations of one role make the performance of another role improbable (Pearlin, 1999). An

example of this would be a caregiver who is unable to participate in recreational activities, or take extra hours at work, because of the caregiving responsibility. Intrapyschic strain arises as a result of continual caregiving responsibility, which causes internal conflict and/or guilt. This guilt and conflict are felt by the caregiver whose family system disagrees about the amount and quality of time one family member makes available to provide care compared to other family members (Bolden & Wicks, 2008).

*Mediators of stress* are used by caregivers to minimize, prevent and manage stress. Pearlin et al. (1990) contended that coping and social support are two principal mediators that determine how a caregiver responds to a stressful event. The stress process model (SPM) defines *coping* as the practices/activities caregivers utilise to care for themselves, for example, taking time off from the responsibilities that come with caregiving. In describing the concept of *social support*, Pearlin et al. (1990) indicated that this concept has two categories, namely, instrumental social support and expressive social support. Instrumental social support refers to the practical and physical assistance that the caregiver receives, for example, assisting with feeding and/or bathing, whereas expressive social support refers to the caregiver's subjective experience or perception of available support, like verbal encouragement from an empathetic significant other/confidant. As a result, caregivers with effective coping mechanisms and satisfactory resources will respond differently to stress, than caregivers with limited resources at their disposal.

*Outcomes* are the last component of the SPM, as noted by Pearlin et al. (1990). The effects of this component are dire, as they involve the well-being of an individual's mental and physical health, as well as an individual's ability to sustain themselves in their social roles. The interplay/interconnectivity of the earlier mentioned components of the SPM (background and context, primary and secondary stressors and mediating factors) are manifest in this component.

The outcomes this model identifies are mental health problems, namely, depression, anger or rage, and anxiety, and physical health problems, cognitive disturbances and the inability to fully engage in roles previously held.

With the adoption of this model comes the importance of bearing in mind that life events, in this case those associated with autism spectrum disorder, could lead to negative changes in caregivers' lives. The persistence of these changes, as suggested by Pearlin et al. (1990), could lead to a diminished self-concept. According to Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, and López-Pousa (2010), coping and social support are critical to mediate the outcome. It is important to understand that experiences and challenges of caregivers are not uniform. Thus, considering caregiver variables, such as context, race, ethnicity, and gender, are of significant importance (Conde-Sala et al., 2010).

## **2.8 Summary**

The literature reviewed in this study indicated crucial themes that are fundamental in understanding what it is like to care for a child with the lifelong disorder of ASD. The multifaceted nature of ASD, and the complexity that comes with it, were discussed. Individuals with ASD are prone to experiencing comorbid conditions, for example, Intellectual Disability or sleep disorders. The disruption in sleep patterns inevitably affects caregiver's sleep patterns as well (Boyd, 2002). Consequently, there is a lack of social involvement, stress and ultimately anxiety or depression (Gobrial, 2018). The literature further indicated that there are a number of strains that caregivers of children with ASD experience, for example, financial burdens, emotional burdens, and stigmas.

Breakthroughs in the understanding of the main causes of ASD are essential in developing new, effective interventions and devise preventative measures. Epidemiological studies of ASD are in demand in Africa for a better conceptualization of this lifelong disability. With this disability comes many changes for caregivers. The experience of the challenges mentioned in the literature review varies from caregiver to caregiver, depending on variables such as race, ethnicity and/or gender. The SPM theoretical framework (Conde-Sala et al., 2010) was chosen to conceptualise the experiences of caregivers in a multicultural context.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Introduction**

This chapter presents the research design and methodology adopted by the current study. The study begins with a discussion of the research design selected for this study. The chapter then defines the sampling methods, the process of data collection and analysis, as well as the procedure followed from the inception of the study through to its completion. The ethical factors considered during data collection and analysis are then discussed. The chapter concludes with a brief summary of what was deliberated in this chapter.

### **3.2 Research Design**

In order to achieve an extensive understanding of the phenomena under study, this study followed a qualitative research design, which Shank and Vilella (2004) defined as “a systematic empirical inquiry into meaning” (p.5). Shank and Vilella (2004) further explored this definition to make it more understandable; by ‘systematic’ they mean that there is a plan and order in the exploration process of a particular phenomenon. In laymen’s terms, this is a process of an investigation where one follows rules implemented by qualitative researchers. Empirical means that the investigation is founded upon the world of experience. The last part, “inquiry into meaning”, means that the individual who undertakes the qualitative stance tries to understand, document and explore how others draw meaning, make sense of the world around them (Goethals, Sorenson, & MacGregor, 2004).

Qualitative design allows for an in-depth and extensive description of individual experiences. Thus, a qualitative design is optimal for the current study, as it tries to explore the experiences of family caregivers living with children with ASD. Raising a child with ASD comes with unique and different experiences or challenges. These experiences are based on each caregiver's meaning-making of the environment/world around them. Mkhize (2004) argued that researchers rely on tools that allow them to make an in-depth consideration of different ways in which different people make meaning of their world.

### **3.3 Data Collection Method**

In qualitative studies, the primary method of data collection is qualitative interviewing. Interviews are perceived to be more effective in acquiring data that allows researchers to document individuals' experiences and views in greater depth, compared to quantitative questionnaires (Alshenqeeti, 2014). In a similar manner, Cohen, Manion, and Morison (2007) added that interviews are an invaluable method in empirical research for exploring the constructions of meaning-making in a natural context. Qualitative interviews allow participants to express their raw emotions and thought processes, as well as speak in their own voice. Qualitative interviewing is a dialogue whose primary purpose is to extract descriptions of the participants' environment, with respect to the interpretation of the meaning of the phenomena being discussed (Kvale, 1996).

In social sciences, there are different types of interviews: the first one is focus group interviewing, whereby a sample is selected for its purposiveness, irrespective of whether it is representative of the sampling frame or population being studied for that particular topic (Barbour & Schostak, 2005).

The second one is a structured interview (close-ended interview), which is structured in a way that is mostly organised around a set of direct questions that typically require yes/no responses. This type of interview is also known as a standardised interview which seeks to ensure that each participant receives the exact same question in the same order. In this form of an interview, participants have little to no freedom of self-expression (Berg, 2007).

The third type of interview is an unstructured (open-ended interview), whereby interviewing is an open process that allows for greater freedom and flexibility for both parties, namely, the participant and the interviewer (Gubrium & Holstein, 2002). Therefore, this form of an interview allows the interviewer to follow up on interesting responses and also allows the participant to further elaborate for more clarity on various issues.

The fourth one is a semi-structured interview which is perceived as more flexible than structured interviews, as it allows the interviewer to probe further for clarity. When using semi-structured interviews, the researcher uses an interview schedule that allows the researcher to cover all overarching issues, for example, the research questions.

This study adopted a semi-structured interview because it allows the researcher to keep the process of an interview within the parameters covered by the aim of the study. Semi-structured interviews are less intrusive to interviewees. They provide uniform information and draw focus from research questions.

### **3.4 Sampling**

The study employed a purposive sampling method, which involved the selection of sampling units “based on perceived richness and relevance of information regarding research



questions” (Yin, 2011, p.311). In a similar vein Creswell and Clark (2011) asserted that, in purposive sampling, participants are selected based on how well-informed and proficient they are on the phenomena of interest. The study utilised this sampling method because the researcher needed caregivers with first hand experiences of raising a child diagnosed with ASD.

The inclusion criteria were that the children’s diagnoses must have been made by health practitioners registered with the Health Professions Council of South Africa (e.g. either as a neurologist, psychologist, paediatrician or psychiatrist) and the participant was to be a primary caregiver. The size of the study sample consisted of seven female caregivers of children with ASD.

### **3.5 Procedure**

The sample of seven participants was drawn from the Action in Autism Centre situated in Parkhill, Durban North, KwaZulu-Natal. The researcher wrote a letter to the coordinator of the Action in Autism Centre requesting permission to interview caregivers of children with ASD. The coordinator issued partial approval and indicated that a full approval was subject to receiving a copy of ethical clearance, which was subsequently sent (see Appendix G).

Invitations to participate were sent via the coordinator of Action in Autism, who then distributed them to all interested family caregivers of children with ASD. The invitations were sent via email, and the list of interested participants, which included their contact details, were sent to the researcher. The invitations provided family caregivers with an information sheet, informed consent form and a sample of questions that would be asked. This was done to provide participants with relevant information pertaining to the study.

Participants were then contacted to schedule a date and time of the interview. Five of seven participants were interviewed in their offices at their place of work during their lunch time, as this was the only time they could be available for interviews, while the remaining two participants were interviewed at their homes.

On the day of the interviews, the study was explained in detail and all participants were assured about the confidentiality and privacy of their responses, as well as the anonymity of their interviews. Participants were also informed that they could withdraw from the study at any stage of the interview without any consequences. All the participants demonstrated adequate understanding of the English language and for this reason most interviews were conducted in English, while some were a mixture of IsiZulu/IsiXhosa and English.

### **3.6 Data Analysis**

Maree (2007) argued that data analysis is the process by which a researcher tries to understand how participants make meaning of selected phenomena by analysing their beliefs, feelings, perception and lived experiences, in an attempt to contextualize their construction of the phenomena. Data analysis is viewed as an ongoing nonlinear process. Phrased differently, data collection, processing and analysis are interwoven.

The interviews were audio recorded, translated and then transcribed. The data was analysed according to thematic analysis, which is a technique for identifying, analysing and reporting themes with qualitative data (Braun & Clarke, 2006).

Boyatzis (1998) argued that thematic analysis often times goes to the extent of analysing some aspect of the research topic. Thematic analysis is widely used by a number of researchers,

but, however, there are ongoing unanswered questions of what exactly thematic analysis is and how one goes about doing it (Attride-Stirling, 2001; Boyatzis, 1998; Tuckett, 2005). Phrased differently, it can be seen as a vaguely ‘branded’ technique, in that it doesn’t appear to exist consistently in the literature as a ‘named’ analysis in the same fashion as other techniques do (e.g. grounded theory, discourse analysis, narrative analysis etc.) (Meehan, Vermeer, & Windsor, 2000). With that said, Braun and Clark (2006) declared that thematic analysis does exist as a method, but one shouldn’t subscribe to a naïvely realist view of qualitative research where everything should be theoretically bound.

Thematic analysis is viewed as a more flexible method even when working with a variety of data, as it allows for a systematic approach that yields accurate results and that is more sensitive in understanding and interpreting observed data (Braun & Clark, 2006). To partake a thematic analysis, Braun and Clark (2006) recommended six stages, which are as follows; (1) familiarization, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report.

### **3.6.1 Familiarisation**

The researcher repeatedly read the data, searching for patterns and meanings within the data set. The researcher familiarised himself with the data set through the process of translating and transcribing. The researcher listened to the audio-recorded data several times, making it possible for him to immerse himself in the data set. This enabled him to understand specific language usage and latent meanings.

### **3.6.2 Generating initial codes**

Through the process of immersion, the researcher generated initial codes by identifying the common words used by the participants and ended this process by collating all the noteworthy data extracts (codes). During this stage of data analysis the researcher also searched for themes, which involved finding similarities within the data set. This was done uniformly across all the data collected from the interviews. This process allowed the researcher to identify data relevant to previously extracted codes.

### **3.6.3 Reviewing themes**

The fourth step of data analysis process involved reviewing themes, which required the researcher to reflect on whether the earlier selected themes held a compelling and convincing narrative about the collected data. This constituted examining whether the themes worked in relation to the entire data set or coded extracts. This stage led to the fifth step, which required the researcher to name and define themes. The researcher had to re-check the details of each chosen theme and its relation to the overall experience of each participant.

### **3.6.4 Producing the report**

According to Braun and Clark (2006), producing a report this is the sixth and final step in data analysis. This step involved putting together the data extracts to form a cohesive narrative about caregivers' experiences and place this narrative in relation to the existing body of knowledge.

### **3.7 Reliability and Validity**

Reliability and validity are important concepts in research as they may equate to the rigor of qualitative research. However, a precise conceptualisation of the ‘quality’ in research continues to be debated among naturalistic inquirers (Cypress, 2017). The researcher considered the following concepts, proposed by Guba and Lincoln (1985), in an attempt to ensure the trustworthiness of the findings: credibility, conformability, transferability, and dependability.

#### **3.7.1 Credibility**

Credibility is one of the important factors to consider as a researcher in order to establish the trustworthiness of the research findings (Guba & Lincoln, 1985). The credibility of the study attends to the question of “how congruent are the results with reality” (Pandey & Patnaik, 2014, p. 5747). The credibility of this study was achieved through prolonged engagement with the participants during the interviews in order to develop rapport. This allowed participants to provide detailed and voluminous descriptions of their experiences.

#### **3.7.2 Transferability**

According to Pandey and Patnaik (2014), the concept of transferability concerns the applicability of the research findings to another context. It is extremely difficult to demonstrate that the findings can be applied to another context due to the small size and the homogeneity of the sample.

#### **3.7.3 Conformability**

The concept of conformability is in preference to the objectivity of the researcher in positivism (Guba & Lincoln, 1985). This concept can be perceived as a degree of neutrality by the researcher, or rather the degree to which the results of the study are participant-driven, and not

shaped by researcher motivation, interest or bias (Pandey & Patnaik, 2014). The researcher ensured that neutrality was maintained throughout the process of interviews; all participants were treated in the same manner. The researcher did not allow his background to affect what was chosen to be investigated, as well as the communication of conclusions.

#### **3.7.4 Dependability**

Dependability shows that the results are consistent, meaning that if the study were to be repeated in the same context, with the same participants, and with the same methods, it would yield similar results (Pandey & Patnaik, 2014). Another researcher was asked to also extract themes from the data set and compared, thereby adding to the consistency and rigour of the study (Smith & Firth, 2011)

### **3.8 Ethical Consideration**

#### **3.8.1 Informed consent**

Respect for participants' rights to make informed decisions about their lives (respect for autonomy) requires that all participants are adequately informed about all aspects of the research process (Ashcroft, Dawson, Draper, & McMillan, 2007). All participants showed a capacity to understand all the information that was provided to them regarding the study, including the unforeseeable implications of participating, as well as the capacity to exercise consent. The participation of all caregivers of children with ASD was free from coercion. Thus, all participants were assured that refusal or dropping out would not negatively affect them.

### **3.8.2 Non-maleficent.**

This ethical principle indicates that the researcher has an ethical obligation to do no harm to their research participants (Wassenaar, 2006). All participants were made aware that in an event of any emotional distress resulting from the questions asked during the interview, psychotherapeutic services would be made available. In such an event, a referral to a psychology centre at the University of KwaZulu-Natal, Howard College, would be arranged.

### **3.8.3 Beneficent**

According to Wassenaar (2006), beneficent, as a clinical research protocol, compels the researcher to minimise harm to the participants and maximise benefits to the participants or the whole population. The researcher will provide, in writing, a copy of the study to the participants, in order for them to keep abreast with new developments regarding ASD.

### **3.8.4 Justice**

The protocol of justice in research refers to the unbiased distribution of the benefits and burdens of research. Phrased differently, the researcher had an obligation to treat all participants equally throughout the study (Wassenaar, 2006). It is noteworthy that all participants were contacted using the same medium of communication and were all treated fairly and equally.

## **3.9 Summary**

The writer discussed the methodology utilised in this study. The study consisted of seven participants, all biological mothers of children with ASD. An interview guide was used to extract relevant information for the study. The study explored a delicate topic with possibly vulnerable

participants, and, hence, careful consideration of research ethics was adopted to minimise harm. The intricate issues of study validity and reliability were constantly considered.



## **CHAPTER FOUR: RESULTS**

### **4.1 Introduction**

The study sought to document the experiences of caregivers of children with autism spectrum disorder. For the researcher to achieve this, family caregivers of children with ASD were interviewed. The inclusion criteria were: the child needed to have a diagnosis of ASD from a qualified health professional registered with the Board of Health Professions Council of South Africa and the participant needed to be a primary caregiver.

This chapter is divided into two sections:

- In the first section, the demographics of the participants are discussed (see Table 2).
- The second section discusses the themes that emerge out of the seven interviews. Any differences and commonalties are discussed in detail.

### **4.2 Participants' Demographical Information**

The study consisted of seven participants: four were Zulu decedents, one was a Xhosa descent, one Coloured, one White and one was originally from Zimbabwe, of Swahili decedent. However, all the participants were residents of the KwaZulu-Natal province of South Africa. Three participants were legally married and one customarily married. The remaining three were single.

The anonymity and confidentiality of all the caregivers who participated in the study were central in this study in order to maintain ethical research practice. Therefore, no names have been

used in the presentation and dissemination of the results (see Table 2 for the summary of demographics).

**Table 2. Participants' Demographic Information**

	Cg/ Gender	P/Age	Race	Ethnicity	MS	R/Ship	A/dx	C/Gender
Participant-1	F	30	Black	Zulu	Single	B/Mother	3	Male
Participant-2	F	46	Black	Zulu	Married	B/mother	3	Male
Participant-3	F	35	Coloured	Coloured	Married	B/Mother	2	Male
Participant-4	F	36	Black	Swahili	Widow	B/Mother	5	Male
Participant-5	F	31	Black	Zulu	Single	B/Mother	3	Male
Participant-6	F	30	White	White	Married	B/Mother	18 mnths	Male
Participant-7	F	34	Black	Xhosa	C/Married	B/Mother	4	Male

*Note:* P-1= Participant 1; A/dx=Age at Diagnosis; MS= Marital Status; F=Female; M=Male; Cg= Caregivers Gender; C/Gender=Child's Gender; R/ship= Relationship; B/Mother=Biological Mother; C/Married=Customary Married; P/Age= Participant's age

### 4.3 Theme Presentation

Having children influences caregivers' subjective wellbeing; it changes people's perception and how they define life (Myrskylä & Margolis, 2014). The experience of raising children may be perceived as a blissful moment, yet other caregivers see it as a challenging and stressful undertaking of their lives (Nelson, Kushlev, & Lyubomirsky, 2014). The challenges are often compounded with ASD; caregivers doubt and question their abilities as parents (Baron, Groden, Groden, & Lipsitt, 2006). It comes as no surprise that caregivers of children with

neurodevelopmental disorders, such as ASD, experience greater challenges (Pisula, 2011) compared to the mothers of typical children, and more especially in a developing country, where there are scarce resources, like in South Africa. Table 3 presents a summary of emergent themes and subthemes.

**Table 3. Summary of Emergent Themes**

<b>Themes and subthemes</b>	<b>Example survey response</b>
<b>Theme 1: Daily challenging behaviour</b>	<p>“...he knows that there is a kid that wears leg braces kinda thing—so that kid sits in the corner because he needs to be stable against that thing and then there is boy that sits next to that boy and then my son is the last one—so if those two kids are not in the buss he doesn't want to jump in...” Participant 3</p> <p>“...everything about him is a routine.” Participant 2</p>
<b>Theme 2: Discipline and its effects on caregiving</b>	<p>“...he will just be like no! And once he has said that whatever he is disagreeing to will never happen...” Participant 3</p> <p>“...with any child it's easier to set limits and say you can't have this and that...” Participant 5</p> <p>“...he chooses whatever he wants to wear and if he says no!—no means no...” Participant 4</p>
<b>Theme 3: Life style change</b>	<p>“...too much light affects him and then he will be reluctant to go into the shop – so that means I can't shop anymore ...” Participant 2</p> <p>“...no more like luxury holidays all the year now and all that stuff ...” participant 2</p>
<b>Theme 4: Financial burden</b>	<p>“...I also need to buy groceries, he is a very choosy eater, it's unlike caring for a normal child and also the fact that he is not yet fully potty trained it's like you are caring for an infant I still buy nappies...” Participant 5</p> <p>“...schooling because it is ridiculously expensive [chuckles] it quite pricy...” Participant 1</p> <p>“...The lunch I can afford to make for him he doesn't want it so he doesn't eat it ...” Participant 4</p>
<b>Theme 5: Communication difficulties and caregiving</b>	<p>“...once he starts talking. I think he would make our lives much, much easier, because now you have to think for him, okay he probably wants this now ...” Participant 7</p> <p>“...he expresses all his emotions by crying ...” Participant 5</p> <p>“...I used to beat him because I thought he was being naughty...” Participant 4</p>
<b>Theme 6: Emotional Burden</b>	<p>“...it has affected my family negatively...” Participant 5</p> <p>“... it was very overwhelming and stuff but it was kinda like it didn't hit me when they were like he is Autistic ...” Participant 6</p>
<b>Theme 7: Support System</b>	<p>“...they always more on the side of assuming that you don't actually need any more support than that what you actual have ...” Participant 1</p>
<b>7.1 Family Support</b>	<p>“...my family is very supportive they understand him ...” Participant 7</p>
<b>7.2 Government Support</b>	<p>“...there is nothing that I know of from governmental facility ...” Participant 1</p> <p>“...I'm not receiving any assistant ...” Participant 5</p> <p>“...There is nothing that I know off beside the school ...” Participant 2</p>
<b>Theme 8: Limited Resources</b>	<p>“...it was a bit of a challenge to find a school...” Participant 7</p> <p>“...I didn't find any early intervention centre ...” Participant 1</p>
<b>Theme 9: Coping strategies</b>	<p>“...we just support each other ...” Participant 7</p> <p>“...I have become a bit more patient ...” Participant 3</p>

### 4.3.1 Daily challenging behaviour

The participants reported the challenging behaviours with which they are faced almost every day in looking after their children with ASD. These challenges were cited as being particularly stressful and difficult to manage. Examples cited include, but were not limited to, repetitive behaviour, temper tantrums and potty training. These behaviours were often described as unpredictable and often difficult to sooth.

**Participant 1** *“He is only five [chuckles]... I think so far, it’s the potty training because that’s really giving me sleepless nights.”*

**Participant 2** *“There is always a motherly instinct that says to you something is wrong but the thing is you don’t know what exactly is wrong—because with him they are not very far apart with his sister—you will see that his sister is now able to do certain things that he has not done and not even near yet—even with potty training--- he delayed yet his sister was well potty trained before she even started crèche.”*

Some parents reported the change in behaviour as a feature that becomes more complex with time. For example, a caregiver described her son’s behaviour change as mysterious and confusing.

**Participant 6** *“He used to love shopping centres, however, the last two visits to the shopping centre. Rocky had to carry him whereas before he would just be happy to walk around, and numerous times we had to watch him because if he sees Wimpy he would just run into the Wimpy premises, because he loves Wimpy. Now it’s a case of carrying him around the shopping centre, we never had to do that in the past, so now it’s like there is that change and we do not know what’s happened.”*

Knowing the child’s routine was another challenge the parents reported. Some parents expressed that as much as they engage with their children regularly, the engagement must always be routinely based and it is important to remember the routines, as the caregiver, to curb tantrums.

**Participant 3** *“So he does engage with us in some kinda way, but definitely a routine. He knows his routines; he knows that he needs to get dressed after the dressing needs to have porridge, he knows he needs to do that kinda thing. He is five and he travels in a school bus, he goes to Browns - he travels in a school bus. He has done that since he was about 4 - since last year kind of, when he started there a little bit uh... in the year and he likes it, he knows what to do. He is very smart in that sense; he knows that he must go to the bus; he is very particular in certain things- he knows certain things have to be done in that way and if you don't know then he kinda gets upset and you don't know why are you not doing this because you should just—so the one thing is uh.. in the bus they are allocated seats so he knows that there is a kid that wears leg braces kinda thing—so that kid sits in the corner because he needs to be stable against that thing and then there is boy that sits next to that boy and then my son is the last one—so if those two kids are not in the buss he doesn't want to jump in—so you literally have to stand and wait until they jump into the bus.”*

**Participant 2** *“Everything about him is a routine, very routine based, so when you get home, at six we have supper, we rest a bit and then we pray, and then homework. Actually it's homework, and then it's eating time, bath time, praying time and then they go to bed so even if you arrive late and you missed one of these – he asks you, so you missed eating time so where did you eat, you have missed praying time so where did you pray- you didn't pray today so how do you think you gonna get God's blessing? So he sorts of tracks back and tells you all those things.”*

**Participant 4** *“It's always difficult to get him ready for school, because in some mornings he wakes up and he doesn't want to be touched and you shouldn't touch him. At times he wakes up at 5 o'clock in morning and put on cartoons and if he does not wanna watch cartoons he doesn't, he gets what he wants.”*

A slightest change in the routine of children with ASD is reported to trigger an uncontrollable tantrum. The participants stressed the importance of being aware of the changes that might trigger tantrum.

**Participant 5** *“...the latest for him to wake up is half past four in morning-that's the time we say he woke up late. The transport to school only comes at 6:30 am, so that means we*

*have about 2 hours of running after him--- but—after he has woken up, he used to eat porridge at 5 o'clock in the morning, so by 4:30 in the morning it should be ready--- you know—they are choosy they don't eat just anything, and he eats porridge. And if it's not ready at 5 o'clock—and should be a right temperature—warm-- .... if it's not ready he will start, crying-- throwing tantrums. When he wakes up he takes a bath and I won't dress him up until quarter to six, because he runs around all over the place --- he attends school at the Action in Autism. He knows that at 6 o'clock he has to go to the bus stop where the car picks him up. If at 6 we are not at the stop sign or if the transport is a bit late he gets, unsettled and agitated.”*

**Participant 7** *“It depends some days are fine other days it's very challenging maybe the child doesn't wanna eat breakfast and he ends up being late for school and all that, he is like hyper or maybe when he comes back from school he's like hyper I mean uhm you can't do anything constructive with him or maybe in other instances when he is watching TV because he loves watching TV. If he is watching TV there is nothing you can do to him, he is like glued to the screen and if you change the channel be ready to fight with him.”*

#### **4.3.2 Discipline and its effects on caregiving**

One of the main challenges reported by the participants when it comes to parenting was the issue of discipline. Participants exhibited concerns about creating boundaries of discipline and spoiling their children. A number of caregivers expressed that they found it difficult to instil discipline with their children who suffer from this lifelong disorder of ASD. Participants felt that their children were more on the spoilt side, irrespective of the amount of effort they spent on discipline on a daily basis. This was further fuelled by harsh comments from the public (church members, community members etc.). For example, comments such as ‘why is your child like this’ or ‘your child is naughty’. The participants felt compelled to explain what was wrong with their children as the result of the judgments they had experienced. Some participants indicated that the difficulties that come with raising a child with ASD are dire and not everyone would understand.

This is consistent with Brohart's (2008) assertion that only primary caregivers of children with ASD can understand how difficult it is to discipline a child with ASD, as demonstrated in the quotes below.

**Participant 1** *"...you know the – drawing the line between spoiling your child and instilling discipline because it's very hard for you to discipline a child that is --well I would say autistic because you feel like you being too harsh on them but at the same time you feel like I'm spoiling them—so maybe at time --- like maybe I have had a bad day at work and I'm just tired or whatever and if he is crying for something I'm just gonna give it to him, by right it should depend--- well there was this point where I was trying to instil some sort of discipline in him because he is a bit on the spoilt side he throws tantrums, he has been throwing tantrums from the age of what—2--- so when he wanted something I would like not give it to him and make him sit in the corner and cry it out and---- but at times you are just so frustrated and with everything that is happening and you don't have the energy to make him do that and you just give in..."*

**Participant 7** *"...it's not really easy but we try by all means, like for example if he is watching his favourite program and then I guess he has been watching it for like uhm more than what he should, so yah, we would change the channel or switch off the TV and then yah there would be a problem obviously and yah our word has to be final. Whether he is crying or not he must know that no means no, it's not gonna happen he has to learn that. Once you have said enough now it means enough, it's not easy I mean because it's not nice to see your kid in a bad space but he has to grow up knowing that but yah it depends on what it is, when it comes to spoiling yeah, the lines are a bit blur you know [chuckles] yeah are a bit blur but yah we do our best like considering the situation he is in you know yeah, yah. I think in a way he is spoilt we do anything for him everyone in the family will be like what did you do, they want to find out..."*

**Participant 5** *"...yes I had to tolerate him more, with any child it's easier to set limits and say you can't have this and that, but with him you can't do that because he just expresses his feelings by crying. At times he cries, you just have to give in. sometimes you really don't know what he wants..."*

**Participant 6** “...you never too sure whether he is having a meltdown or he is just doing it just to have his own way because he is not a stupid boy he knows what he wants and what he doesn't want. I battle with that line like do you discipline him now or is it a genuine meltdown something that he is not happy with, and uhm if he gets angry he generally throws things like hard and what do you do in a situation like that do you. Do you smack him and discipline him or you try and explain to him that you can't do that, is he gonna understand that he can't do that...”

The above quotes give a clear indication about the challenges that caregivers of children with ASD face when it comes to disciplining and managing behavioural difficulties. The following quotes show how caregivers tend to be more lenient in terms of discipline with children with ASD because of the perception that these children do not have the mental capacity to distinguish between right and wrong. The participants tried to discipline their children with ASD differently, which at times failed as it appeared as favouritism, against another siblings. Brohart (2008) argued that trying to discipline a child with ASD as one would with a typical growing child is a mistake.

**Participant 3** “...I think she sees at times that the way we deal with her and the way we deal with him is a bit different so I think she understand it—so you know why you did that! You know [John] also might know but he doesn't fully understand the outcome of it, so he knows that if he does this and that something might happen but he doesn't know the extent—whereas you do know, you know because you older, you know because you probably done this at this age. Touching the stove for example you are going to get burnt—you know this. Sometimes she kind of feel we are more nicer on him...”

**Participant 6** “...obviously you can't discipline a normal child as you would an Autistic child, because he doesn't speak and he doesn't understand so yah it did change. Even now with his sister I would tell her to go in her room but obviously I can't do that with him, so yah it definitely did. I have two children, its him and his younger sister and my parenting style with the two of them is different....”



Some participants felt judged or perceived as incompetent parents who do not know how to discipline their children. Participants tended to receive judgments from places where they believed they would receive support, for example a place like a church and/or family gatherings.

**Participant 4** “...even at church and on the beach. Like last Saturday I was with him on the beach and one of the children hit him, [he] was there [pointing] he was running there, but the child hits him. They all thought my son was being naughty. Everyone asks why does it look like your child doesn't wanna listen huh! Look at your child, why doesn't he wanna listen—and I don't know how to explain. Even in church they are always complaining--- why every time you come sit on the chair and you leave your child making trouble there and other people are supposed to run after him to stop him from doing this and that, and you are just sitting there looking and doing nothing or beat him because he is your child. Since he is your child you must hit him so he could listen when you talk to him...”

**Participant 2** “...for example when the church is packed, they ask all the parents to bring their children at the front, and I can't do that they need to be with me, at least now some church members do understand but before they never use to understand, they will be like that parent is protecting her children because sometimes the ushers will come and address you that they would like all the children to go to the front-and I would tell them I can't I have got my reasons I will explain to you later as to why they need to be here with me...”

### 4.3.3 Lifestyle change

The discipline, or perceived lack thereof, and social judgments exacerbate the changes caregivers have to make in their lifestyle as a result of caring for a child with ASD. The participants in the study indicated that they had to make changes in their lifestyles in order to manage the demands of caring for a child with ASD. Some of the lifestyle changes were seemingly motivated by the need to protect their children with ASD from emotional trauma and/or harmful responses.

**Participant 5** “.... It's hard when it comes to attending the family gathering--- when there are functions/rituals. Luckily his nanny is our neighbour, back where I grew up in my

*mother's house—so when there are wedding functions, or family rituals I just leave him with his nanny—because people just see an ill-behaved child. A child with absolutely no respect. ...”*

**Participant 7** “... *I locked it, because if we gonna say that we only gonna lock only when he is around we gonna forget. We always need to get used to the idea that we always keep the gate locked ...”*

**Participant 2** “...*Uhhh you walk into a shop with him and there is too much light and obviously it affects him—too much light affects him and then he will be reluctant to go into the shop – so that means I can't shop anymore. Or when you arrive with him in a party or function and there are just far too many people for him, or the sound it's just too much and he is like no, mom lets go home---no but we all here the family is here and you want to be here as well—but he doesn't wanna be there so you have to leave and people say---oh no--lets –but no are you leaving guys? And I'm he can't be here so I cannot be here, he doesn't wanna be here he wants to go home, so you go home you know. What I'm saying is you miss out on those things just to accommodate him...”*

The responses indicated that not only did the participants feel the need to make lifestyle changes just to accommodate the emotional wellbeing of their children, they also needed to make financial lifestyle changes in order to accommodate their children's needs. The changes included less engagement in certain activities or curtailing a luxurious life.

**Participant 2** “... *Yeah obviously there is a bit of compromise, no more like luxury holidays all the year now and all that stuff. We needed to do that compromise you know cut down all the luxury life you used to and make sure that everything is taken care of ...”*

**Participant 3** “...*we just taking away maybe from going out—you go to cheaper activities you go to free parks that kinda thing but uhm—yah we manage—like the school fees I think it's like, one five [R1500] ...”*

Overall, it is clear from the participants' self-reports that having a child with ASD comes with multiple challenges. As a result of the reception of harsh or undesirable treatment, caregivers

reported feelings of shame. Broady et al. (2017) viewed such feelings of humiliation and shame as signs of felt stigma. The treatment that the participants received from the public made them view the world differently. However, some of the changes in lifestyle were as a result of economic challenges.

#### **4.3.4 Financial burden**

Financial stability was seen as a major factor contributing to a lifestyle change in the majority of participants. ‘Autism Speaks’ estimated that in the United States of America (USA), autism costs society an astounding \$126 billion per year (Kamaralzaman, Toran, Mohamed, & Abdullah, 2018). Non-medical costs were seen to account for the greatest proportion of the yearly expenditure. This is consistent with the participants’ reports that most of the costs include intervention services, special schools and food, as evidenced by the following quotes:

**Participant 6** “...I cover half of the fees, the disability grant helps us and we pay the other half...”

**Participant 5** “Mmm it’s very expensive, I think it’s better for someone who is unemployed because there is a governmental support grant offered in everything. I tried applying for it but I didn’t qualify because of my salary package as a mother. But at the same time, I have to pay for school, buy his medication, transport and his nanny. I also need to buy groceries, he is a very choosy eater, it’s unlike caring for a normal child and also the fact that he is not yet fully potty trained it’s like you are caring for an infant I still buy nappies. It’s very expensive ... and the fact that we still need to attend the speech therapist sessions, audiologist, a general practitioner ey a whole lot of doctors. So, obviously you can’t tell how much you will spend on a monthly basis...”

For some participants, tuition fees account for the greater part of the financial burden. Participants reported feeling the strain of tuition fees, as well as intervention services. The following quotes demonstrate that:

**Participant 3** “...I phoned around and got like prices that’s were like ---eish it was like five grand [R5000] a month and you still gonna pay for like extra therapy sessions that kinda thing---- I mean sometimes you had to pay 500 like a session so we kinda have to do it, so what we have notice is that a lot of those that don’t take medical aids, whether it’s a psychologist or a speech therapist they are much more flexible in terms of how often you come----- you know ---you gotta come twice a week and its 500—and I’m like no like a thousand rand a week are you nuts ...”

**Participant 1** “...schooling because it is ridiculously expensive [chuckles] it quite pricy at the Action in Autism, but they are doing a fantastic job and I wouldn’t take him out of there. But also, the location of the school out of Durban now he has to get transport from here to there so there is lot of costs involved ...”

**Participant 7** “...so I said I need to apply for social grant to sustain the expenses because the school on its own is expensive, transport on its own just to go to school we were paying R800.00 a month and the school is R2900.00. It was likely to bring the expenses down, plus we have got other kids he is not the only the child...”

Participants reported a number of struggles that they face on a daily basis. These struggles include challenges at shopping centres, not having sufficient money to obtain whatever their child needs, having to deal with public humiliation and judgments as a result of unaffordability and lack of information regarding their children’s condition.

**Participant 2** “... if for an example we are in a shop and he wants something that I can’t afford, something that I know very well that he won’t use it. It’s expensive for one and it’s not something he can play with, I don’t know why he wants it, because it has got no value to him it’s not something he can play with, and I will just put him on my back and people will be shocked and ask why are you carrying an “old man” on your back you spoiling him! Ohh this parent! You know—people just talk and they don’t understand why are you doing this...”

**Participant 4** “...I can’t afford because I don’t have money and support. If you could have seen him even now he has lost his weight. The school called me and asked why is this child

*losing weight. The lunch I can afford to make for him he doesn't want it so he doesn't eat it. Even in shop he just runs and chose what he wants, he takes things expensive things that you can't afford. I'll tell him, James please you can't have this mummy doesn't have money. He will scream and everybody in the shop will know that you don't have money to buy for him..."*

#### **4.3.5 Communication difficulties and caregiving**

Caregivers experiences of caring for a child with ASD present an extremely complex and challenging life (Gobrial, 2018). As much as finances play a huge role in the burden of care, communication difficulties could also exacerbate the burden that caregivers experience (Gobrial, 2018). One of the core features associated with the symptoms of ASD is impaired communication (APA, 2013). Many of the caregivers in the study experienced difficulties in terms of communicating with their children, as some of them were nonverbal and others could say minimal words. The following quotes illustrate the difficulties and frustrating times the caregivers faced as a result of their children's impaired communication.

**Participant 7** *"...when he wants something he would come to you and pull you to the kitchen or whatever and whatever that he wants is probably not available. He would point at the fridge you would open the fridge and he looks, it's not there and then he looks around for this thing. So, its communication basically that you cannot—uhm you don't know what he wants, next thing he starts crying and you like but what do you want. Uhm its better if what he wants is there, he will pull towards the fridge and sometimes he will open the fridge and then point and then —uhm you will then offer but yah mostly is communication. Because I think if we could cross that barrier of communication—uhm once he starts talking. I think he would make our lives much, much easier, because now you have to think for him, okay he probably wants this now, he probably wants that..."*

**Participant 5** *"...He has difficulties with speech. So, he expresses all his emotions by crying. When he is hungry, when the nappy is full you know he just cries. I think it is all caused by the fact that he can't speak to express his emotions..."*

**Participant 4** “.... I use to beat him, beat him and beat him even though he is a small boy but ill beat him, beat him-- because I thought he was being naughty. Now I understand him I no longer hit him. If he wants something he will take your hand to show you. Before he will come and take my hand and I’ll be like LEAVE ME ALONE!! LEAVE ME ALONE!! Why everytime you want to disturb me like this huh!? ...”

It is evident through the participants’ statements that, with time, caregivers did become attuned to their children’s ways of communicating. Even though it continues to be a barrier, participants reported that they were willing to learn both from their children and other sources of knowledge.

**Participant 6** “...he doesn’t speak. He will take a hand and he will show us to the microwave or to the toaster or to whatever he wants so that the way he communicates. But they are working on sign language and with pictures. ...”

**Participant 3** “...he has got a speech delay or developmental issue but he does try to talk but you do understand him sometimes- but sometimes it’s just like a baby bubbling and you have no idea what’s going on. ...”

**Participant 1** “...The only thing that is a challenge is sometimes.... is obviously communication, because he is not verbal, so for me its fine because most times I can understand what he is trying to say to me even though he won’t use words but he will be able to get to the message across that now I want this or I want this but the challenge lies now when there is other people involved that are not, I’m not sure how to put this but that are not in our direct circle...”

Irrespective of all the efforts they invested in fostering and facilitating mutual communication with their children, the participants seemed overwhelmed and questioned whether their efforts in caring for their children were adequate, thus creating an increase of anxiety. This is consistent with Gobrial’s (2018) argument that the incurable nature of the disorder, and the guilt that one is not doing enough as a parent, lead to caregivers experiencing poor emotional well-being.

### 4.3.6 Emotional burden

Caregivers experiences of poor emotional wellbeing, as well as the despair and guilt that they may have caused their children’s disability, compounds the challenging experience of caring for a child with autism (Gobrial, 2018). The following quotes depict the emotional turmoil caregivers experience as a result of caring for a child with ASD:

**Participant 5** “... *I think it has affected my family negatively--- you know in every family they expect that you will have a normal child ...*”

**Participant 1** “...*it affected me [chuckles]—yah it affected me—okay what happened was, he was diagnosed at the age of 3 when he was about to turn 4 but obviously I had known that there was something wrong from the time he was about 12 months so he wasn’t verbal, he met all of his other milestones so that was fine but he wasn’t talking, he wasn’t bubbling, he wasn’t doing anything...*”

**Participant 6** “...*it did change my life I must say uhm because I never knew what autism was or nothing like that obviously I knew of special needs but never in my life have I ever come across that, so uhm I wasn’t, it was very overwhelming and stuff but it was kinda like it didn’t hit me when they were like he is Autistic and I went and did some more research and then it eventually came to realization that he is special needs and there are things that I’m gonna do and change...*”

**Participant 3** “...*with him all we want—is he gonna be able to speak, am I gonna look out for this person forever—ever. I think that’s what I’m of kinda thinking of now—like this person is literally gonna stay with us until whatever age and we sort of need to do things for him...*”

Some participants attributed the occurrence of ASD in their children to themselves. Self-blame was the biggest factor in the narratives. Janoff-Bulman (1979) argued that the direction of blame has major implications for individuals’ emotional well-being following a stressful event. The following quote depicts the level of self-blame caregivers felt:

**Participant 7** “...we even asked the doctor why the child has got autism he was like well there is no straight answer. So, when someone says there is no straight answer it leaves you like blank, because you asking yourself ---is it something that I did, maybe related to my family my genes or his genes—the father’s genes, we don’t know...”

#### **4.3.7 Support system.**

##### **4.3.7.1 Family support.**

The importance of social and emotional support is paramount in mediating the stressors. According to Miller et al. (2001), social support buffers the amount of stress caregivers’ experience. Some caregivers in the study felt they were being supported by their family members and that helped to mediate the amount of stress they experienced. Others felt they were not receiving enough support from their family members. The following quotes indicate the perceived support that the participants felt they receive.

**Participant 6** “...I live with my mother in-law and his uncle and they support us, yah, we live here with them ...”

**Participant 1** “I think just because people don’t necessarily understand like.... Caring for a child that has special needs what it entails so I think they always more on the side of assuming that you don’t actually need any more support than that what you actual have, or maybe----- I’m a professional nurse –I’m a nurse by profession. I think that they assume that just because I’m in the health field I have it sorted out basically, so not that they are not supportive it’s like I think they assume I don’t need their support.”

**Participant 5** “My partner is very supportive, it’s just that at the moment we do not stay together full time. He tries his utmost best to understand him to normalize his condition ... because even if we are going to the mall and he starts doing his things his father tries to understand him.”

**Participant 7** “Uhm my family is very supportive they understand him very well as we speak now he is with his gran from the father’s side. They understand him because there



*are other kids there. They support us and him in all aspects. My mother is a retired nurse so she did have a clue about autism and all that and she did say that I think this child has autism. She also came in very handy in terms of –do this and do that and she asked around...”*

Another source of support came in the form of siblings. The relationship between a typically growing child and child with ASD sometimes become ‘parentified’ (Boszormenyi-Nagy, 2014). That means that parental characteristics are displayed by the typical child towards with ASD child. There are certain dangers that this poses once it becomes burdensome to the child assuming the duties of being a parent (Hooper, 2007). However, caregivers reported the positive outcomes this has had on their children with autism.

**Participant 2** *“...his sister was born in 2008 so---- she is clever by nature, she is the one who is actually---I would say who actually helped him grow and understand certain things better in life and how things should be done -----big time ...”*

Some caregivers felt isolated and lonely with no support. Having a child with ASD is depicted as a hindrance in the amount of support they felt they had received as a caregiver.

Participant 4 *“...well I don’t have a family here. It was just me, my husband and my child. And my husband passed away in 2013. My daughter also I can’t take care of her, so one of the family members—my husband’s brother one day came to take her to Zimbabwe because I was struggling. But he has a problem and he can’t go anywhere that’s why he is living with me...”*

#### **4.3.7.2 Governmental support.**

The participants indicated that they were trying by all means to cope with the condition that was confusing to them or which they knew little about. They tried getting support from government facilities, such as information on autism spectrum disorder, in order to empower and educate themselves. A number of participants reported not receiving any support from the

government, for reasons such as getting a better salary package, while others reported receiving governmental financial support. The following quotes portray the participant's perception about governmental support:

**Participant 3** *"...No! Maybe there is, it's just that we not taking advantage of it—uhh I don't know any that I could or get. Maybe it's just because I don't need it for a lack of a better word ..."*

**Participant 1** *"Ahh nope, there is nothing that I know of from governmental facility. I know they do have schools for children with special needs but their schools don't cater to their needs..."*

**Participant 5** *"Yah I'm not receiving any assistant.....they told me that because of my salary package I don't qualify."*

**Participant 7** *"...I went to pharmacy and the pharmacist said do you know that you can get this medication because I am a pharmacist at King Edwards—free—instead of paying, because we were paying about R700 on a monthly basis and at time he was not in school because it was just too much for us, we took him out of school. So, what we did was we followed the procedure where he continued to receive his medication through the clinic..."*

**Participant 2** *"There is nothing that I know of beside the school, I think it's subsidized by the government since we don't pay any school fees I would take that as the government support."*

**Participant 6** *"...we have a disability grant, yah, we went through SASSA so they pay us every month. The process was long and hard, yah since last year November and we got it this year in February..."*

#### **4.3.7.3 Limited resources**

The limited number of resources was another theme that emerged. Participants expressed concerns in terms of finding schools for their children with autism, as well as finding early

intervention centres. The participants indicated that there were few schools available and some were extremely expensive.

**Participant 2** *“... it wasn't that easy in a sense but it helped being part of the Action in Autism centre because that's where we got the list and then we looked at the area I stay near the Woodpark area so we learnt that there was one in woodlands which was close by so they were the first school to approach---parents were complaining that their kids are 10 years others 15 years and they have never been to school because there is just nothing available for them.”*

**Participant 7** *“...it was a bit of a challenge to find a school, because we applied first at Golden gateway around November and they told us that based on the report they received from his previous school [Action in Autism], that their school is not the best school for him because of his condition. He is a smart child and they won't be doing him any favour by accepting him and they only told us this in November so we had a bit of a challenge its November he can't go back to Action in Autism . The school are opening early in 2018 and we need to get a school and there aren't so many schools that accept kids with autism and so what we did is we ended up approaching the Department of Education ...”*

**Participant 1** *“...I didn't find any early intervention centre so they basically take kids after they are 6—from the age of 7 onwards and by then is a little bit too late--- also the facilities that they do have, they don't--- okay the ones that I actually went to and got information on--- they don't separate their children on what you call--- their developmental levels, so they sort of like ahh all children are group together—ahh because you can assess even if you don't do a proper assessment on a child but you can tell that this child is better off than this child, so they all group into one so my question will then be how do you stimulate this child in his way and then also stimulate this one when they have completely different needs...”*

**Participant 3** *“...you have got to go through an Educational Psychologist, you gotta have a report, they look if they can fit you into the school because the numbers are quite low...”*

#### 4.3.8 Coping strategies

In all the adversity that comes with caring for a child with ASD, caregivers find ways to cope and lead a meaningful life. Coping can be seen as an action taken with an aim of diminishing the burden of challenges. It can also be seen as related to resilience (Bouwer, 2014), which is conceptualised as the ability to recover from adversity in order to lead a meaningful life. Participants reported devising strategies to cope with the challenges of caring for a child with ASD. The strategies included patience, avoidance, continuing with what works and sharing responsibilities.

**Participant 7** “...fortunate part is that we are both here and if she is under a bit of stress or if he is stressing her and then I’m around to sort of relieve that stress. She would go somewhere, go to the bedroom or whatever and then I will stick around. So, yah we just support each other...”

**Participant 5** “When he wants to sleep I take him to the bed and stay with him, he will jump until he tires out and falls asleep...”

**Participant 3** “I will tell you once or twice and then I’ll have to raise my voice maybe that will do it. But uhm like I said I have become a bit more patient.”

**Participant 2** “...You know as he grows up you find things that work, attending the support group it really helped a lot because you get to hear what works for others, so you also try that to see if it also works for you. And then uhm but the main thing is not knowing how to solve -----you try everything --- and eventual you find what works, for example when I remember when he throws tantrums, I’ll carry him on my back (ngizombeletha) that used to calm him, somehow he used to enjoy that, it calmed him down...”

**Participant 6** “...we brush him uhm also when he is overwhelmed and that his uncle will take him out like undress him and take him out on the balcony and he seems to calm down or we hold him tight when he has his meltdowns and stuff like that ...”

**Participant 4** *“I try but it’s hard because I don’t have money, I can’t buy him everything. Maybe today he is supposed to eat fruits or something –I can’t. He likes pizza, for example when he sees the ad on television he will start shouting “pizza, pizza, pizza”. So I’ll try and buy him pizza and he will eat nicely.”*

#### **4.4 Summary**

Participants spoke about the challenges they face on a daily basis as a result of caring for a child with ASD. Challenges included difficulties with potty training; their children insisting on sameness and disciplinary issues. However, they try and find common ground with their ASD child through patience and sometimes giving in. Participants described the challenges they face in trying to find schools for their children which included financial issues. However, once they managed to get their children into schools, they felt that the schools they found offered invaluable support in their lives. Participants used words such as *‘brilliant’*, *‘compassionate’*, and *‘well-established’* to describe the teachers and learners. The reports from the participants speak volumes about the experiences of being a caregiver of a child with ASD.

## CHAPTER FIVE: DISCUSSION

### 5.1 Introduction

The main aim of this study was to understand and document the experiences of family caregivers living with children with ASD in Durban, KwaZulu-Natal. This chapter entails a discussion of the results based on the experiences of seven female caregivers, who identified themselves as biological mothers of children with ASD. The use of semi-structured interviews allowed for rich data collection and an insight into their 'lived' experiences. The presentation of this discussion chapter is informed by the research objectives and the literature is used to find general consensus with the existing body of knowledge.

The participants described their experiences of caring for a child with ASD as a '*roller coaster*' ride. Each day is full of surprises, as some participants reported that they never knew what to expect and would have to take each day as it comes. This is consistent with the findings that caregivers' experiences of raising children with ASD fluctuate over time (Dixon, 2015). Each participant shared challenges they faced from the moment they received the diagnosis of ASD. The diagnosis of ASD was noted to do one of the two things within families: it drew families together (making them stronger) or drove them apart. This was echoed through the relevant body of knowledge by Myers, Mackintosh, and Goin-Kochel (2009).

### 5.2 Caregivers' Day to Day Experience of Raising a Child with ASD

The participants described that the diagnoses of their children came with major life changes. Their everyday life began to change drastically as they began to face many challenges. It

was evident from the data collected that the participants were faced with challenges, including having to instil discipline, dealing with temper tantrums, understanding their children's routines, as well as a limited social life. Consequently, participants experienced huge lifestyle changes. These changes potentially affect caregivers in numerous ways, including increased stress (Chu, Mohd-Normal, McConnell, Tan, & Joginder-Singh, 2018). Additionally, some participants expressed the desire to understand what their children were trying to say to them as this could lessen the burden.

The caregivers felt that they needed to do more than just conventional parenting. As one participant expressed, at times they felt they also needed to think for their child. This meant that they had to redefine or rethink ways of interacting with their children. Almost all the participants expressed that they eventually understood what their children were trying to communicate; however, this understanding revolved around the child's basic needs, for example, pointing to the fridge when hungry.

Raising a child with ASD comes with many demands physically and mentally (Myers et al., 2009). Participants reported the difficulties they face in trying to instil discipline in their children. Most participants alluded to how stressful it is raising a child, who is perceived by the public of being overindulged by their parents. Consistent with findings by previous studies (Davis & Carter, 2008; Ludlow et al., 2012), the challenging behaviours in need of discipline included changes to routines and temper tantrums. Some participants reported trying different ways to discipline their children. This mostly ended in failure, whereas other participants were conflicted with regard to a proper method of discipline. One participant admitted to using corporal/physical punishment as a means of disciplining her child but this subsequently ceased after becoming a

member of Action in Autism. The use of corporal punishment as means to discipline a child with ASD is also evident in a study conducted by Barends and Mohamed (2013).

Many participants reported that they eventually learnt to accept the difficult behaviour, but the judgement received as a result of the lack of understanding by the public proved to be difficult for participants to handle. Ludlow et al. (2012) also found that perceived stigma or social judgment made caregivers perceive themselves as not 'good-enough' parents. Consequently, caregivers reported avoiding social situations. Phrased differently, participants reported having to change their lifestyles. These lifestyle changes came at a cost to caregivers of children with ASD, as they either had to avoid social interactions by cancelling events or put excessive amount of time in planning events. Similarly, participants reported that as much as they want to socialise, they also need to protect their children's psychological and physical state. This was found to be congruent with other research studies (Barends & Mohamed, 2013; Davis & Carter, 2008; Ludlow et al., 2012).

### **5.3 The Available Support for Caregivers Living with Children with ASD**

Another social implication for caregivers was the perceived limited support. The support system varied from the governmental support, family support and the support from the Action in Autism organization. The majority of participants felt that they are not receiving any support from governmental facilities to minimise the burden of care and to also educate themselves about ASD. The participants expressed that they wished the government could be more involved with ASD.

Participants reported having to browse online to understand what exactly ASD was and to their disappointment only the worst was depicted by the internet. This is congruent with a study by



(Barends & Mohamed, 2013), which also reported that participants turn to the internet which to their dismay gave misleading information.

Some participants reported receiving support from family members, but despite receiving this support, they still felt that they have little time to socialise. One particular participant reported feeling lonely and stressed at times as there was no immediate family member around for them. This was evident in a study by Ludlow et al. (2012) that discussed how some caregivers felt isolated.

An important source of support for all the participants appeared to be the contact they had with Action in Autism. This was where all the participants felt heard and understood as they could compare their children's difficulties, and talk about their experiences. Some participants found this social interaction by means of comparison to be helpful in coping with stress. In contrast, some participants were 'put off' by the comparison and stopped attending the groups. A study on caregivers of children with Duchenne muscular dystrophy found social comparison to be somewhat therapeutic (Hodges & Dibb, 2010). According to Ludlow et al. (2012), however, such comparisons could also be counter therapeutic as they could evoke negative feelings, such as frustration or feeling threatened. Schools are another source of support; however, participants reported facing difficulties in trying to find schools for their children around Durban, South Africa. It is evident that in South Africa it is hard to find early intervention centres for children with ASD (Barends & Mohamed, 2013; Madlala, 2012).

#### **5.4 The Burden of Care**

Participants expressed that limited resources were one of the major issues in Durban, South Africa. As a result, participants reported extreme economic difficulties as they could not afford

school fees, transportation costs, as well medical and psychological interventions. This is in line with the finding that locating a well-equipped intervention centre is extremely difficult (Barends & Mohamed, 2013).

Caring for a child with ASD has emotional implications (Ludlow et al., 2012). Participants were cautious about stating their love for their children with ASD; however, it was evident in their narratives that there has been extreme emotional strain on them, as well as their loved ones. This was expressed by participants who overtly stated feeling stressed at times; one further stated that she sometimes resorted to a glass of wine as a coping mechanism. Other participants' stress levels compounded to a point of self-blame. Another participant felt emotionally isolated and desperate for support. This is in line with a study of Ludlow et al. (2012) which also found caregivers of children with ASD to feel lonely and emotionally distant from others. Caregivers of children with ASD deal with an exclusive set of challenges. Chu et al. (2018) argued that this makes it hard for caregivers to obtain the required emotional support, as well as to be understood by their families.

Caregivers who reported that their children cannot speak, are not fully potty trained and that they have extreme temper tantrums, were observed to be experiencing a higher burden of care, compared to caregivers of children who could take care of themselves and had better communication skills. This is believed to be as a result of the increased time needed in taking care of the ASD child and the limited time for self (Lerthattasilp, Charernboon, Chunsuwan, & Siriumpunkul, 2015).

### **5.5 Strategies Caregivers Employ to Deal with the Challenges**

As much as the burden of care is stressful to the caregivers, they have developed numerous coping mechanisms over time. Participants reported how some of the challenges became easier to

handle over time, as they learned what their children were attempting to communicate and respond when spoken to. Participants expressed the importance of being patient and trying to understand the uniqueness of each and every situation. One participant reported that patience has never been part of her character but that she needed to learn to be patient with her child as this was one of the things that seemed to work.

Some participants felt that the support they received from Action in Autism was invaluable, regardless of the meetings being infrequent. Interacting and sharing ideas with other caregivers of children with ASD was found to be crucial. One participant reported that through group interaction they were introduced to the method of gradual immersion. They gradually introduced their children to new things, and this helped them deal with challenging behaviours, such as temper tantrums. This is consistent with the argument that support, as a way of coping, alleviates feelings of burden (Lerthattasilp et al., 2015).

Another participant reported that in her family, she and her partner share responsibilities as a couple, such that when one feels drained, the other takes over. The participant reported that sharing responsibilities helps them deal with stress. This is congruent with the Barends and Mohamed's (2013) study which also found that participants stressed the role of co-parenting in elevating stress.

Two participants commented on how affectionate their children were. One child enjoyed moments where her caregiver brushes his hair and that appeared to calm him down. The other caregiver reported that carrying her child on her back had calming effects irrespective of the judgment she received from the public. Affectionate methods of coping are also seen in the study by Ludlow et al. (2012), where participants report cuddling their children as a way of dealing with tantrums.

## 5.6 Conceptual Framework and Research Findings

The compressive model used in this study to understand caregivers' experiences is the stress process model (SPM), earlier discussed in detail. This model was proposed by Pearlin et al. (1990), who argued that the amount of stress caregivers experience is determined by four aspects, namely, (1) background and context, (2) sources of stress, (3) mediators of stress, and (4) outcomes.

In this study, it is evident that the background and context plays a significant role in the amount of stress each caregiver experiences in caring for a child with ASD. Caregivers who reported poor socio-economic status and limited family composition expressed extreme challenges and difficult caregiving experiences. For example, one participant reported having no family members in Durban, as they were all in Zimbabwe. The participant reported feeling lonely and she was also struggling financially.

Participants with somewhat adequate support from their family members reported that family support lessened the burden, even though they still didn't have enough time to themselves. Furthermore, the amount of available community-based resources (e.g. school/early intervention centres) was also seen to potentially affect the amount of stress caregivers perceived and eventually experienced.

The second aspect of the model is the source of stress/stressors. These are the demands and constant needs of the care recipient, in this case an ASD child. The demands are a consequence of the severity of the symptoms (Bolden & Wicks, 2008), for example, communication difficulties, memory difficulties, and sleep problems. Pearlin (1985) argued that these play a role of a primary stressor. As a result of the primary stressor, a secondary stressor is experienced, which arises out

of situations wherein the caregiver has other roles to assume, excluding caring for their child with ASD. For example, a caregiver spends a lot of time caring for their child with ASD to the point where performance of another role becomes improbable. Aspects of these stressors were evident in the descriptions provided by the caregivers raising a child with ASD. For example, there was evidence of lifestyle changes reported by the caregivers. Communication difficulties and potty training were also among the aspects of stressors that made the caregiving experience difficult.

Thirdly, there are mediators of stress which are seen as mechanisms that caregivers employ to alleviate and prevent stress (Pearlin, 1999). Coping and social support are perceived as the two main mediators of stress for caregivers. Pearlin et al. (1990) described the mechanisms of coping as the practices caregivers employ to care for themselves. This refers to caregivers' ability to take time off from their caregiving responsibilities, which helps them respond much better to stress than those with limited support or resources at their disposal. One participant reported that she shares the responsibility with her husband, such that if one is tired, the other takes over. All the participants reported that the support they receive from Action in Autism is important and valuable in their caregiving experience.

Lastly, the outcomes are the crucial part of this model. The outcomes involve the psychological well-being of an individual, as well as physical health, as these determine the individuals' ability to sustain themselves in their social roles (Pearlin et al., 1990). The interplay of the earlier mentioned components of this model manifest in this last component. The outcomes identified by SPM include, but are not limited to, depression, anxiety, anger, and inability to fully engage in roles previously held. Caregivers who reported limited family support, as well as severe ASD symptoms, expressed feeling stressed and preoccupied by what to do next or where to get the next meal.

## **5.7 Summary**

This chapter presented the discussion of the results which was informed by the research objectives. Literature was utilised to compare the findings of the current study with the existing body of knowledge. The chapter further integrated the theoretical framework with the result of the participants. The evidence of stress and other difficulties experienced by caregivers of children with ASD were evident. Regardless of the stressful nature of caring for children with ASD, most participants were hopeful about their circumstances, reporting that they dealt with challenges when, and if, they came their way. This relates to the finding by Barends and Mohamed (2013) that caregivers usually find ways of adapting accordingly.

## **CHAPTER SIX: CONCLUSION AND LIMITATIONS**

This study aimed to document events and encounters that family caregivers face in raising their children living with the lifelong disorder of ASD in the area of Durban, KwaZulu-Natal. There is evidence provided in this study on the impact of caring for a child with ASD on the daily lives of caregivers. The study highlighted a number of encounters that caregivers face which may lead to lifestyle changes and/or financial difficulties, to name only a few. This study also provides insight into areas relating to schooling, and the support that caregivers need, as well as their children with ASD.

### **6.1 Clinical Implications and Further Research**

Despite this study's limitations, it has provided some insight into caregivers' experiences of caring for a child with ASD in Durban, South Africa. It provided an invaluable insight from the caregivers' perspectives, as to how they struggle and cope with the burden that arises as a result of caring for a child with ASD.

The study raised a number of issues, such as the lack of knowledge about ASD, the impact of ASD, the challenges that caregivers were faced with when seeking professional help, and finding appropriate schools for their children. A better understanding of these complex issues can lead to improved support from the government and society. It can also ensure that an empathetic caregiver-health professional relationship is easily established and maintained (Chu et al., 2018).

It is hoped that this study will bring about the awareness and knowledge of what caregivers of children living ASD face in their struggle to obtain relevant information, coming to a full

understanding of the diagnosis, finding effective early intervention and receiving sufficient support from educational and health facilities..

Further research that focuses on the lived experiences of fathers living with children with ASD in Durban is highly recommended as their perspectives of raising a child with ASD may create a holistic picture and further understanding of caregivers' experiences of raising a child diagnosed with ASD.

Furthermore, the majority of participants were black, calling for a need of a large qualitative study that would be representative of the South African population. Such a study would lead to a more generalised view, understanding and conclusive perspective about experiences of family caregivers of children living with ASD.

## **6.2 Limitations**

The major limit of this study, which is well-documented in literature about qualitative studies such as this one, is its generalisability (Cresswell & Poth, 2017). The findings, however, do allow the reader to get a subjective account of caregivers' lived experiences and how they eventually cope with adversity, which can be viewed as an indication of shared experiences (Ludlow et al., 2012).

The second limitation is the study's sample size. The researcher managed to interview seven participants: one white, one coloured and five black. Therefore, the study may not be entirely representative of the Durban population. According to Durban Population Statistics (2019), Indian or Asian people makes up about one quarter of the population in Durban and their absence in this study should be noted.



The venues used to interview participants were challenging as most participants were interviewed from home and others from their places of work during lunch time, as they could not make time to come to the university clinic for interviews. This affected the length interview time.

The process of transcription took longer than anticipated, as some recordings had to be transcribed and translated into English. It is possible that certain narratives may have been lost through translation.

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## APPENDICES

### APPENDIX A: Interview Schedule

#### Family caregiver interview schedule

##### Aim of the study

To document experiences of family caregivers of children living with autism spectrum disorder in Durban, KwaZulu-Natal.

I am interested in finding background information relating to your child's developmental milestones which will assist in the ongoing study. I will be asking you some questions about your child, you, and your family. Please feel free to withdraw from answering any question that makes you feel uncomfortable.

##### 1. Participant details

Participant: 1

Age .....

Marital status

Single	Married	Divorced	Widow	Widower
--------	---------	----------	-------	---------

Race

Black	White	Indian	Coloured	Other
-------	-------	--------	----------	-------

Gender

Female	Male	Other
--------	------	-------

Relationship to the child .....

Signature .....



## 2. Child's Details

Date of Birth .....

Gender .....

Official Diagnosis .....

Age at Diagnosis .....

Diagnosed by      Psychologist..... Paediatrician ..... Psychiatrist.....

### **Part 2**

#### **Exploration of caregiver's experiences**

1. Tell me about your day-to-day experiences of caring for a child living with autism spectrum disorder.
2. Tell me about the nature of support that you receive from family members.
3. Tell me about the nature of support that you receive from the government.
4. What difficulties do you encounter in raising a child living with autism spectrum disorder?
5. What strategies do you employ in dealing with challenges that come with raising a child with autism spectrum disorder?

## **APPENDIX B: Information Sheet**

Dear Participant

### **Aim of the Study**

This study will be conducted by Siluleko Zulu (a Clinical Psychology Master's Student). I am interested in exploring the experiences of family caregivers of children living with autism spectrum disorder. The study aims to document experiences of family caregivers of children living with autism spectrum disorder in Durban, KwaZulu-Natal.

### **Description of the study procedure**

- If you agree to participate in this study, you will be asked to have a 45-minute interview with the researcher.
- You will be interviewed once; the interview will be audio recorded. The material recorder will be held in a password protected file accessible only to me and my supervisor. After a period of 5 years, it will be wiped clean; documents will be shredded and burned as stipulated by University rules.

### **Risks/discomforts of being in this study.**

- This study may evoke some emotional discomfort. Consequently, therapy will be made available to you should you need to address any issues.
- The University of KwaZulu-Natal Student Counselling will offer therapy for free to any individual who may feel emotionally distressed following his/her participation in this study.
- There are no other foreseeable risks.

### **Benefits of being in the study**

Participation in the study will offer you an opportunity to talk about your experiences related to raising a child living with autism spectrum disorder.

**Privacy and confidentiality**

- This study is anonymous; your identifying information will not be retained. The records of this study will be kept strictly confidential.

**Payments**

- There will be no payments received for participating in the study.

**Right to refuse or withdraw**

- The decision to participate in this study is entirely upon you. You may, at any stage of the study, refuse to continue without affecting your relationship with the University of KwaZulu-Natal. You have a right not to answer any single question, as well as withdraw completely at any stage during the process of the interview, or to request the interviewer not to use any of your information.

**Right to ask questions and report concerns**

- As a participant in this study, you have a right to ask questions and to have those questions answered before, during or after the research interview.

If I have any further questions/concerns or queries related to the study, I understand that I may contact the researcher at ([215080548@stu.ukzn.ac.za](mailto:215080548@stu.ukzn.ac.za) or 0783790904), or his supervisor, Professor Steven Collings at ([collings@ukzn.ac.za](mailto:collings@ukzn.ac.za) 031 260 2414).

In the event of any problems or concerns/questions you may contact the researcher at (provide contact details) or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

**HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X54001

Durban

4000

Kwazulu-Natal South Africa

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: [HSSREC@ukzn.ac.za](mailto:HSSREC@ukzn.ac.za)

## **APPENDIX C: IsiZulu Information Sheet**

### **IPHESHANA LOLWAZI**

Sawubona: Mhlanganyeli

#### **Inhloso vocwaningo**

Lolucwaningo lizokwenziwa ngu-Siluleko Zulu (umfundi owenza i-master's kwi-clinical psychology). Intshisekelo yami ukuphenya kabanzi mayelana nezinto abazali abanakakela abantwana abanesifo okuthiwa- iautism spectrum disorder abahlangabezana nazo. Inhloso yaloluphenyo ukuthola kabanzi ngezinqinamba abazali babantwana abene-autism spectrum disorder abahlangabezana nazo.

#### **Incazelo mayelana nenqubo yaloluphenyo**

- Uma uvuma ukubamba iqhaza kulolu cwano, ngizocela ukuba nengxoxo nawe lapho ngizokubuza khona imibuzo ezothatha imizulu engamashumi amane nanhlanu.
- Ingxoxo sizoba nayo kanye, futhi izoqoshwa. Konke okuqoshiwe kuzogcinwa kuyinfihlo kwifayela elivikelekile elizoba sendaweni ekhiyekayo iminyaka emihlanu, bese kuyabhujiswa ngomlilo njengoba kulotshiwe emigomeni yase-Nyuvesi.

#### **Ingozi mayelana nokuzibandakanya kulolucwaningo**

- Lolucwaningo lingavusa ukukhathazeka ngokomzwelo. Ngakho-ke ukulashwa ngokomoya kuzoba khona ukuze usizeke kunoma iziphi izinkinga.
- Igumbi lokululekwa kwabafundi e-Nyuvesi yakwa-Zulu lizohlinzeka ngolasho ngokomoya mahhala kunoma imuphi umuntu ozibandakanye kulolucwaningo wase ehlukumezeka ngokomoya.
- Azikho ezinye izingozi esilindele ukuthi zingabakhona kulolucwaningo.

#### **Izinzuzo zokuzibandakanya kulolucwaningo**

Ukubamba iqhaza kulolu cwano kuzokunikeza ithuba lokukhuluma ngezinto ohlangabezane nazo ezihlobene nokukhulisa ingane ephila ne-autism spectrum disorder.

#### **Ubumfihlo nokuyimfihlo**

Ulwazi lwakho elikumazisi ngeke lugcinwe. Ulwazi oluqoshiwe mayelana nalolucwaningo lizokulondolozwa ngokuyimfihlo.

## **Ukukhokha**

- Ngeke kube khona umvuzo wemali ngokuzibandakanya kwakho kulolucwaningo.

## **Ilungelo lokunqaba noma ukuhoxisa**

Isinqumo sokubamba iqhaza kulolu cwaningo siphezu kwakho. Kungenzeka, nganoma isiphi isigaba socwaningo, wenqabe ukuqhubeka ngaphandle kokuthinta ubuhlobo bakho neNyuvesi yaKwaZulu-Natali bulimazeke. Unelungelo lokungaphenduli imibuzo, futhi uhoxise ngokuphelele kunoma yisiphi isigaba ngesikhathi senqubo yokuxoxisana, noma ucele lowo obuza imibuzo ukuba angasebenzisi ulwazi lwakho.

## **Ilungelo lokubuza imibuzo nokubika ukukhathazeka.**

- Ngokubamba kwakho iqhaza kulolu cwaningo, unelungelo lokubuza imibuzo nokuthi iphendulwe le mibuzo ngaphambi, ngesikhathi noma emva kokuxoxwa kocwaningo

Uma ngineminye imibuzo noma ukukhathazeka okuhlobene nocwaningo, ngiyaqonda ukuthi ngingathintana nomcwaningi ku (215080548@stu.ukzn.ac.za noma 0783790904), noma umphathi wakhe, uProfesa Steven Collings at (collings @ ukzn .ac.za 031 260 2414).

Uma kwenzeka kunoma yiziphi izinkinga noma ukukhathazeka noma imibuzo ungaxhumana nomcwaningi (215080548@stu.ukzn.ac.za noma 0783790904) noma iKomidi lezokuHlaliswa kwezokuHlaliswa koBuntu ne-Social Sciences yase-UKZN, imininingwane yokuxhumana kanje

## **HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

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KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609

Email: [HSSREC@ukzn.ac.za](mailto:HSSREC@ukzn.ac.za)

## APPENDIX D: Informed Consent

I,..... have been informed about the study entitled (the experiences of family caregivers of children living with autism spectrum disorder) by Siluleko Zulu (Researcher).

I understand the purpose and procedures of the study.

I have been given an opportunity to ask questions about the study, and have had them answered to my satisfaction.

I declare that my participation in this study is entirely voluntary, and that I may withdraw at any time.

If I have any further questions/concerns or queries related to the study, I understand that I may contact the researcher at ([215080548@stu.ukzn.ac.za](mailto:215080548@stu.ukzn.ac.za) or 0783790904), or his supervisor, Professor Steven Collings at ([collings@ukzn.ac.za](mailto:collings@ukzn.ac.za) 031 260 2414).

I hereby provide consent to:

Participate in the study YES/NO

Audio-record my interview YES / NO

\_\_\_\_\_

\_\_\_\_\_

Signature

Date

## **APPENDIX E: IsiZulu Informed Consent**

### **Ingcwadi Yocwaningo Enemvumo**

Igama lami Ngingu,..... (Bhala amagama akho Ngokuphelele), ngalokhu ngiyaqiniseka ukuba ulwazi oluqokethwe kulelipheshana Kanye nenhloso cwaningo ngiyayiqonda ngokuphelele. Ngiyavuma ukuthi besengazisiwe kabanzi mayelana cwaningo, nayoyonke imibuzo yami iphenduliwe kabanzi. Ngalokhu ngiyavuma ukubamba iqhaza kuloluphenyo.

Ngियाqonda ukuthi nginenkululeko, nelungelo lokwenyula kuloluphenyo kunoma kusiphi isikhathi, uma ngifisa kanjalo.

### **Nginikeza imvume:**

Yokuzimbandakanya kulophenyo

**Yebo/ Qha**

Yokuba ingxoxo yami iqoshwe

**Yebo/ Qha**

---

Sayina lapha

---

Usuku

## APPENDIX F: Ethical Clearance



02 October 2017

Mr Siluleko Zamakuhle Zulu (215080548)  
School of Applied Human Sciences – Psychology  
Howard College Campus

Dear Mr Zulu,

Protocol reference number: HSS/1161/017M

Project title: The experiences of family caregivers of children living with Autism Spectrum Disorder

### Approval Notification – Expedited Approval

In response to your application received on 21 July 2017, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

**PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

Cc Supervisor: Professor Steve Collins  
Cc Academic Leader Research: Dr Jean Steyn  
Cc School Administrator: Ms Ayanda Mtshali

Humanities & Social Sciences Research Ethics Committee

Dr Shenuka Singh (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X51001, Durban 4000

Telephone: +27 (0) 31 260 8887/03504655 / Facsimile: +27 (0) 31 260 4899 Email: [ai-ban@ukzn.ac.za](mailto:ai-ban@ukzn.ac.za) / [swmarin@ukzn.ac.za](mailto:swmarin@ukzn.ac.za) / [mbhuc@ukzn.ac.za](mailto:mbhuc@ukzn.ac.za)

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## APPENDIX G: Gatekeeper's Letter



A Non-Profit Organisation (NPO)  
 94 Keal Road, Sydenham, Durban  
 Kwa Zulu Natal P.O. Box 30210, Mayville South Africa  
 Tel: 031 2074858  
 E-mail: [info@actioninautism.org.za](mailto:info@actioninautism.org.za)  
 Website: [www.actioninautism.org.za](http://www.actioninautism.org.za)  
 Registration No. 047-002-NPO

---

7 February, 2017

Dear Siluleko

Further to your request for permission to conduct a study in our organization. We have reviewed your request and would like to have the following documents before permission can be considered:

1. A copy of ethical clearance from your institution
2. Data collection instrument (questions that will be asked)
3. A letter of consent for the participants

We look forward to hearing from you.

Sincerely,

Liza  
**Liza Aziz**  
 Chairperson: Action in Autism

## APPENDIX H: Editor's Certificate



**Helen Bond**

IMPELA EDITING SERVICES

impelaediting@gmail.com

079 395 5873

26 August 2019

### CERTIFICATE

SILULEKO ZULU

[sluleko.zulu501@gmail.com](mailto:sluleko.zulu501@gmail.com)

Dear Mr Zulu

Thank you for using Impela Editing Services to proofread your Master's dissertation.

We have proofread for errors of grammar, punctuation, spelling, syntax and typing mistakes. We have formatted your work according to the APA guidelines, added a digital table of contents, and checked the references (this means checking the formatting).

Please note that Impela Editing does not accept any fault for changes made to a document after emailing the final draft and issuing a certificate.

I wish you the very best in your submission and for your future career.

Kind regards

Helen Bond (Bachelor of Arts, HDE)

## APPENDIX I: Turnitin Digital Receipt

[Skip to Main Content](#)



### Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

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