

**LIVING WITH A CHILD WITH AUTISM SPECTRUM DISORDER:**

**TWO SOTHO MOTHERS' EXPERIENCES**

**by**

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**BLOEMFONTEIN**

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**July 2021**

**Declaration by student**

I, Kaizer Witty Ndlovu, hereby declare that the dissertation titled "*Living with a child with autism spectrum disorder: Two Sotho mothers' experiences*" is my own work and it has not been submitted by me at any other university or faculty for graduation.

Signature \_\_\_\_\_ Date \_\_\_\_\_

## **Declaration by Supervisor**

### **Supervisor's Permission to Submit**

I hereby approve of KAIZER WITTY NDLOVU (2007139757) submitting this dissertation "*Living with a child with autism spectrum disorder: Two Sotho mothers' experiences*" in fulfilment of the requirements for the degree Magister Artium in the Department of Psychology, Faculty of Humanities, at the University of the Free State. I also declare that this dissertation has not been submitted as a whole or partially to the examiners previously.



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**July 2021**

## Proof of language editing

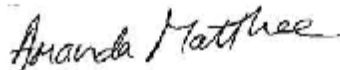


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## Abstract

Autism spectrum disorder (ASD) is a developmental disorder that affects individuals' social, emotional, and communication. Raising a child with ASD is challenging for families, especially the mothers as primary caregiver. This study aimed to explore and describe two Sotho mothers' experiences of living with a child with ASD. The study was qualitative and phenomenological in nature. Semi-structured interviews were conducted with two Sotho mothers living with an ASD-diagnosed child. Thematic analysis was used to analyse the data collected from the interviews. A biopsychosocial-spiritual model (BPSS) was used as the underpinning theory of this study. The findings revealed both the negative and positive experiences of these two Sotho mothers. The study showed that the negative experiences of the mothers could be ascribed to a lack of knowledge and understanding of ASD-related issues, schooling issues, the challenge of managing the child's symptoms, and poor social support. On the other hand, the mothers' positive attitude and acceptance of the children's diagnosis positively impacted their experiences. The study also highlighted that despite the myriad of challenges with which the Sotho mothers had to cope, they continued to appreciate and support their ASD-diagnosed children. It was evident that cultural sensitivity and the lived experiences of mothers need to be taken into account in the diagnosis and treatment of ASD.

This research adds to the body of knowledge about the experiences of mothers living with a child with ASD. There is a need for further research about the experiences of mothers and families living with a child with ASD, especially within indigenous communities.

- **Keywords:** Autism spectrum disorder, culture, experiences, mothers, Sotho

### **Abbreviations and acronyms**

ABA	applied behavioural analysis
APA	American Psychological Association
ASA	Autism South Africa
ASD	autism spectrum disorder
BPSS	biopsychosocial-spiritual model
CBT	cognitive behavioural therapy
CDC	Centers for Disease Control and Prevention (USA)
CNS	central nervous system
DoH	Department of Health (South Africa)
DSM	Diagnostic Statistical Manual
PECS	Picture Exchange Communication System
SSRI	selective serotonin reuptake inhibitor
TEACCH	Treatment and Education of Autistic and Related Communication- Handicapped Children
WHO	World Health Organization

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## CHAPTER ONE

### BACKGROUND AND INTRODUCTION

#### 1.1 Introduction

Autism spectrum disorder (ASD) is a developmental disorder that affects individuals. It is considered stressful for a family to cope with a family member with ASD (Fewster & Gurayah, 2015). Children with ASD experience deficits in emotional expression as well as behavioural and communication problems, which can cause stress for these children's families, especially the parents (Fewster & Gurayah, 2015; Gobrial, 2018).

According to the South African Department of Health [DoH] (2017), there has been a marked rise in the prevalence of ASD in the country over the past 30 years. About 2% of the South African population is affected by ASD (DoH, 2017). Autism South Africa, as cited in Fewster and Gurayah (2015), stated that the prevalence of ASD in South Africa is about 1 in every 150 infants. The increasing prevalence of ASD implies that more and more families are prone to stress and have to cope with the challenges related to living with a child with autism.

Caring for a child living with ASD presents significant challenges and affect the mothers as the primary caregiver's quality of life (Tathgur & Kang, 2021). Psychological distress, anxiety, depression and other physical and mental problems are some of the negative experiences that caregiver face while caring for the children living with ASD (Geertsema et al., 2016; Tathgur & Kang, 2021). Parents living with a child with autism in South Africa are faced with challenges such as delayed diagnosis and management of the child's condition, and uncertainty about the future of the child in terms of education and career pathing (Brown & Kapp, 2014; Geertsema et al., 2016; Mubaiwa, 2008; South African Department of Basic Education, 2016). Living with a child with ASD requires parents, especially the mothers as primary caregiver to strive to meet the demand associated with the management of the child's

symptoms; and this requires more time, effort and patience from them (Tathgur & Kang, 2021). Hayes and Watson (2013) indicated that mothers of children living with ASD experienced significantly higher levels of distress and depression compared to parents with normally developing children. Fewster and Gurayah (2015) also observed that parents living with a child with autism are uncertain about the future of their child as they have restricted access to services.

## **1.2 Problem Statement**

ASD has become a global concern affecting increasing numbers of families, especially mothers as primary caregivers in many families especially in Africa. In developing countries such as South Africa, there is a lack of data on the prevalence rate of ASD. This delays progress with interventions aimed at mitigating the effects of ASD or supporting families of children with ASD. Bayat (2007) as well as Fewster and Gurayah (2015) noted the lack of studies on ASD and the experience of mothers with children with ASD in developing nations (including South Africa). The few available studies mostly focus on quantitative methodologies and the negative experiences of the mother.

South Africa is a country with a diversity of cultures and beliefs. Here, the Basotho people have a unique cultural belief regarding disease and illness (Edward, 2011; Sodi et al., 2011). These cultural beliefs can play a key role in the conceptualisation of illness and the help-seeking behaviour of parents (Edward, 2011, Sodi et al., 2011). This raises the question: How does the Sotho culture influence the experiences of mothers living with a child with ASD? Given this background, it is essential to gain a better understanding of the experiences of Sotho mothers living with a child with ASD.

### 1.3 Aim of the Study

This study aimed to explore and describe two Sotho mothers' experiences of living with a child with ASD.

### 1.4 Research Question

This study sought to answer the following research question:

*What are the Sotho mothers' experiences of living with a child with autism spectrum disorder?*

### 1.5 Significance of the Study

This study may add to the body of knowledge on ASD. Practically, the findings of this study can enhance existing interventions used by psychologists, doctors, social workers, and other professionals to assist parents living with children with an ASD condition. The Basotho people have their own cultural beliefs regarding the aetiology, diagnosis and treatment of ASD. Thus, this study will add value by providing insight into the importance of cultural sensitivity when working with children and parents in the context of ASD. The findings will also add value towards theory development, especially in the context of academia.

### 1.6 Definition of Key Concepts

**Autism spectrum disorder** (ASD) refers to a neurological condition that negatively affects the development of a child. It is marked by deficits in social communication, and also repetitive behaviours and the presence of restricted interest which results in lifelong disability and impairment (American Psychological Association [APA], 2013).

**Sotho** (plural *Basotho*) refers to a member of a group of people living chiefly in Botswana, Lesotho, and Southern and Northern South Africa. In this study, reference is made only to Southern Sotho who reside in the Free State province of South Africa.

**Sesotho** refers to a group of Bantu languages spoken by the Sotho peoples, of which the most important are Sepedi (also called *Northern Sotho*), Setswana (also called *Western Sotho*), and Sesotho (called *Southern Sotho*). In this study, reference is made to Southern Sotho which is spoken in the Free State province of South Africa.

**Culture** refers to the set of practices by which meanings are produced and exchanged within a group, according to the definition of Garuba and Raditlhalo (2008).

### 1.7 Academic and Personal Motivation

Autism spectrum disorder was identified as a psychiatric disorder in the 1940s (Kanner, 1943). Yet, it is still not well understood by the general public. The majority of studies on ASD seem to have focused on the causes, diagnosis and treatment of ASD, with special reference to the individuals rather than the family as a system (Bakare et al., 2009; Ruparelia et al., 2016;). The current identification of the autism as falling on a spectrum led to an increase of the number of diagnoses and subsequently the number of people affected, especially mothers (APA, 2013). Focusing on mothers from rural areas in South Africa provides a new perspective as most studies to date have focused on parents in developed and urban communities.

On a personal level, when I first saw an awareness campaign about ASD in 2008 at the University of the Free State, I become curious as to why this diagnosis was receiving such special attention. Through my interaction with parents and families living with a child with ASD I became aware of the needs of such families in rural areas, especially the mothers. Thus, I felt the need to conduct this study that could provide insight to practitioners assisting families affected by ASD. Bringing the cultural element into the study was critical for me because it is an ethical responsibility of any clinician to be culturally sensitive when assessing and intervening on different conditions. The aim of this study was therefore to gain a deeper

understanding of the Sotho cultural perspective on ASD as a critical step towards better interventions for families living with a child with ASD.

### 1.8 Outline of Chapters

This document consists of seven chapters which are outlined below.

- **Chapter 1 – Background and rationale:** This chapter presents the background to the study. The aim of the study is explained and the key research question is outlined. The envisaged value-add of the study is also explained.
- **Chapter 2 – Literature review of autism spectrum disorder:** This chapter discusses a literature review of ASD. It provides context for the study and highlights a possible research gap about ASD. Reference is made to the early accounts of ASD, definition complexities, the Diagnostic Statistical Manual [DSM] (American Psychological Association [APA], 2013), etiology and epigenetics, as well as interventions.
- **Chapter 3 – Sotho mothers and ASD: A biopsychosocial-spiritual perspective:** This chapter presents a literature review on mothers' experience of living with a child with ASD with special reference to Sotho mothers. The chapter uses the biopsychosocial-spiritual model (King, 2000; Sulmasy, 2002) to describe the mothers' experiences of different domains of the model.
- **Chapter 4 – Methodology:** The research methodology guiding this study is discussed in this chapter. The chapter provides a breakdown of the steps followed to answer the research question of the study.
- **Chapter 5 – Findings.** This chapter presents the findings of the study. It also outlines the themes and sub-themes gathered from the semi-structured interviews conducted with the mothers.

- **Chapter 6 – Discussion:** This chapter presents a discussion of the study's findings, focusing on the five themes that emerged from the study, namely lack of knowledge and understanding, schooling, social support, the management of ASD symptoms, and attitude.
- **Chapter 7 – Conclusion:** The outcomes and value-add of this study are explained in this chapter. This chapter also touches on the limitations of the study as well as recommendations for future research.

## CHAPTER TWO

### LITERATURE REVIEW ON AUTISM SPECTRUM DISORDER

#### 2.1 Introduction

In this chapter, a literature review of ASD will be presented. This is aimed at providing context for the study and at highlighting a possible research gap about ASD. The chapter will also cover the early account of ASD, definition complexities, the Diagnostic Statistical Manual (DSM) (American Psychological Association, 2013), etiology and epigenetics, as well as interventions.

#### 2.2 Early Account of Autism Spectrum Disorder

According to Witkin et al. (2011), the word autism was first used by Eugen Bleuler, a Swiss psychiatrist referring to mental illness or schizophrenia. This narrative was later changed by Kanner (1943) who referred to autism as a neurological condition that affects child development. Kanner (1943) identified symptoms such as communication problems, echolalia, and engaging in activities that are self-damaging such as hitting one's head on the wall. Other early symptoms identified included obsessing about monotonous activities and unusual objects. Kanner (1943) developed an *early infantile autism* diagnostic category which helped to develop the autism concept. More importantly, Kanner (1943) described this condition as very rare.

An early study by Asperger (1944) described autism as consisting of repetitive behaviour and the inability to make eye contact. Asperger (1944) termed children with this condition as *autistic psychopaths*. The conceptualisation of autism as childhood schizophrenia was refuted by Kolvin (1971), who identified autism as a developmental disorder rather than psychosis. The British psychiatrist Wing (1981) refined Asperger's concept of autistic psychopaths and termed it *Asperger's syndrome*, arguing that it was a

separate concept from autism. This view by Wing (1981) contributed to the reconceptualisation of autism as a condition that occurs on a spectrum, as identified in the current DSM5 (Zaky, 2017).

### ***2.2.1 The Prevalence of Autism Spectrum Disorder***

Classifying autism as being on a spectrum (ASD) has led to an increase in its diagnosis worldwide (Chiarotti & Venerosi, 2020; Franz et al., 2017). According to the Centers for Disease Control and Prevention (CDC) (2020), the number of children eight-year-old children diagnosed with ASD has increased from 1 in 59 in 2018 to 1 in 54 in 2020. This in part stem from the fact that the previous Diagnostic and Statistical Manuals (DSMs) did not allow for children to be diagnosed with both autism and Attention Hyper Activity Disorder (ADHD). Instead, the current DSM-5 allows for multiple diagnoses to be made. Also, ASD includes a broader spectrum of disorders with following symptoms, thus accommodating more children under the title ASD who would previously be diagnosed with other disorders. The same report (CDC, 2020) has shown that ASD tends to affect 29.7 per 1000 boys and 6.9 per 1000 girls who are eight years old.

ASD is a global problem. Various countries are raising awareness through campaigns such as ASD Day (Franz et al., 2017). This is primarily aimed at showing solidarity with the families who are dealing with ASD. ASD has become so prevalent globally that strategic organisations such as the World Health Organization (WHO) acknowledge it as among the worrisome problems affecting children and their families (Franz et al., 2017).

Chiarotti and Venerosi (2020) also indicated that the number of ASD cases continues to increase globally. Their study assessed the prevalence rate of ASD in regions such as Asia, America, Europe, and the Middle East. The study found that even though the prevalence rates

are different, ASD is on the rise. This calls for workable interventions to help families impacted by ASD.

According to the South African Department of Health (DoH) (2017), there has been a marked rise in the prevalence of ASD in the country over the past 30 years. About 2% of the South African population are affected by ASD (DoH, 2017). According to Fewster and Gurayah (2015), the number of children with ASD is projected to increase significantly every year, which is worrying given the challenges associated with ASD. There is still a lack of accurate data on the prevalence rate of ASD in South Africa (DoH, 2017; Fewster & Gurayah, 2015). Sadly, this lack of data may delay the roll-out of awareness campaigns and interventions among communities (Van Schalkwyk et al., 2015). Van Schalkwyk et al. (2015) further remarked that it took longer for autism to become a topic of studies in South Africa.

Van Schalkwyk et al. (2015) explained that progress was being made regarding an autism database for South Africa due to the emergence of pressure groups such as Autism South Africa (ASA). The ASA has established several branches across the country to help families of children with ASD. This will help to capture data on ASD that can easily be accessed by practitioners and scholars.

### **2.3 Definition Complexities**

ASD presents itself differently based on the age of onset, the severity of symptoms, and child's individual characteristics (Hens, 2019). Regardless of the commonly and strongly shared characteristics of ASD, such as social deficits, there is no single identifiable behaviour that is typical of ASD (Powers, 2000; Yergeau, 2018). Therefore, autism is a heterogenic and polysemic concept (Hens, 2019). ASD is heterogenic because it has biological, cognitive, environmental, and social connotations (Hens, 2019; Yergeau, 2018). It is also polysemic as

it has multiple meanings to different people in different contexts (Hens, 2019). Based on the above argument, no single definition can adequately capture autism spectrum disorder.

The first definition of ASD from genetic perspective is from Kanner (1943, p. 242) who defined autism as “a rare condition that affects speech development, causes abnormal behaviour, and a proclivity for loneliness among children”. Powers (2000) highlighted the biological perspective by defining ASD as a condition that negatively affects brain development and consequently delays growth in the child. Fewster and Gurayah (2015) considered the cognitive perspective as they defined ASD as a condition among children which affects their mental functioning and ability to communicate which overall affects how they socialise. The implications are that the child may lag in terms of achieving the typical developmental milestones (Fewster & Gurayah, 2015; Powers, 2000).

From a phenomenological perspective, Hens (2019) and Yergeau (2018) defined ASD as a phenomenon rather than a cognitive and genetic concept. They maintained that ASD is a lived and shared experience. Also, Hens (2019) posited that ASD can create different ways in which people meaningfully interpret their experiences. Yergeau (2018) believed that ASD is a narrative condition because people affected are constantly defining and redefining their experiences based on their context, making ASD an ever-evolving phenomenon (Hens, 2019; Yergeau, 2018). However, the commonly used definition of ASD is the one formulated by the APA (2013) which defines ASD as a neurological condition that negatively affects the social, communication and behavioural development of a child.

### ***2.3.1 Diagnosis Issues***

The differences in the definition and etiology of ASD have led to challenges in the diagnosis of ASD (Ruparelia et al., 2016). The meta-analysis conducted by Bakare and Munir (2011) found that late diagnosis was a common problem in African countries compared to

their developed counterparts. It was also found that most children in Africa were diagnosed with ASD between the age of eight years and adolescence. According to Bakare and Munir (2011) and Ruparelia et al. (2016), a number of these children that were diagnosed late in their lives were presenting with severe symptoms of ASD. For Ruparelia et al. (2016), this could signify that a cohort of children presenting with mild and moderate symptoms of ASD may be left undiagnosed. This, in part, may contribute to the lack of accurate data about the prevalence of ASD in developing countries.

Another practical challenge associated with the diagnosis and treatment of ASD is the lack of appropriate facilities in developing countries (Bakare et al., 2009; Ruparelia et al., 2016; Van Der Walt, 2008). This makes the pathway to the diagnosis of and therapy for ASD a daunting task for parents living with a child with ASD as they sometimes have to travel long distances to access a health facility that can help with a diagnosis (Bakare & Munir, 2017; Ludlow et al., 2011; Ruparelia et al.; 2016).

Lack of awareness and knowledge about ASD by both the parents of children with ASD and clinicians can contribute to the challenges associated with the diagnosis of ASD (Bakare et al., 2009). In a study that investigated Nigerian clinicians' view of the etiology of ASD, Bakare et al. (2009) found that a significant number of clinicians attributed ASD to supernatural forces because the patient or their parents having angered the ancestors. Mthombeni and Nwoye (2016), in their study on the caregivers' response and understanding of ASD, found that a number of them also considered supernatural beings as the cause of ASD. They found that this contributed to the delays in seeking a medical diagnosis and interventions because caregivers often consult traditional diviners and healers before consulting medical practitioners (Edwards, 2011; Mthombeni & Nwoye, 2018).

Developed countries have standardised tools for screening and diagnosing ASD. However, these tools are often not adapted for use in most if not all African countries

(Ruparelia et al., 2016). For example, in African countries minimal consideration is given to the impact of language and culture on the screening and diagnosis of ASD. This calls for the development of culturally appropriate tools for African countries. Such tools should at least take into consideration the narrative tradition of African compared to the writing tradition of the Western countries (Ruparelia et al., 2016).

Another challenge is that ASD is often accompanied by comorbid and other psychological problems that present with symptoms that may be confused with the symptoms of ASD in the absence of repetitive and restricted behaviours. For example, Basu and Parry (2013) asserted that children's tendency to over-indulge in computer and cell phone games may affect their social and communication skills. This, in turn, may be construed as a clear symptom of ASD if not critically investigated (Ruparelia et al., 2016).

#### **2.4 Development of the DSM Classifications and Criteria**

Literature indicates that in the original Diagnostic Statistical Manual (DSM) published in 1952 and in DSM-2 published in 1968, autism was classified under schizophrenia (Gane, 2008). Therefore, even though Kanner's work (1943) played a significant role in providing a better understanding of autism, the diagnosis remained covered under schizophrenia until the compilation of DSM-3 in 1980 in which autism was included as an individual diagnosis (APA, 1980). In this case, autism gained a diagnosis status together with Pervasive Developmental Disorder Not Otherwise Specified [PDD NOS] and was classified as Pervasive Developmental Disorder [PDD] in axis II of DSM-3.

The development of DSM-IV saw the inclusion of Asperger's disorder (Gane, 2008). Specifically, it was DSM-4-TR that managed to align Asperger's disorder in the same spectrum as autism and PDD NOS (APA, 1994). Currently, DSM-5 (APA, 2013) provides the new standard for an ASD diagnosis. It has eliminated all the subcategories under which ASD was categorised and now uses one category called autism spectrum disorders (APA,

2013). The implication of this is the removal of Asperger's disorder and PDD NOS as diagnostic labels.

#### ***2.4.1 Diagnostic and Statistical Manual-5 – Criteria for ASD***

The DSM-5 (APA, 2013) criteria for ASD are based on two main domains of functioning, which are deficits in social communication and interaction, and a repetitive pattern of behaviour, interests, and activities.

The qualitative deficits in social communication and interaction in different contexts include the following:

- The deficit in social-emotional reciprocity such as limited sharing of interest and affect, or failure to initiate reciprocal social interactions
- Deficits in non-verbal communication necessary in social interaction as manifested by age-inappropriate integration of verbal and non-verbal communication, abnormal eye contact, and deficits in understanding and use of gesture which may be absent for some children living with ASD
- Deficits in the development, maintenance, and understanding of relationships as manifested by challenges in adjusting behaviour to suit different social contexts, difficulty in making friends, or not being interested in peer relationships.

Also, DSM-5 specifies that at least two symptoms should be present in the domain of restricted, repetitive pattern of behaviour, interest, and activities, and hyper or hyporeactivity to sensory input as manifested by:

- Stereotypical or repetitive motor movement, use of objects or toys, such as the lining of toys, flipping objects, echolalia, or simple motor stereotypes

- Highly restricted and fixed interests that are abnormal in intensity or focus, such as strong attachments to or preoccupation with usual objects or persistent interest
- Insistence in sameness, inflexible adherence to the routinely ritualised pattern or verbal behaviour, expressed through extreme stress due to small changes, rigid thoughts, and greeting ritual.
- Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment such as apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement.

## **2.5 Etiology and Epigenetics**

This section will highlight literature on the etiology of ASD, and role of epigenetics in ASD. Research conducted by Campisi et al. (2018), Hallmayer et al. (2011), and Modabbernia et al. (2017) point to the literature consensus that ASD has multiple causalities, which include genetic and environmental factors. Various studies have shown that a genetic component plays a role in the etiology of idiopathic autism (Campisi et al., 2018; Hallmayer et al., 2011; Modabbernia et al., 2017; Taylor et al., 2014). However, environmental factors may also play a role in the etiology of ASD (Campisi et al., 2018).

A meta-analysis study conducted by Hallmayer et al. (2011) identified environmental factors such as heavy metals, pollutants, vaccines, nutrition, and substances to be risk factors from pre-conception to early childhood for development of ASD. Loth et al. (2017) cited that there are about 500 different genetic variants that may be linked to the development of ASD. Various researchers believe that vaccinations for measles, mumps, and rubella play a role in the development of ASD (Campisi et al., 2018; Loth et al., 2017). The debate about whether genetic or environmental factors lead to the development of ASD will continue. However, the

above findings by Hallmayer et al. (2011), Campisi et al. (2018), and Loth et al. (2017) contribute significantly to the management and treatment of children living with ASD.

Duffney et al. (2018) postulated that epigenetics dysregulation contributes to the etiology of ASD. The mutation of genes responsible for protein regulation results in the lowering of protein expression which in turn may result in the development of ASD, intellectual disability, and possible behavioural problems (Duffney et al., 2018; Wiśniowiecka-Kowalnik & Nowakowska, 2019)

Researchers such as Duffney et al. (2018), Nardone and Elliott (2016), and Wiśniowiecka-Kowalnik and Nowakowska, (2019) revealed that ASD has multiple etiological factors. These factors may be genetic or environmental. However, none of these factors on their own can cause ASD (Nardone & Elliott, 2016). Therefore, research shows that both genetic and environmental factors have a causal relationship with ASD (Nardone & Elliott, 2016; Wiśniowiecka-Kowalnik & Nowakowska, 2019).

## **2.6 Treatment of Autism Spectrum Disorder**

The increase in the number of people diagnosed with ASD highlights the need for appropriate and effective treatment and interventions for the individuals diagnosed with ASD and their families (Campisi et al., 2018). Brentani et al. (2013) postulated that the treatment and interventions for ASD should focus on addressing social, communication, organisational, and adaptive skills of both the child and the family. In the next section, ASD treatment modalities and intervention programmes aimed at helping the patients and their families will be presented. This includes psychotherapeutic, pharmacological, parental education, and tailor-made programmes.

### ***2.6.1 Psychotherapeutic Treatment***

Individual psychotherapeutic approaches such as person-centred therapy (Rogers, 1986), logotherapy (Frankl, 1981), mindfulness (Kabat-Zinn, 1982) and cognitive behavioural therapy (Beck, Rush, Shaw, & Emery, 1979) are often used to help parents and children living with ASD, depending on the severity of the child's ASD condition. Group cognitive behavioural therapy (CBT) (Reaven et al., 2012) is used in some cases to help school-age and adolescents living with ASD with skills to manage comorbid factors such as anxiety and depression that they may be experiencing. This model used CBT techniques to help change the thinking and behavioural pattern of children diagnosed with ASD. According to Reaven et al. (2012), care should be taken when using this approach because its efficacy has been proven to be high among high-functioning children who may be struggling with anxiety or depression which may affect the prognosis.

### ***2.5.2 Pharmacological Treatment***

ASD is viewed as a heterogenic condition that has both clinical and behavioural presentations (Eissa et al., 2018). Children diagnosed with ASD may present with different symptoms, disorders, and medical conditions such as impulsivity, heteroaggressiveness, inattention, anxiety, depression, anger, epilepsy, sleep problems, and structural learning challenges (APA, 2013; Campisi et al., 2018; Sadock et al., 2015).

There is no specific pharmacological treatment that can be effective for all children living with ASD (Eissa et al., 2018; Campisi et al., 2018). Thus, pharmacological treatments are often directed to ameliorate specific ASD symptoms. Risperidone is one of the main drugs used in the treatment of ASD for children above five years of age who present with irritability, self-harming behaviours and aggressive symptoms (Kumar et al., 2012).

Clozapine and olanzapine are also assumed to be effective pharmacological interventions for ASD patients presenting with suicidal behaviours (Eissa et al., 2018; Miral et al., 2008).

Risperidone is also indicated for the treatment of sensory motor and language symptoms of ASD among children between the ages of eight and 18 (Eissa et al., 2018; Leclerc & Easley, 2015). Ritalin is considered to be a stimulant for the central nervous system (CNS). Thus, it contributes in the treatment of inattention, hyperactivity and impulsivity (Sathe et al., 2017). Leclerc and Easley (2015) found that fluoxetine is a selective serotonin reuptake inhibitor (SSRI) that is indicated in the treatment of repetitive behaviour (the obsessive-compulsive symptoms) and anxiety among patients living with ASD. Cognitive disorders and insomnia's symptoms are also treated using pharmacology among patients living with ASD.

Currently, there is no absolute pharmacological treatment for ASD. However, the combination of behavioural therapy, pharmacological drugs such as SSRIs and a controlled learning environment remains the main areas of investigation for the future management of ASD (Eissa et al., 2018; Campisi et al., 2018; Sathe et al., 2017).

### ***2.5.3 Parental Education***

Parent training interventions involve the family and the parents of a child living with ASD as the family and parents play an integral part in the assessment and management of the child (Soorya et al., 2011). Parent training is based on the premise that behaviour is learned through different contingencies in a family setting. Therefore, any attempt to change such contingencies to reinforce and promote appropriate behaviour is considered critical (Corcoran, 2000). This intervention programme aims to improve the parent and family's social skills required to help with the management and coping with living with a child

diagnosed with ASD. Brentani et al. (2013) warned that for this programme to be effective the functioning and motivation of the family or parents is paramount.

One of the commonly used interventions for parents' education is applied behavioural analysis (ABA) (Cooper et al., 2007) which is a behavioural modification intervention based on the operant conditioning principle. The ABA approach addresses behavioural deficits or excesses that a child living with ASD may present with. It utilises reinforcement techniques to foster social adaptive skills for the child living with ASD. This intervention was reported to be effective when used to help children diagnosed with ASD in their early childhood stages (Brentani et al., 2013; Cooper et al. 2007).

#### ***2.5.4 Formal Programmes***

Since the work of Wing (1981), tailor-made programmes have been developed to help both parents and children living with ASD. This section presents some of the commonly used programmes in ASD interventions.

*Treatment and Education of Autistic and Related Communication-Handicapped Children* (TEACCH) (Brentani et al., 2013) is a classroom-based clinical and training service that is provided by professionals to a child living with ASD. It focuses on the behaviour and communication of a child living with ASD, and on understanding the child's world view. The intervention is directed towards reorganising the child's environment and activities to suit the strengths and interests of the child. This, in turn, helps the child living with ASD to learn and initiate meaningful communication that is critical for forming and maintaining social relationships (Brentani et al., 2013; Cooper et al., 2007).

*The Behavioural Discrete-Trial Programme* (Bogin et al., 2010) is aimed at helping children living with ASD to obtain communication skills. It includes training children to sit, concentrate to a trainer, and imitating verbal commands and nonverbal behaviours. Through

this programme, children living with ASD learn speech through imitating the naming of body parts, people's names, and the use of pictures. This is intended to help children living with ASD improve communication and social skills over time (Bogin et al., 2010).

*Assistive technology programmes* use technological devices such as tablets, computers, and communication boards to help children with ASD to interact with other people. The *Picture Exchange Communication System* (PECS) is one of the strategies used through which a child is taught to use picture symbols to make requests, and to ask and answer questions.

## **2.7 Conclusion**

Based on the above discussion it is evident that research on ASD is growing to provide a better understanding of children on the autism spectrum, and to provide appropriate interventions to such children and their families. The need for research on intervention programmes that are culturally appropriate for African children and families living with ASD has also been highlighted. The chapter will also inform the discussion of this study's findings in Chapter 6.

## **CHAPTER THREE**

### **SOTHO MOTHERS AND ASD: A BIOPSYCHOSOCIAL-SPIRITUAL PERSPECTIVE**

#### **3.1 Introduction**

This chapter covers mothers' experiences of living with a child with ASD with special reference to Sotho mothers. The *biopsychosocial-spiritual model* is used to describe the mothers' experiences in terms of the different domains of the model (Leigh, 1983; King, 2000; Sulmasy, 2002).

#### **3.2 The Biopsychosocial-Spiritual Model**

The biopsychosocial-spiritual model (BPSS) (Engel, 1977; King, 2000; McKee & Chappel, 1992; Sulmasy, 2002) was initially proposed as an alternative to the biomedical model (Varela et al. 1991), which was viewed as a reductionist perspective to conceptualise disease and illness. According to Leigh (1983), the biomedical model did not significantly acknowledge the individual's illness, attitude, experiences, culture, and language in its conceptualisation, diagnosis, and treatment of illnesses. It was also argued that the reductionist perspective of the biomedical model minimally took into account the influence of the health system, family, and professionals in the broader understanding and treatment of illness. Leigh (1983) conceptualised illnesses as complex phenomena that cannot have a single primary cause but can stem from multiple factors that may be biological, psychological, and/or social.

The amendment of the constitution of the World Health Organization (WHO) (1999) to include spiritual wellbeing in the conceptualisation of health has led to the inclusion of a spiritual domain in the initial biopsychosocial model, turning it into a biopsychosocial-spiritual model (King, 2000; Sulmasy, 2002; Winiarski, 1997). This model has been used in

research to look at the formulation of the diagnosis and treatment of illnesses (Engel, 1992; King, 2000; Leigh, 1983; McKee & Chappel, 1992; Saad et al., 2017; Sulmasy, 2002).

Although this model was used extensively in research, little has been done to use this model in qualitative research to understand the subjective experiences of those directly and indirectly affected by illnesses such as ASD. Consequently, this study intended to use the BPSS model to explore the experiences of Sotho mothers living with a child with ASD.

### **3.3 Parenting a Child with ASD Through the Lens of the BPSS Model**

Several studies have investigated the experiences of parents living with a child with ASD using other theoretical models. Gane (2008), for example, used attachment theory (Bowlby, 1980) to study mothers' experience of having a child diagnosed with ASD. Van Rooyen (2016) used Bronfenbrenner's (1977) ecological systems theory to study South African fathers' experiences of caring for a child with ASD. Matenge (2013) and Rabba et al. (2019) used a phenomenological perspective to explore the experiences of parenting a child with ASD. This section presents a review of the literature associated with the parents' experience of living with a child with ASD, with special emphasis on Sotho mother's experiences using the BPSS model.

#### **3.3.1 Biological Domain**

This section will discuss literature about the mothers' experience of managing the biological implications of living with a child with ASD. This will include mothers' experiences of the symptoms and diagnosis of ASD both from the Western and Sotho cultural perspectives.

##### ***3.3.1.1 Symptoms***

Individuals living with ASD present with different symptomology depending of their age and cognitive abilities. Mothers of individuals living with ASD are constantly impacted

by the manifestation of these symptoms. Bal et al. (2019) indicated that parents are mostly impacted by three core ASD symptoms, namely deficits in language development (communication), behavioural problems, and sensory challenges.

The language development of children with ASD exacerbates their parents' predisposition to stress (Sturm et al., 2017). ASD children's regulation problems associated with eating, emotions, and sleeping have also been found to negatively affect the parents' experience. The child's intolerance to change and preference for repetitive, non-functioning activities and interests, including routine and ritual behaviours, is also linked to parental stress and frustrations (Sturm et al., 2017). Change in these routines often results in the development of new obsessions, tantrums or anger, which can also become challenging to manage for the parents (Bal et al., 2019; Sturm et al., 2017).

Children living with ASD sensory challenges related to touch and noise are some of the common causes of negative experiences by parents (Bakare et al., 2009). Also, sensory challenges are constantly forcing parents to adjust their family environment to accommodate the needs of the child.

In the Sotho culture, ASD symptoms are recognised although they may not be associated with the diagnosis. Communication and behavioural challenges, combined with other psychiatric symptoms, may be deemed as communication by the ancestors rather than ASD symptoms. This can be caused by two ancestral spirits, namely those who are related to the patient (which is acknowledged as a way to communicate a certain message to the patient or family), and those that come from a foreign tribe (evil or harmful spirits) (Edwards, 2011; Kriel, 2003; Obioha & T'soeunyane, 2012; Sodi, 1998). Although mental disorder symptoms are recognised within the Sotho culture, there is no diagnosis of a mental disorder such as ASD.

### ***3.3.1.2 Autism Spectrum Disorder Symptoms Across the Developmental Stages***

The symptoms of ASD differ widely based on the age, and the cognitive and language development of the individual (Bal et al., 2019). ASD is generally expected to change as an individual develops. However, researchers have found that certain symptoms may remain stable across an individual's developmental trajectory (Bal et al., 2019; Sturm et al., 2017). This section focuses on reviewing the presentation of ASD symptoms across different developmental stages.

#### ***The Infancy and Early Childhood Stages***

ASD symptoms may be present but not overtly noticeable among infants before the age of two years. Infants younger than 24 months of age living with ASD may have difficulties with verbalisation, gestures and responding to their names (Seltzer et al., 2003). During toddlerhood, children with ASD may present with regression from previously mastered skills in language, communication and social interaction (Bal et al., 2019). During this stage, children with ASD may struggle to maintain eye contact, show interest in play and express their emotions. Children in early childhood stage may present with poor social interest, the inability to develop peer relations and differentiate between people, lack of social play, and preference for aloneness (Bal et al., 2019; Seltzer et al., 2003; Sturm et al., 2017).

#### ***The Middle, Late Childhood and Adolescent Stages***

This is a stage between seven and 18 years of age. During these stage individuals are expected to have developed significant skills in language, communication and social interactions (Bal et al., 2019; Sturm et al., 2017). During the middle, late childhood and early adolescent stages, individuals with ASD may find it difficult to take turns during an interaction, form and maintain friendships, adapt to change, handle sensory challenges, have unusual interests, and struggle with anxiety and depression (Bal et al., 2019). In addition,

teenagers with ASD may be hyperactive, impulsive and aggressive, and become involved in self-injurious behaviour. They may also present with unusual mood or emotional reactions, and sleeping or eating habits. Research shows that during these stages, adolescents may experience an increase in behavioural and psychiatric symptoms, and the onset of seizures associated with puberty (Bal et al., 2019; Piven et al., 1996; Sturm et al., 2017). Also significant improvement in self-care, educational achievement and communication skills was observed in these stages (Sturm et al., 2017).

### ***The Adulthood Stage***

This stage starts at the age of 18 years. Adults living with ASD show greater improvement in language development, and in restricted and repetitive behaviour and interests (Piven et al., 1996; Sturm et al., 2017). However, adults may struggle to understand what others feel or think, which may affect their social interactions. Seltzer et al. (2003) explained that adults may show symptoms of anxiety in social situations and thus prefer to be alone. Adults may also not be interested in forming relationships and may experience depression and anxiety when routines are changed (Piven et al., 1996; Sturm et al., 2017). This corresponds with the assertion by Piven et al. (1996, p. 527) that “ASD is a lifelong disorder whose features change with development”.

#### ***3.3.1.3 Diagnosis***

According to Clark et al. (2017), Mayers (2013), and Ward et al. (2016), parents often report that when their children were between the ages of one and four years they could notice certain developmental delays. The mothers in these studies reported that observing symptoms such as delayed speech, difficulty with eye contact, and behavioural problems led them to seek medical help for a possible diagnosis and treatment options. Ward et al. (2019), in a study examining the practitioners' view of the assessment and diagnosis of ASD, found

that 92% of clinicians preferred not to give a diagnosis of ASD to a child especially when they are younger. This was found to be one of the causes of delayed diagnosis and intervention that results in parents being stressed and anxious about their child's symptoms (Ludlow et al., 2011; Matenge, 2013; Mayers, 2013).

Receiving a child's diagnosis of ASD was found to have an emotional impact both during and after the diagnosis (Ward et al., 2017). Mothers often reported that they mourned and experienced feelings of ambivalence after receiving their child's diagnosis (Rabba et al., 2019). This has resulted in parents oscillating between the denial and acceptance of the diagnosis (Rabba et al., 2019). A study by Fernández-Alcántara et al. (2016) found that parents, after receiving their child's diagnosis, experienced unexpected loss, and also viewed the diagnosis as unjust. This often leads to feelings of shock, denial, fear, anger, and sadness among parents (Fernández-Alcántara et al., 2016).

Sharing the diagnosis is an important part of managing the aftermath of an ASD diagnosis (Crane et al., 2016). Mothers often mentioned that having to comprehend what it means to live with a child with ASD while at the same time being expected to inform and educate the family about ASD has been a difficult experience for them (Watermeyer, 2009). The inability to disclose the diagnosis was found to be associated with difficulties in acceptance by the parents, which in turn made them feel isolated and hopeless. Lack of validation from family members hampered the mothers' ability to move on with their lives because they felt helpless (Crane et al., 2016). Being resolute after receiving the diagnosis was found to help improve how mothers experience their relationship with their child living with ASD (Rabba et al. 2019).

Bakare et al. (2009; 2011), and Ludlow et al. (2011) agreed that behavioural problems are one of the critical predictors of parental stress, especially among those raising younger

children living with ASD. Likewise, the studies of Bakare et al. (2009) and Weiss (2015) showed a positive correlation between the behavioural problems of a child living with ASD, and parental stress. Crane et al. (2016) affirmed that externalising behavioural problems was deemed to be an important predictor of parental stress.

Within the Sotho culture, the process of diagnosing mental disorders, including ASD, requires one to determine who caused the illness or why the illness occurred in the first place (Edwards, 2011; Sodi, 2011). Thus, just like the DSM-5 classification, the Basotho people have their own classification of illnesses (Mthombeni & Nwoye, 2015). The Basotho people have two categories of illness classifications. The first is *the natural causes of illness* (Kriel, 2003; Sodi, 1998). These are illnesses caused by physiological malfunctioning such as epilepsy and hypertension. The second is *supernatural causes of illness* (Sodi, 1998), which are illnesses caused by supernatural forces. The manifestation of ASD falls into the second category (Edwards, 2011; Kriel, 2003).

According to the Basotho people, illnesses caused by supernatural forces are often associated with people who have used *ditlari* (traditional medicine) to cause the illness out of malicious intent, or they are the result of the *Badimo* having withdrawn their protection of the person due to particular displeasure. Therefore, among the Basotho, the cause of illness can be traced back to what has happened in the past (Edwards, 2011).

The Basotho people have their way of a) making a diagnosis, b) determining the etiology, and c) treating the illnesses, including mental disorders. The most common method is the *dingaka tsa ditaola* (divination doctor) (Obioha & T'soeunyane, 2012). They often use bones in combination with other methods depending on the patient's chief complaint. Each *dingaka tsa ditaola* uses different bones depending on the training they have received and their preferences (Kriel, 2003). The Basotho people believe the divination bones are able to

diagnose and answer any problem or question (Sodi, 1998). Through the divination, the cause, nature, and treatment of a patient's condition will be discussed with the patient who should respond by saying "*siya vuma*" (we agree) (Obioha & T'soeunyane, 2012). After the divination a prescription of what the patient should do will be given. This may include instructions and *dihlare* (medicine) depending on the nature of the problem (Kriel, 2003; Sodi, 1998). The patient is often referred to the *dingaka tsa dihlare* (medicine healer) for treatment or intervention (Edwards, 2011; Kriel, 2003; Mosotho et al., 2008; Obioha & T'soeunyane, 2012; Sodi, 1998; Sodi, 2008).

The increase in the number of ASD diagnoses in South Africa requires awareness and sensitivity towards the above assertions about how mental health is conceptualised, diagnosed, and treated in different cultures (Edwards, 2011). This would require mental health practitioners and clinicians to be sensitive to the cultural diversity of South Africa, including the Basotho culture (Edwards, 2011; Mthombeni & Nwoye, 2015; Sodi, 2011).

### **3.3.2 The Psychological Domain**

This section presents a review of the literature about the psychological and affective experiences of mothers living with a child with ASD. These experiences include the mothers' lack of knowledge and understanding, different emotions, and personal identity changes and motivation. It should be noted that these psychological experiences are also shared by Sotho mothers living with a child with ASD.

A study by Gobrial (2018) provided significant insight into what it means to be a mother in Africa and, most importantly, what it means to be a mother of a child living with ASD on the continent. In his studies, Gobrial (2015, 2018) found that mothers experience a plethora of negative emotions due to their poor knowledge and understanding of ASD. Various researchers have reported that lack of knowledge about ASD contributed to the delay in early diagnosis and treatment of ASD (Gane, 2008; Ludlow et al., 2011; Matenge, 2013;

Van der Walt, 2006). Among the Sotho people there appears to be a lack of understanding of ASD, which leads to the broader community having certain myths about the cause and management of ASD. Mothers living with a child with ASD in the Sotho culture may be stigmatised and discriminated against at social gatherings because of the assumption that she is the cause of the child's condition (Van der Walt, 2006). According to Mthombeni and Nwoye (2015), this is one of the causes of emotional challenges for Sotho mothers.

According to Van der Walt (2006), mothers typically sought a diagnosis after a teacher, health professional or other members of the community raised concern about the behaviour or developmental delays of their child. Various researchers have reported that parents consulted multiple professionals and traditional healers before an ASD diagnosis is made (Bayat & Schuntermann, 2013; DePape & Lindsay, 2014; Ludlow et al., 2011; Matenge, 2013; Van der Walt, 2006). This is often attributed to poor knowledge and understanding of ASD by most professionals (Bayat & Schuntermann, 2013). Studies have indicated that Sotho mothers also experienced lack of sensitivity from and stigmatisation of their children by their family members (DePape & Lindsay, 2015; Ludlow et al., 2011).

Unlike other medical and psychiatric diagnoses (such as hypertension, epilepsy, depression or anxiety) that have specific treatment protocols, ASD does not have a clear pathway or intervention (Rabba et al., 2019). As a result, ASD has a debilitating effect on how parents living with a child with ASD experience and define themselves. Depression, anxiety, ill health, and substance abuse are indicated to be associated with these experiences (Ogston et al., 2011). Among the Sotho culture, mothers consult multiple traditional healers and perform a number of rituals in order to help their children to heal, all of which have financial and psychological consequences for them and their children (Rabba et al., 2019).

Parents of children living with ASD find that they (the parents) become less spontaneous (Crowell et al., 2019). This, in part, stems from fewer events in their lives and less forward planning (Rabba et al., 2019). The parents' actions and communication become characterised by a routine way of doing things, and the way they adjust their communication according to the child's behaviour (Crowell et al., 2019; Rabba et al., 2019). Parents often have to repeat statements, and use less humour and teasing which makes interaction with their child less interesting. The lack of spontaneity predisposes parents to stress and frustration, and sometimes forces parents to incorporate their ASD-affected child's need for routine into their identity (Rabba et al., 2019). Sotho mothers participate in various traditional activities such as initiation, birth and death rituals. However, living with a child with ASD can force mothers to withdraw from social activities, and thus become isolated and depressed (Crowell et al., 2019; Rabba et al., 2019).

Parents who are raising children with ASD have less time and energy to plan and implement personal goals such as making time for a romantic relationship, sport and self-interests (Rabba et al., 2019). The child-parent relationship becomes central to the parents' lives, and these parents tend to incorporate this relationship into their identity (Rabba et al., 2019). Cashin (2004) and Crowell et al. (2019) found that parents also sometimes lack comfort and respite because they constantly have to monitor the symptoms of their child, which may cause anxiety, frustration, and exhaustion for the parents. The future self of the parent can get lost in the all-pervading demands of the child living with ASD (Cashin, 2004).

Rabba et al. (2019) explained that uncertainty about the future of a child living with autism can at times predispose parents to anxiety and depression. Parents with children living with ASD are often concerned about the prospects of their children being in a romantic relationship, accessing higher education, getting a job, and living independently after their (the parents') death. This forces such parents to become more concerned about the future

instead of living more in the here-and-now; hence, mindfulness is one of the recommended interventions for parents living with a child with ASD (Cashin, 2004; Ludlow et al., 2011; Rabba et al., 2019).

Cashin (2004) argued that when a child and the parent begin to engage in similar activities their connection improves. According to Cashin (2004), it is the achievement of small milestones by the child that builds the child-parent relationship. This relationship motivates the parent to have the courage to continue hoping for a better future. Also, parenting a child with ASD was found to contribute to the development of patience as a personality trait of such parents (Rabba et al., 2019).

### **3.3.3 The Social Domain**

This section focuses on mothers' experiences of the social setting when raising an ASD-affected child, with special reference to the Sotho culture. This includes reviewing literature discussions about mothers' experiences of financial challenges, family challenges, social support, and access to health and education.

Various researchers found that some parents shared the challenges of raising their ASD child while other parents separated (Bakare et al., 2009; Ludlow et al., 2011). Single parenting may contribute to the parents' depression and suicidal thoughts due to the hardship associated with living with a child with ASD (Ludlow et al., 2011).

Parenting a child with ASD implies that the mother will experience emotional challenges (Mayers, 2013) while also taking on an advocacy role because she has to educate others about the child's diagnosis (Ludlow et al., 2011). Mayers (2013) postulated that parents often experience anger from or towards family members after receiving a child's diagnosis. According to Obioha and T'soeunyane (2012), it is often the maternal grandmother

who understands and helps a mother with caregiving, while the in-laws in some cases may accuse the mother's ancestors of the child's illness.

Parents of children living with ASD often have to cope with loss of financial stability (Bakare et al., 2009) as they now have the additional burden of paying for medical and other treatment interventions. This can lead to changes in family goals and activities that depend on the availability of money. Some parents have reported that they were forced to quit their jobs or work extra hours in order to afford the care of an ASD-affected child, which subsequently impacted the financial status of the family (Mayers, 2013). Within the Sotho culture, males are considered to be the main financial providers while mothers are deemed to be the social and emotional caregivers (Edwards, 2011, Sodi, 1998). Sotho mothers often report being financially burdened because of raising children without the fathers who are viewed as the main bread winners (Obioha & T'soeunyane, 2012).

The relationship between ASD-affected children and other typically developing siblings in the family is also a challenge for parents in terms of balancing family roles. Feelings of guilt and shame are often associated with parents' experiences when observing the imbalances in how they give attention or relate to all their children. The typically developing siblings can sometimes feel embarrassed by the behaviour of their atypically developing sibling, which can have a negative effect on their relationship (Ludlow et al., 2011; Midence & O'Neill, 1999; Whitaker & Hirst, 2002). Sotho mothers often live in extended families which implies caring for all the children in the household regardless of who the biological mother is. This puts an extra burden on mothers living with a child with ASD, which may cause conflict between mothers within the family (Sodi, 1998).

The culture of the Basotho people is characterised by an abundance of social gatherings and activities. However, living with a child with ASD can at times force parents to

withdraw from social engagements (Cashin, 2004). Visiting places that are not part of the ASD-affected child's routine may require the child to change their behaviour, which can make it difficult for parents to manage the new behaviour (Crowell et al., 2019). Fear of being judged for parental incompetence and lack of responsibility when an ASD-affected child presents with tantrums or other odd behaviour can result in parents withdrawing from social visits (Cashin, 2004; Crowell et al., 2019). The Sotho people have rites of passage rituals which have clear rules and taboos (Sodi, 1998). Mothers of ASD-affected children may not attend such ceremonies because of fear that their child may behave inappropriately and invoke ancestral punishments on the family as a consequence (Kriel, 2003; Sodi, 1998).

Various studies have highlighted that inadequate access to health, education, and specific interventions for ASD-affected children was one of the greatest challenges experienced by the mothers of children living with ASD in developing countries such as South Africa and Egypt (Blake et al., 2017; Gobrial, 2017; Ludlow et al., 2011). Parents of children with ASD experience distress when recalling their journey of sourcing special schools for their ASD-affected children (DePape & Lindsay, 2015; Matenge, 2013). Van Der Walt (2006) found that in the Western Cape Province (South Africa) there is a significant number of special schools for children and people with disabilities. However, research found that there is a lack of special schools catering for the needs of children with ASD. This is also a challenge elsewhere in developing countries in Africa, and in Asia and Europe (Bakare et al. 2017; Clark et al., 2017; Crane et al., 2017; DePape & Lindsay, 2015; Gobrial, 2018).

Limited access to health facilities, or an underdeveloped health care system, is another challenge that impacts negatively on parents of children living with ASD (DePape & Lindsay, 2015; Gane, 2008). Parents travel long distances to public health facilities and/or wait for a longer period of time to get their children diagnosed with ASD (DePape & Lindsay, 2015). Such parents typically do not have the financial resources or a medical aid to

afford access to therapeutic interventions for their child living with ASD (Clark et al., 2017; DePape & Lindsay, 2015; Gobrial, 2018; Ludlow et al., 2011; McKenzie, & McConkey, 2015).

### 3.3.4 The Spiritual Domain

Spirituality refers to, among others, how people relate with the transcendent (Astrow et al., 2001). This section discusses how mothers living with a child with ASD experience their search for spiritual meaning through religious beliefs and practices.

According to the Basotho world view, a person comprises of two components. The first is *mmele* (the physical being), and the second is *seriti* or shadow (a person's character, including dignity). The Basotho believe that the *mmele* can die, but the *seriti* continues to live even after the physical death of a person. This is the part of the human being that continues to form the *Badimo* (ancestor or the living dead) who is an important mediator between living persons and the supreme God. Therefore, the spiritual connection or disconnection that Sotho mothers have with the ancestral spirits will determine the protection or calamities that one will experience, also when giving birth to and raising a child with ASD (Edwards, 2011; Sodi, 1998).

Spirituality, regardless of its characteristics and how people practice it, helps to shape the person as a whole (Sulmasy, 2002). When people experience life challenges and threats, it is not only the biological, psychological, and social aspects of their lives that are affected, as proposed by Leigh (1983), but also their spirituality (Sulmasy, 2002). Therefore, taking spirituality into account in the diagnosis and treatment of ASD is an ethical responsibility of all clinicians and traditional healers. For example, among the Basotho people, symptoms such as auditory hallucinations, disorientation or stupor are not an indication of psychosis but a message from the ancestors, and this intended message and possible intervention need to be determined by the diviner (Edwards, 2011, Kriel, 203; Sodi, 1998).

### 3.4 The Treatment of Illness within the Sotho Culture

A number of researchers have indicated that the Basotho people have their own cultural practices with which to treat illnesses, including mental disorders (Edwards, 2011; Kriel, 2003; Sodi, 1998; 2011). This section explores the treatment of illness according to Sotho culture.

According to Edwards (2011), Kriel (2003), Obioha and T'soeunyane (2012), and Sodi (1998), the Basotho people subscribe to various traditional healing practices. Five of these healing practices will be discussed below:

- **Herbal healing (*Dingaka tse ditshupsa*):** Healers use traditional medicines such as tree roots, bark, the leaves of trees and shrubs, and twigs – on their own or as combinations. These medicines can be administered to patient as a syrup or juice (Edwards, 2011; Kriel, 2003; Sodi, 1998).
- **Body contact (*Go hlabela*):** This vaccination-like process involves using a blade to make small cuts into the patient's skin and applying *Tshidi* (powder medicine) into the cuts. This serves to prevent illnesses and witchcraft, or to treat an illness. In the past, this was associated with the perpetuation of cross-infection of diseases such as HIV, but now traditional healers have been trained to conduct this healing process in a safe way (Sodi, 1998).
- **Therapeutic dance (*Ho thuela* or *Malopo*):** When using this process, a patient can appear to be presented with what in Western culture could be termed psychiatric symptoms such as auditory hallucinations, disorientation, or stupor. This can be caused by two ancestral spirits: those who are related to the patient and who are seen as communicating a certain message to the patient, and those who come from a foreign tribe. This form of dancing is often accompanied by a group performance that includes drumming, singing, clapping of the hands, and the rattling of the calabash. If

it was a calling to become a *ngaka*, the patient is expected to be healed after performing *malopo* (Edwards, 2011; Kriel, 2003; Sodi, 1998).

- **Ritual** (*tloaelo*): This is a ceremony that is performed to mark a human transition or rite of passage such as birth, marriage, or death. However, this can be performed to appease the displeasure of the ancestors, where this displeasure manifests as illness, including ASD, in a member of a family. A ritual can be performed by an individual, family, or community in a quest to help heal the ill person. Rituals can be performed to ask for forgiveness and to introduce a child who was born outside of wedlock and who may be ill because the ancestors do not know and protect such a child (Edwards, 2011; Obioha & T'soeunyane, 2012; Sodi, 1998).
- **Prevention** (*thibelo*): Basotho people believe that most of the illnesses are caused by *blood* (witchcraft), which makes protection very important. This is often done through the use of *dihlari* which is put at the gate, doorway, or fence of the house to prevent witches from causing bad situations in the house (Edwards, 2011; Sodi, 1998).

According to Edwards (2011) and Mthombeni and Nwoye (2015), there is a need to integrate culture and traditional healing into the treatment of patients, including those with mental disorders. However, their study found that both African traditional healing and Western healing did not yield positive results in treating ASD symptoms (Mthombeni & Nwoye, 2015). According to Mthombeni and Nwoye (2015), this finding points to a need for the sharing of knowledge between the Western and the traditional ways of healing ASD.

### 3.5 Conclusion

The chapter reviewed literature about the experiences of Sotho mothers living with a child with ASD using the biopsychosocial-spiritual (BPSS) model. The mothers' experiences before, during, and after the diagnosis of a child with ASD were also discussed, referring to,

among others, access to health care, the coping mechanisms of the parents, and treatment options for ASD children – both in terms of Western medicine and traditional healing practices. It also highlighted the cultural context of Sotho mothers with ASD-diagnosed children, calling for closer collaboration between Western medicine and traditional African healing practices. This will inform the discussion of this study in Chapter 6.

## CHAPTER FOUR

### METHODOLOGY

#### 4.1 Introduction

The research methodology guiding this study is discussed in this chapter. The chapter provides a breakdown of the systematic steps followed in answering the research question of the study, namely *What are the Sotho mothers' experiences of living with a child with autism spectrum disorder?* Furthermore, this chapter outlines the research process followed in conducting this study.

#### 4.2 The Research Design

The study adopted a phenomenological framework (Finlay, 2009; Leavy, 2014). The focus of this framework is to provide a wealthy, textured description of the lived experiences of the people being studied (Kafle, 2013, Yin, 2017). According to Langdridge (2011, p. 4), phenomenology "intends to focus on people's perceptions of the world which they live in and what it means to them; a focus on people's lived experiences". This epistemological approach is aimed at how people make meaning and how this meaning emanates from those people's lived experiences. Thus, this methodology was deemed relevant to explore and describe the lived experiences of two mothers living with a child with ASD.

A qualitative research design was used in this study to gain insight into the experiences of two Sotho mothers living with a child on the autism spectrum. A qualitative research design was considered for this study because the researcher intended to explore and understand the first-hand, in-depth, and subjective experiences of mothers living with a child with ASD. Furthermore, a qualitative research design allows for new themes to emerge, and it helps to highlight new developments in terms of the interventions and support for mothers living with a child with ASD (Yin, 2017).

Furthermore, a case study design was used to explore and describe the lived experiences of two Sotho mothers living with a child with ASD (Choy, 2014; Creswell, 2014; Yin, 2017). This study's design allowed the researcher to explore the similarities and differences (themes) within and between the participants' experiences (Yin, 2017).

### **4.3 Participants and Sampling**

Purposive sampling (Etikan et al., 2016) was used to recruit two Sesotho-speaking mothers as participants. According to Etikan and his co-researchers (2016), purposive sampling (also called judgement sampling) is the deliberate choice of participants based on the qualities of these participants. Ideally, using purposive sampling means the researcher sets a criterion, for example, selecting participants based on their experience or their knowledge about the subject under study. Ryan and Bernard (2000) emphasised the importance of selecting participants who can easily communicate their experiences and views about the topic. Hence, using purposive sampling, the researcher considered the participants' ability to converse during the interview and also their experience in raising an ASD-diagnosed child. Another important criterion suggested by Etikan et al. (2016) was the availability of the participants and their willingness to participate in the interviews.

As such, the researcher worked closely with Dr David Griessel, who is a neuro-developmental paediatrician and advocate for Autism South Africa, to recruit the participants from his patient base. The following criteria were considered for inclusion of the participants:

- The participant's child was assessed and diagnosed with ASD by Dr Griessel, using the Autism Diagnosis Observation Schedule (Lord et al., 1999).
- The mother's child should have been diagnosed with moderate or severe ASD.
- The mother of the child should be Sesotho-speaking and from the Free State Province (to allow for similarity in the cultural background of the mothers).

- To accommodate for an initial adjustment period after diagnosis and to enable meaningful reflections, only mothers who have lived with their child for two to five years after the diagnosis were selected.
- The age and gender of the child were not considered for inclusion.
- The age, marital status, and occupation of the mother were not considered (see Table 1).

**Table 1**

*Demographic details of the participants*

<b>Participants</b>	<b>Age of the mother</b>	<b>Marital status</b>	<b>Occupation</b>	<b>Age of the child</b>	<b>Gender of the child</b>
Thapelo	51	Single	Unemployed	12	Male
Mapaseka	38	Single	Technician	14	Male

Only two participants were selected for the study because it created a climate in which to explore a deeper understanding of the subject (Dyer & Wilkins, 2008; Gustafsson, 2017). In addition, exploring the lived experiences of a mother with a child living with ASD is an emotional subject. Thus, working with fewer participants would allow the researcher to better observe the participants' emotions and possibly take reasonable steps to manage any emotional distress that may have emanated from the interview. Concurring with Dyer and Wilkins (2008), Gustafsson (2017), and Yin (2017), the researcher also believes that the number of cases used in the study is not significant in qualitative studies; what is critical is the researcher's understanding and description of the subject being studied, and ability to produce a report that may contribute to knowledge building. Therefore, using only two

mothers can create a climate conducive to gaining more insight into the experiences of mothers living with a child with ASD.

#### **4.4 Data Collection Procedure**

Data was gathered using semi-structured interviews (Leavy, 2017) in English. A semi-structured interview schedule (Appendix D) was used to guide the interview. This allowed the researcher to be flexible, and in turn allowed the participants to express their subjective experiences (Leavy, 2017). This data collection method was relevant for the phenomenological approach used in the study because it allowed participants to be experts in expressing their lived experiences (Yin, 2017). Furthermore, it fostered a reciprocal relationship between the participants and the researcher, which was critical for building collaboration in the research process. The interview schedule (Appendix D) used in this data-gathering process assisted by covering the main topics of the study. This ensured that the data gathered during the interview helped to answer the research question.

Participants were contacted telephonically by the researcher to ask for consent and make an appointment for an interview. Before the interview, the researcher explained the rationale of the study and its implications through an informed consent letter (Appendix C), which was subsequently signed by both the participant and the researcher before the interview started. A single interview was held with each mother, ranging between 40 and 45 minutes. Questions were asked according to the interview schedule, and both participants answered all questions openly without any emotional difficulty.

#### **4.5 Data Analysis**

The collected data was analysed using the six steps of thematic analysis as adopted from Braun and Clarke (2006). This required the researcher to use a data analysis method that is flexible and adaptable. It allowed the researcher to easily identify similarities and

differences from the data set, which also makes the data analysis method appropriate for studying the experiences of more than participant. The thematic analysis method allows for the possibility of generating new themes related to the topic, which may in turn help to build knowledge.

The steps of the thematic analysis included a) familiarising oneself with the data, b) generating the initial codes, c) searching for themes, d) reviewing the themes, e) defining and naming the themes, and f) producing a research report in the form of a mini-dissertation. Braun and Clarke (2006) warned that thematic analysis should not be treated as a rigid and systematic process but rather as an activity that may require the researcher to go back and reconnect with the data. The six steps of thematic analysis taken by the researcher are outlined in the next section.

The data was analysed using a hybrid approach where the researcher incorporated the approaches from two different schools of thought, namely inductive and deductive reasoning (Boyatzis, 1998; Braun & Clarke, 2006). The researcher generated codes from the data, and also used the theoretical framework of the study, i.e. the biopsychosocial-spiritual model, to generate themes. The researcher ensured that the combination of these two methods links to the methodology used in the study and helps to answer the research question. The method was also used because it is suitable for the analysis of data based on studies with relatively few participants, such as in this study.

#### ***4.5.1 Familiarising Oneself with the Data***

According to Braun and Clarke (2006), the researcher should be familiar with the data. This is a crucial step as it determines the success of the remainder of the steps (Braun et al., 2019; Vaismoradi et al., 2016). Failing to understand the data can result in inappropriate themes which could weaken the quality of the findings (Braun & Clarke, 2006). In this study,

the researcher revisited all field notes taken during the interviews to familiarise himself with the data. Furthermore, the researcher listened to all the recordings several times to ensure that all the key points raised by the participants were properly captured. Essentially, all the recorded interviews were transcribed. The researcher read through the transcribed interviews various times in an attempt to gain more familiarity with the participants' experiences.

#### *4.5.2 Generating the Codes*

The second step involves developing codes from the data sets. Data coding is very important as it helps the researcher to prepare the data for further analysis (Braun & Clarke, 2006; Braun et al., 2019). At this stage, the transcripts were read systematically, giving each data set full and same attention. This was part of identifying important segments of the data that would form the basis of theme development. From the data set, 29 codes were identified from Interview 1 while 34 codes were identified from Interview 2 (see Appendix E).

#### *4.5.3 Searching for Themes*

During this step, the various codes were analysed and potential themes were identified. The relationship between the potential themes was identified, and 12 major themes emerged which were categorised according to the BPSS model (see Table 2):

- **The biological domain** – the diagnosis journey, and the management of ASD symptoms
- **The psychological domain** – lack of knowledge and understanding, stigmatisation, attitude, and affective experiences
- **The social domain** – schooling, social support, emotional support, and cultural influences
- **The spiritual domain** – the role of spiritual ascent, and role of religious beliefs and practices.

**Table 2***Identified themes*

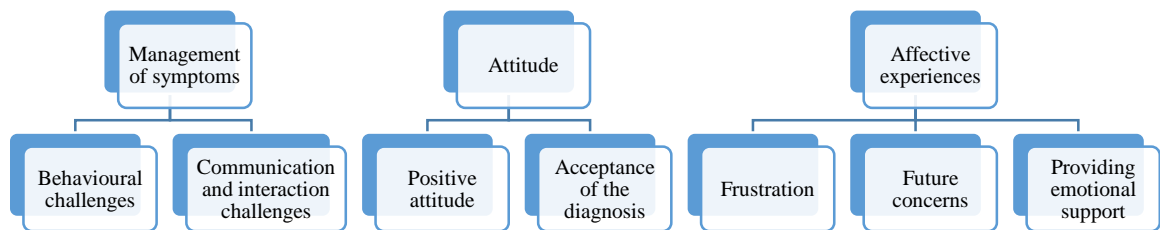
Categories	Themes
Biological domain	The diagnosis journey
	The management of ASD symptoms
Psychological domain	Lack of knowledge and understanding
	Attitude
	Affective experiences
Social domain	Schooling
	Social support
	Emotional support
	Culture influences
Spiritual domain	Role of spiritual ascent
	Role of religious belief and practices

**4.5.4 Reviewing and Refining the Themes**

During this step, the researcher refined the themes identified in Step 3. According to Braun et al. (2019), care should be taken to eliminate overlapping themes. Eight sub-themes from the three main themes were identified after reorganising the themes (see Figure 1):

- **The management of symptoms** – behavioural challenges, communication and interaction challenges
- **Attitude** – positive attitude and acceptance of the diagnosis
- **Affective experiences** – frustration, future concerns, and providing emotional support.

Therefore, the researcher made sure there were no overlapping themes as he revisited the initial codes while bearing the research question in mind. This helped the researcher to properly refine the themes for further analysis.

**Figure 1***Identified sub-themes*

#### ***4.5.5 Defining and Naming the Themes***

For this step, the researcher uniquely labelled each key theme that emerged from all the above steps. The essence of each theme was identified, and the data sets supporting each theme were determined. This was accompanied by a description that contextualised each theme. The themes were analysed to ascertain whether they are responding to the research question. Each theme was also analysed to establish whether the themes linked to the broader description of the mothers' experiences of living with a child with ASD. A relationship between themes was also considered as part of the process in this step. In addition, sub-themes for certain themes were considered during this step. Next, the researcher evaluated the names given to each theme in order to determine the relevance of the names based on the themes that were identified.

#### ***4.5.6 Producing the Report***

For this step, the researcher identified all the major themes and sub-themes from the data. To validate the significance and relevance of the themes, a concise account of the participants' experiences of living with a child with ASD was compiled across all main themes and sub-themes. This was supported by verbatim extracts from the data.

## **4.6 Trustworthiness and Rigour**

Researchers must document how relevant steps were taken to enhance the trustworthiness and rigour of their studies (Guba, 1981). To ensure integrity and rigour, the researcher considered Guba's four criteria for qualitative research (1981) as outlined below.

### ***4.6.1 Dependability***

According to Moon et al. (2016), the first criterion is dependability. The study achieved this by carefully documenting the research process. Dependability is defined by Moon et al. (2016, p. 17) as "the consistency of the findings emanating from proper documentation of the research process which can make it possible to obtain the same findings from the same sample if a similar method is used". In this study, the researcher ensured dependability of the findings by clearly outlining the research methods, design, data collection steps, and analysis method used.

### ***4.6.2 Credibility***

As explained by Guba and Lincoln (1985), credibility helps to ensure trustworthiness in qualitative research. They defined credibility as a measure of the extent to which the research represents reality. In this study, credibility was attained by ensuring that the research design and methodology answered the research question. According to Botma et al. (2009), credibility can be achieved through prolonged engagement, the researcher's reflexivity, member checking, and an interview technique. In this study, semi-structured interview schedules were used to allow the participants to be the experts, and to express their experiences without time constraints. Member checking was ensured by informing the participants that the researcher may contact them to verify the data gathered should the need arise.

### ***4.6.3 Confirmability***

The third criterion is confirmability which refers to the extent to which the findings can be replicated or corroborated by other researchers (Blackman & Moon, 2014; Guba, 1981). Researchers are encouraged to appropriately link the findings to conclusions so that other scholars can easily use the study to confirm their own research (Forero et al., 2018). Following recommendations from Guba (1981), this study adopted several strategies of methodological triangulation to enhance confirmability. In terms of triangulation, the researcher used several sources, including existing literature, field notes, observations, and interviews. Furthermore, confirmability was achieved by describing the research process in such a way that replication is possible.

### ***4.6.4 Transferability***

Transferability refers to the extent to which the findings can be applied to other settings (Guba & Lincoln, 1985). Shenton (2004, p. 9) asserted that "since the findings of a qualitative project are specific to a small number of particular environments and individuals, it is impossible to demonstrate that the findings and conclusions apply to other situations and populations". Existing literature showed that transferability is possible if the researcher can adopt certain strategies that describe the phenomenon (Forero et al., 2018). In this study, transferability was achieved through the use of purposive sampling, where only Sotho mothers, who have lived with an ASD-affected child for two to five years after the diagnosis, were selected.

## **4.7 Ethical Considerations**

This section aims to outline the ethical issues considered important when conducting research.

#### ***4.7.1 Permission to Conduct the Study***

The research proposal was tabled and approved by the Department of Psychology at the University of the Free State. Ethical clearance was obtained from the Research Ethics Committee of the Faculty of the Humanities of the University of the Free State, with ethical clearance number: UFS-HSD2018/0944 (Appendix F).

#### ***4.7.2 Informed Consent***

Informed consent is regarded as one of the most important aspects of ethical research (Denzin & Lincoln, 2011). According to Fleming and Zegwaard (2018, p. 210), "participants must be fully informed of what will be asked of them, how the data will be used, and what (if any) consequences there could be". In this study, the researcher outlined the purpose of the study to the participants through a consent form (Appendix C). Thereafter, the participants were informed that participation in the research was voluntary and they had a right to withdraw at any time. The two participants who volunteered to participate in the study signed the informed consent forms as proof that they agreed to voluntarily participate in the research.

#### ***4.7.3 Anonymity and Confidentiality***

According to Fleming and Zegwaard (2018, p. 211), "it is important that the identity of participants is kept confidential or anonymous and the assurances extend beyond protecting their names to also include the avoidance of using self-identifying statements and information". All research evidence was kept confidential in a password-locked computer, which could only be accessed by the researcher and the supervisor. Pseudonyms were used to eliminate the issue of identification and to ensure anonymity. All the notes and written papers were shredded after the completion of the study.

#### ***4.7.4 Protection from harm***

It is crucial to minimise, eliminate or mitigate harm to both the participants, the researcher, and the institution (Fleming & Zegwaard, 2018). The researcher followed all the proper protocols proposed for the use of semi-structured interviews. The researcher also ensured that the interview room eliminated the possibility of physical harm. The researcher planned to refer any participants who needed debriefing after the interview to the Master's students in Psychology at the University of the Free State. During the study, no participant indicated or was observed to need debriefing.

#### **4.8 Conclusion**

This chapter provided the methodology adopted by the researcher to answer the research question. The sample consisted of two mothers living with children diagnosed with ASD. Data was collected using semi-structured interviews. The collected data was analysed using thematic analysis. The chapter also outlined the steps taken to attain trustworthiness and rigour in the study. The last section of the chapter detailed all the relevant steps taken to ensure ethical standards. The following chapter presents the findings of this study.

## CHAPTER FIVE

### THE FINDINGS

#### 5.1 Introduction

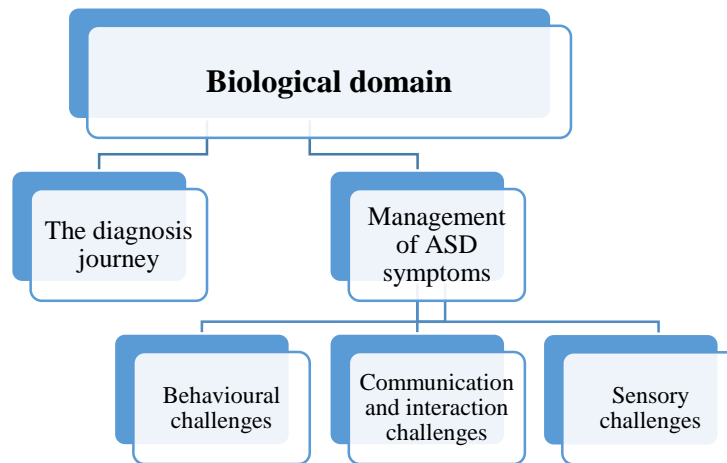
The study endeavoured to explore and describe the experiences of two Sotho mothers living with a child with autism spectrum disorder. This chapter will outline the themes and sub-themes extracted from the semi-structured interviews conducted with the mothers. Based on the data, 12 major themes emerged, which were categorised according to the biopsychosocial-spiritual model (BPSS model). The chapter will illustrate the identified themes and their sub-themes with verbatim quotes from the interview transcripts. The quotes are referenced using each participant's pseudonym, and page number and question number as indicated on the interview transcripts. The transcripts containing the quotes are found in Appendix E.

#### 5.2 The Biological Domain

This section does not focus on the biological description of ASD, but on the themes and sub-themes describing how the mothers experienced their *child's diagnosis process* and how they *dealt with their child's symptoms*, including behavioural, communication, social and sensory challenges (see Figure 2).

## Figure 2

### *Biological domain and themes*



### 5.2.1 Theme 1: The Diagnosis Journey

Within this theme, the mothers described how they experienced the diagnosis journey of their children, starting with the early identification of symptoms and logistical arrangements to the final diagnosis. Both participants discussed the symptoms they noticed in their children before a formal diagnosis of ASD was made.

#### ***Thapelo recalled:***

*The problem was his communication when he was three years. He could only sing all the 2010 World Cup whatever, but when you talk to him he couldn't answer you. He could only say one word, not even a sentence, but when he was about six he could at least say a sentence. (Thapelo, 1, Q00)*

#### ***Mapaseka:***

*... [he] was not speaking at all, but he was very naughty. He was hyper, hyper, hyperactive ... (Mapaseka, 2, Q2)*

Mapaseka indicated that she did not know where to go with her child to be formally diagnosed with ASD. She explained that she needed to travel a long distance for her child to be diagnosed:

*I did not know all those special speech therapists ... the OT, he made all the arrangements, I guess. Gave me the address, I just went there. Then from there, they referred me to Pretoria for him to be diagnosed. (Mapaseka, 5, Q6)*

Thapelo discussed how she had to explain to the treating doctor the reasons she wanted her child to be diagnosed.

***Thapelo:***

*The doctor at [...], they asked me, the first question he asked me: 'When you say the child, something is wrong with him, does he poop himself?' I said no, when it is time he goes to the toilet. He helps himself. 'What tells you now that there is something wrong with the child?'* (Thapelo, 4, Q2)

## **5.2.2 Theme 2: Management of ASD Symptoms**

Dealing with the child's ASD symptoms presents the mothers with different experiences in all spheres of their lives (Mandell & Mandy, 2015). This theme captures the mothers' description of how they experienced their child's symptoms. Both the participants expressed negative experiences associated with managing the symptoms of their children.

### ***5.2.2.1 Sub-theme 1: Behavioural Challenges***

This sub-theme focuses on how mothers explained the impact of their child's preference for the same activities. Both the participants discussed how their child would prefer to engage in the same activities and how this negatively impacted their daily activities and interaction with other persons.

**Thapelo:**

*They know when he comes in the shop he will say, 'I want this Lunch Bar', and he will say "LUNCH BAR" [spelling the name]. (Thapelo, 7, Q6)*

*... when he meets you he greets you. He will ask you what is your name. He will ask you surname and he will ask you the date of birth ... Next year when its your birthday he will tell me, 'Mommy, did you call so and so is his or her birthday tomorrow, today?'" (Thapelo, 7, Q7)*

**Mapeseka:**

*He likes TV a lot. He will wake up and watch TV, and I will be busy doing my things and then at 06:00 AM he will still be busy, he is still watching TV. 'Did you do the lunch box?' 'Did you bath?' All those things, it's a struggle every morning. If I don't follow him, 'Do this! Do this!', it's a struggle every day. (Mapeseka, 9, Q17)*

Both the participants explained how they experienced their own and other people's perceptions about their child's behaviour. Both participants reflected on how they experienced the daunting task of managing their child's behaviour at home and in public.

**Thapelo:**

*They talk behind my back with my son, that my son is this, and this and this ... They didn't ... they could not accept my son. They thought my son was naughty. (Thapelo, 2, Q2)*

**Mapeseka:**

*... but he was very naughty. He was hyper, hyper, hyperactive ... but I got irritated when he starts doing those things in a taxi. I got irritated, eh, but I think ... [she never finished the statement]. (Mapeseka, 2, Q2)*

*... but shouting started even before because he was naughty. He was naughty sometimes. He would be there and I would have had to say they come here, all those things ... (Mapeseka, 4, Q5)*

### **5.2.2.2 Sub-theme 2: Communication and Interaction Challenges**

This sub-theme emerged from how the mothers spoke about their challenging experiences of living with an ASD-affected child struggling with speech – one of the core characteristics of ASD. They also reported how their child used certain behaviours as a form of communication rather than using verbal speech.

#### **Thapelo:**

*The problem was his communication when he was three years. He could only sing all the 2010 World Cup whatever, but when you talk to him he couldn't answer you. He could only say one word, not even a sentence. But when he was about six he could at least say a sentence. (Thapelo, 1, Q00)*

#### **Mapeseka:**

*... like I had to accept because [he] was not speaking at all ... (Mapeseka, 2, Q2)*

*She would call him and say [child's name]. He could not respond. He could just look at her without anything. (Mapeseka, 5, Q5)*

*If he wants to watch something, he watched it and after he finishes he knows what I like. He would change the TV and then he put something that I like and that means, it's my turn. He does not communicate but he acts. (Mapeseka, 6, Q7)*

### **5.2.2.3 Sub-theme 3: Sensory Challenges**

This sub-theme describes how the mothers observed their child deal with sensory problems and how it impacted the mothers both at home and in public. Both participants stated that managing their children's symptoms – such as sensitivity or irritation to noise – was one of the major challenges.

#### ***Thapelo:***

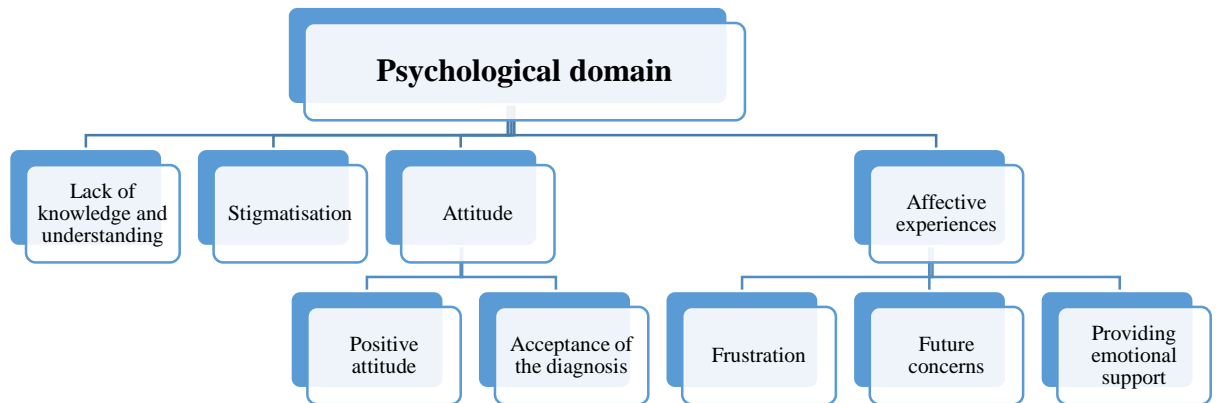
*He was having ASD signs. When there is loud music he becomes irritated. He would close his ears and he would stand still in one place. You see, he did not also want to hear other kids cry. Everything loud was irritating him. (Thapelo, 3, Q01)*

#### ***Mapeseka:***

*Even that one gives me time to relax because I will be alone and then no TV, no noise. He [doesn't] like the noise. I just relax. (Mapeseka, 6, Q8)*

## **5.3 The Psychological Domain**

This section discusses the mothers' cognitive, behavioural and emotional experiences of living with a child with ASD. The section covers the themes and sub-themes as illustrated below (see Figure 3).

**Figure 3***Psychological domain and themes***5.3.1 Theme 1: Lack of Knowledge and Understanding**

This theme focuses on the mothers' lack of knowledge and understanding about ASD. The mothers also referred to the community's lack of knowledge regarding ASD. Both the participants indicated that they had to rely on professionals for information about ASD before and after their child was diagnosed with ASD.

***Thapelo:***

*But in the beginning, I was struggling because I didn't understand and have any knowledge about hyper-epileptic and autism. But I went and looked for help. I read a lot and make research, and I went to the clinic. They asked me where to attend the sessions so that I can understand how is my son. (Thapelo, 1, Q00)*

**Mapeseka:**

*Yah, maybe it's because I did not understand what is autism to start with. Maybe I am ignorant. I was not worried. I was not worried, or maybe it's because I did not know anything about, about autism. (Mapeseka, 2, Q1)*

Thapelo said that she was frustrated because of the lack of knowledge about ASD in her community, and she had to explain to the members of the community her child's presentation.

*Then I had to teach them [the community members] that my son is not naughty but this and this and this [he is living with autism]. (Thapelo, 3, Q4)*

**5.3.2 Theme 2: Stigmatisation**

This theme focuses on how the mothers in the study experienced, and dealt with, the negative perceptions and behaviours directed to their child. Thapelo said that the stigmatisation of her child by the community and family members was a challenging experience for her.

**Thapelo:**

*... and people call my son names. They say he was mad, he was deaf, he was all that. But I was always, I was arguing with them. I told them the doctors who study people like my son did not tell me he was mad. (Thapelo, 2, Q01)*

*You see, they [the family] talk behind my back with my son, that my son is this, and this and this ... They didn't ... they could not accept my son school. (Thapelo, 4, Q3)*

**Mapeseka:**

*Even there I struggled. Even the department said this one is not going to cope here without ... They were supposed to do the assessment but they just saw autism and said no. (Mapeseka, 12, Q23)*

*So it was very difficult to find a school because I applied to almost every school, neh. But they will tell you that, 'We don't accept ... we don't deal with those kinds of kids here. We don't deal with those kinds.' (Mapeseka, 3, Q3)*

**5.3.3 Theme 3: Attitude**

This theme captures how the mothers constantly evaluated and responded to their experiences of living with a child with ASD. It describes the role of the mothers' positive attitude and acceptance of the ASD diagnosis of their children.

**5.3.3.1 Sub-theme 1: Positive Attitude**

This sub-theme describes how the mothers, without ignoring the hardships that they are experiencing, perceived the condition, abilities, and achievements of their children in a positive light. Both mothers reported that remaining hopeful and focusing on the good and the achievements of their child have helped them to positively experience the ASD presentation of their children and their development.

**Thapelo:**

*... the teachers since he was schooling from grade R and crèche and all that. They gave me hope so that I do everything for my son. (Thapelo, 13, Q21)*

**Mapeseka:**

*Maybe I did not have a choice because we are the only two. And so, if I am starting to act somehow now that he has that [ASD] and we are only two, what is going to happen? I think in a way I had to be strong for him. So I had to show him the love.*  
(Mapeseka, 4, Q4)

Thapelo also stated that she experienced living with a child living with ASD positively because she looked beyond her hardships and focused on the positives, doing the best for her child.

**Thapelo:**

*I just say to myself, and life is not always smooth. To be strong, what does not kill you, makes you strong. You must know life will not be smooth all the way. There are sometimes up and downs. The determination is how strong? It's not to say how many times you fall, but how many times you rise. And how do you take things. Most of the time I teach myself to take things in a positive way rather than on a negative. Negative energy takes you nowhere. If you look at things from a positive perspective you will get there, fruitful results.* (Thapelo, 10, Q13)

*... although in the beginning, it was hard. After understanding I just told myself I will help my son to go through. I will tell the world that there is nothing wrong with my son.* (Thapelo, 3, Q1)

**5.3.3.2 Sub-theme 2: Acceptance of the Diagnosis**

Within this sub-theme, the mothers talked about what helped them to accept the ASD diagnosis, and how they are adjusting to living with their children. Both the participants stated that accepting their children's diagnosis contributed to a positive experience. Both

mothers also reported that their children's diagnosis was both frustrating and comforting. However, they also pointed out that the diagnosis enabled them to find relevant interventions for their children.

**Thapelo:**

*I just put myself in a ... although in the beginning, it was hard after understanding. I just told myself I will help my son to go through. (Thapelo, 3, Q1)*

**Mapaseka:**

*I was open. It did not take me long. Maybe it's because of the people I was surrounded with. It was not difficult. Most of the people, especially the teacher from the pre-school, helped a lot, helped with the speech therapist, occupational, like she did everything for me. (Mapaseka, 1, Q01)*

*No, they [the family] don't have a problem. They understand him. Maybe their mothers explained to them. But they do understand that [he] likes to stay alone there, and it is fine. (Mapaseka, 8, Q14)*

### **5.3.4 Theme 4: Affective Experiences**

Experiencing difficult emotions when facing a challenging situation or event is to be expected. These experienced feelings help us to make judgements about a situation, and they inform the behaviour that may be appropriate for the situation (LeDoux, 2000). This theme presents the emotions that the mothers experienced in terms of living with a child living with ASD.

#### **5.3.4.1 Sub-theme 1: Frustration**

Both participants were in agreement that dealing with their child's tantrums and the reaction of other people to such symptoms caused frustration to them.

**Thapelo:**

*They thought my son was naughty. Then I had to teach them that my son is not naughty but this and this and this [he is living with autism]. And I withdraw myself from going to people because I did not want them to harass my son while they did not understand. (Thapelo, 4, Q3)*

**Mapeseka:**

*... but he was very naughty. He was hyper, hyper, hyperactive [her son Hloni interrupted and said he is not naughty anymore] ... Yah, you are not naughty anymore. Yes, I was not worried about the speech, the tantrums, I was not worried, but I got irritated when he starts doing those things in a taxi, I got irritated ... (Mapeseka, 2, Q2)*

Additionally, Mapeseka also indicated that dealing with schools' administration and family was another source of frustration.

*So it was very difficult to find a school because I applied to almost every school neh. But they will tell you that, 'We don't accept, we don't deal with those kinds of kids here. We don't deal with those kinds.' We almost went to a special school of the blind. (Mapeseka, 3, Q3)*

*He will wake up and watch TV, and I will be busy doing my things. And then at 06:00 AM he will still be busy. He is still watching TV. 'Did you do the lunch box?' 'Did you bath?' All those things, it's a struggle every morning. If I don't follow him, 'Do this! Do this!' It's a struggle every day, see. (Mapeseka, 9, Q17)*

### 5.3.4.2 Sub-theme 2: Future Concerns

This theme presents the mothers' concerns about the uncertainties associated with their child's future. Both participants said that they experienced uncertainty about their child's ability to form romantic relationships and live an independent life during adulthood.

**Thapelo:**

*I just pray that he will find someone [romantic partner] who will understand him and who will also love him. Who will not judge him the way he is. (Thapelo, 13, Q18)*

**Mapeseka:**

*That one, yoh! Now that he is growing up I don't know what is gonna happen. Now he is starting to be a teenager and then he does not have a father figure, and I don't know what to do. If he can come now and say this and this is happening to me. How will I respond? I don't know. (Mapeseka, 9, Q18)*

Both mothers also said they were concerned about what will happen to their child if they would pass away.

**Thapelo:**

*I pray God to give me a very long life so that I can see my son one day married and standing [up] for himself because I don't know for how long I will be there for him. (Thapelo, 8, Q8)*

Additionally, Mapeseka expressed anxiety about her child's reaction should her family structure change, such as her moving in with a romantic partner.

**Mapeseka:**

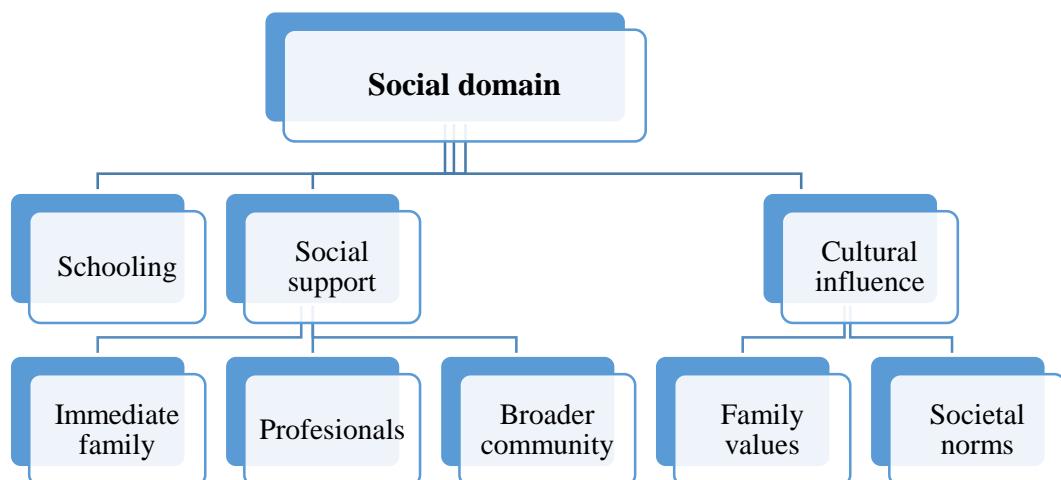
*Yes, I am not sure how is he going to behave or react if I can say I am having a boyfriend to him now, something like that. (Mapeseka, 10, Q19)*

**5.4 The Social Domain**

This section focuses on how both participants described their experiences of schooling, social support, and the role of culture in living with a child with ASD (see Figure 4).

**Figure 4**

*Social domain and themes*



### 5.4.1 Theme 5: Schooling

South Africa appears to have a significant number of special schools for learners with disabilities (Autism South Africa, 2020). However, schools specifically and exclusively for children with ASD are limited (ASA, 2020). This theme provides insight into the experiences of mothers regarding the school system. Both participants spoke about their struggle to access an appropriate school for their child with ASD.

#### **Thapelo:**

*I struggled very much for him to get an education. (Thapelo, 1, Q00)*

*I took him to the multiracial crèche in town and I explained my child's situation. And then we talk and they said to me they will take him and watch him for the first month how will he attend – function with other kids. And then the first month, they said to me by the second month I have to hire someone special who will watch him at the crèche, you see, so that when he plays with other kids ... (Thapelo, 5, Q5)*

#### **Mapeseka:**

*The thing I struggled with was the school. I think the thing that I was stressing about was the school. That is when I felt that there is something wrong with me. (Mapeseka, 2, Q1)*

Thapelo recounted that she took her child to a mainstream school. The other mother pointed out that she was considering placing her child in a special school for the blind.

#### **Thapelo:**

*... and even at the normal school, he was attending a normal school, with English from his grade R, grade 1 report up to grade 4, he is [got] level 7 or level 6 [in] English. (Thapelo, 6, Q6)*

**Mapeseka:**

*So it was very difficult to find a school because I applied to almost every school, neh. But they will tell you that, 'We don't accept ... we don't deal with those kinds of kids here. We don't deal with those kinds.' We almost went to the blind [school]. Then we got a space at [name of the school]. (Mapeseka, 3, Q3)*

Both mothers put in an effort to help their child access education because of lack of reasonable access to a special school for children living with ASD. Mapeseka concluded the interview by explaining:

*And I think most of the parents – the thing they are struggling with is schools, even here in Bloemfontein. I was one of the luckiest because [we] got transferred from [name of town] to this site. So I was never on the waiting list. They sent him to [name of school]. Even there I struggled. Even the Department [of Education] said this one is not going to cope here without ... They were supposed to do the assessment but they just saw autism and said no. I said, 'No, you guys don't know what you are talking about. Did you see [him] or you just assume?' I had to stand up for him. I just go to the MEC [Member of Executive Committee] because I did not refer myself there. The Department [of Education] referred me there. Then they got him probation for one month. Then that is when we had a meeting and they said we are eating our pie – it is not what we think ... Some of the parents are struggling. I think they have been on the waiting list for more than 10 years. I think what you are doing, don't just do it for the sake of research. What you are doing, whatever the parents are complaining about, please help where you can. Convince where you can. We need schools on this side! (Mapeseka, 12, Q23)*

### 5.4.2 Theme 6: Social Support

Studies by Mandell and Mandy (2015) and Ludlow et al. (2011) found that mothers living with a child with ASD without social support are more prone to experience depression, anxiety, and other health-related problems than those who do receive social support. This theme with its sub-themes unpacks the mothers' experiences of social support from family, professionals, and the broader community.

#### 5.4.2.1 Sub-theme 1: Immediate Family

This sub-theme focuses on the mothers' experiences of relationships and interactions with immediate family members, including the fathers of their children. The mothers voiced that the lack of support from their family impacted them significantly, regardless of whether positive or negative. Both participants were separated from the fathers of their children. The participants presented conflicting experiences in that Thapelo pointed out that the father of her child was financially supportive while Mapeseka said the father of her child was completely absent. According to Thapelo, her family was not understanding. Hence, she withdrew from social interactions.

#### **Thapelo:**

*I was not in a relationship. My only concern was my child. But eh eh ... his father stays in another place and I stay at another place. But financially, I don't want to lie, he was always there, even when I took [him] to doctors or whatever, he was there financially. (Thapelo, 2, Q01)*

*The bad thing was my family did not support me. You see, they talk behind my back with my son, that my son is this, and this and this ... They didn't ... they could not accept my son. They thought my son was naughty. Then I had to teach them that my son is not naughty but this and this and this [he is living with autism]. And I withdraw*

*myself from going to people because I did not want them to harass my son while they did not understand. (Thapelo, 3, Q4)*

Mapeseka indicated that her family's support helped her to positively experience living with her child.

***Mapeseka:***

*Like my older sister is here ... So she also likes sweets. Sometimes ... [interruption by the child] ... he goes and visits the whole week. They don't have a problem. Even that one gives me time to relax because I will be alone and then no TV, no noise. He [doesn't] like the noise, no noise. I just relax. (Mapeseka, 6, Q8)*

***5.4.2.2 Sub-theme 2: Professionals***

Mothers of children living with ASD often consult various professionals – from health practitioners to social institutions – before getting a diagnosis (Ludlow et al., 2011). As such, mothers have different experiences of their interaction with these professionals. This sub-theme describes the mothers' experiences of engaging with professionals.

It emerged from the study that the mothers' experiences with the professionals were both positive and negative. According to Thapelo, she experienced negative treatment from the health professionals and more positive interaction with the educators.

***Thapelo:***

*Even the first time when I went to [name of the hospital], the doctors asked me why I brought the child there. And then I said I think my child is not well psychologically. The doctors asked me where I studied psychiatry so that I can tell my son is not well. What have I noticed? I say he is always – he was having ASD signs. When there is*

*loud music he becomes irritated. He would close his ears and he would stand still at one place. (Thapelo, 2, Q01)*

*The doctor at [name of the hospital] asked me – the first question he asked me, ‘When you say the child, something is wrong with him, does he poop himself?’ I said no, when it is time he goes to the toilet. He helps himself. (Thapelo, 4, Q2)*

In contrast, Mapeseka discussed passionately how she was helped by the pre-school teacher and health professional. However, she experienced negative treatment from the basic education professionals.

***Mapeseka:***

*The pre-school teacher, like he was so involved. I did not know all those special speech therapists. The OT – he made all the arrangements I guess. Gave me the address. I just went there. Then from there, they referred me to Pretoria for him to be diagnosed. Maybe that is why it was easy for me. (Mapeseka, 5, Q6)*

*Even there I struggled. Even the Department said this one is not going to cope here without ... They were supposed to do the assessment but they just saw autism and said no. I said, ‘No, you guys don’t know what you are talking about. Did you see Hloni [her son] or you just assuming?’ I had to stand up for him. I just go to the MEC because I did not refer myself there. The Department referred me there. (Mapeseka, 12, Q23)*

**5.4.2.3 Sub-theme 3: Broader Community**

Within this sub-theme, both participants spoke about the perceptions and behaviour of the community, such as a lack of understanding, compassion, sensitivity, and empathy. The study findings revealed mixed experiences of the mothers regarding the community’s

response levels. Thapelo stated that she felt highly supported by a community member in most areas of her life.

***Thapelo:***

*... and people [the community] call my son names. They say he was mad. He was deaf. He was all that. (Thapelo, 2, Q01)*

*They [the community] like him because they always laugh where he is. He likes peace. People are always happy about him. (Thapelo, 12, Q16)*

*He is everybody's bundle of joy. If I did not have Thato, ah ... People could have not known me because he is a jolly good fellow who greets and loves everyone. (Thapelo, 13, Q22)*

Mapeseka indicated that her community accepted her child, although she noted that they responded negatively towards her child's tantrums, and this impacted her negatively.

***Mapeseka:***

*I think, hmmm ... my friend, naturally and physically there. Finance, whenever I have problems, he is even concerned when I am not well. I don't want to talk, so she is always there for me. She is the one forcing me to talk because I don't like talking, especially my emotions ... So she is forcing me. (Mapeseka, 10, Q21)*

***5.4.2.4 Sub-theme 4: Caring for the Child's Emotional Needs***

As children living with ASD develop, they begin to experience all the emotional challenges associated with autism spectrum disorder – such as insensitivity, criticism, and being misunderstood. These emotions call for increased support from their caregivers. This sub-theme describes the mothers' experiences regarding supporting their ASD-affected child. The mothers reported how they provided emotional support to their child when the child

faced challenges. Sadly, the mothers said nothing about receiving emotional support for themselves.

**Thapelo:**

*I just put myself in a ... although, in the beginning, it was hard after understanding. I just told myself I will help my son to go through. I will tell the world that there is nothing wrong with my son. (Thapelo, 3, Q1)*

*When he wants to kick the ball I become the keeper [laughed]. (Thapelo, 9, Q10)*

**Mapeseka:**

*I wanted him to feel that I am the mother. Maybe I did not have a choice because we are the only two, and so if I am starting to act somehow now that he has that [ASD] and we are only two, what is going to happen? I think in a way I had to be strong for him. So I had to show him the love. (Mapeseka, 4, Q4)*

### **5.4.3 Theme 7: Cultural Influences**

When faced with a challenging situation, culture plays a key role in one's perceptions and thoughts about the issue (Mandell & Novak, 2005; Pitten, 2008). According to Pitten (2008), how the past generation has conceptualised and solved a particular issue will influence how the current generation will deal with similar issues. This theme and its sub-themes focus on the impact of cultural values and norms on the mothers' experiences of living with a child with ASD.

#### **5.4.3.1 Sub-theme 1: Family Values**

Cultural values are commonly held ideas about a particular way of life, and are shaped by cultural norms. It influences the way people perceive and deal with challenging situations (Frese, 2015). This sub-theme describes the mothers' perceived influence of values

on their experiences of living with a child with ASD. It transpired from the study that the participants and their children have cultivated and embraced family values such as honesty, communication, and cooperation, which contributed to the mothers' satisfactory experiences.

***Thapelo:***

*He knows that the first thing I want [is] honesty. I ask him, 'What is the problem?'*

*And he will tell me this and this and this. You must also teach your child that life is not always, eh, is not always according to him. You teach him to share, to love, and to accommodate. (Thapelo, 9, Q12)*

*... and you must communicate everything with ... even the financial status in the house, I tell him. Your pension this month is this much. Mine is this much. This is my tenants, what ... what. And when he wants something. When I don't have money I would tell him, no, my boy, this and this and this. I don't just say I don't have. When I can't afford I tell him, no, there are things that you need and things you want.*

*(Thapelo, 7, Q7)*

***Mapeseka:***

*Mmmm, I think honesty. Honestly, I don't know these kids, when they grow up, yoh, they are lying too much, yoh. I try by all means to make him ... Sweetheart, you cannot lie and just get away with it. You must take responsibility. If you messed up, you must come and tell me. Even if you messed up, I will find out anyway and I will get mad. (Mapeseka, 7, Q13)*

**5.4.3.2 Sub-theme 2: Societal Norms**

Across cultures, women are seen as important social and emotional caregivers of children, regardless of whether these children have developmental delays or not. Among the

Sotho cultures, adult males are expected to have a career or job, have a family, and be independent (Obioh & T'soeunyane, 2012; Pitten, 2008). The mothers in the study had the same expectations for their children. This filled them with concern and anxiety about the future of their children.

**Thapelo:**

*I just pray that he will find someone [romantic partner] who will understand him and who will also love him. Who will not judge him the way he is. (Thapelo,13, Q18)*

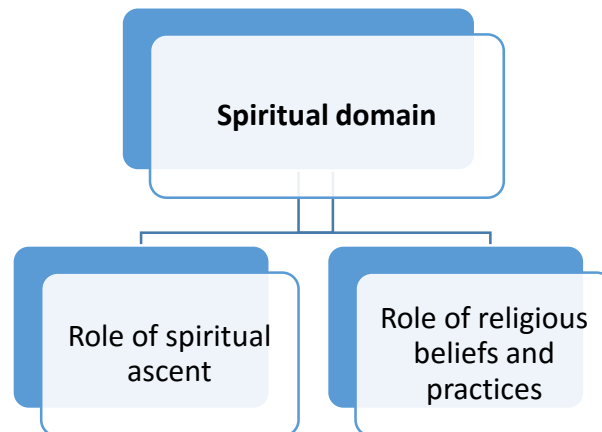
*I pray God to give me a very long life so that I can see my son one day married and standing [up] for himself because I don't know for how long I will be there for him. (Thapelo, 8, Q8)*

**Mapeseka:**

*That one, yoh! Now that he is growing up I don't know what is going to happen. Now he is starting to be a teenager and then he does not have a father figure, and I don't know what to do. If he can come now and say this [I am in a relationship] and this is happening to me. How will I respond? I don't know. (Mapeseka, 9, Q18)*

## **5.5 The Spiritual Domain**

In Western culture, having a child with ASD may be viewed as a task coming from God. However, in the Sotho culture, this may be seen as punishment from the ancestors (*Badimo*) or an evil spell from the witches (*Boloi*) (Edwards, 2011; Heidaryet al., 2015; Ivtzan, Chan et al., 2013; Nwoye, 2015). Spirituality influences people's understanding of the meaning attached to their life experiences (Ekas et al., 2009; Heidary et al., 2015; Ivtzan et al., 2013). This theme and its sub-themes focus on both mothers' perceived role of spirituality in their experiences (see Figure 5).

**Figure 5***Spiritual domain and themes*

### 5.5.1 Theme 1: Role of Spiritual Ascent

Within this sub-theme, mothers reported on the role of spirituality when living with a child with ASD. Both participants stated that they were fulfilling a spiritual responsibility by taking care of their children. In this study, faith in the Supreme Being (God) was found to be the cradle of strength, patience, and hope for the participants. Thapelo spoke emotionally about the role that her spirituality played in raising her child.

***Thapelo:***

*Now I make peace with myself. I say God knows what he is doing. He knows He will give me one son who will need my whole attention, and [I] have made peace with it and live with it. (Thapelo, 11, Q14)*

### 5.5.2 Theme 2: The role of Religious Belief and Practices

This sub-theme shares insight into how the mothers' ideas and values about their relationship with God shaped their experiences of living with their ASD-affected child. The

study found that being involved in a religious organisation, such as a church and its activities, played a role in how the mothers experienced living with a child with ASD.

***Thapelo:***

*What helps me and my son is that we go to church, read the Bible, and sing in the house. He can sing [Gospel songs]. We dance and play together. (Thapelo, 9, Q10)*

It appeared from the study that religious support for a mother living with a child with ASD is a source of emotional comfort and strength. Mapeseka indicated that she does get social support from the church.

***Mapeseka:***

*I just talk to people. I just talk to the church. (Mapeseka, 6, Q10)*

*Even in the church, they do ask about him. They are concerned and I say he is fine. If*

*I have anything I will let you guys know. (Mapeseka, 10, Q21)*

## **5.6 Conclusion**

The chapter covered the themes and their sub-themes extracted from the interview data. These findings will be discussed in the next chapter, with special reference to how they relate to relevant literature and the biopsychosocial-spiritual model.

## CHAPTER SIX

### DISCUSSION OF THE FINDINGS

#### 6.1 Introduction

This study aimed to explore the experiences of two Sotho mothers living with a child with ASD. This chapter presents a discussion of the study findings. The discussion will focus on six themes that emerged from the study, namely (a) lack of knowledge and understanding of ASD, (b) schooling issues, (c) the role of social support, (d) different symptoms and their impact on mothers' negative experiences, (e) positive attitude as a buffer to negative emotions, and (f) acceptance of the diagnosis as the first step towards a positive relationship with the child.

#### 6.2 Lack of Knowledge and Understanding of ASD

The commonly held idea that knowledge is power holds. Knowledge and understanding of an illness is critical for all people living with a person with a chronic medical condition, disability, or mental disorder (Franz et al., 2017). Knowledge can help parents or caregivers to understand the reactions and feelings of the patient (Gona et al., 2025; Van der Merwe, 2020). Knowledge and understanding can also help parents and family members living with a person with an undiagnosed illness to identify early warning signs indicating something may be wrong medically or developmentally. Lack of knowledge and understanding may result in an inability to recognise symptoms and to act accordingly.

Among the Basotho people and in other non-Western societies, people often believe that ASD is caused by, among others, spirituality, parental wrongdoing, stress, witchcraft, or head trauma (De Vries, 2016; Van der Merwe, 2020). Some studies found that non-Western communities, including the Basotho community, may see the cause of ASD as parental mistakes and parenting inadequacies (Franz et al., 2017; Gona et al., 2015; Van der Merwe,

2020). Also, most Sotho communities are fighting an HIV/Aids pandemic, causing many parents to confuse the symptoms of an HIV-positive child with those of a child with ASD because of a lack of knowledge (Van der Merwe, 2020). Interestingly, acquiring knowledge about the Western way of making a diagnosis has helped the Basotho people to let go of parental blaming and to foster support for the parents and the patient (Franz et al., 2017; Mathye & Eksteen, 2016).

Knowledge and understanding of ASD play an integral part in the diagnosis, interventions, and experiences of ASD (Bakare et al., 2018; Ludlow et al., 2011; Wiese, 2014). Lack of knowledge and understanding of ASD among community members is well documented in previous research, and it was found to negatively affect parents living with children with ASD (Bakare et al., 2018; Del Villar, 2018; Gane, 2008; Van der Walt, 2006). In this study, the findings confirmed that view. Parents in this study reported experiencing stigmatisation and misunderstanding due to a lack of knowledge from the community. The lack of knowledge about ASD was also cited by Weise (2014), who asserted that parents often only learn about the term autism when their children are diagnosed with ASD. Among the Basotho people, the lack of knowledge and understanding of ASD has resulted in members of the family and the community upholding certain myths about its cause and treatment. This, in turn, may lead to delayed diagnosis and interventions.

Despite ongoing awareness programmes about ASD worldwide, it appears that many people, including parents, are still confused and believe various myths about the causes, treatment and impact of ASD.

As a result of the initial lack of understanding of the disorder, parents typically face challenges such as stigmatisation by family members and the broader community. Individuals and families who live with disabilities often experience stigmatisation based on the

characteristics of the disability that they display. Individuals living with ASD experience a unique stigma from people who lack adequate knowledge because ASD is considered an 'invisible' disability compared to other forms of disabilities. Bakare et al. (2018) found that Egyptian mothers living with ASD experienced stigmatisation and lack of compassion from family members who did not have sufficient knowledge of ASD. Similarly, this study showed that the participants' children were stigmatised and criticised by family members who did not understand ASD.

Mothers' advocacy becomes an additional role when parenting a child living with ASD. In many societies, mothers are blamed by their families and communities for their children's disabilities, and are thought to be responsible for their children's cure. Mothers, therefore, play a significant advocacy role in challenging the mothers' blame and in promoting acceptance, support, and empowerment of themselves and their children. Mothers also advocate for access to medical and other treatment interventions, and participate in studies that build knowledge about ASD. Studies have found that even professionals can have insufficient knowledge and understanding of ASD, which may be due to inadequate training or little involvement in the treatment of ASD patients (Bakare et al., 2018; Fong et al., 1993; Gane, 2008; Ludlow et al., 2015). In concurrence with the current findings, previous research found that mothers consulted multiple clinicians who gave them conflicting guidance about ASD (Ilias, Liaw et al., 2017; Safe et al., 2012). Similarly, in this study, both mothers have experienced negative emotions as a result of the professionals' inadequate understanding of ASD.

When a child is diagnosed with ASD, the parents typically try to find out more about their child's condition, and about the etiology, treatment, and services available.

Professionals working with mothers taking care of ASD children need knowledge and understanding of the challenges that the mothers experience and the various interventions available to such parents. Lack of knowledge and understanding from families, communities, and professionals exacerbates the challenges that these mothers need to handle.

### **6.3 Schooling Issues**

It is important to place learners with disabilities in an appropriate schooling programme and to provide supportive resources. For example, children with severe ASD may require placement in special schools while those with mild to moderate ASD may benefit from mainstream schools (Van Schalkwyk et al., 2016). Access to schools can help children with ASD to be integrated beyond the school system. Also, schools are an important instrument for social development (Erasmus et al., 2019; Van Schalkwyk et al., 2016). Schooling a child with ASD can therefore help to curb the endured rejection, isolation, and stigmatisation experienced by family and society. The schooling of children with ASD is recommended globally because it helps them to improve both academically and socially, form peer relationships, and obtain skills with which to secure jobs (Anderson et al., 2020; Erasmus et al., 2019; Linton, 2015; Van Schalkwyk et al., 2016). It also helps teachers in inclusive schools to learn how to teach in diverse schools and to develop curricula that are more accessible to all (Erasmus et al., 2019).

The United Nations guidelines (1989, 2006) and the South African Department of Education's White Paper 6 (2001) emphasise the rights of children with disabilities to access both segregated and inclusive education. The findings in this study do not necessarily agree with this. Difficulty to access proper schooling can have a significant negative impact on mothers' experience of parenting a child with ASD, as shown in this study as well (Erasmus et al., 2019; Van Schalkwyk et al., 2016). Other studies reached similar conclusions

(Anderson et al., 2020; Erasmus et al., 2019; Linton, 2015; Van Schalkwyk et al., 2016).

Gobrial (2018) reported that 64% of children of Nigerian mothers who participated in her study were not attending school, and mothers expressed the need for special schools for children with ASD.

### ***6.3.1 The Efforts Made***

The scarcity of special schools and limited access to mainstream schools for children living with disabilities, especially ASD, challenges mothers to assume an advocacy role. Gane (2008) found that one mother had to attend a short course in law to advocate for their children's access to schools within the ambits of the law. In this study, one of the Sotho mothers had to consult the provincial executive officials to advocate for her child's admission to a special school.

### ***6.3.2 The Challenges of Admission, and More so in Rural Areas***

The South African Department of Education's White Paper 6 (DoE, 2001) points out that the government prioritises the rights of children with disability to access quality and inclusive education. Despite these policy guidelines children with disabilities continue to experience discrimination in mainstream schools. Children with disabilities are therefore left with special schools as the only alternative for access to education. South Africa, as in other developing countries, is experiencing a scarcity of special schools for children with ASD (Erasmus et al., 2019; Mandell & Novak, 2005; Van der Walt; 2006; Van Schalkwyk et al., 2016). In this study it was mentioned that the children of both participants were attending special schools in urban areas rather than in their home villages. This demonstrates the need for the development of special schools for ASD-diagnosed children in rural areas across South Africa.

Despite special schools being the main absorber of children with ASD in South Africa, parents often wait for long periods of time before their children can be admitted. Pillay, Duncan and De Vries (2020) found that the demand for ASD special schools grew by 276% in the Western Cape of South Africa. The above findings show that long waiting lists are inevitable, especially for rural children living with ASD. In this study, it was evident that accessing special schools is one of the major hurdles for mothers of ASD-affected children.

### ***6.3.3 Educators' Challenges within the School***

Educators play a significant role in the integration of children in both mainstream and special schools. However, various studies have shown that educators do not always adequately understand the needs of children with ASD (DePape & Lindsay, 2015; Gane, 2008). Also, studies have highlighted that teachers have limited knowledge of how to manage the behavioural challenges presented by children with ASD (Bakare et al., 2018; Gobrial, 2018; Ilias et al., 2017; Ludlow et al., 2011; Van der Walt, 2006). Similarly, mothers in this study shared the same experiences, as they reported that at some point they had to educate teachers about ASD. In their study, Corkum et al. (2014) also mentioned that educators indicated a need to upskill in terms of ASD and its educational interventions. In short, there is a need for special schools for ASD individuals, capacity building for school administrators and teachers, and inclusive education.

### **6.4 The Role of Social Support**

Social support is understood to refer to external personal resources that an individual has, especially when faced with hardship or stressful situations (Del Villar, 2018). Social support can also be a perception that a person has about the availability of support (Kapp, 2018). Among the Basotho people, this support may include members of the extended family who may not be living in the same household. The availability of social support can

significantly reduce the stress associated with raising a child with developmental challenges (Del Villar, 2018; Wiese, 2015). Social support has also been linked to better coping strategies and adjustment when raising children with illnesses, diseases or mental disorders. Social support also contributes to positive cognitive appraisal and adaptation, and can help to mitigate the challenges associated with parenting a child with ASD (Kapp, 2018; Wiese, 2015). The availability of social support provides parents with psychosocial aid, information, and professional advice on where to find help for their children. It also provides parents with emotional and practical support in the absence of formal service providers. The Basotho people provide social support to community members facing hardship by contributing their resources and performing rituals as an extended family, where necessary. This practice helps the parents and the child living with ASD to feel less burdened socially, financially, and psychologically (Del Villar, 2018; Kapp, 2018; Wiese, 2015).

Researchers have found that lack of social support negatively influences parents' experiences of living with a child with ASD because they feel socially isolated and overwhelmed by the constant supervision of the child (Del Villar, 2018; Ludlow et al., 2011; Wiese, 2015). Research findings from this study and other studies relating to mothers' experiences of social support from immediate family members, the broader community, and professionals are discussed below.

#### ***6.4.1 The Argument of Single-parenting***

In the Sotho culture, gender roles are clearly defined in a family, with the mother providing social and emotional support while the father provides financial support. When raising a child with ASD, the ideal is to have both parents contributing to the child's care.

In their study, Greeff and Van der Walt (2010) found that all their study participants' partners were committed and supportive in caring for their children, which contributed to the

mothers' psychological wellbeing. However, when raising a child with ASD, the absence of one partner can be psychologically challenging for the remaining partner. Various studies have found that fathers of children with ASD were mostly absent, resulting in mothers raising their children as single parents (Gane, 2008; Wiese, 2015). In short, when mothers are single-parenting a child with ASD it can result in psychological challenges such as depression.

#### ***6.4.2 Support from the Family***

Within the Sotho culture, the family plays an active role during different transitions and their rituals. The support that an individual receives from family members during life transitions such as marriage, the birth of a child, and death is crucial. Transitions, such as the birth of a child with ASD, can increase stress levels in families, and change family roles and relationships. Within the Sotho culture, the family's perception of the cause of the child's condition will determine the amount of support the parents will receive from the family.

Family support plays a major role in helping the parents of a newly diagnosed child to understand and accept the diagnosis of autism spectrum disorder. This support can also help the parents to find specialists and intervention services, and to pay for such services. Similarly, in the Sotho culture, the family may help the affected family member to consult the diviner for a diagnosis, and the healer for treatment, and pay for such services as well. However, in this study, it emerged that the mothers had different experiences about family members' support. The two Sotho mothers in this study found that parenting a child with ASD was exhausting and time-consuming. Various studies have highlighted the importance of support from family members for mothers raising ASD-affected children (Del Villar, 2018; Gobrial, 2018; Wiese, 2015).

### ***6.4.3 Support from Professionals***

In South Africa, access to health services and professional support is far more challenging for people from rural areas. Finding relevant information and having a clear treatment plan have a positive impact on parents raising children with disabilities (Rabat et al., 2019). In this context, professionals can play a significant role by providing a safe space for parents with ASD-diagnosed children to debrief, by supplying reliable and relevant information, and by helping families to plan based on their children's needs (Gobrial, 2018; Rabat et al., 2019). Among the Basotho people, the role played by traditional healers is similar to that played by health professionals in Westernised communities.

The role of professionals in mothers' experiences of living with a child with ASD is well documented (Del Villar, 2018; Gobrial, 2018; Ludlow et al., 2015; Wiese, 2015). Various studies have shown that mothers needed to consult with a range of professionals for a diagnosis and treatment interventions for their children. In this study, the one participant's interactions with health professionals were negative. Yet, she found good support from the school. In their study, Ludlow et al. (2011) also mentioned that parents experienced special schools' educators as a valuable resource and support. In short, support from professionals is critically important for mothers raising children living with ASD.

### ***6.3.5 Support from the Broader Community***

There is an African proverb that says, "It takes the community to raise a child". This is also true for the Basotho people. The community plays an important part in the rituals associated with transitions such as the birth of a child, marriage, death, initiation, and the treatment of illnesses. Similarly, the community can play a significant role in helping a family to cope with an ASD-diagnosed child. Various studies have pointed out that parents often struggle to deal with public criticism of their ASD children's behaviour (DePape &

Lindsay, 2015; Ludlow et al., 2011; Safe et al., 2012; Woodgate, Ateah, & Secco, 2008). Similarly, this study found that the two Sotho mothers experienced the reaction of the public towards their children as negative. Hence, the mothers were anxious about going out into the public with their children. In their study, DePape and Lindsay (2015) said that the parents responded to public criticism by ignoring or confronting the public, and sometimes by educating the public. The two Sotho mothers in this study also mentioned that they sometimes had to confront or educate the public about ASD. Social support from the community can help parents to face the challenges associated with raising ASD-diagnosed children. Indeed, social support from the community is needed to create positive experiences for such parents.

### **6.5 Different Symptoms and their Impact on Mothers' Negative Experiences**

Parenting a child with a disability or chronic illness may cause emotional rage, especially after learning about such a diagnosis (Gobrial, 2018). Parents living with a child with a disability go through stages such as denial, grieving, depression, and anxiety as the management of the child's condition becomes the new role for the parent (Ludlow et al., 2011; Wiese, 2015). Parenting a child living with ASD becomes more challenging when there is no clearly defined treatment plan (Gobrial, 2018). In this study, the two Sotho mothers found it difficult to manage their children's ASD symptoms, which included tantrums and aggressive behaviour. Other researchers also referred to the parents' frustration and depression caused by the struggle to manage their children's symptoms (Gane, 2008; Ludlow et al., 2011; Wiese, 2015).

Studies have highlighted that mothers found it difficult to cope with their children's preference for routine activities and repetitive behaviours (Del Villar, 2018; Woodgate et al., 2008). The two Sotho mothers in this study also found their children's preference for routine

activities and repetitive behaviours disturbing. In other studies, mothers reported that they sometimes changed their family environment to suit the needs of their children living with ASD (Gane, 2008; Ilias et al., 2017; Wiese, 2015). Some mothers even had to resign from their jobs, as did one of the participants in this study.

Both Sotho mothers pointed out that managing their children's tantrums in public areas contributed to their psychological stress. The mothers commented that their children's tantrums resulted in negative reactions from the public. Similarly, according to previous studies, mothers found it highly challenging to manage the reaction of the public towards their children (Gane, 2008; Gobrial, 2018; Van der Walt, 2006; Wiese, 2015).

Based on the evidence presented in this study, the two Sotho mothers did not always cope well with their children's impaired speech development. Deficiencies in speech development among children with ASD can make it difficult for the child and the mother to interact, which can affect their connection and relationship. Mothers in other studies mentioned that, as their children developed, their speech also improved, which added to the mothers' wellbeing (Bakare et al., 2018; DePape & Lindsay, 2015; Gane, 2008). The mothers said that their children's improvement in speech development motivated them to continue caring for their children.

Various studies have referred to ASD children's sensitivity to excessive noise, and how the mothers had to adjust their circumstances accordingly (Ilias et al., 2017; Woodgate et al., 2008). In this study, the one participant's child was very sensitive to excessive noise, especially in public. The other participant stated that she struggled to cope with her child's preference for excessive noise. The Basotho people typically live in a community-based environment, and households often accommodate extended families. This can make it difficult for parents to control noise levels for their ASD-affected children, which may impact

the child's behaviour. The study also showed that managing the sensory symptoms of ASD adversely influences how the mothers lived with their children. Various studies highlighted that mothers should receive training on how to manage their children's ASD symptoms (Bakare et al., 2018; DePape & Lindsay, 2015; Gane, 2008; Ilias et al., 2017).

Within the Sotho culture, the symptoms of ASD are recognised and attempts are made to manage these by using traditional herbs and performing rituals. According to Mthombeni and Nwoye (2016), there is no evidence that this has helped to alleviate the symptoms associated with ASD.

### **6.6 Positive Attitude as a Buffer to Negative Emotions**

Living in a household with a child with a disability can disturb daily routines, plans, and relationships. Receiving a child's diagnosis of ASD can awaken negative reactions such as anger, depression, anxiety, and shock (Reddy, Fewster, & Gurayah, 2019). In this context, a positive attitude can help to alleviate the emotional burden associated with managing a child with ASD. It can also positively influence relationships between the child living with ASD and other family members. Maintaining a positive attitude is a first step to build support for children living with disabilities and for their families (Reddy et al., 2019).

This study found that the two Sotho mothers' positive attitude towards their ASD children enhanced their interaction with the children. This finding concurs with Walsh (2016) who found that maintaining a positive attitude during hardship contributes to positive experiences and helps to build resilience. Similarly, Ekas et al. (2010) found a link between maintaining a positive attitude towards an ASD-diagnosed child and the mother's physical and psychological wellbeing.

This study highlighted that focusing on the ASD child's abilities and achievement of developmental milestones helped the mothers to cope better with their circumstances. A

positive attitude towards the child's ASD condition and hopefulness also contributed significantly towards the mothers' resilience. As confirmed by other studies, a positive attitude by the mother supported the development of the child's personality, which in turn enhanced the mother's experience of the child (Del Villar, 2018; Ekas et al., 2015).

### **6.7 Acceptance of the Diagnosis as a First Step Towards a Positive Relationship with the Child**

Parenting a child with a chronic illness, mental disorder or disability is no easy task. Upon receiving the child's diagnosis, the parent needs to adapt to a new normal. However, the acceptance of the child's diagnosis can serve as a protective factor for such parents. Acceptance has been found to reduce self-blame, anger, depression, and anxiety. Parents who accept their children's diagnosis tend to bolster their psychological resilience over time (DePape & Lindsay, 2015; Di Renzo et al., 2020).

Various studies have confirmed the positive shift in mothers' experiences and psychological wellbeing when they accept the child's diagnosis (Bakare et al., 2018; Del Villar, 2018). Yet, there are also parents who struggle to accept their children's diagnosis of ASD (Brown & Kapp, 2016; Ekas et al., 2015; Gane, 2008; Ilias et al., 2018). This study highlighted that the Sotho mothers' eventual acceptance of their children's diagnosis contributed to their positive experience of the situation.

When mothers accepted the child's ASD diagnosis, they were no longer overwhelmed by self-blame and feelings of despair (Di Renzo et al., 2020; Ekas et al., 2015; Oppenheim et al., 2009). Equally, in the current study, the acceptance of the child's diagnosis helped the mothers to curb feelings of guilt and self-blame.

Based on this study's findings, once the mothers had accepted the children's diagnosis, they could focus on sourcing relevant interventions for their children. Past studies

also pointed out that parents who positively accepted their child's diagnosis were more responsive to their children's needs; and this helped them to build their children's strength and abilities (DePape & Lindsay, 2015; Fong et al., 1993; Gobrial, 2018; Igwe et al., 2011). Thus, assisting the mothers to accept their children's diagnosis and maintain a positive attitude can mitigate the mother's challenges and foster positive experiences.

## **6.8 Conclusion**

This chapter presented a discussion of mothers' experiences of living with a child with ASD, referring to the two Sotho mothers participating in this study as well as the mothers who participated in other researchers' studies. It is evident that raising a child with ASD comes with challenges for the mother, the family and the community. The contributions and limitations of this study will be discussed in the next chapter.

## CHAPTER SEVEN

### CONCLUSION AND RECOMMENDATIONS

#### 7.1 Introduction

This chapter concludes the study by highlighting the contributions of the study and outlining the practical implications of the study's findings to clinical psychology. It also points out the limitations of the study, and makes recommendations for the future studies.

#### 7.2 Contributions of the Study

This study provided insight into the experiences of Sotho mothers living with a child with ASD. The study revealed that the mothers' encountered both negative and positive experiences. Also, the study highlighted the parents' need for social support from immediate family members, the broader community, and professionals. The research also confirmed the need for awareness campaigns about ASD, and the need for cultural sensitivity regarding the diagnosis and treatment of ASD. It emerged from the research that there is an urgent need for the development of special schools for children with ASD, especially in rural areas. Based on this study, it seemed there is a need for psychotherapy specifically aimed at mothers living with a child with ASD in South Africa, especially in rural communities.

#### 7.3 Practical Implications for Clinical Psychology

This study contributes to clinical psychology in several ways. Firstly, it contributes to the body of knowledge about the psychological implications of mothering a child with ASD. Practically, the findings of this study can help to enhance existing interventions used by psychologists, doctors, social workers, and other professionals to assist parents living with children with ASD. The findings also add value to theory development, especially in the context of academia where other scholars interested in expanding this field can leverage the

insights generated from this study. The Basotho people have a unique cultural belief system about the causes, diagnosis and treatment of illnesses including mental disorders. Therefore, this study will assist clinicians to become more culturally sensitive when working with parents and their ASD-affected children in non-Westernised contexts.

#### **7.4 Limitations of the Study**

Although the small sample was deliberately chosen to fit the case study design, it can also be seen as a limitation because a large sample would possibly strengthen the generalisation of the findings. The study did not use a gender and racially diverse sample because the study focused on exploring the impact of Sotho culture on mothers' experiences of living with a child with ASD. Hence, the generalisation of the study's findings may be difficult. The stigma associated with ASD, the culture of not disclosing ASD-affected children's condition, the parents' hesitance in discussing their children's condition, and time pressure made it difficult to source participants for this study. In addition, the study used face-to-face interviews which could have resulted in the researcher being subjective and biased when analysing the data. However, the researcher used the participants' direct quotes for content analysis and ensured that themes emerge objectively from the data sets.

#### **7.5 Recommendation for Future Research**

This study showed that there is a gap in the understanding of the experiences of mothers living with a child with ASD, especially the experiences of mothers from indigenous groups in developing countries. Future studies will benefit from larger samples with diverse cultural, socio-economic, race, and geographic backgrounds. Qualitative studies exploring the broader personal and family experiences of living with a child with ASD are also critical. Studies based on other research methodologies will also help to strengthen the findings gathered using qualitative methods. There is also a need for studies aimed at the development

of intervention programmes for ASD-affected families in rural indigenous contexts. Future research can also focus on the early diagnosis of ASD, and interventions and supportive psychotherapy for those affected, especially within underdeveloped societies. The current study also pointed to the need to explore how knowledge and understanding of ASD, and access to health care facilities and schools for ASD children could be promoted in rural areas and developing countries. In short, there is a significant need to grow the existing body of knowledge about ASD.

## 7.6 Reflections

Living with a child with a disability or mental disorder is an emotionally challenging task, and talking about it is not a common practice, especially among the Basotho people. However, I was impressed by how openly the participants spoke during the interviews. It should not be taken for granted that professionals and community members have considerable knowledge about ASD. Instead, this study showed that there is a huge need for such knowledge on different levels of society. As an African, I expected that social support from family members, professionals, and community members would be the obvious case based on our commonly held ideology of Ubuntu and communitarian principles. During the interviews, I was challenged and learned that, regardless of our shared culture, race, and location, our experiences and world views are different. As a novice mental health practitioner I was not fully aware of the challenges that mothers of children living with ASD face in terms of the diagnosis journey, treatment, stigmatisation, and access to schools. As I recall the words of one of the participants in this study, *"I think what you are doing, don't just do it for the sake of research ... Whatever the parents are complaining about, please help where you can. Convince where you can. We need schools on this side!"* Regardless of all of the above, the data collected appeared to be rich and reflected the lived experiences of the participants more than my subjective views.

## **7.7 Conclusion of the Study**

Autism spectrum disorder is a developmental disorder that is affecting growing numbers of families around the world, especially the mothers who are mostly the primary caregivers of children diagnosed with ASD. Various studies have focused on the causes and management of ASD, leaving a gap in the understanding of the lived experiences of the mother. This qualitative study, underpinned by a biopsychosocial-spiritual model, was used to explore and describe the experiences of Sotho mothers living with a child with ASD. The findings showed that living with a child with ASD remains a challenge – even more so for Sotho mothers and those living in rural areas. Mothers raising ASD children need to take on different roles and adjust their circumstances based on the functioning level and severity of the symptoms presented by their children. Lack of knowledge and understanding, and lack of access to early diagnosis, intervention, and appropriate education for ASD-affected children are ongoing challenges for the Sotho mothers. The study also highlighted the need for awareness campaigns about ASD aimed at various levels and systems of society to help curb the stigma and distress experienced by families coping with ASD-diagnosed children. This study also found that cultural sensitivity, especially towards indigenous people, can help to design better interventions in a diverse country like South Africa. The study contributes to the body of knowledge on how to cope with an ASD-diagnosed child within the family system.

## References

- American Psychiatric Association (APA) (1994). Diagnostic and statistical manual of mental disorders. *American Psychologist*, 32(7), 513-531. <https://doi.org/10.1037/0003-066X.32.7.513>
- American Psychiatric Association (APA). (1980). *Diagnostic and Statistical Manual of Mental Disorders: DSM-III*. Washington, DC.
- American Psychiatric Association (APA). (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. Washington, DC.
- Anderson, J., Marley, C., Gillespie-Smith, K., Carter, L., & MacMahon, K. (2020). When the mask comes off: Mothers' experiences of parenting a daughter with autism spectrum condition. *Autism*, 24(6), 1546-1556. <https://doi.org/10.1177/1362361320913668>
- Asperger H. (1944). Die Autistische Psychopathen im Kindesalter. *Archiv für Psychiatrie und Nervenkrankheiten*, 117 76–136. <https://doi.org/10.1007/BF01837709>
- Asperger, H. (1991). *Autistic psychopathy in childhood*. Cambridge: Cambridge University Press. (Original work published 1944.)
- Astrow, A. B., Puchalski, C. M., & Sulmasy, D. P. (2001). Religion, spirituality, and health care: Social, ethical, and practical considerations. *The American Journal of Medicine*, 110(4), 283-287. [https://doi.org/10.1016/s0002-9343\(00\)00708-7](https://doi.org/10.1016/s0002-9343(00)00708-7)
- Autism Society of America (ASA). (2020, December 5). *Facts and Statistics*. <https://www.autism-society.org/what-is/facts-and-statistics/>
- Bakare, M. O., Agomoh, A. O., Ebigbo, P. O., Eaton, J., Okonkwo, K. O., Onwukwe, J. U., & Onyeama, G. M. (2009). Etiological explanation, treatability and preventability of

- childhood autism: A survey of Nigerian healthcare workers' opinion. *Annals of General Psychiatry*, 8, 6. <https://doi.org/10.1186/1744-859X-8-6>
- Bakare, M. O., & Munir, K. M. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, 14(3), 208-210. <https://doi.org/10.4314/ajpsy.v14i3.3>
- Bakare, M. O., & Munir, K. M. (2011). Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa: A trend possibly resulting from late diagnosis and intervention. *The South African Journal of Psychiatry*, 17(4), 118-120. <https://doi.org/10.4102/sajpsy.v17i4.295>
- Bakare, M. O., Taiwo, O. G., Bello-Mojeed, M. A., & Munir, K. M. (2018). Autism Spectrum Disorders in Nigeria: A scoping review of literature and opinion on future research and social policy directions. *Journal of Health Care for the Poor and Underserved*, 30(3), 899-909. <https://doi.org/10.1353/hpu.2019.0063>
- Bakare, M. O., Agomoh A. O., Ebigbo, P. O., Eaton, J., Okonkwo, K. O., Onwukwe J. U., & Onyeama, G. M. (2009). Etiological explanation, treatability and preventability of childhood autism: A survey of Nigerian healthcare workers' opinion. *Annual Genetic Psychiatry*, 8(6), 61-81. <https://doi.org/10.1186/1744-859X-8-6>
- Bal, A., Betters-Bubon, J., & Fish, R. (2019). A multilevel analysis of state-wide disproportionality in exclusionary discipline and the identification of emotional disturbance. *Education and Urban Society*, 51(2), 247-268. <https://doi.org/10.1177/0013124517716260>
- Basu, S., & Parry, P. (2013). The autism spectrum disorder 'epidemic': Need for biopsychosocial formulation. *Australian & New Zealand Journal of Psychiatry*, 47(12), 1116-1118. <https://doi.org/10.1177/0004867413509694>

- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 13(4), 544-559. <https://doi.org/10.46743/2160-3715/2008.1573>
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 5(10), 702-714. <https://doi.org/10.1111/j.1365-2788.2007.00960.x>
- Bayat, M., & Schuntermann, P. (2013). Enhancing Resilience in Families of Children with Autism Spectrum Disorder. In D. Becvar (Ed.), *Handbook of Family Resilience* (pp. 409-424). New York, NY: Springer.
- Beck, A. T., Rush, A. J., Shaw, B. F., & Emery, G. (1979). *Cognitive therapy for depression*. New York, NY: Guilford Press.
- Blackman, D. & Moon, K. (2014). A guide to understanding social science research for natural scientists. *Journal of Conservation Biology*, 28(5), 1167-1177. <https://doi.org/doi:10.1111/cobi.12326>
- Blake, J., Rubenstein, E., Tsai, P., Rahman, H., Rieth, S., Ali, H., & Lee, L. (2017). Lessons learned while developing, adapting and implementing a pilot parent-mediated behavioural intervention for children with autism spectrum disorder in rural Bangladesh. *Journal of Autism*, 21(13), 611-621. <https://doi.org/10.1177/1362361316683890>
- Bogin, J., Sullivan, L., Rogers, S., & Stabel, A. (2010). *Steps for implementation: Discrete trial training*. Sacramento, CA: The National Professional Development Center on Autism Spectrum Disorders, The M.I.N.D. Institute, University of California at Davis School of Medicine.

- Botma, Y., Greeff, M., Mulaudzi, F. M. & Wright, S. C. D. (2009). *Research in Health Sciences*. Cape Town: Pearson Education South Africa.
- Bowlby, J. (1980). *Attachment and Loss. Volume 3: Loss, Sadness and Depression*. New York, NY: Basic Books.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications.
- Braun V., Clarke V., Hayfield, N., & Terry, G. (2019). Thematic Analysis. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences*. Singapore: Springer. [https://doi.org/10.1007/978-981-10-5251-4\\_103](https://doi.org/10.1007/978-981-10-5251-4_103)
- Braun, V. & Clarke V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Brentani, H., Paula, C. S., Bordini, D., Rolim, D., Sato, F., Portolese, J., Pacifico, M. C., & McCracken, J. T. (2013). Autism spectrum disorders: An overview on diagnosis and treatment. *Brazilian Journal of Psychiatry*, 35(1), 62-72. <https://doi.org/10.1590/1516-4446-2013-S104>
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513-531. <https://doi.org/10.1037/0003-066X.32.7.513>
- Brown, O., & Kapp, L. (2014). Resilience in families adapting to autism spectrum disorder. *Journal of Psychology in Africa*, 21(3), 459-464. <https://doi.org/10.1080/14330237.2014.10820482>
- Campisi, L., Imran, N., Nazeer, A., Skokauskas, N., & Azeem, M. W. (2018). Autism spectrum disorder. *British Medical Bulletin*, 127(1), 91-100. <https://doi.org/10.1093/bmb/ldy026>

- Cashin, A. (2004). Painting the vortex: The existential structure of the experience of parenting a child with autism. *International Forum of Psychoanalysis*, 13(3), 164-174, <https://doi:10.1080/08037060410000632>
- Chiarotti, F., & Venerosi, A. (2020). Epidemiology of autism spectrum disorders: A review of worldwide prevalence estimates since 2014. *Journal of Brain Sciences*, 10(5), 274. <https://doi.org/10.3390/brainsci10050274>
- Choy, L. T. (2014). The strengths and weaknesses of research methodology: Comparison and complimentary between qualitative and quantitative approaches. *Journal of Humanities and Social Science*, 19(15), 99-104. <https://doi.org/10.9790/0837-194399104>
- Clark, M., Vinen, Z., Barbaro, J., & Dissanayake, C. (2017). School age outcomes of children diagnosed early and later with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(1), 92-102. <https://doi.org/10.1007/s10803-017-3279-x>
- Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2<sup>nd</sup> ed). Upper Saddle River, NJ: Pearson Education.
- Corcoran, J. (2000). Family treatment of preschool behavior problems. *Research on Social Work Practice*, 10(5), 547-588. <https://doi.org/10.1177/104973150001000502>
- Corkum, P., Davidson, F. D., Tan-MacNeill, K., & Weiss, S. K. (2014). Sleep in children with neurodevelopmental disorders: A focus on insomnia in children with ADHD and ASD. *Sleep Medicine Clinics*, 9(7), 149-168. <https://doi.org/10.1016/j.jsmc.2014.02.006>
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The*

*International Journal of Research and Practice*, 20(2), 153-162. <https://doi.org/10.1177/1362361315573636>

Crane, R. S., Brewer, J., Feldman, C., Kabat-Zinn, J., Santorelli, S., Williams, J. M., & Kuyken, W. (2017). What defines mindfulness-based programs? The warp and the weft. *Psychological Medicine*, 47(6), 990-999. <https://doi.org/10.1017/S0033291716003317>

Creswell, J. W. (2014). *Research design: Qualitative, quantitative and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage Publishing.

Creswell, J. W., Hanson, W. E., Plano, C. V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counselling Psychologist*, 35(2), 236-264. <https://doi.org/10.1177/0011000006287390>

Crowell, J. A., Keluskar, J. & Gorecki, A. (2019). Parenting behaviour and the development of children with autism spectrum disorder. *Journal of Comprehensive Psychiatry*, 90(16), 21-29. <https://doi.org/10.1016/j.comppsy.2018.11.007>

De Vries P. J. (2016). Thinking globally to meet local needs: Autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology*, 29(2), 130-136. <https://doi.org/10.1097/WCO.0000000000000297>

Del Villar, A. (2018). *Effects of autism spectrum disorder on mothers*.

Electronic Theses, Projects, and Dissertations. San Bernardino: California State University. <https://scholarworks.lib.csusb.edu/etd/674>

Denzin, N., & Lincoln, Y. (2011). *The SAGE handbook of qualitative research*. Thousand Oaks, CA: Sage.

- DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research, 25*(4), 569-583. <https://doi.org/10.1177/1049732314552455>
- Di Renzo, M., Guerriero, V., Zavattini, G.C., Petrillo, M., Racinaro, L. & Bianchi di Castelbianco, F. (2020). Parental attunement, insightfulness, and acceptance of child diagnosis in parents of children with autism: Clinical implications. *Frontiers in Psychology, 11*(3), 18-29. <https://doi.org/10.3389/fpsyg.2020.01849>
- Duffney, L. J., Valdez, P., Tremblay, M. W., Cao, X., Montgomery, S., McConkie-Rosell, A., & Jiang, Y. H. (2018). Epigenetics and autism spectrum disorder: A report of an autism case with mutation in H1 linker histone HIST1H1E and literature review. *American Journal of Medical Genetics. Part B, Neuropsychiatric Genetics: The Official Publication of the International Society of Psychiatric Genetics, 177*(4), 426-433. <https://doi.org/10.1002/ajmg.b.32631>
- Dyer, W. G., Jr, & Wilkins, A. L. (1991). Better stories, not better constructs, to generate better theory: A rejoinder to Eisenhardt. *The Academy of Management Review, 16*(3), 613. <https://doi.org/10.5465/amr.1991.4279492>
- Edwards, S. D. (2011). A psychology of indigenous healing in Southern Africa. *Journal of Psychology in Africa, 21*(3), 335-347. <https://doi.org/10.1080/14330237.2011.1082046>
- Eissa, N., Al-Houqani, M., Sadeq, A., Ojha, S. K., Sasse, A., & Sadek, B. (2018). Current enlightenment about etiology and pharmacological treatment of autism spectrum disorder. *Frontiers in Neuroscience, 12*(13), 304-312. <https://doi.org/10.3389/fnins.2018.00304>

- Ekas, N. V., Whitman, T. L., & Shivers, C. (2009). Religiosity, spirituality, and socio-emotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 39*(5), 706-719. <https://doi.org/10.1007/s10803-008-0673-4>
- Elliott, K. (2016). Caring masculinities: Theorizing an emerging concept. *Men and Masculinities, 19*(3), 240-259. <https://doi.org/10.1177/1097184X15576203>
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129-136. <https://doi.org/10.1126/science.847460>
- Engel, J. D. (1992). Introduction: Issues of methodology in qualitative inquiry. *Qualitative Health Research, 2*(4), 373-374. <https://doi.org/10.1177/104973239200200401>
- Erasmus, S., Kritzinger, A., & Van der Linde, J. (2019). Profiles of public and private autism-specific schools in Gauteng. *South African Journal of Childhood Education, 9*(1), 9-13. <https://doi.org/10.4102/sajc.v9i1.691>
- Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics, 5*(1), 1-4. <https://doi.org/10.11648/j.ajtas.20160501.11>
- Fernández-Alcántara, M., García-Caro, M. P., Pérez-Marfil, M. N., Hueso-Montoro, C., Laynez-Rubio, C., & Cruz-Quintana, F. (2016). Feelings of loss and grief in parents of children diagnosed with autism spectrum disorder (ASD). *Research in Developmental Disabilities, 55*(15), 312-321. <https://doi.org/10.1016/j.ridd.2016.05.007>

- Fewster D. L., & Gurayah, T. (2015). First port of call: Facing the parents of autism spectrum disorder. *South African Family Practice*, 57(1), 31-34. doi:10.1080/20786190.2014.995917
- Finlay, L. (2009). Debating phenomenological research. *Phenomenology & Practice*, 3(1), 6-25. <https://doi.org/10.29173/pandpr19818>.
- Fleming, J., & Zegwaard, K. E. (2018). Methodologies, methods and ethical considerations for conducting research in work-integrated learning. *International Journal of Work Integrated Learning*, 19(3), 205-213. [https://www.ijwil.org/files/IJWIL\\_19\\_3\\_205\\_213.pdf](https://www.ijwil.org/files/IJWIL_19_3_205_213.pdf)
- Fong, T. M., Huang, R. R., Yu, H., & Strader, C. D. (1993). Mapping the ligand binding site of the NK-1 receptor. *Regulatory Peptides*, 46(12), 43-48. [https://doi.org/10.1016/0167-0115\(93\)90010-6](https://doi.org/10.1016/0167-0115(93)90010-6)
- Forero, R., Nahidi, S., De Costa, J., Mohsin, M., Fitzgerald, G., Gibson, N., McCarthy S., & Aboagye-Sarfo, P. (2018). Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. *BMC Health Services Research*, 18(1), 1-11. <https://doi.org/10.1186/s12913-018-2915-2>
- Frankl, V. E. (1981). *The will to meaning: Foundations and applications of logotherapy*. New York: New American Library. (Original work published 1969.)
- Franz, L., Chambers, N., Von Isenburg, M., & De Vries, P. J. (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. *Autism Research: Official Journal of the International Society for Autism Research*, 10(5), 723-749. <https://doi.org/10.1002/aur.1766>

- Frese, M. (2015). Cultural Practices, Norms, and Values. *Journal of Cross-Cultural Psychology, 46*(10), 1327-1330. <https://doi:10.1177/0022022115600267>
- Gane, A. (2008). *Mothers' experience of having a child diagnosed with an autism spectrum disorder*. Master's thesis. Northampton, MA: Smith College. <https://scholarworks.smith.edu/theses/1232>
- Garuba, H., & Raditlhalo, S. (2008). Culture. In N. Shepherd & S. Robins, *New South African keywords*, (pp. 35-46). Auckland Park: Jacana.
- Geertsema, S., Kritzinger, A. & Van Biljon, S. (2016). A retrospective case report on demographic changes of learners at a school for children with Autism Spectrum Disorders in the Gauteng Province. *South African Journal of Childhood Education, 5*(1), 11-26. <http://www.scielo.org.za/scielo.php?script>
- Gobrial, E. (2012). Mind the gap: The human rights of children with intellectual disabilities in Egypt. *Journal of Intellectual Disability Research, 56*(11), 1058-1064. <https://doi.org/10.1111/j.1365-2788.2012.01650.x>
- Gobrial, E. (2015). Attitude towards people with autism spectrum disorder in Egypt. *Journal of Special Education, 12*, 50-73. <http://dx.doi.org/10.3390/socsci7080133>
- Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Journal of Social Sciences, 7*(8), 133-147. <http://dx.doi.org/10.3390/socsci7080133>
- Gona, J. K., Newton, C. R., Rimba, K., Mapenzi, R., Kihara, M., Van de Vijver, F. J., & Abubakar, A. (2015). Parents' and professionals' perceptions on causes and treatment options for Autism Spectrum Disorders (ASD) in a multicultural context on the Kenyan Coast. *PloS One, 10*(8), 27-34. <https://doi.org/10.1371/journal.pone.0132729>

- Greeff, A., & Van der Walt, K. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities, 45*(3), 347-355. <https://www.jstor.org/stable/23880109>
- Guba E. G., & Lincoln, Y. S. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Technology Research and Development, 29*(2), 75-91. <https://doi.org/10.1007/BF02766777>
- Gustafsson, J. (2017). *Single case studies vs. multiple case studies: A comparative study*. Thesis. Halmstad, Sweden: Halmstad University.
- Hallmayer, J., Cleveland, S., Torres, A., Phillips, J., Cohen, B., Torigoe, T., ... & Risch, N. (2011). Genetic heritability and shared environmental factors among twin pairs with autism. *Archives of General Psychiatry, 68*, 1095-1102.
- Hammersley, M. (2013). *What is Qualitative Research?* New York, NY: Bloomsbury Publishers.
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629-642. <https://doi.org/10.1007/s10803-012-1604-y>
- Heidary, A., Hosseini Shahidi, L., & Mohammadpuor, A. (2015). Spiritual journey in mothers' lived experiences of caring for children with autism spectrum disorders. *Global Journal of Health Science, 7*(6), 79-87. <https://doi.org/10.5539/gjhs.v7n6p79>

- Hens, K. (2019). The many meanings of autism: Conceptual and ethical reflections. *Developmental Medicine & Child Neurology*, 61(9), 1025-1029. <https://doi.org/10.1111/dmcn.14278>
- Igwe, M. N., Ahanotu, A. C., Bakare, M. O., Achor, J. U., & Igwe, C. (2011). Assessment of knowledge about childhood autism among paediatric and psychiatric nurses in Ebonyi state, Nigeria. *Child and Adolescent Psychiatry and Mental Health*, 5(1), 1. <https://doi.org/10.1186/1753-2000-5-1>
- Ilias, K., Liaw, J., Cornish, K., Sang-Ah Park, M., & Golden, K. (2017). Wellbeing of mothers of children with “A-U-T-I-S-M” in Malaysia: An interpretative phenomenological analysis study. *Journal of Intellectual & Developmental Disability*, 2(42), 74-89. <https://doi.org/10.3109/13668250.2016.1196657>
- Ivtzan, I., Chan, C. P. L., Gardner, H. E., & Prashar, K. (2013). Linking religion and spirituality with psychological well-being: Examining self-actualisation, meaning in life, and personal growth initiative. *Journal of Religious Health*, 52(9), 915-929. <https://doi.org/10.1007/s10943-011-9540-2>
- Kabat-Zinn, J. (1982). An outpatient program in behavioral medicine for chronic pain patients based on the practice of mindfulness meditation: Theoretical considerations and preliminary results. *General Hospital Psychiatry*, 4(1), 33-47. [https://doi.org/10.1016/0163-8343\(82\)90026-3](https://doi.org/10.1016/0163-8343(82)90026-3)
- Kafle, N. (2013). Hermeneutic phenomenological research method simplified. *Bodhi: An Interdisciplinary Journal*, 5(1), 181-200. <https://doi.org/10.3126/bodhi.v5i1.8053>
- Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured

- interview guide. *Journal of Advanced Nursing*, 72(12), 2954-2965. <https://doi.org/10.1111/jan.13031>.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2(10), 217-50. <https://psycnet.apa.org/record/1943-03624-001>
- Kapp, S. K. (2018). Social support, well-being, and quality of life among individuals on the autism spectrum. *Pediatrics*, 141(4), 362-368. <https://doi.org/10.1542/peds.2016-4300N>
- Keyes, C. L. M. (2014). Mental health as a complete state: How the salutogenic perspective completes the picture. *Journal of Adult Development*, 3(11), 179-192. <https://doi.org/10.1007/978-94-007-5640-3-11>
- King, D. E. (2000). *Faith, spirituality and medicine: Toward the making of a healing practitioner*. Binghamton, NY: Haworth Pastoral Press.
- Kolvin, I. (1971). Studies in the childhood psychoses. I. Diagnostic criteria and classification. *The British Journal of Psychiatry*, 118(545), 381-384. <https://doi.org/10.1192/bjp.118.545.381>
- Kriel, J. D. (2003). Witches, healers, and helminths: Sotho beliefs regarding the utilization of the latent power of phenomena. *Anthropology Southern Africa*, 26(3), 167-171. <https://doi.org/10.1177/001132550403400401>
- Kumar, B., Prakash, A., Sewal, R. K., Medhi, B., & Modi, M. (2012). Drug therapy in autism: A present and future perspective. *Pharmacological Reports*, 64(6), 1291-1304. [https://doi.org/10.1016/s1734-1140\(12\)70927-1](https://doi.org/10.1016/s1734-1140(12)70927-1)
- Langdridge, D. (2007). *Phenomenological Psychology: Theory, Research and Method*. Harlow, UK: Pearson Education.

- Leavy, P. (2014). *The Oxford handbook of qualitative research*. Oxford: Oxford University Press.
- Leavy, P. (2017). *Research design: Quantitative, qualitative, mixed methods, art-base, and communication-based participatory research approaches*. New York, NY: Guilford Press.
- LeClerc, S., & Easley, D. (2015). Pharmacological therapies for autism spectrum disorder: A review. *P & T: A Peer-reviewed Journal for Formulary Management*, 40(6), 389-397. <https://pubmed.ncbi.nlm.nih.gov/26045648/>
- LeDoux, J. E. (2000). Emotion circuits in the brain. *Annual Review of Neuroscience*, 23(8), 155-184. <https://doi.org/10.1146/annurev.neuro.23.1.155>
- Leigh, H. (1983). The clinical applications of the biopsychosocial model. In A. J. Krakowski, & C. P. Kimball (Eds.), *Psychosomatic Medicine*. Boston, MA: Springer. [https://doi.org/10.1007/978-1-4684-4496-4\\_58](https://doi.org/10.1007/978-1-4684-4496-4_58)
- Linton, A. (2017). *To include or not to include: Teachers' social representations of inclusion of students with Asperger syndrome*. Doctoral thesis. Linköping, Sweden: Linköping University. <https://doi.org/10.3384/diss.diva-121062>
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr, Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The autism diagnostic observation schedule-generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205-223. <https://doi.org/10.1037/t17256-000>.
- Loth, E., Charman, T., Mason, L., Tillmann, J., Jones, E., Wooldridge, C., Ahmad, J., Auyeung, B., Brogna, C., Ambrosino, S., Banaschewski, T., Baron-Cohen, S.,

- Baumeister, S., Beckmann, C., Brammer, M., Brandeis, D., Bölte, S., Bourgeron, T., Bours, C., de Bruijn, Y., & Buitelaar, J. K. (2017). The EU-AIMS Longitudinal European Autism Project (LEAP): Design and methodologies to identify and validate stratification biomarkers for autism spectrum disorders. *Molecular Autism*, 8(24), 53-62. <https://doi.org/10.1186/s13229-017-0146-8>
- Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health & Psychology*, 17(5), 702-711. <https://doi:10.1177/1359105311422955>
- Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(2), 110-115. <https://doi.org/10.1002/mrdd.20061>
- Mandell, D., & Mandy, W. (2015). Should all young children be screened for autism spectrum disorder? *Autism*, 19(8), 895-896. [doi.org/10.1177/1362361315608323](https://doi.org/10.1177/1362361315608323)
- Mosotho, N., Louw, D., Calitz, F. J. W., & Esterhuysen, K. (2008). Depression among Sesotho speakers in Mangaung, South Africa. *African Journal of Psychiatry*, 11, 35-43. [10.4314/ajpsy.v11i1.30253](https://doi.org/10.4314/ajpsy.v11i1.30253).
- Matenge, B. (2013). *An Exploration of the Lived Experiences of Mothers Raising Children with Autism*. Master's dissertation. Cape Town: University of Cape Town.
- Mathye, D., & Eksteen, C. (2016). A qualitative investigation of the role of paediatric rehabilitation professionals in rural South Africa: Rehabilitation professionals' perspectives. *South African Journal of Physiotherapy*, 72(1), 290-297. <http://dx.doi.org/10.4102/sajp.v72i1.290>

- Mayers, A. (2013). *Introduction to Statistics and SPSS in Psychology*. New York, NY: Pearson Education.
- McKee, D. D., & Chappel, J. N. (1992). Spirituality and medical practice. *The Journal of Family Practice*, 35(2), 201-208.
- McKenzie, J., & McConkey, R. (2015). Caring for adults with intellectual disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*, 29(6), 531-541. <https://doi.org/10.1111/jar.12209>
- Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Journal of Autism*, 3(3), 273-285. <https://doi.org/10.1177/1362361399003003005>
- Miral, S., Gencer, O., Inal-Emiroglu, F. N., Baykara, B., Baykara, A., & Dirik, E. (2008). Risperidone versus haloperidol in children and adolescents with AD: A randomized, controlled, double-blind trial. *European Child & Adolescent Psychiatry*, 17(1), 1-8. <https://doi.org/10.1007/s00787-007-0620-5>
- Modabbernia, A., Velthorst, E., & Reichenberg, A. (2017). Environmental risk factors for autism: An evidence-based review of systematic reviews and meta-analyses. *Molecular Autism*, 8(22), 13-25. <https://doi.org/10.1186/s13229-017-0121-4>
- Moon, K., Brewer, T. D., Januchowski-Hartley, S. R., Adams, V. M., & Blackman, D. A. (2016). A guideline to improve qualitative social science publishing in ecology and conservation journals. *Ecology and Society*, 21(3), 1-20. <http://dx.doi.org/10.5751/ES-08663-210317>
- Mthombeni, Z. C., & Nwoye, A. (2018). Black South African caregivers' understanding and responses to their children with autism spectrum disorder symptoms: A qualitative

- study. *South African Journal of Psychology*, 48(1), 99-111. <https://doi.org/10.1177/0081246317696453>
- Mubaiwa, L. (2008). Autism: Understanding basic concepts. *South African Journal of Child Health*, 2(1), 6-7. <https://doi.org/10.7196/SAJCH.89>
- Nardone, S., & Elliott, E. (2016). The Interaction between the Immune System and Epigenetics in the Etiology of Autism Spectrum Disorders. *Frontiers in Neuroscience*, 10(14), 329. <https://doi.org/10.3389/fnins.2016.00329>
- Nwoye, A. (2015). African psychology and the Africentric paradigm to clinical diagnosis and treatment. *South African Journal of Psychology*, 45(3), 305-317. <https://doi.org/10.1177/0081246315570960>
- Obioha, E. E., & T'soeunyan, P. G. (2012). The roles of the elderly in the Sotho family system and society of Lesotho, Southern Africa. *Anthropologist*, 14(3), 251-260. <https://doi.org/10.1080/09720073.2012.11891246>
- Ogston, P. L., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Research in Autism Spectrum Disorders*, 5(4), 1378-1384. <https://doi.org/10.1016/j.rasd.2011.01.020>
- Oppenheim, D., Koren-Karie, N., Dolev, S., and Yirmiya, N. (2012). Maternal sensitivity mediates the link between maternal insightfulness/resolution and child–mother attachment: the case of children with Autism Spectrum Disorder. *Journal of Attachment and Human Development*, 14(6), 567-584. <http://dx.doi.org/10.1080/14616734.2012.727256>
- Pillay, S., Duncan, M., & De Vries, P. J. (2020). Autism in the Western Cape Province of South Africa: Rates, socio-demographics, disability and educational characteristics in

- one million school children. *Autism: The International Journal of Research and Practice*, 25(4), 1076-1089. <https://doi.org/10.1177/1362361320978042>
- Pitten, K. (2008). How cultural values influence diagnosis, treatment and the welfare of families with an autistic child. *InSight: Rivier Academic Journal*, 4, 1-5.
- Piven, J., Harper, J., Palmer, P., & Arndt, S. (1996). Course of behavioral change in autism: A retrospective study of high-IQ adolescents and adults. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35(4), 523-529. <https://doi.org/10.1097/00004583-199604000-00019>
- Powers, M. D. (2000). *Children with autism: A parent's guide* (2nd ed.). Bethesda, MD: Woodbine House.
- Rabat, A., Arnal, P. J., Monnard, H., Erblang, M., Van Beers, P., Bougard, C., Drogou, C., Guillard, M., Sauvet, F., Leger, D., Gomez-Merino, D., & Chennaoui, M. (2019). Limited benefit of sleep extension on cognitive deficits during total sleep deprivation: Illustration with two executive processes. *Frontiers in Neuroscience*, 13(21), 591-598. <https://doi.org/10.3389/fnins.2019.00591>
- Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, 66(9), 101-113. <https://doi.org/10.1016/j.rasd.2019.101415>
- Reaven, J., Blakeley-Smith, A., Culhane-Shelburne, K., & Hepburn, S. (2012). Group cognitive behavior therapy for children with high-functioning autism spectrum disorders and anxiety: A randomized trial. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 53(4), 410-419. <https://doi.org/10.1111/j.14697610.2011.02486.x>

- Reddy, G., Fewster, D. L., & Gurayah, T. (2019). Parents' voices: Experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy*, 49(1), 43-50. <https://dx.doi.org/10.17159/2310-3833/2019/vol49n1a7>
- Rogers, C. R. (1986). Reflection of feelings. *Person-Centered Review*, 1, 375–377.
- Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., Chugani, H. T., Donald, K. A., Wilmshurst, J. M., Shih, A., Skuse, D., & Newton, C. R. (2016). Autism spectrum disorders in Africa: Current challenges in identification, assessment, and treatment: A report on the International Child Neurology Association meeting on ASD in Africa, Ghana, April 3-5, 2014. *Journal of Child Neurology*, 31(8), 1018-1026. <https://doi.org/10.1177/0883073816635748>
- Ryan, G. W. & Bernard, H. R. (2000). *Data management and analysis methods*. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed.) (pp. 769-802). Thousand Oaks, CA: Sage Publishing.
- Saad, M., De Medeiros, R., & Mosini, A. C. (2017). Are we ready for a true biopsychosocial-spiritual model? The many meanings of "spiritual". *Medicines*, 4(4), 79. <https://doi.org/10.3390/medicines4040079>
- Sadock, B. J., Sadock, V. A., & Ruiz, P. (2015). *Kaplan and Sadock's synopsis of psychiatry: Behavioural sciences/clinical psychiatry* (11th ed.). New York: Wolters Kluwer.
- Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual & Developmental Disability*, 37(4), 294-302. <https://doi.org/10.3109/13668250.2012.736614>

- Sathe, N., Andrews, J. C., McPheeters, M. L., & Warren, Z. E. (2017). Nutritional and dietary interventions for autism spectrum disorder: A systematic review. *Journal of Pediatrics*, *139*(6), 17-28. <https://doi.org/10.1542/peds.2017-0346>
- Schopler, E., Reichler, R. J., & Renner, B. R. (1986). *The Childhood Autism Rating Scale (CARS): For diagnostic screening and classification of autism*. New York, NY: Irvington Publishers.
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, *33*(6), 565-581. <https://doi.org/10.1023/b:jadd.0000005995.02453.0b>
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63-75. <https://doi.org/10.3233/EFI-2004-22201>.
- Sodi, T. (1998). A phenomenological study of healing in a North Sotho community. Cape Town: University of Cape Town. <http://hdl.handle.net/11427/9601>
- Sodi, T., Mudhovozi, P., Mashamba, T., Radzalani-Makatu, M., Takalani, J. & Mabunda, J. (2011). Indigenous healing practices in the Limpopo Province of South Africa: A qualitative study. *International Journal of Health Promotion & Education*, *49*(7), 101-110.
- Soorya, L.V., Carpenter, L.A., & Romanczyk, R. G. (2011). *Applied behavior analysis*. In E. Hollander, A. Kolevzon, & J. T. Coyle (Eds.), *Textbook of autism spectrum disorders* (pp. 525-536). Washington, DC: American Psychiatric Association Publishing.

South African Department of Basic Education. (2016). *Study on children with disabilities from birth to four years old*. www.doe.gov.za.

South African Department of Health. (2017). *World Autism Awareness Day*. Retrieved from www.dh.gov.za.

Sturm, D., Pfister, S. M., & Jones, D. (2017). Pediatric Gliomas: Current concepts on diagnosis, biology, and clinical management. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 35(21), 2370-2377. <https://doi.org/10.1200/JCO.2017.73.0242>

Sulmasy, D. P. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. *The Journal of Gerontologist*, 42(3), 24-33. [https://doi.org/10.1093/geront/42.suppl\\_3.24](https://doi.org/10.1093/geront/42.suppl_3.24)

Tathgur, M. K., & Kang, H. K. (2021). Challenges of the Caregivers in Managing a Child with Autism Spectrum Disorder— A Qualitative Analysis. *Indian Journal of Psychological Medicine*, 43(5), 416-421. <https://doi.org/10.1177/02537176211000769>

Taylor, L. E., Swerdfeger, A. L., & Eslick, G. D. (2014). Vaccines are not associated with autism: An evidence-based meta-analysis of case-control and cohort studies. *Vaccine*, 32(29), 3623-3629. <https://doi.org/10.1016/j.vaccine.2014.04.085>

United Nations (UN). (2006). *Convention on the rights of persons with disabilities*. New York: United Nations – Disability.

United Nations (UN). (1989). *Convention on the rights of the child*. Geneva: United Nations – Human Rights.

- Vaismoradi, M., Jones, J., Turunen, H., & Snelgrove, S. (2016). Theme development in qualitative content analysis and thematic analysis. *Journal of Nursing Education and Practice*, 6(5), 100-110. <https://doi.org/10.5430/jnep.v6n5p100>.
- Van der Merwe, A. (2020). *Sepedi cultural views on Autism Spectrum Disorder*. Master's Dissertation. Pretoria: University of Pretoria. <http://hdl.handle.net/2263/79201>
- Van Der Walt, K. (2006). *Resilience in families with an autistic child*. Master's thesis. Stellenbosch: Stellenbosch University.
- Van Rooyen, M. (2016). *The father's experience: A South African perspective on caring for a child with autism spectrum disorder*. Master's thesis. Stellenbosch: Stellenbosch University. <http://hdl.handle.net/10019.1/98394>
- Van Schalkwyk, G. I., Peluso, F., Qayyum, Z., McPartland, J. C., & Volkmar, F. R. (2015). Varieties of misdiagnosis in ASD: An illustrative case series. *Journal of Autism Developmental Disorders*, 45(4), 911-918. <https://doi.org/10.1007/s10803-014-2239-y>
- Van Schalkwyk, G. I., Beyer, C., & De Vries, P. J. (2016). South Africa and autism. In F. R. Volkmar (Ed.), *Encyclopedia of Autism Spectrum Disorders* (pp. 1-7). New York: Springer.
- Varela, F. J., Rosch, E., & Thompson, E. (1991). *The Embodied Mind: Cognitive Science and Human Experience*. Cambridge, MA: MIT Press.
- Walsh, F. (2016). Family resilience: A developmental systems framework. *European Journal of Developmental Psychology*, 13(3), 313-324. doi:10.1080/17405629.2016.1154035

- Ward, J., Brown, P., Sherwood, J., & Simner, J. (2019). An autistic-like profile of attention and perception in synaesthesia. *Cortex; A Journal Devoted to the Study of the Nervous System and Behaviour*, *107*(2), 121-130. <https://doi.org/10.1016/j.cortex.2017.10.008>
- Ward, S. L., Sullivan, K. A., & Gilmore, L. (2016). Practitioner perceptions of the assessment and diagnosis of autism in Australia. *Australian Psychologist*, *51*(4), 272–279. <https://doi.org/10.1111/ap.12211>
- Watermeyer, B. (2009). Claiming loss in disability. *Disability & Society*, *24*(1), 91-102. <https://doi.org/10.1080/09687590802535717>
- Weiss, J. A., Wingsong, A., & Lunsy, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism: The International Journal of Research and Practice*, *18*(8), 985-995. <https://doi.org/10.1177/1362361313508024>
- Whitaker, S., & Hirst, D. (2002). Correlational analysis of challenging behaviours. *British Journal of Learning Disabilities*, *30*(1), 28-31. <https://doi.org/10.1046/j.1468-3156.2002.00081.x>
- World Health Organization (WHO). (1999). Fifty-Second World Health Assembly. 7 April 1999. Retrieved from [http://apps.who.int/gb/archive/pdf\\_files/WHA52/ew24.pdf](http://apps.who.int/gb/archive/pdf_files/WHA52/ew24.pdf)
- Wiese, M. (2014). *Mothers' experiences of their child's diagnosis with an autism spectrum disorder*. Master's thesis. Potchefstroom: North-West University. <http://hdl.handle.net/10394/15819>
- Wing, L. (1981). Asperger's syndrome: A clinical account. *Psychological Medicine*, *11*(1), 115-129. <https://doi.org/10.1017/s0033291700053332>

- Winiarski, M. G. (1997). Understanding HIV/AIDS using the biopsychosocial/spiritual model. In M. G. Winiarski (Ed.), *HIV mental health for the 21st century* (pp. 3–22). New York University Press
- Wiśniowiecka-Kowalnik, B., & Nowakowska, B. A. (2019). Genetics and epigenetics of autism spectrum disorder: Current evidence in the field. *Journal of Applied Genetics*, 60(1), 37-47. <https://doi.org/10.1007/s13353-018-00480-w>
- Witkin, S. S., Linhares, I. M., Bongiovanni, A. M., Herway, C., & Skupski, D. (2011). Unique alterations in infection-induced immune activation during pregnancy. *BJOG: An International Journal of Obstetrics and Gynaecology*, 118(2), 145-153. <https://doi.org/10.1111/j.1471-0528.2010.02773.x>
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075-1083. <https://doi.org/10.1177/1049732308320112>
- Yergeau, M. (2018). *Authoring autism: On rhetoric and neurological queerness (Thought in the Act)*. Durham, NC: Duke University Press.
- Yin, R. (2017). *Case Study Research and Applications: Design and Methods* (6th ed.). Beverly Hills, CA: Sage Publishing.
- Zaky, E. A. (2017). Autism Spectrum Disorder (ASD): The past, the present, and the future. *Journal of Child & Adolescent Behaviour*, 5(8), 3-13. <https://doi.org/10.4172/2375-4494.1000e116>

## Appendix A

### Participant's recruitment letter

PO BOX 576  
Hluvukani  
1363  
082 745 6645  
kaizerwitty@gmail.com

Dear prospective research participant

I am a Master's student in Psychology at the University of the Free State. As part of the requirements for the completion of the degree I am conducting a research study with the following topic:

***Living with a child with autism spectrum disorder: Two Sotho mothers' experiences.***

Based on the above information I need to interview two both/single Sesotho speaking mothers living with a child diagnosed with moderate to severe ASD and has been living with this child for a period between 2 to 5 years after diagnosis. I therefore, request you to volunteer as research participants.

Please also note that the information that will be shared during the interview will be kept confidential and stored in a safe place and will only be used for the purpose of the research; it will also only be accessed by the researcher and the research supervisors. You also have the right to decline or withdraw from participation any time.

The participants will have an opportunity to receive the final research report that is intended to contribute to the existing body of knowledge on ASD among South Africans and the development of interventions to families living with a child with ASD.

I thank you for volunteering to participate in this study in advance. Should you wish to participate please respond to me with an SMS or email to the details indicated above.

Kind regards

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Kaizer Ndlovu (Researcher)

## Appendix B

### Research study information leaflet

**DATE**

2019

**TITLE OF THE RESEARCH PROJECT**

*Living with a child with autism spectrum disorder: Two Sotho mothers' experiences.*

**PRINCIPLE INVESTIGATOR / RESEARCHER(S) NAME(S) AND CONTACT NUMBER(S):**

*Ndlovu Kaizer W.*

2007139757

082 745 6645

**FACULTY AND DEPARTMENT:**

*Faculty of Humanities*

*Department of Psychology*

**STUDYLEADER(S) NAME AND CONTACT NUMBER:**

Dr Lindi Nel

051 401 2188

**WHAT IS THE AIM / PURPOSE OF THE STUDY?**

*This study aims to explore and describe the two Sotho mothers' experiences of living with a child with ASD.*

**WHO IS DOING THE RESEARCH?**

*My name is Kaizer Ndlovu and I am currently doing my Master's degree in Clinical Psychology at the University of the Free State. I have an Honours degree in Social Science (Psychology) and I have worked as a Student Counsellor and Community Development Practitioner for the Department of Agriculture, Forestry and Fisheries and Department of Rural Development and Land Reform*

*respectively. As part of my Master's course, I am required to conduct research, which I am currently doing under the supervision of Dr. L. Nel, and herewith invite you to participate in my study.*

#### **HAS THE STUDY RECEIVED ETHICAL APPROVAL?**

YES.

**Approval number: UFS-HSD2018/0944**

#### **WHY ARE YOU INVITED TO TAKE PART IN THIS RESEARCH PROJECT?**

*Sesotho is one of the most prevalent languages spoken in the Free State province, the researcher will only include Sesotho speaking both married or single-mothers families whose child obtained a score between moderate and severe on the Autism Diagnosis Observation Schedule. The researcher will work closely with Dr David Griessel who is a Neuro-Developmental Paediatrician and advocate for Autism to recruit two (02) participants from his patient base and this is the person whom information about you have been obtained from. To accommodate for an initial adjustment period after diagnosis and enable meaningful reflections, only mothers who have lived with the diagnosis between 2 to 5 years will be selected.*

#### **WHAT IS THE NATURE OF PARTICIPATION IN THIS STUDY?**

*You will be requested to participate in one semi-structured interview of approximately 1 hour in duration, which will explore your subjective experiences with regard living with a child with Autism Spectrum Disorder. However, you may be required to participate in follow-up interviews until enough information has been gathered. Notes will be taken during the interview which will also be audio recorded. The tapes and transcripts will not be seen or heard by anyone other than the researcher and her supervisor. The audio recordings and transcripts will be kept in a safe place for a period of five years and will be destroyed thereafter. No identifying information will be used in the transcripts or in the research report. Although direct quotes from my interview may be used in the research report, the participant will be referred to by a pseudonym.*

**CAN THE PARTICIPANT WITHDRAW FROM THE STUDY?**

*The participation on this research is voluntary and there is no penalty or loss of benefit for non-participation. Participation in this research is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason.*

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

*There are no financial benefits for participating on this research. However, the research will add to the existing body of knowledge of Autism Spectrum Disorder. It will also contribute to the development of resilience-oriented approaches to family functioning by focusing on family strengths rather than family deficits.*

**WHAT IS THE ANTICIPATED INCONVENIENCE OF TAKING PART IN THIS STUDY?**

*The researcher will not engage in any practice or behaviour that will be harmful to you or which would put you at risk in any way. The researcher will also ensure that you are respected at all times. However, should you experience emotional distress during or after participation on the research due to the nature of the interview questions, we will arrange for a debriefing or counselling session with University of Free State, Department of Psychology Adult Practice.*

**HOW WILL THE INFORMATION BE STORED AND ULTIMATELY DESTROYED?**

*Hard copies of your answers will be stored by the researcher for a period of five years in a locked cupboard/filing cabinet for future research or academic purposes; electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable.*

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

*No payment will be received for participating in the study.*

**HOW WILL THE PARTICIPANT BE INFORMED OF THE FINDINGS / RESULTS OF THE STUDY?**

*If you would like to be informed of the final research findings, please contact Kaizer Ndlovu on kaizerwitty@gmail.com. The findings are accessible for www.ufs.ac.za. Please do not use home telephone numbers. Departmental and/or mobile phone numbers are acceptable. Should you require any further information or want to contact the researcher about any aspect of this study, please contact 0827456645. Should you have concerns about the way in which the research has been conducted, you may contact Dr. Lindi Nel at (051) 401 2188. The researcher will endeavour to avoid potential harm or risk to self and participants. If research participants need debriefing after the interview, the researcher will refer them to the Adult Practice of the Master's students in Psychology at the University of the Free State.*

**Thank you for taking time to read this information sheet and for participating in this study.**

## Appendix C

### Consent to participate in this study

I, \_\_\_\_\_ (participant name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet. I have had sufficient opportunity to ask questions and am prepared to participate in the study. I understand that my participation is voluntary and that I am free to withdraw at any time without penalty (if applicable). I am aware that the findings of this study will be anonymously processed into a research report, journal publications and/or conference proceedings.

I agree to the recording of the *semi structured interview*.

I have received a signed copy of the informed consent agreement.

Full Name of Participant: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Full Name(s) of Researcher(s):  
\_\_\_\_\_

Signature of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix D

### Interview schedule

**Title of research project:**

*Living with a child with autism spectrum disorder: Two Sotho mothers' experiences.*

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**MAIN RESEARCHER:** Kaizer Ndlovu

**FACULTY AND DEPARTMENT:** Faculty of the Humanities, Department of Psychology

**SUPERVISORS:**

Name: Dr. Lindi Nel (PhD)

Contact details: (051) 401 2188

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**DETAILS OF PARTICIPANTS:**

Name and surname (Mother): \_\_\_\_\_

Name and surname (Father): \_\_\_\_\_

Home language: \_\_\_\_\_

Date of interview: \_\_\_\_\_

Case study number: \_\_\_\_\_

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**INTERVIEW SCHEDULE (1):**

- Tell me more about yourself?

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- At what age was \_\_\_\_\_ (name of child) diagnosed? How long were you in a relationship at the time? How long did it take you to adapt and accept the diagnosis?

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**QUESTIONS SIGNIFICANT TO THE FAMILY'S RELIGION:**

1. What was your initial feelings when you found out about your child's limitations?

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2. What did you do in order to accept it?

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3. What was bad and challenging about the process?

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4. What was your initial attitude towards the diagnosis?

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5. How have your attitude change during the process?

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6. What helped you to change your attitude?

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7. What do you do to build up a strong relationship?

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8. Which coping strategies do you use in order to ensure family cooperation?

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9. Who is the primary caregiver?

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10. How do you rebuild strength?

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11. What fulfils you as a person(s)?

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12. How do you deal with difficult episodes (tantrums, insomnia, repetitive behaviour)?

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13. Which values do you emphasise in your family?

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14. How does your other children feel about disability and how do you facilitate their feelings?

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15. How do you divide your attention between all your children?

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16. How do you share responsibilities in order to avoid daily difficulties?

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17. Which kind of difficulties do you expect daily?

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18. What are your fears and worries for the future of your child with his/her limitations?

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19. What are your worries for your family's future?

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20. How do you address it?

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21. What type of support do you receive and from where or whom?

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22. How does your child's limitations influence your lives (work abilities / social relationships)?

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**REFLECT:**

Interviewer: "Thank you very much for participating in the interview."

Please take a few minutes to reflect on the interview; and what your experience was during the past hour.

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Did any one of you experience any distress, embarrassment or discomfort during the interview due to the topics addressed?

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Do you have any questions relating to the interview or the research study? You are welcome to contact me should you reflect further about today's discussion and want to add anything else.

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Once again, thank you very much for your contribution to the research study!

Kind regards

## Appendix E

### Transcripts

#### LIVING WITH A CHILD WITH AUTISM SPECTRUM DISORDER: TWO SOTHO MOTHERS' EXPERIENCES.

QUESTION	RESPONSE
001. Tell me more about yourself?	<p>Okay, my is.... I am a single parent, currently unemployed, I am pensioner because I am stroke survivor, I am having a son who is hyper-epileptic and autistic. But in the beginning I was struggling because I didn't understand and have any knowledge about hyper-epileptic and autism, but I went and look for help, I read a lot and make research and I went to the clinic, they asked me where to attend the sessions so that I can understand how is my son. After understanding my son then life was easier, because I also read a wanting to know more. I struggled very much for him to get education. The problem was his communication, when he was 3 years he could only sing all the 2010 wold cup whatever, but when you talk to him he couldn't answer you. He could only say one word, not even a sentence, but when he was about from 6 he could at least say a sentence.</p>
01. At what age was _____ (name of child) diagnosed? How long were you in a relationship at the time? How long did	<p>I was not in a relationship. My only concern was my child. But eh eh ...his father stays in another place and I stay at another place. But financially I don't want to lie, he was always there, even when I took (he) to doctors or whatever he was there financially. He was around 3, yah it was 3 to 4 yah. It did not take more than a year because I</p>

QUESTION	RESPONSE
<p>it take you to adapt and accept the diagnosis?</p>	<p>was eager to learn, I wanted to understand my son. And when someone tells me there is a doctor there so and so, I went all over I did not mind just for understanding. And people call my son names they say he was mad, he was death, he was all that. But I was always I was arguing with them. I told them the doctors who study people like my son did not tell me he was mad. Even the first time when I went to Oranje the doctors asked me why did I brought the child there, and then I said I think my child is not well psychologically. The doctors asked me where did I study psychiatry so that I can tell my son is not well, what have I notice? I say he is always, he was having ASD signs, when there is a loud music he becomes irritated, he would close his ears and he would stand still at one place. You see, he did not also want to hear other kids cry. Everything that is loud was irritating him. And the problem I understand because he was born prematurely, he was born in 5 months and 2 weeks. And that is why the doctor told me the not thing will be normal like a normal child because he come too early, the others will come late and the others will come to earlier. They told me he would walk after 2 years but he walked after 14 months.</p>
<p>1. What was your initial feelings when you found out about your child's limitations?</p>	<p>I just put myself in a .....although in the beginning it was hard but after understanding I just told myself I will help my son to go through. I will tell the world that there is nothing wrong with my son.</p>

QUESTION	RESPONSE
2. What did you do in order to accept it?	I read a lot. Consulted professionals. I asked questions. The doctor at (Hospital) they asked me, the first question he asked me, when you say the child something is wrong with him does he poop himself? I said no when it is time he goes to the toilet he helps himself. What tell you now that there is something wrong with the child?
3. What was bad and challenging about the process?	The bad thing was my family did not support me. You see, they talk behind my back with my son, that my son is this, and this and this... they didn't...they could not accept my son. They thought my son was naughty. Then I had to teach them that my son is not naughty but this and this and this (he is living with autism). And I withdraw myself from going to people because I did not want them to harass my son while they did not understand. You see, they would say I spoil him, I do this, I do this. At the time I was already unemployed. I quit job when he was 2 years. I thought that people will not protect him the way like me parent would protect they will not take him like me.
4. What was your initial attitude towards the diagnosis?	I was already prepared because the doctor on birth time he told me I must expect.... you see, yah, that is why I was calm, I was already prepared. I had just to expect everything, but to find a solution towards the problem. I did not just agree and don't do anything.
5. How have your attitude change during the process?	I took him to the multiracial crèche in town and I explained my child's situation. And then we talk and they said to me they will take him and watch for the first month how will he attend.... function

QUESTION	RESPONSE
	<p>with other kids. And then the first month, they said to me by the second month I have to hire someone special who will watch him at the crèche, you see, so that when he plays with other kids.... And the first month went by, the second month, he even finishes the whole year at the crèche with no complain. They taught him, he could read, he does everything, he could teach kids who were struggling at a normal school he could teach them to write their own. And I only bought him alphabets A-Z. After that he I saw him, he can write his name, he can write my name, he can read. The academic improvement helped me to keep on.</p>
<p>6. What helped you to change your attitude?</p>	<p>His intellectual, he is very intelligent, even when he walks around he speaks English people they don't understand, they become surprised why he speaks English, because even at home he does not want to listen to this Setswana radio or Sesotho, he only wants to listen to English, and he only writes and speaks English. And even at the normal school, he was attending a normal school, with English from his grade R, grade 1 report up to grade 4 he is level 7 or level 6 English. Even when he goes to the shop and buys something, he will spell the name of the thing that he wants. The Pakistan likes him very much. They know when he comes in the shop he will say I want this lunch bar and he will say "LUNCH BAR" (spell the name).</p>
<p>7. What do you do to build up a strong relationship?</p>	<p>He surprises then most of them because he knows, when he meets you, he greets you. He will ask you: What is your name? He will ask you surname and he will ask you date of birth. I don't know where</p>

QUESTION	RESPONSE
	<p>does – he stored all these dates of birth. You tell him once and it stays in there. Next year when is your birthday he will tell me “mommy did you call so and so is his or her birthday tomorrow today”. He surprises ... even at school, at a normal school, he knows all his classmates date of birth ... the teachers and all that.</p> <p>Ah, everybody is saying, ‘God gave me a special child’ because he surprises most of them, they see things that they did not expect. Such children you must just give them love and understanding, and you must communicate everything with ... even the financial status in the house I tell him. You pension this month is this much, mine is this much, this is my tenants what...what. And when he wants something, when I don’t have money I would tell him no my boy this and this and this. I don’t just say I don’t have. When I can’t afford I tell him no there are things that you need and things you want. You see, if you need something you know you can always have it and there are some we can omit.</p>
<p>8. Which coping strategies do you use in order to ensure family cooperation?</p>	<p>Even I am having a boyfriend they understand. I pray God to give me a very long life so that I can see my son one day married and standing for himself because I don’t know for how long I will be there for him. That is why I prepare for him. It was tough when he walks away from me to boarding school, but there was nothing I can do because while I am still alive there is something I can do because when you see you have a problem you must do something about it.</p>

QUESTION	RESPONSE
9. Who is the primary caregiver?	After I was employed I stayed with him. He turned 12 on the 17 of May, I stayed with him for almost 10 years. If you as parent, you can stand up for yourself you will see progress for your child.
10. How do you rebuild strength?	Go to church, when we are together we sing in the house and he can sing, we dance and play together. When he wants to kick the ball I become the keeper (laughed).
11. What fulfils you as a person(s)?	I am proud mother. To be proud and to love this kids like I do. Even my boyfriend know that I come first, my son and then he is the third one and does not have a problem.
12. How do you deal with difficult episodes (tantrums, insomnia, repetitive behaviour)?	<p>He knows that first thing I want honesty, I ask him what is the problem and he will tell me this and this and this. You must also teach your child that life is not always eh is not always according to him. You teach him to share, to love and to accommodate. You can't just teach your child to when you have one sweet among 5 other kids. When the sweet is 1 you don't have 5 you don't give him that, because he knows you can't give others children. You must teach your child to love and share.</p> <p>When he comes from school I ask him how was school he would tell me. But we have a very problem. Where I stay is a small town. If you know people if they can't find you they will get you with your child. They will teach your child bad things like to smoke and what... what. Now I have organized transport to take him to and from school. But the lady who took him to school even coming from the classroom to</p>

QUESTION	RESPONSE
	<p>the gate he would come crying maybe somebody did something to him. I always went to school.</p>
<p>13. Which values do you emphasise in your family?</p>	<p>Respect, me I pray and go to church. I just say to myself and life is not always smooth. To be strong, that does not kill you makes you strong. You must know life will not be smooth all the way, there are sometime up and downs. The determination is how strong, is not to say how many times you fall, but how many times you rise. And how do you take things, most of the time I teach myself to take things in a positive way rather than on a negative. Negative energy takes you nowhere, if you look things on the positive perspective you will get there, fruitful results.</p>
<p>14. How does your other children feel about disability and how do you facilitate their feelings?</p>	<p>No, I had two stillborn. I had also my first born was still born maybe for 14 days. "James" (Pseudoname) came 14 years after his older brother. Three years after James I tried again still born, after that other one three years again stillborn. Now I make peace with myself I say God knows what he is doing. He knows he will give me one son who will need my whole attention and have made peace with it and live with it.</p> <p>Even there where he stays I bought him keyboard, tablet, speakers, he loves music and playing with a cell phone. Last time surprised me I had this eh...tablet, kids' laptop. It stayed there since 2010, it was my sister's daughter tablet. It was just there, she took it to the mechanic and they said if its dead is dead. James asked the tenant</p>

QUESTION	RESPONSE
	to open it and he fixed it after 30 minutes. He also has that time to go and play soccer with other kids.
15. How do you divide your attention between all your children?	They know James's mother loves all children equally. Yah, I am not that person that .....my son is special to me when we are both, but when there are other children they are all the same.
16. How do you share responsibilities in order to avoid daily difficulties?	I only share responsibility when I have something to do, when I have to go somewhere, then I will ask him to look after him. They like him because they always laugh where he is, he likes peace people are always happy about him.
17. Which kind of difficulties do you expect daily?	When he is around he will just be there doing his things and continue with my household work.
18. What are your fears and worries for the future of your child with his/her limitations?	I just pray that he will find someone who will understand him and who will also love him. Who will not judge him the way he is.
19. What are your worries for your family's future?	I just pray God that me and James, eh...James must surprise me. One day he must give them what they did not expect from him. He must become somebody who is highly educated and who is stable in life.
20. How do you address it?	That is why I want education for him.
21. What type of support do you receive and from where or whom?	Financially, his biological father, and the teachers since he was schooling from grade R and crèche and all that. They gave me hope

QUESTION	RESPONSE
	so that I do everything for my son. We go to church and read the bible.
22. How does your child's limitations influence your lives (work abilities / social relationships)?	He is everybody's bundle of joy. If I did not have James ah... people could have not known me because he is jolly good fellow who greets and love everyone. Even when we go to town he greets whites and say "MOO GAAN DIT" (Who gaan dit).
23. Please take a few minutes to reflect on the interview; and what your experience was during the past hour.	I feel very delighted because my perseverance and my love for my child I am not the only one who sees it, other people I interact with saw it. they give me hope and courage to continue do a good work parenting. I did not work hard for nothing, somewhere somehow there are somebody who admires my hard work.  I did not take effort for nothing.
Did any one of you experience any distress, embarrassment or discomfort during the interview due to the topics addressed?	Not at all. I am an extrovert I could have told you.
Do you have any questions relating to the interview or the research study? You are welcome to contact me should you reflect further	Eh the interview went smooth. You must emphasise that every child like the way he is, is for us parents to give our children support and to love them. That is the biggest golden rule. To make research about the child, this study will open other parents' eyes that there is nothing impossible with that child, nothing wrong.

QUESTION	RESPONSE
about today's discussion and want to add anything else.	

## LIVING WITH A CHILD WITH AUTISM SPECTRUM DISORDER: TWO SOTHO MOTHERS' EXPERIENCES.

QUESTION	RESPONSE
Tell me more about yourself?	I am "Mapaseka" (Pseudoname), I am from Qwaqwa I work here in Bloemfontein as Technician GIS technician at Eskom. I live with Buti, and we are only two in the house
•At what age was _____ (name of child) diagnosed? How long were you in a relationship at the time? How long did it take you to adapt and accept the diagnosis?	Yes, I was, ("Buti" (Pseudoname) indicated that they broke up, and the mother laughed a lot). Yes, the time Buti was diagnosed I was in a relationship (she laughed a lot) yes, it was in 2010, as Buti has said the same year we broke up 2010. I think it's two years, it was in 2008. I was open it did not take me long, maybe it's because of the people I was surrounded with. It was not difficult, most of the people, especially the teacher from the pre-school helped a lot, helped with the speech therapist, occupational, like she did everything for me. Yah so they helped a lot, I did not take time. Yah maybe is because I did not understand what is autism to start with.
1. What was your initial feelings when you found out about your child's limitations?	Mmmm, I am not sure. Maybe I am ignorant I was not worried, I was not worried, or maybe is because I did not know anything about, about autism. The first time I heard about autism (interrupted).... I am not sure. The thing I struggled with was the school. I think the thing that I was stressing about was the school, that is when I felt that there is something wrong about me. Otherwise, I was not that.... (never finished the statement).
2. What did you do in order to accept it?	I can't say there was something, like I had to accept because Buti was not speaking at all, but he was very naughty, he was hyper, hyper,

QUESTION	RESPONSE
	<p>hyperactive (Buti interrupted and said he is not naughty anymore), yah you are not naughty anymore. Yes, I was not worried about the speech, the tantrums, I was not worried, but I got irritated when he starts doing those things in a taxi, I got irritated, eh but I think.....(never finished the statement)</p>
<p>3.What was bad and challenging about the process?</p>	<p>I was in Limpopo that time. So it was very difficult to find a school, because I applied to almost every school neh, but they will tell you that we don't accept, we don't deal with those kind of kids here, we don't deal with those kinds. We almost went to the blind. Then we got a space Trinity, but even Trinity I think did not understand him because he repeated, no he did not repeat, the thing he repeated is grade R because the principal just said let him stay for another year. He will do the things for grade 1, but yah so when he goes that side. But when he gets that side they did not understand him and they wanted him to repeat a grade. But they said they deal with special kids, if deal with special kids at the end of the year you can't tell, you can't come and tell me that this kid need to repeat, but he was passing and he was doing everything right I don't know, maybe. Okay, he was hyper neh, he could not sit in class, that he could not, maybe for that thing. Then luckily he went to grade 2 they did not make him repeat. Then I think around June or April, somewhere there, we got, we got a space again at Parkhuis Meshell House. So there that is where they accepted him because he was excelling.</p>

QUESTION	RESPONSE
4. What was your initial attitude towards the diagnosis?	I think it was positive, I think it was, I was, I wanted him to feel that I am her mother. Maybe I did not have a choice because we are the only two and so if I am starting to act somehow now that he has that and we are only two what is gona happen. I think in a way I had to be strong for him. So I had to show him the love. Even though sometimes I do shout, even though I do shout a lot, but I think we understand.
5. How have your attitude change during the process?	No, but shouting started even before because he was naughty. He was naughty sometime he would be there and I would have had to say they come here, all those things, see. But I think the attitude it made me like in general to have that, that heart for ASD kids. Maybe for Buti, for Buti is not that severe, they said its mild. He can do so many things others can't do, including speaking. Even for him to speak he just woke up he could speak. Like I think my younger sister was more involved than me. Always, she was the one always interested, she would call him and say Buti..Buti he could not respond he could just look at her without anything. And one day she called him and then Buti responded and we were happy, we were all happy. Yeah that was it, there was no special thing she did.
6. What helped you to change your attitude?	My sister's support. The pre-school teacher, like he was so involved. I did not know all those special Speech Therapists, the OT, he made all the arrangement I guess. Gave me the address, I just went there. Then from there they referred me to Pretoria for him to be diagnosed. Maybe that is why it was easy for me.

QUESTION	RESPONSE
7. What do you do to build up a strong relationship?	What do I do (laughter)? Nothing really, just being a mother. We fight a lot but when I am not there he misses me. But I don't do.... but maybe we can go out to watch a movie, because we don't watch TV together. He gives me a space. If he wants to watch something he watched it and after he finishes he knows what I like he would change the TV and then he put something that I like and that means, it's my turn. He does not communicate but he acts.
8. Which coping strategies do you use in order to ensure family cooperation?	Yoh, I don't..., I don't know much, ah... (laughter) what can I say. Okay here we are staying with my...we are not staying like my sister... Like my older sister is here. So she also like sweets, sometime... (interruption by Buti) he goes and visit the whole week. They don't have a problem. Even that one gives me time to relax because I will be alone and then no TV, no noise, he likes the noise, no noise, I just relax.
9. Who is the primary caregiver?	Me, he does not want to go to boarding school. He said I want to bottle him (laughter) when I talk about him staying at school.
10. How do you rebuild strength?	mmmm.... what do I do? I just talk to people. I just talk to the church. Then not to leave me if I am down I have a sister, I talk to her on a daily basis. She likes Buti too. The father is not there. Music therapy and exercising, I walk, I just go.
11. What fulfils you as a person(s)?	(Laughter) Huweeee! Maybe being able to help someone. At work this month we are collecting things for the children and I am helping.
12. How do you deal with difficult episodes	Now that he is understanding I try to talk to him, but then I was just tired. I was helpless with his tantrums. But now if he is doing

QUESTION	RESPONSE
(tantrums, insomnia, repetitive behaviour)?	something I talk to him. You see if you do 1..2..3, 1..2...3 is gona happen. Like if you don't want to clean your room you not gona sleep in your room and then I am not gona buy you anything for you and you not gona get anything because you don't want to prepare yourself, all those things. I guess, sometimes he listens and sometime he does not listen, I like my moment. Now I talk to him even in the mall, "do you see what you are doing and why are you doing it?"
13. Which values do you emphasise in your family?	Mmmm I think honesty. Honestly I don't know these kids when they grow up, yoh, they are lying too much yoh. I try by all means to make him sweetheart. You cannot lie and just get away with it. You must take responsibility. If you messed up, you must come and tell me. Even if you messed up I will find out anyway and I will get mad. We are Christians. (interruption by Buti)
14. How does your other children feel about disability and how do you facilitate their feelings?	No they don't have a problem. They understand him. Maybe their mothers explained to them, but they do understand that Buti likes to stay alone there and it is fine.
15. How do you divide your attention between all your children?	In most cases like we don't stay like together. If I am staying with my sister they will be there in the bedroom watching laptop...
16. How do you share responsibilities in order to avoid daily difficulties?	It's only me and my sister. Buti is not close to the rest of the family, its only me and my sister.

QUESTION	RESPONSE
17. Which kind of difficulties do you expect daily?	Yoh, I think mostly in the morning just to wake up, yoh! It's a struggle for Buti to wake up. And I force him to sleep early but even if I can wake him up at 04:00AM he like TV a lot. He will wake up and watch TV and I will be busy doing my things and then 06:00AM he will still be busy he is still watching TV. Did you do lunch box? Did you bath? All those things, it's a struggle every morning. If I don't follow him do this, do this, is a struggle every day.
18. What are your fears and worries for the future of your child with his/her limitations?	That one yoh now that he is growing up I don't know what is gona happen. Now he is starting to be a teenager and he then he does not have a father figure and I don't know what to do. If he can come now and say this and this is happening to me. How will I respond? I don't know. I think it's that time he needs a father figure in his life. And he does not like talking to me about those things because sometimes I do ask, do you have a girlfriend? This and this, and then he just looks at me "and then this woman is crazy". The academics he is doing well; I don't think anything will change. He is doing great. Top student. He gets level 6 and 7 only.
19. What are your worries for your family's future?	Yes, I am not sure how is he going to behave or to react if I can say I am having a boyfriend to him now, something like that.
20. How do you address it?	I am not sure because I did ask him, would he mind if I have a boyfriend and he said no, would you be sad or something? and he said no.

QUESTION	RESPONSE
<p>21. What type of support do you receive and from where or whom?</p>	<p>I think mmm my friend, naturally and physically there. Finance whenever I have problems he is even concerned when I am not well. I don't want to talk, so she is always there for me. She is the one forcing me to talk because I don't like talking, especially my emotions, so she is forcing me. Even in church they do ask about him, they are concerned and I say he is fine, if I have anything I will let you guys know. They (family) do support even if they are far, they are there in Qwaqwa. Here it's only me and my sister. Even her she is supportive because whenever I need space she is always willing take Buti and then I get my space there.</p>
<p>22. How does your child's limitations influence your lives (work abilities / social relationships)?</p>	<p>Does not affect. (I do) anything I want to do, I can leave him alone and go to town. He does not have any problem, if he needs something he will call. Sometimes I do forget him at school, yoh, I do. Maybe they change times. I usually fetch him after work. That day they will send a message that today there is no study come fetch your child at 2:00PM then o forgets because I am used to after work. When he called he is fine but if we did not call he gets angry. There was time he was not able to call me he was so angry because I was working late and then I asked my sister to go fetch him and then she forgot, and then it was something past 6 to7 and he was all alone there at school. He was so angry, I had to apologise, and apologise, and apologise. Yah these things they do happen.</p>
<p>Please take a few minutes to reflect on the</p>	<p>Yoh (laughter). I think eh it's a good thing, what you guys are doing is a good thing. Don't just end here in doing this research. And I think</p>

QUESTION	RESPONSE
<p>interview; and what your experience was during the past hour.</p>	<p>most of the parents the thing they are struggling with is schools, even here in Bloemfontein. I was one of the luckiest because got transferred from Polokwane to this side, so I was never on the waiting list. They sent him to Martie. Even there I struggled even the department said this one is not gone cope here without ..... they were supposed to do the assessment but they just saw autism and said no. I said no you guys don't know what you are talking about did you see Buti or you just assuming. I had to stand up for him, I just go to the MEC, because I did not refer myself there, the department referred me there. Then they got him a probation for one month, then that is when we had a meeting and they said we are eating our pie it is not what we think. Some of the parents they are really struggling, I think they have been on the waiting list for more than 10 years. I think what you are doing don't just do it for the sake of research. What you are doing whatever the parents are complaining about please help where you can, convince where you can. We need schools this side!</p>
<p>Did any one of you experience any distress, embarrassment or discomfort during the interview due to the topics addressed?</p>	<p>No.</p>

QUESTION	RESPONSE
<p>Do you have any questions relating to the interview or the research study? You are welcome to contact me should you reflect further about today's discussion and want to add anything else.</p>	<p>No I do not have any question. (this was not recorded because there were many children coming out of the cinema).</p>

## Appendix F



### GENERAL/HUMAN RESEARCH ETHICS COMMITTEE (GHREC)

10-Apr-2019

Dear Mr Ndlovu, Kaizer KW

#### Application Approved

Research Project Title:

**Living with a child with Autism Spectrum Disorder: Parents' experiences of family resilience.**

Ethical Clearance number:

**UFS-HSD2018/0944**

We are pleased to inform you that your application for ethical clearance has been approved. Your ethical clearance is valid for twelve (12) months from the date of issue. We request that any changes that may take place during the course of your study/research project be submitted to the ethics office to ensure ethical transparency. Furthermore, you are requested to submit the final report of your study/research project to the ethics office. Should you require more time to complete this research, please apply for an extension. Thank you for submitting your proposal for ethical clearance; we wish you the best of luck and success with your research.

Yours sincerely

**Dr. Petrus Nel**

**Chairperson: General/Human Research Ethics Committee**

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## Appendix G



27/8/2018

The Chairperson  
Ethics Committee  
University of the Free State  
**BLOEMFONTEIN**  
9301

**M. Psych Degree: Mr Kaizer Ndlovo**

**Living with a child with Autism Spectrum Disorder (ASD): parent's experiences of family resilience.**

I will identify children in my practice where the family profile fits the inclusion criteria in the research proposal.

After identification I will phone them to ask permission for the researcher to contact them, provide information about the study and obtain informed consent if they decide to be part of the study.

Yours sincerely

**DR DJ GRIESSEL**

**PRINCIPAL SPECIALIST/NEURODEVELOPMENTAL CLINIC  
DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH**

C: Autism Study August 2018 Dr Griessel.doc

