

Exploring Autism Spectrum Disorder in African Children Using Multiple Case Study Methodology

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6. A turnitin originality report is attached (see Appendix F).

Michelle Dixon

December 2015

This thesis is submitted with the approval of



Supervisor Dr Nicholas Munro

Co-supervisor Dr Beverly Killian

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Abstract

Despite the sharp global increase in prevalence, there is a paucity of South African research into autism spectrum disorders (ASD), so little is known about how ASD manifests in African children. This qualitative multiple case study explores six family units with a boy child with ASD (ranging in age from six to eleven years). The sample was recruited from five public schools for learners with special education needs (LSEN) in KwaZulu-Natal. The methodology incorporated (i) in-depth individual interviews with the parents to obtain an understanding of their experiences of raising a child with ASD, and (ii) the administration of the Autism Diagnostic Observation Schedule (ADOS) to the children to confirm the diagnosis, contextualise parental accounts, and to observe the children's responses to the ADOS activities. The findings indicate that the parents experienced a difficult help-seeking journey, which began when they first noticed signs of atypical development (most frequently related to delayed speech development and lack of social interaction), to the time when the diagnosis was made. Lack of awareness of ASD, at both the community and primary healthcare levels, made the journey unnecessarily prolonged. Most of the participants in this sample explored cultural factors that could account for their child's difficulties and engaged in various rituals to appease ancestors. Initially, African cultural beliefs strongly influenced their views about the causes of ASD, but over time, they drifted towards a Western perspective. Since there are no physically detectable features associated with ASD, the parents experienced much criticism in response to the child's challenging behaviours in various social and religious contexts. The ADOS observations provided insight into South African children's responses to the tasks, suggesting more universality into the way in which ASD manifests than had been expected from an African worldview perspective. This small qualitative study is critiqued and suggestions made for future research focal areas.

(306 words)

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List of Abbreviations

ASD	Autism spectrum disorder
ADOS	Autism Diagnostic Observation Schedule assessment
ID	Intellectual disability
KZN	KwaZulu-Natal
K-ASD Study	KwaZulu-Natal Autism Spectrum Disorder Study
LMIC	Low-and middle-income countries
LSEN	Learners with special education needs
OT	Occupational Therapist

Chapter 1

1.1. Overview

Autism spectrum disorders (ASD) are neurodevelopmental in origin and characterised by impairments in communication and reciprocal social interactions, along with the presence of restricted, repetitive behaviours, interests or activities (Jang, Matson, Cervantes, & Konst, 2014). In addition to the core symptoms of ASD, aggression, tantrums, and self-injurious behaviour commonly occur but are not required for a diagnosis of ASD (Adams, Matson, Cervantes, & Goldin, 2014).

Despite the recognition of autism¹ in Africa over forty years ago (Grinker et al., 2012; Sotgiu et al., 2011), very little is known about the prevalence, major developmental features, and course of this disorder in African people, and more specifically, in South Africans (Elsabbagh et al., 2012). Research into the factors related to the initial concerns and ways in which the ASD present in South Africa is scarce (Springer, van Toorn, Laughton, & Kidd, 2013). In contrast, scientific research into the field of autism has exploded in Western² countries as many try to determine the aetiology and nature of ASD: 78% of all journal articles published on infant development and behaviour is generated from North America (Springer et al., 2013).

Autism is more common than previously suspected, with a dramatic increase in prevalence rates globally over the last few decades (Jang et al., 2014). Furthermore, ASD was once thought to predominantly affect White children (Jang et al., 2014) but the rate of ASD has rapidly increased in all ethnic, racial and socioeconomic groups (Centers for Disease Control and Prevention [CDC], 2012). More recent estimates suggest that 1 in 68 children in the United States are affected by ASD (CDC, 2014).

Although there is relative consistency in the core features of this developmental disorder from a global perspective (Matson, Beighley, & Turygin, 2012), “the clinical presentation of the condition in Africa remains vague” (Elsabbagh et al., 2012, p. 172). Thus, it is unknown

¹ Autism has been variously defined as a form of Autistic Spectrum Disorder and as a distinct disorder. The empirical research that relates to this thesis has not made a strong distinction between Autism and ASD, so these terms are used interchangeably in much of this thesis. Whenever the distinction is relevant, this is made clear in the text.

² Western Europe and the United States.

whether African³ children present with the same features as described internationally (Springer et al., 2013).

In order to consider African constructions of childhood, Mkhize (2004) argues that it is essential first to examine the overall African worldview (the basic assumptions by which Africans attribute meaning to reality). The African worldview has important consequences for the way in which African children are raised and this may directly affect the manner in which a neurodevelopmental disorder may be understood and identified. For example, lack of eye contact is considered to be indicative of difficulties in social interaction commonly associated with ASD in Western societies (DeWeerd, 2012). There is little available research, though much anecdotal information, on cultural differences in the use of social and respectful eye contact between adults and children in African communities; and how this normative cultural behaviour may affect early diagnosis. There are also significant cultural differences in childhood experience and expectations for individuation and development of competency (Grinker et al., 2012). For example, expectations for children to initiate communication and the responsiveness of adults to children's speech could influence the identification of ASD.

Parents play a crucial role in the identification of difficulties manifested in their children as they are the first to detect symptoms and make choices about early interventions (Braunstein, Peniston, Perelman, & Cassano, 2013). Indeed, many studies have established that parents of different cultural groups identify atypical development in direct relationship to their knowledge of typical childhood development (Quilendrin, Castor, Mendoza, Vea, & Castillo-Carandang, 2015). Additionally, parents' initial help-seeking behaviours are usually directed towards the elders of their communities: for example, grandparents, older relatives, and members of a community who are considered to be more knowledgeable and experienced about early childhood development (Grinker et al., 2012; Quilendrin et al., 2015).

The earlier a parent recognises atypical developmental features, the earlier they are likely to seek assistance from both within their communities and within the medical field (El-

³ In South Africa the term *Black* may be used for racial classification of ethnicity. In this study the term *African* is considered a more appropriate term to refer to members of the Zulu, Xhosa, and Swahili cultural and ethnic groups who currently reside in KwaZulu-Natal.

Ghoroury & Krackow, 2012). Early diagnosis, enables earlier appropriate and prolonged interventions and increases the likelihood of a more adaptive outcome (Kozlowski, Matson, Horovitz, Worley, & Neal, 2011). Indeed, the long-term prognosis of ASD is poor without an early diagnosis (Centers for Disease Control and Prevention, 2014; Matson & Goldin, 2014). However, before being able to make valid and reliable diagnoses in African children, in-depth knowledge is needed about how and when the symptoms of ASD manifest and are understood by the parents. In turn, this depends on parents noticing various early forms of atypical development and then taking the necessary help-seeking steps to obtain assistance for their children.

Thus, a large KwaZulu-Natal Autism Study (K-ASD) aimed to find the best method for correctly identifying and assessing Zulu-speaking children with ASD (Kauchali, 2008). The broad aim of this large study was to build empirical data that could contribute to improving early detection, epidemiology, and delivery of services. The early detection of autism would be especially valuable as this would enable interventions aimed at minimising or even, possibly, preventing some of the symptoms of the disorder.

Working within the auspices of K-ASD, the present study aimed to investigate possible cross-cultural differences in a small sample of African families with a child diagnosed with ASD. The current study also sought to contribute to the K-ASD study, by conducting multiple case studies tracking parental experiences from the time of first parental concern through to the time when a diagnosis was made. The purpose of tracing this path across different family units was to provide a tentative framework that would enable further exploration and increased awareness and insight into the ways in which atypical developmental patterns are identified, responded to, and eventually diagnosed by a medical practitioner within the South African context.

1.2. Aims of the Dissertation

This study aimed to qualitatively explore how African parents recalled the processes of identifying features of atypical development, seeking assistance and subsequently developing an understanding of their child. By conducting in-depth interviews with the parents, the researcher aimed to (i) identify the early features of ASD that these parents noticed as issues of concern, (ii) generate insight into the way in which these parents have experienced raising a child with ASD in the South African context, and (iii) explore their parental understanding of the causes of the difficulties experienced by their children (i.e. the aetiology of ASD from

their own cultural and other perspectives). A multiple case study methodology was adopted so several data sources could be used to develop a multifaceted understanding of ASD.

The participants in this study represented various complex family structures that will be described in more detail in Chapter 5. In total, there were six mothers and three fathers of seven children with ASD. All participants were Black African and currently residing in KwaZulu-Natal, South Africa. Two individual interviews were conducted (i) an in-depth clinical history, together with retrospective recollections of pregnancy and their child's early development; (ii) a follow-up interview that focused on cultural perspectives of raising a child diagnosed with ASD, and enabled further exploration and clarification of previously raised or other issues.

Another aspect of this study explored the relevance and applicability of the *Autism Diagnostic Observation Schedule* (ADOS) assessment (Lord, Rutter, DiLavore, & Risi, 2002) assessment in the South African context. Significant progress in developing and validating screening and diagnostic assessments to identify children at risk of ASD has been made in Western countries (Elsabbagh et al., 2012). However, no fully standardised assessment is currently available in the South African context. The lack of appropriate, culturally sensitive tools compromises the early identification of ASD in African children (Elsabbagh et al., 2012). Currently, the ADOS is regarded as a gold standard for diagnostic purposes since it presents the child with a series of tasks or presses⁴ that are likely to create opportunities for behaviours associated with ASD to be observed, coded and algorithms to be calculated.

There are several motivations for including the administration of the ADOS as part of the current study: (i) the ADOS algorithms would confirm a child's diagnosis of ASD (in two of the children in this sample, no formal assessment had taken place even though the children were generally recognised as experiencing ASD), (ii) the observation of the child enabled the researcher to contextualise information obtained from the parent interviews and other collateral sources, and (iii) to investigate how African children respond to activities, tasks or presses of an instrument designed and tested in the United Kingdom (UK) and the United States (US). Thus, the observations of how the children responded to the activities on the ADOS were of interest from multiple perspectives, yielding information that could confirm

⁴ The ADOS consists of standardized activities that allow the examiner to observe the occurrence or non-occurrence of behaviours that have been identified as important to the diagnosis of autism. These activities provide different combinations of presses for particular social, communicative or other atypical behaviours.

having a child diagnosed with ASD as part of this study; and provide a spectrum of culturally rich information about how these African children responded to the ADOS tasks.

1.3. Outline of the Dissertation

The overall structure of the study takes the form of seven chapters, including this introductory chapter. Chapter 2 will incorporate relevant empirical research beginning with an overview of ASD and ending with an introduction to the ADOS assessment. Chapter 3 concludes the literature review, with the focus changing to an African cultural perspective of child raising and beliefs about parenting, since this may impact on the manner in which the symptoms of ASD are identified and understood from within African communities.

The fourth chapter is concerned with the methodology and research design used for this study. An explanation of multiple case study methodology is given followed by descriptions of the sample recruitment along with data collection. The chapter ends by describing the steps in the data analysis and concludes with the ethical considerations that were relevant throughout this study with vulnerable participants. A brief introduction to the families and children who participated in the study is given in Chapter 5, followed by the findings that are organised into three key themes. Chapter 6 draws upon the entire dissertation, tying the important findings and various empirical strands together. The final chapter concludes this study and ends with a critique of the findings along with suggestions for future research.

Chapter 2

Literature Review

Autism is presently considered one of the most debilitating and serious of all developmental disorders (Copeland, 2012; Matson, Riekse, & Tureck, 2011), and is more prevalent in children than Down syndrome, diabetes and cancer (Wilkinson, 2014). The disorder affects the course of a child's development and interferes with a person's ability to relate and communicate with others throughout the course of a lifetime (Dietert, Dietert, & DeWitt, 2011; Fuentes et al., 2012; Matson et al., 2011). While some people are still able to lead fairly independent lives, the quality of life for others is severely affected, leaving them dependent on services throughout adulthood (Elsabbagh et al., 2012). Hence, ASD can be emotionally and financially draining for many families (Matson & Jang, 2014).

The focus of this chapter is largely from a Western perspective and starts with a discussion of the core features that characterise ASD along with the recent changes to *The Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013) criteria. This will be followed by outlining the possible reasons for the increase in prevalence, the aetiology of ASD, the age of first parental concerns and issues around the diagnosis of autism. The frequently occurring comorbid disorders are included and the chapter ends with an introduction to the ADOS assessment. In Chapter 3, an African cultural perspective of childrearing will be reviewed.

2.1. The Core Symptoms of ASD

While the fundamental symptoms of ASD become apparent during early childhood, and impair everyday functioning (Bölte et al., 2013), symptom expression varies considerably in onset, presentation, and severity in individuals (Schaaf & Zoghbi, 2011). Usually, symptoms become more evident over time as the abilities of typically developing children outpace the skills of peers with ASD (Matson & Jang, 2014).

One of the essential diagnostic features of ASD includes a range of language impairments such as a lack of speech (nonverbal), language delays, echoed speech (echolalia), and poor comprehension of speech (APA, 2013). Additionally, communication difficulties range in severity, often reduce a child's ability to socialise (Matson & Sipes, 2010), and may increase problem behaviours (Beighley, Matson, Rieske, Konst, & Tureck, 2014). Although higher

functioning individuals can present with intact vocabulary and grammar, they often have difficulties with pragmatic skills (Landa, 2008).

The first edition of the ADOS, developed on *The Diagnostic and Statistical Manual of Mental Disorders* (4th ed. revised; DSM-IV-TR; American Psychiatric Association, 2000), was administered in this study. Thus, the symptoms of ASD are discussed according to Table 1 (APA, 2000), while also referring to the DSM-5 diagnostic criteria.

Table 1

DSM-IV-TR (APA, 2000) Criteria for a Diagnosis of ASD

-
- A. *Six or more items from (1), (2), and (3), with at least two from (1) and one each from (2) and (3):*
- (1) Impairments in social interaction, at least, two of the following:
 - (a) Marked impairment in nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) Failure to develop peer relationships appropriate to developmental level
 - (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out objects of interest)
 - (d) Lack of social or emotional reciprocity
 - (2) Impairments in communication, at least one of the following:
 - (a) Delay in / or lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) Stereotyped and repetitive use of language or idiosyncratic language
 - (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 - (3) Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, at least, one of the following:
 - (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) Apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) Stereotyped and repetitive motor mannerisms (hand or finger flapping or twisting, or complex whole-body movements)
 - (d) Persistent preoccupation with parts of objects
- B. *Delays or abnormal functioning in at least one of the following areas, with onset before age 3 years (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.*
- C. *The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.*
-

The research literature identifies several characteristics that commonly occur in children with ASD, but have been excluded in the DSM-5 (Matson & Jang, 2014). Although hyper-or hyporeactivity and tactile seeking are included in the DSM-5, it has been further proposed that this characteristic should be included as a core symptom (Matson & Jang, 2014).

Another feature not included in the DSM-5, but believed to be a fundamental characteristic of ASD, is a decreased ability to predict consequences (Wing, Gould, & Gillberg, 2011). For now, it is suggested that a lack of socialisation and an inclusion of ritualistic behaviours, best separate ASD from other developmental disorders (Matson & Jang, 2014).

2.2. Progress and Challenges of Diagnostic Criteria in the DSM

Since the publication of the DSM-IV in 1994, there has been an explosion of research on autism and autism-related disorders (Volkmar & Reichow, 2013). Part of the development in knowledge has arisen from a more flexible approach to diagnosis in both the *International Classification of Disease* (ICD-10) and the DSM-IV (Volkmar & Reichow, 2013). However, different views have been expressed in the empirical literature about the revised guidelines in the DSM-5, both before and after its release. There is consensus over the introduction of the term *autism spectrum disorders* in the DSM-5, to replace the pervasive developmental disorder (PDD) label (Wing et al., 2011) and further agreement that autism is a spectrum disorder (Falkmer, Anderson, Falkmer, & Horlin, 2013). Thus, the spectrum of behaviours that describe ASD may be conceptualised as a normal continuum of human functioning (Tincani, Travers, & Boutot, 2009).

Another positively viewed contribution in the DSM-5 is the later age of detection owing to some young children not having enough social exposure to peers before 36 months and symptoms only becoming evident in middle childhood (Ghaziuddin, 2010). Most noticeably, the three core domains have now been merged into two in the DSM-5, by combining the impairments of communication and social interaction into a single domain (Lord & Bishop, 2010).

The criticism attracted by the DSM-5 firstly involves the more specific guidelines now needed for a diagnosis of ASD (Volkmar & Reichow, 2013). Concerns have been raised that some individuals may be excluded from a diagnosis of ASD using the narrower DSM-5 requirements (Volkmar & Reichow, 2013). The omission of Asperger's Syndrome from the DSM-5 has been harshly criticised, by many researchers, as some studies have shown that it is a disorder distinct from high-functioning autism (Matson & Jang, 2014). Nevertheless, it

remains unclear what the impact of the DSM-5 criteria will have on diagnoses until more research is completed (Beighley et al., 2014; Volkmar & Reichow, 2013).

2.3. Early Recognition of Symptoms of ASD

Symptoms of ASD usually become evident in early development when parents or primary caregivers first notice behavioural indicators of the disorder (Hess & Landa, 2012).

However, it is possible for symptoms to go unnoticed for many months (Matson et al., 2011) because parents find it difficult to identify exactly what is wrong with their infant (Matson & Goldin, 2014). Many parents first notice developmental delays around 19 months of age (Guinchat et al., 2012) and by 2 years, clear difficulties in play, language, social communication, as well as motor and sensory abnormalities are identified (Zwaigenbaum et al., 2009). While severe forms of ASD may be detected and reported earlier (Matson & Goldin, 2014), higher functioning children with ASD are often reported at a later age (Turygin, Matson, Williams, & Belva, 2014).

A promising new longitudinal study, in the US, following at-risk infants with older siblings diagnosed with ASD, aims to investigate the early developmental signs that precede a diagnosis of ASD (Bölte et al., 2013). Preliminary findings from the study indicate that behaviours linked to ASD only arise after the first six months of life (Fuentes et al., 2012).

There seems to be an agreement in the research literature that recognition of ASD symptoms occurs in stages (Matson & Jang, 2014). First parental concerns usually include language delay, followed by poor social skills as well as the presence of repetitive behaviours or restricted interests (Kozlowski et al., 2011). Additionally, a range of features such as deficits in adaptive functioning such as sleeping and feeding problems are also frequently reported (Jang et al., 2014).

A recent study in the US proposes that primary caregivers first concerns emerge around the same age, independent of race/ethnicity (Jang et al., 2014). Since little is known about the influence of African culture on the early parental recognition of symptoms, it is unknown whether more culturally specific symptoms of ASD may emerge (DeWeerdt, 2012). The detection of some early features of ASD are found to differ according to culture, for example, 5 to 12-year-old children with ASD in the US were found to be more sensitive to sounds and sights than children in Israel (DeWeerdt, 2012).

2.4. Age at Diagnosis of ASD

Symptoms of ASD can remain undiagnosed for three or four years after the first contact with a healthcare professional (Marquez-Caraveo & Albores-Gallo, 2011; Moh & Magiati, 2012). Further findings suggest that African American children in the US are older at diagnosis than White American children, and less likely to be diagnosed with ASD at the first visit to a doctor (Mandell et al., 2009). However, the average age at diagnoses in disadvantaged communities are predicted to be older than 4 years of age (Zwaigenbaum et al., 2009). In particular, prolonged waiting periods between health professionals are found to be very stressful for parents (Mulligan et al., 2012).

In the past, it was uncommon for children in the US to be diagnosed with ASD before the age of 4 (Bölte et al., 2013) and often occurred when a child started school between 5 and 7 years of age (Yeargin-Allsopp et al., 2003). In recent years, there has been more focus on early detection of ASD, mostly driven by findings that early detection and appropriate interventions lead to improved outcomes in core areas (Mayes, Black, & Tierney, 2013). Screening assessments such as the Modified Checklist for Autism in Toddlers (M-CHAT) have demonstrated the possibility to detect a risk of autism at 18 months (Bölte et al., 2013). Thus, formal screening is recommended as a necessary step to identifying children at risk for ASD, beginning at 18 months (Soto et al., 2015). It has further been suggested that a late age at diagnosis may be due to physicians failing to conduct early routine screening tests (Self, Parham, & Rajagopalan, 2015).

While there is evidence of diagnoses being confirmed between 12 and 36 months of age (Matson et al., 2012), an accurate diagnosis before 36 months may be problematic due to the considerable clinical variations of the disorder (Falkmer et al., 2013). In addition, a diagnosis between 14 and 30 months may be unstable in up to a third of cases (Chawarska, Klin, Paul, & Volkmar, 2007; Landa, 2008; Zwaigenbaum et al., 2009). At present, there is agreement that ASD cannot be reliably diagnosed before 2 years of age (Bölte et al., 2013). It is also proposed that a diagnosis of ASD, when a child is approaching his/her third birthday, is likely to be more stable and reliable (Chawarska et al., 2007; Landa, 2008). This study explored the age at diagnosis of seven African children in KZN.

2.5. Increased Prevalence of ASD

Since the early 1970s, autism prevalence is reported to have increased twenty to thirty fold (Centers for Disease Control and Prevention, 2014). Currently, an estimated 1 in 68 children in the US is believed to meet the diagnostic criteria for ASD (CDC, 2014). Despite the documentation of sharp increases of ASD diagnoses globally, no epidemiological studies have been conducted on the African continent (Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). More specifically, the incidence and prevalence of ASD in Africa have been reported to be either preliminary or non-existent (Elsabbagh et al., 2012) and the impact of this disorder is almost entirely lacking in South Africa (Bakare & Munir, 2011a). Based on the 2007 statistics from the US, over 270 000 people are predicted to be affected with ASD in South Africa, with approximately 5 000 new cases every year (Springer et al., 2013). Nonetheless, the prevalence of ASD in all ethnic groups worldwide has been reported to have significantly increased (Matson & Jang, 2014).

Another consistently observed global characteristic is the higher proportion of males than females diagnosed with ASD (Elsabbagh et al., 2012). The CDC (2014) estimates that 1 in 42 boys, versus 1 in 189 girls are affected, making this condition almost five times more common in boys than girls. If these numbers are applied to the population in KwaZulu-Natal a male predominance of 77% is estimated in KwaZulu-Natal (Springer et al., 2013). It is unknown whether the higher prevalence of males affected globally, is an accurate reflection or if girls are more frequently overlooked due to a different clinical presentations (Goldman, 2013; Wing et al., 2011). Overall, the rising prevalence of ASD may be reflective of a real increase in the number of cases or linked to a greater awareness of ASD by clinicians and society, and changing diagnostic criteria over the decades (Elsabbagh et al., 2012; Quilendrin et al., 2015).

2.6. Aetiology of ASD

Despite various explanations about the aetiology of autism emerging over the last forty years, it is still poorly understood (Rossi, Newschaffer, & Yudell, 2013). Kanner (1943) first proposed that *refrigerator mothering* caused childhood autism after he noticed that mothers of autistic children were somewhat distant and cold. However, Kanner's (1943) view has been rejected after discovering that a non-nurturing environment does not cause autism (Grinker, 2007). Another strongly refuted explanation was the association between the

measles component in the MMR (measles, mumps/rubella) vaccine and autism (Dietert et al., 2011; Rutter, 2011).

While the exact cause of ASD is yet to be determined, it was initially believed that environmental factors caused the condition (Matson & Jang, 2014). However, genetics are undoubtedly involved and infants with older siblings diagnosed with ASD have been found to be at a 20% greater risk of developing autism (Bölte et al., 2013). Recent research points to biological causes and/or a number of triggers such as maternal stress or immigration during pregnancy, in-utero exposure to illness, drugs, alcohol, and low levels of vitamin D (Dietert et al., 2011; Matson & Jang, 2014; Rutter, 2011). Further risks for ASD may include paternal age over the age of 40 years at conception (Rutter, 2011). Possible risks of ASD for infants include heavier birth weight, longer gestation age (Matson & Sipes, 2010) as well as preterm births less than 35 weeks, and low birth weight less than 2 500g (CDC, 2012). The presence of toxins after gestation, have further been identified as possible causes of ASD (Matson & Goldin, 2014). For example, the exposure to pesticides, solvents, and air pollution from living in cities are suggested to increase the risks of ASD (Larsson, Weiss, Janson, Sundell, & Bornehag, 2009). In addition, the exact aetiology of ASD is highly unlikely to exist for any two individuals (Matson & Jang, 2014).

A study in Africa found that three children around 2 years of age were diagnosed with autism after a severe malaria infection, but this has not been further substantiated (Elsabbagh et al., 2012; Mankoski et al., 2006).

2.7. Comorbidity

The DSM-5 predicts that 70% of individuals with ASD are likely to have one comorbid mental disorder while 40% are reported to have two or more (APA, 2013). Thus, disorders such as anxiety, depression, obsessive-compulsive disorder, and developmental coordination disorder, frequently co-occur with ASD (Matson et al., 2012; Matson & Sipes, 2010).

Similarity, co-occurring medical conditions such as sleep problems, avoidant-restrictive food intake disorder, epilepsy and cerebral palsy are also frequently present from young (Rutter, 2011). Comorbid challenging behaviours and adaptive behaviour problems such as impulsivity, inattention, restlessness, tantrums, irritability, and aggression (Bacalman, Hendren, Schreibman, & Scahill, 2009) often add further to the heterogeneity of the disorder (Matson & Jang, 2014).

A high overlap between intellectual disability (ID) and ASD has been found to exist as well as the identification that poor prognosis is related to the severity of cognitive deficits (Matson & Goldin, 2014). The CDC (2014) predicts that 50% of children with ASD have an average to above average intellectual ability (IQ > 85%). The frequent overlap of ID makes differentiating between children with or without ASD, exceptionally challenging (Falkmer et al., 2013; Lord, Luyster, Guthrie, & Pickles, 2012; Zwaigenbaum et al., 2009). Severe ID may result in stereotypic body movements, and communication and speech difficulties, which are also found in ASD (Matson & Jang, 2014). Hence, the determining factors for a diagnosis of ASD is a lack of interest in socialising, increased echolalia and third person instead of first person speech, in relation to individuals with ID only (Matson & Jang, 2014). Therefore, researchers emphasise the importance of clinicians developing expertise in the evaluation and identification of ASD as well as being able to distinguish between ASD and other psychiatric disorders (Reaven, Hepburn, & Ross, 2008). Although at present, no pharmacological methods have been shown to be effective for the treatment of core symptoms of ASD, medication is often prescribed to treat comorbid conditions such as ADHD, anxiety, depression, and seizures (Matson & Goldin, 2014).

One study in Africa reported more children with ASD had ID than without (Mankoski et al., 2006). In order to account for the higher occurrence of ID in African children, it has been suggested that children with less severe forms of ASD may be taken to sangomas or traditional healers whereas severe cases may report to hospitals and clinics for advice (Bakare & Munir, 2011a).

2.8. Diagnostic Features

As more research has emerged globally, it is evident that the assessment and diagnosis of ASD are highly complex (Matson & Jang, 2014). Furthermore, a diagnosis of ASD cannot be detected by scans or blood tests hence behavioural assessments are presently the only available means of diagnosis (Falkmer et al., 2013). Thus, the gold standard for assessment and diagnosis of ASD remains clinical judgement, based on caregiver history, multidisciplinary evaluations, school observations, and multiple assessments (Andersson, Miniscalco, & Gillberg, 2014).

Of particular concern in South Africa, are research findings indicating that many African children from low socio-economic communities are either incorrectly diagnosed or remain undiagnosed (Malcolm-Smith et al., 2013). Furthermore, there is evidence of an over-

representation of White South African children diagnosed with ASD, compared to Black children (Ametepee & Chitiyo, 2009; Elsabbagh et al., 2012; Malcolm-Smith et al., 2013). Thus, there is an urgent need to develop culturally appropriate screening assessments such as brief formalised questionnaires, and diagnostic instruments, to identify children of African ethnicity at risk for ASD.

2.9. The Autism Diagnostic Observation Schedule (ADOS)

The ADOS is an observational instrument used for diagnostic purposes with individuals suspected of having ASD (Lord, Rutter, DiLavore, & Risi, 2011). The aim of the ADOS is to elicit spontaneous behaviour of reciprocal social interaction, communication and play in a semi-structured but standardised setting (Lord et al., 2011). It is one of the most widely used measures with good inter-rater reliability and has been subjected to rigorous, independent examinations (Lord et al., 2002). The ADOS is further predicted to have the strongest accuracy compared with other instruments (Falkmer et al., 2013).

To administer the ADOS, a clinician selects from four modules of increasing difficulty that best fits an individual's expressive ability (Hurwitz & Yirmiya, 2014). In this study, the most suitable module was identified in collaboration with the school O.T or mother, who was familiar with the child's expressive language ability. Once the administration began, clinical judgement was used to determine whether the child was suited to the module.

Modules include both structured activities and unstructured play, and share a similar approach in which set instructions are given to draw out particular behaviours (Hurwitz & Yirmiya, 2014). Standardised settings provide opportunities to observe the child's communicative and social behaviour (Lord et al., 2002). Module 1 and 2 include activities such as inflating and releasing a balloon and blowing bubbles. Social settings that children may be familiar with such as a birthday party scenario may also be administered. The child's behaviours are coded along with repetitive or restrictive behaviours, which are used to inform diagnoses (Hurwitz & Yirmiya, 2014).

While there has been a reported rise in the number of screening and diagnostic tools developed worldwide (Matson & Jang, 2014), many have not been validated in other cultural settings (Soto et al., 2015). Thus, it is unknown whether the ADOS activities that were developed for children in the US and UK such as a pretend birthday party, will be culturally appropriate for African children from rural contexts. (Wallace et al., 2012). It is further

debated whether the ADOS will be able to capture cultural variations in behaviour (Malcolm-Smith et al., 2013). Given the significance of early detection and diagnosis of ASD, on a child's long-term outcomes, there is an urgent need to develop culturally appropriate diagnostic tools for the South African context. Failure to adapt existing instruments may result in the over- or under- detection of children at risk of ASD (Soto et al., 2015).

The first edition of the ADOS that was developed on DSM-IV-TR criteria (Matson & Sipes, 2010), was administered in this study as the ADOS 2, developed on the DSM-5 criteria, was not available in South Africa. The results of the ADOS assessment were used to investigate whether this measure could correctly identify ASD in African children, already diagnosed with ASD.

Certain sociocultural differences were also evaluated to determine the appropriateness of the tool (Wallace et al., 2012). Thus, the study further sought to explore the cultural appropriateness of the ADOS activities by observing the African children's reactions and responses to the tasks. However, determining the appropriateness of the ADOS to African cultural contexts goes beyond translation to include a thorough process of identifying potential incompatibilities (Soto et al., 2015) and is beyond the scope of the dissertation.

2.10. Summary

A description of ASD has been provided from a largely Western-based perspective that assumes the signs and symptoms of this disorder are essentially similar across all ethnic groups. Although the exact origin of this pervasive neurodevelopmental disorder is unknown, the core symptoms become evident in early childhood and vary in onset and severity. While there is presently no cure for ASD, early detection, diagnosis, and intervention at a young age may significantly improve a child's long-term outcomes. The gold standard diagnostic tool for identifying ASD in Western countries is considered to be the ADOS. However, culturally appropriate and reliable measures are yet to be developed for the South African context (Soto et al., 2015).

The next chapter explores the way in which African cultural belief systems may influence parental understandings of child development and child rearing. It is suggested, that cultural norms regarding child development are shaped and transferred from generation to generation by primary caregivers in everyday life (Mandell & Novak, 2005). It is also proposed that

African cultural beliefs may influence parental understandings of how ASD is interpreted, and the meanings of disability (Ravindran & Myers, 2012).

Chapter 3

The Intersection between ASD and African Culture

It has been suggested that traditional African belief systems may influence the way in which parents perceive and interpret the causes and symptoms of ASD (Mandell & Novak, 2005). Thus, in order to investigate African parents' experiences of raising a child with ASD, it is imperative to gain an understanding of an African worldview and traditional belief systems. South Africa is a multicultural society with eleven official languages, and diverse religious and ethnic groups (Ross, 2007).

The participants involved in this study all reside in KZN, a province that comprises of a quickly growing, diverse society with various economic, environmental, and social challenges (Statistics South Africa, 2011). While fathers of children with ASD rarely participate in empirical studies, despite increased co-parenting responsibilities (Braunstein et al., 2013), it was fortunate that three African fathers were able to participate. The study benefitted from obtaining valuable insight into the experiences of raising a child with ASD, from a paternal perspective as mothers and fathers have been found to have different perspectives of raising a child with ASD (Pisula & Kossakowska, 2010).

Research suggests that children living with both parents, compared to households with one parent, are more likely to be from wealthier households as both parents may financially contribute to a household (Hall & Posel, 2012). Since the majority of children in the study lived with both parents, these families may have had access to better resources than many others living in KZN (KZN is one of the more resource-scarce provinces in South Africa). According to the level of parental education, 83% of the participants obtained their senior certificate (matric). In KZN, 37.1% of the population are estimated to have a matric certificate by 20 years old (Stats SA, 2011). Two of the participants had undergraduate degrees while two were currently studying part-time towards undergraduate degrees. According to surveys, about 12.3% of people living in KZN are predicted to hold higher education certificates or degrees (Stats SA, 2011).

3.1. A Theoretical Perspective of Childrearing

Several theorists have developed explanations to account for the impact of cultural belief systems on childrearing practices. A particularly relevant theory that accounts for

commonalities and deviations in childrearing across cultures has been proposed by Super and Harkness (1986) in the *developmental niche* framework. Super and Harkness's (1986) theory has been based on studies of children in different cultures and the framework provides an opportunity for examining cultural effects on child rearing. Since the developmental niche framework has a specific focus on the successful development of a child with a disability, it is narrower in scope than Bronfenbrenner's bioecological model, making it applicable to this study (Womble, 2010). According to the developmental niche theory, a child is perceived to be at the centre of a niche and is influenced by (i) the physical and social settings of everyday life, (ii) the customary practices of child care, and (iii) the psychology of the caretakers, which includes cultural belief systems or parental ethnotheories (Super & Harkness, 1986).

Parental ethnotheories are intuitive views about childrearing that are passed down through the generations and believed to be the "right" ways of raising children (Harkness & Super, 2000). In other words, parents may respond instinctively when solving everyday problems. Another assumption based on the developmental niche theory is that parents may adjust their beliefs of childcare to the settings in which they live hence discipline strategies may vary according to the type of reactions and influences from society towards a child behaviour (Penderi & Petrogiannis, 2011). Furthermore, cultural beliefs about childrearing may also be influenced by environmental factors. For example, the first complaint, from Latino mothers was that their child with ASD was a "picky eater" (DeWeerd, 2012). Since these mothers were migrant workers, it has been suggested that they were more conscious of their child's eating habits due to poverty and food shortages than mothers from more affluent countries (DeWeerd, 2012).

3.2. African Spiritual Beliefs and Traditional Practices

According to African cosmology, beings and objects in the universe are all interconnected thus human beings can communicate with deceased family members, living as spirits (Mkhize, 2004). Furthermore, ancestral spirits are believed to act as intermediaries between God and are greatly feared as they possess the power to discipline the living (Van der Merwe et al., 2010). The living respect ancestral spirits by performing traditional cultural rituals and failure to comply may expose people to the powers of witchcraft (Berg, 2003a). A common cause that may evoke ancestor wrath in African cultures is not introducing a child to the ancestors, a ceremony that is referred to as "amagobongo" in isiZulu (Mabaso & Uys, 1990).

Cultural rituals are also conducted as corrective measures, in an attempt to appeal to supernatural powers to reverse situations (Mabaso & Uys, 1990).

In low-and-middle-income countries (LMICs) such as South Africa, approximately 50% of individuals seeking help for mental health concerns are reported to consult traditional and religious healers as their first care provider (Burns, 2015). According to traditional African belief systems, mental health issues are often seen to result from bewitchment by ancestral spirits hence religious advisors and traditional healers are regarded as having expertise in this area (Sorsdahl et al., 2009). Furthermore, the majority of African families are reported to follow a Christian religion while still retaining traditional African beliefs so the two belief systems may be intertwined without one necessarily replacing the other (Van der Merwe, Van Eeden, & Deventer, 2010).

When an infant is born into an African culture with a noticeable deformity such as cerebral palsy, it is usually accepted as a medical condition (Berg, 2003a). However, when a condition is not apparent at birth such as ASD, the later appearance of a disorder is often attributed to ancestral spirits being angered by some parental wrongdoing (Berg, 2003b). Traditional African rituals may involve calling on ancestral spirits for guidance or solutions to a child's problems. A goat may be slaughtered to appease ancestral spirits (Mabaso & Uys, 1990) and the ritual is concluded by the child wearing a bangle *isiphandla* made from goat skin as a symbol that the ceremony was performed.

Western parents have been found to hold a wide variety of beliefs for their child's ASD, including events surrounding the birth, environmental influences in early childhood, and genetic factors (Hebert & Koulouglioti, 2010). Since cultural beliefs are likely to impact on the way parents view and respond to the characteristics of ASD (Matson et al., 2012), one aim of this study was to investigate the way in which African parents understand and respond to the aetiology of this neurodevelopmental disorder. It seems that individuals who are traditional in their African beliefs and practices have a greater likelihood of attributing their child's symptoms of ASD, to upsetting the ancestral spirits. However, an under-researched area concerns the way in which traditional African culture impacts the type of interventions parents' may implement as a way of resolving a child's mental health difficulties (Sorsdahl et al., 2009). Thus, it is postulated that if African parents interpret the causes of ASD to result from the ancestors' displeasure, then traditional rituals may be performed in an attempt to resolve a child's condition.

3.3. The Impact of ASD on Parents and Families

Undoubtedly, the social impact of ASD in any culture is highly problematic as features of ASD negatively affect both the child and family members' lives (Siniscalco, Di Marsilio, & Antonucci, 2013). However, very few studies have examined the social and cultural impact of ASD on African parents' lives (Rossi et al., 2013). Relationships, in African cultures, are often highly valued as they offer people a sense of belonging within a community hence childrearing is seen as a collective responsibility (Mkhize, 2004). In addition, the fear of stigmatisation and becoming isolated is often too overwhelming for someone from an African culture to consider (Van der Merwe et al., 2010).

Parent and family distress, related to ASD often starts long before a diagnosis is confirmed (Karst & Van Heke, 2012). In fact, parents of children with ASD often experience higher stress levels than parents of typically developing children (Pisula & Kossakowska, 2010), and have been found to use harsher discipline measures in an attempt to manage problematic behaviour, especially when behaviours are viewed to be rebellious or acting-out (Mandell et al., 2009). Thus, an advantage of an early ASD diagnosis is that parents may be provided with early support and psychoeducation to help them understand and manage challenging behaviour that often present in children with autism (Pisula & Kossakowska, 2010).

3.4. Features of ASD in Africa

KZN has been reported to have limited availability of treatment services within the mental health system (Uwemedimo et al., 2014). Furthermore, medical practitioners in South Africa have been found to have a limited knowledge and expertise of developmental disorders in order to assess and reliably diagnose ASD (Bakare & Munir, 2011b; Elsabbagh et al., 2012). Additionally, diagnostic services have been found to be scarce in South Africa, and the available services overburdened (Malcolm-Smith et al., 2013). Thus, parents are likely to invest a significant amount of time and resources trying to establish a diagnosis of ASD for their child in South Africa (Wallace, 2012).

There is a reported under diagnosis of ASD in African children in Africa (Elsabbagh et al., 2012). Speculative research, regarding the reasons for a later diagnosis of ASD outside Western countries, has suggested that a parent's lack of awareness of autism and developmental norms may account for these differences (DeWeerd, 2012). For example,

parental knowledge of appropriate milestones is important to be able to identify the late development of speech.

A study conducted in Africa reported a predominance of nonverbal cases of children with ASD (Bakare & Munir, 2011a). Another study confirmed that 71% of children who visited a clinic were nonverbal (Mankoski et al., 2006). It has further been documented that participants diagnosed with ASD in Africa often lacked expressive language abilities and had little or no speech (Bakare & Munir, 2011a).

As mentioned earlier, little has been reported on the behavioural characteristics of African children with ASD in South Africa (Elsabbagh et al., 2012; Grinker et al., 2012). However, cultural expectations about what is appropriate behaviour for children may vary according to culture. For example, children from African cultures may be reprimanded for looking adults directly in the eye as it is considered disrespectful (DeWeerd, 2012). Since most autism research stems from the UK and US, Western clinicians observe the lack of eye contact as a symptom of social deficits (DeWeerd, 2012). Cultural values might influence the way African children are socialised, both within their family and by the community as a whole (De Weerd, 2012). However, it is unknown whether cultural views of behaviour also play a role, when parents identify unusual behavioural symptoms in their children.

Similarities of features such as using an adult's hand to communicate intent have been found to indicate early signs of autism in both children in the US and SA (DeWeerd, 2012).

African parents tend to value obedience and respect from their children (Mkhezi, 2004).

Hence, children are required to show respect towards anyone older than themselves. Since children are socialised not to engage spontaneously in adult conversation, this may mean that African children suppress responses in comparison to their Western counterparts.

Consequently, suppressed spontaneity may reduce a child's use of gesture and inhibit a child's requesting and showing behaviours. Although a decrease of these features is associated with ASD, in Western countries, it is critical to consider the impact of the way in which African children are socialised and expected to behave in social contexts, as this may influence the manner in which a child interacts with an adult in clinical or research settings. Also, in many clinical settings, African children may be required to interact with a White adult clinician, yet they may have relatively little familiarity with this sort of person which would further reduce their responses to activities that are used in assessments of ASD.

In summary, it appears that childrearing practices are embedded in culture and largely determine the behaviours and expectations for child development. Therefore, childrearing has been proposed to be based on cultural beliefs about what *should* be done according to accepted norms of the culture.

Since appropriate early intervention has been shown to improve a child's outcomes, early identification of the disorder is critical. Thus, understanding and exploring the ways in which parents experience childrearing may give an indication of whether the presentation of core features also presents in African children with ASD. Furthermore, by understanding the way that African parents perceive and report the first characteristics of ASD, may provide clinicians with information about the kind of symptoms that parents are likely to report.

3.5. Aim and Rationale

The United Nations has acknowledged that ASD is an emerging public health issue (Wallace et al., 2012). In addition, there is a growing global concern about the burden of life-long costs for the state and families (Malcolm-Smith et al., 2013). Although ASD has received little research attention in South Africa to date, several researchers are appealing for more studies to investigate the characteristics of ASD in African children (Elsabbagh et al., 2012; Grinker, 2007; Springer et al., 2013; Van Biljon, Kritzinger, & Geertsema, 2015). As mentioned earlier, this study fell under the auspices of the larger K-ASD study that aimed to find the best way in which to assess and identify children with ASD in a Zulu culture (Kauchali, 2008). It was proposed that by understanding the way autism occurs in South Africa, the information will better assist health professionals to help African children (Kauchali, 2008).

Although the importance of early identification and intervention of ASD in young children is regarded a priority in Western countries, early identification does not seem to be receiving the same focus in South Africa (Elsabbagh et al., 2012). This may stem from research in South Africa focussing on issues such as malnutrition and HIV/AIDS (Malcolm-Smith et al., 2013). Thus, the rationale behind this study was to develop a better understanding of ASD in African children by considering the way in which cultural belief systems may influence the recognition and understanding of the manifestation of the early symptoms of ASD. A greater understanding was also sought into how African parents perceive and interpret the features of ASD according to cultural belief systems.

On the basis of the above, it seems that there is a gap in the literature about the specific ways in which ASD may present in an African child, and how the parents may experience the atypical development of this child. Maladaptive patterns in the areas of communication and reciprocal social interaction are especially likely to be affected by the way in which a child is raised (DeWeerd, 2012). Although South African society is in a state of rapid transition, many still hold traditional African worldviews and would raise their children with these in mind.

This study has two focal areas, each with specific aims.

3.5.1. Experiences of African parents of children with ASD.

Since parents are often the first to identify symptoms of ASD in their child, they are considered to be fundamental role players in the recognition of symptoms of ASD (Tincani et al., 2009). Retrospective reports from African parents may offer unique insight into the early behaviours of young children with ASD. In addition, parents have the advantage of observing their children across a variety of settings and over time (Zwaigenbaum et al., 2009). This study included African parents of children with ASD to examine the age at which first parental concerns arose and the types of concerns that were detected by parents of African ethnicity. It was hoped that the findings would contribute to a better understanding of the kinds of symptoms that parents are inclined to report to healthcare professionals, with a view to improving early diagnoses of ASD in other African children; and to investigate African parents' perceptions and experiences of raising a child with ASD in an African cultural context.

3.5.2. Observations of the child with ASD during the ADOS administration.

The most widely recognised screening and diagnostic tests for ASD are developed and used in the UK and the US and no standardised assessment tool exists for identifying ASD in African children (Soto et al., 2015). Researchers in other countries are finding that they need to adapt activities from tests, according to different cultures (Soto et al., 2015). However, before being able to do this in South Africa more information is needed about the way children of African ethnicity, diagnosed with ASD, respond to the activities on the ADOS. Thus, observations from the ADOS were used to contextualise the parents' accounts of the manifestations of ASD, and to provide an indication of whether it is a culturally fair assessment for our context. It was hoped that these preliminary findings would provide an indication about whether a Western-based measure could be used or adapted for an African

context and whether the activities provided an appropriate environment for observing behaviours characteristic of ASD.

While the international prevalence of ASD has grown exponentially, prevalence rates in South Africa have not grown to the same extent (Wallace et al., 2012). There are several possible explanations for this difference; among other things, the disorder occurs less frequently in African children or that it is less well recognised, or that the children are not being accurately diagnosed. It could be that many children in South Africa remain undiagnosed and so do not have access to appropriate interventions. It is essential that insights about the manifestation of ASD be generated with a view to educating parents and health professionals about the features of ASD that may arise in African children.

The aims of this study were:

1. To investigate Black South African parents' experiences of raising a child with ASD.
2. To collect descriptive information about ASD in African children within the South African culture and context.
3. To generate insight into the manifestation of ASD in African children.
4. To observe African children's responses to the ADOS activities presses in the ADOS.

The research questions were:

1. What early features of ASD do Black South African parents identify in their children?
2. What are African parents' experiences of raising a child with ASD in the KZN context?
3. What are African parents' cultural understandings or perspectives regarding the aetiology of ASD?
4. How do African children respond to the activities, tasks or presses in the ADOS?

Chapter 4

Methodology

This chapter begins by outlining the rationale for adopting a multiple case study method to best explore the research questions. Important ethical considerations were taken into account throughout this study, from inception through to completion and into the future. These ethical factors are described along with the sampling techniques; the instruments used to collect data, followed by the approaches to data analysis.

4.1. Research Paradigm and Design

As little research has investigated the general assumptions of ASD within an African context (Ametepee & Chitiyo, 2009), this study was exploratory in nature, and was based on an interpretivist approach that focused on descriptions and experiences of participants. Essentially, interpretivists hold that reality is constructed in the mind of the individual (Yin, 2003). As such, an interpretivist approach allowed for an in-depth exploration of African parents' understandings of parenting a child who developed in an atypical way, and was later diagnosed with ASD.

Although raising a child with ASD is neither a 'normal' nor an 'expected' experience, the responses and challenges are based on the parents' worldviews and the ways in which they tried to create meaning of their circumstances. Most cross-cultural research relies on an approach that enables an in-depth consideration of the ways in which different groups of people create meaning in the world (Mkhize, 2004). The aim was to make sense of participants' understandings of their reality with rich data and detailed descriptions (Terre Blanche, Durrheim, & Painter, 2006).

This study implemented a qualitative multiple case study design to explore the central phenomenon of ASD in African children and the African cultural context in which it occurs. The participants' accounts were understood to be a description of their subjective reality (Baxter & Jack, 2008), thereby helping this researcher to better understand how African parents make meaning of raising a child with ASD. Thus, qualitative methodology allowed an investigation of the understanding of African parents' perspectives of ASD (Rule & John, 2011).

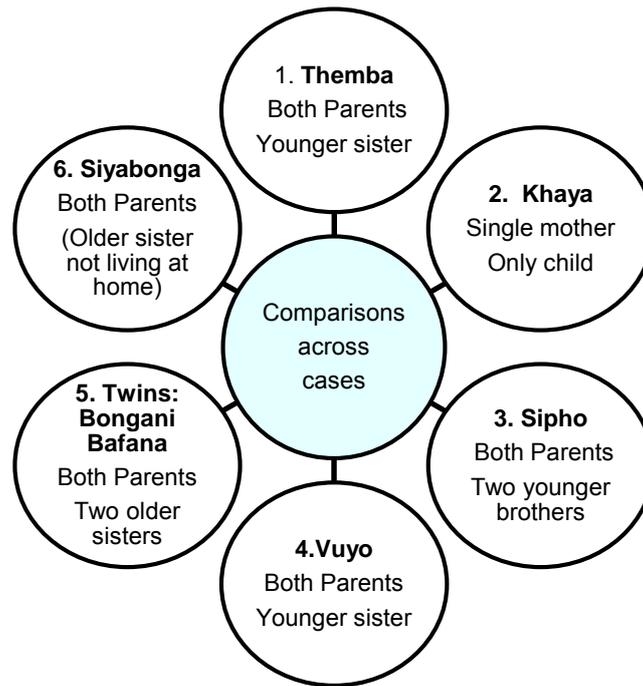


Figure 1. Conceptualisation of the case study comprising of six cases.

It turned out that this research paradigm and design were especially well suited as family contexts varied. Thus, the multiple case study design enabled the researcher to make comparisons both between and within cases (Baxter & Jack, 2008). A case was conceptualised as a child with ASD in his family context, except for the set of twin boy children who were combined into a single case due to them being in the same family. The parents were accessed once the child had been identified. The children and parents were given pseudonyms to protect their privacy. Figure 1 shows the parents and siblings who reside with the child (extended family members living in a household have not been included).

4.2. Sampling

Since a case study design involves collecting detailed observations, a limited number of cases were selected (Baxter & Jack, 2008). Hence, purposeful sampling, a nonprobability sampling technique, was used to select specific cases that best represented the population (Rule & John, 2011). Purposive sampling describes the selection of particular predetermined cases of a population: in this study, African South African, aged between six and eleven years, and diagnosed with ASD (Terre Blanche et al., 2006).

A sample of seven boy children (mean age 9 years 3 months) was identified as having met the sampling criteria. A total of nine adult participants (three married couples, two married mothers without their spouses, and one single mother) indicated a willingness to participate in the study. The intention had been to recruit children of Zulu descent. However, the individuals who were willing to participate had various ancestries: two of the parents who were of Zulu ancestry, were married to spouses of Xhosa decent, and the twins' parents were of Swahili origin.

There was a considerably higher rate of boy children who met the sampling criteria, so it was decided not to add gender as an additional variable. It was interesting to note that none of the five special needs schools had girl children who met the criteria. This is consistent with international literature that describes a higher incidence of boys than girls with ASD (Mulligan, MacCulloch, Good, & Nicholas, 2012). In fact, a 2014 study using three case studies to demonstrate potential gender difference, suggests an under-identification of ASD in girl children (Trubanova, Donlon, Kreiser, Ollendick, & White, 2014). Since this study involved children and adult participants, the terms participants or parents are used interchangeably when referring to the parent/s while the children are referred to as children, sons, or boys.

As in many qualitative studies, the sampling process was more time consuming than one would expect. Initially, the plan had been that a specialist paediatrician (who was a Principal Investigator and part of the K-ASD Study) would identify children who met the following criteria: African South African, aged between six and eleven years, and diagnosed with ASD. This age range was selected so that Modules one, two or three of the ADOS could be administered. However, when after some months, only one child was identified in this manner, it was decided to recruit children through public LSEN schools where more children with ASD may be located. Five schools situated within KwaZulu-Natal Province were identified: three in Pietermaritzburg (Msunduzi) and two in Durban (eThekweni).

4.3. Procedure for Data Collection

This dissertation fell under the auspices of both the K-ASD study as well as the University Ethics Review Board. The data from this study supplemented data from the K-ASD study, and the Principal Investigators (PIs) of the larger K-ASD provided clinical oversight and supervision. This research study was conducted as an entirely separate process in all respects except for the clinical oversight, and assistance with accessing potential participants.

The PI's of the larger K-ASD study were granted ethical approval and consent to approach schools by the Department of Education (DoE) before the proposal for this study had been submitted through relevant university channels (see Appendix A). The PIs of the K-ASD study recognised that special ethical precautions were needed when working with this vulnerable sample: children with ASD (and their parents) are considered vulnerable as they may lack the ability to verbalise concerns or predict harmful situations. Hence, clinical oversight was exercised by a child psychiatrist from the US, who worked alongside the researcher from this study, and a registered clinical psychologist (Dr Killian).

For the sake of clarity, the roles of these professionals is described below:

1. The author of this study designed this study and submitted a proposal for sanctioning. The University Faculty of Human and Social Sciences Research Ethics Committee obtained ethical approval (see [Appendix A](#)). Cases were initially referred to Dr Killian (who supervised this academic research and oversaw interaction with participants, and maintained overall clinical responsibility for the child and parents).
2. The author also participated in all data collection processes (i) interviewed all of the parents, (ii) administered the ADOS to five of the children while a psychologist, trained in the ADOS and fluent in isiZulu, conducted the administration with two of the children, with the author observing and operating the video camera, (iii) analysed all data, and (iv) independently wrote up this dissertation.
3. A registered clinician psychologist (Dr Killian) was present for interviews and one ADOS assessment and reviewed the video-recording of the ADOS administrations.
4. Either a psychologist, psychiatrist or a researcher from the K-ASD study, trained in the ADOS, observed the children and operated the video camera. Immediately after the ADOS, both observers jointly coded the child's performance according to the manual. The video footage was later viewed by professionals from the K-ASD study, consensus coding was completed, and an algorithm for ASD diagnosis cutoff was calculated.

4.4. Research Process

An interesting factor emerged regarding the children's diagnoses of ASD. A paediatrician, two occupational therapists (OTs), and a school principal were responsible for recruiting

children for the study. Additionally, these professionals were certain that the children were on the Autistic Spectrum. However, the school principal who referred the twin boys mistook a speech and language therapist's report as a formal diagnosis and the mother did not have a written diagnosis from the medical doctor who had diagnosed the children. This was only discovered in the final stages of the research when investigating the personal school files.

An in-depth discussion of the details and processes involved in the administration and coding of the ADOS is beyond the scope of this dissertation. Furthermore, the validation of the ADOS for African South African children was not the focus of this study. Nevertheless, the researcher of this study accessed the specialised and extensive training required to administer the ADOS, through the larger K-ASD study. Training included learning comprehensive ADOS manuals and repeatedly viewing recommended training DVDs, as recommended by the developers of the ADOS (Lord et al., 2002). Competency was attained by comparing coding scores with clinicians trained in the ADOS. On completion of the K-ASD study, the author of this study had coded and/or administered the ADOS to a total of 35 children on both studies.

Once the DoE had granted consent to approach public schools, identified principals of LSEN schools or gatekeepers in the greater Durban and Pietermaritzburg areas were contacted telephonically by the author of this study or another Masters research student (A. Wilford) or Dr Killian. After briefly informing school principals of the purpose and process of the overarching K-ASD study, two principals declined an invitation to participate. Hence, emails with the details of the study were sent to five principals (see Appendix B). An additional email was sent to the principals, by the author of this study, requesting permission to interview the African parents of children with ASD at the school, as this was not included in the K-ASD study (see Appendix C).

Staff members such as OTs were selected by the principals at participating schools and were responsible for identifying children for the study. Involved staff members then contacted children's parents, explained the nature of the study to them, and invited participation. After obtaining verbal consent, from the parent/s, they were sent a letter outlining what was required of them (see Appendix D). As the interviews with the parents were to be audio-recorded, and the ADOS assessment with the children video-recorded, it was necessary to draw the participants' attention to this at the consent stage of this research. Participants were

also asked for their consent for the clinical psychologist and researcher to access their child's personal school file (see Appendix D).

The participants were asked to bring the completed informed consent form with them to the first interview. Before the commencement of interviews, the aims of the study were clarified. Participants were also assured that the information would remain confidential and video footage from the ADOS assessments would only be viewed by researchers on the K-ASD study for research purposes.

An important component of case study research is the use of multiple data sources which enhances data credibility and validity through triangulation (Baxter & Jack, 2008; Yin, 2003). The essential elements of the various data gathering processes used in this study appear in Figure 2 (see below). Two in-depth, semi-structured interviews were conducted with parents (see Appendix E). Although an isiZulu speaking psychologist was available to translate interviews, only one mother used this service. The interviews ranged in duration from 1 hour 30 minutes to 2 hours 30 minutes. The longer sessions enabled detailed clinical data and in-depth discussion to be recorded.

The ADOS took approximately 45 to 70 minutes to complete. A small table and chairs, appropriate for young children, were used so the examiner could be at the same level as the child, and part of Module 1 was administered on a mat on the floor. Consistent with the ADOS protocol for Module 1, the mother of the child was present and assisted the examiner when necessary (Lord et al., 2002). The OTs at two of the schools, with whom the children are familiar and comfortable, were present during Module 2 sessions. This was done to ensure each child's comfort, in line with a primary ethical consideration. The examiner closely monitored the children's behaviour for signs of anxiety, distress or fatigue. One assessment was discontinued when a child started to become agitated and could not be re-engaged in activities. Immediately after the ADOS assessment, the codes that most accurately reflected a child's performance were discussed, and consensus reached between the researcher and a psychologist or trained researcher who operated the video camera.

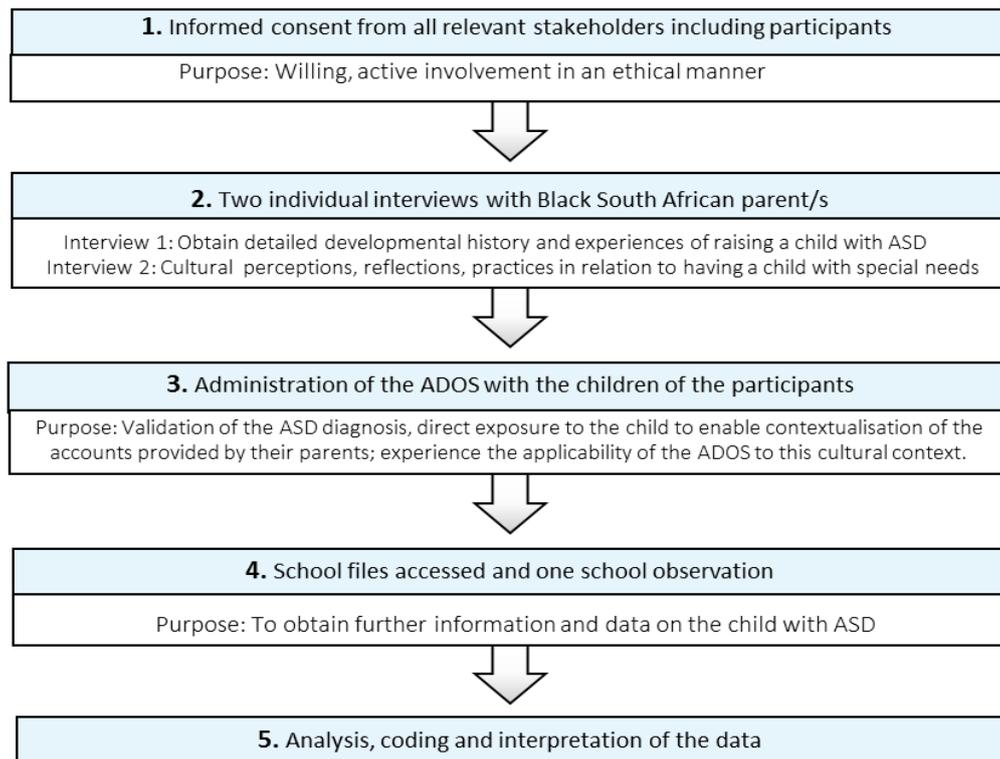


Figure 2. Stages of data collection

The video-recordings of the children's assessments were carefully viewed by members of the K-ASD study, systematically checked for clinical accuracy, and the coding verified. The involvement of additional clinicians was fully explained to the participants before the commencement of the research. All diagnoses were made in collaboration with a registered clinical psychologist. Oral feedback of the ADOS was offered to the parents, and appropriate interventions discussed, where necessary. This feedback session was considered ethically appropriate and was not used for the information gathering process of this research.

4.5. Instruments for Data Collection

4.5.1. In-depth semi-structured interviews.

An individual interview setting provided the participants with privacy as opposed to a focus group approach. This setting also offered participants an opportunity to develop rapport with the researcher and feel more comfortable about sharing sensitive information (Mulligan et al., 2012). Interviews were scheduled around times that suited participants. The format was semi-structured because some level of flexibility was needed to capture the complexities of cases (Rule & John, 2011). The interview schedule (see Appendix E) allowed interview questions to be adapted according to the participant's responses (Mulligan et al., 2012).

Open-ended questions were also introduced to encourage participants to share their perspectives and cultural understanding of their child's disorder.

The involvement of three fathers enhance the findings of the study since they provided perspectives of raising a child with ASD from a father's perspective. The following interviews were conducted:

1. After Themba's mother had been interviewed alone at the first session, both parents were briefly interviewed together for part of the second session, followed by the father alone for the remainder of the session.
2. Both Vuyo's parents participated in the first interview, after that the mother was present at the following session with an isiZulu speaking translator.
3. Khaya and Siyabonga's mothers, as well as the twins' mother, were interviewed alone on both occasions.
4. Siphos parents participated together in both sessions.

During the first interview, clinical details of the child's developmental history were collected, moving from infancy to the child's current level of functioning. After that, more specific questions were discussed such as the first unusual features identified, the age of the child at symptom recognition, the help-seeking process, the challenges of raising a child with ASD, and the path to the diagnosis (Daley, 2004). The second session provided an opportunity for the researcher to gain a deeper understanding of the participants' cultural beliefs about the causes of ASD, their perceptions of symptoms, and the conception of disability, within the African cultural context. Rich narratives from the parents' retrospective memories, of raising a child with ASD, were collected.

4.5.2. The Autism Diagnostic Observation Schedule (ADOS).

Before administration, the examiner explained to the mother observing the session, that her role was to interact naturally with her child, only when the examiner invited her to (Lord et al., 2002). A child-centred approach was adopted whereby activities were adjusted according to individual needs, encouraging child cooperation and interaction (Lord et al., 2002). Four of the children were easily distracted and struggled to remain seated hence activities such as blowing bubbles were administered while standing. Three children were not compliant and removed toys from the kit box, in this instance the order of activities was changed.



Figure 3. The standardised ADOS Kit.

Since the ADOS is not yet standardised for the African context, a few changes were made to the activities after first administering the instrument to about 50 typically developing 4 to 6-year-old African children, involved in the Asenze study. The Asenze study is an on-going epidemiological study that is being conducted with preschool children in KZN (Uwemedimo et al., 2014). The rationale was first to evaluate whether the activities on the ADOS were appropriate for typically developing Black African children before administering to children with ASD. The ADOS prompts were translated into isiZulu, back-translated to ensure the accuracy of the translated version, and then authorised by the test publishers.

Findings from the Asenze study indicated that typically developing African children were unfamiliar with the Western based ADOS pictures used for discussion. Thus, pictures of ski-boats, tennis courts and golf courses were replaced with scenes depicting African huts, people feeding chickens and milking cows with goats in the background. Another cultural adaptation included exchanging dolls with light complexions for dolls with brown complexions. Since the typically developing African children from the Asenze study were reacted positively to the adaptations, the test publishers gave their permission via the K-ASD Principal Investigators, for adaptations to be made in the ADOS for research purposes.

Although the main purpose of the ADOS was to confirm a diagnosis of ASD, each child's responses to tasks were carefully observed and recorded. In order to meet a diagnostic cut-off, the combination of a child's *Social Interaction* and *Communication* score must be equal or greater than the algorithm score (Lord et al., 2002). Although not included in the criteria

for ASD on the ADOS, the presence of anxiety, over activity, tantrums, aggression, negative or disruptive behaviour and self-injurious behaviour were also coded. Stereotyped behaviours or restricted interests are noted but not scored.

4.5.3. Information from personal school files.

Personal school files were accessed by a clinician and the researcher after concluding parent interviews and finalising the ADOS results. The researcher was aware of the ethical considerations in gaining sensitive, confidential information. Relevant biological, clinical, educational and physical data were extracted from the school files. Of particular interest, were the reports by health professionals and the process through which the child had been diagnosed, before school placement. In some instances, professionals' reports were insightful and assisted clarifying information from parents.

4.6. Data Analysis

Data collection and analysis occurred concurrently (Baxter & Jack, 2008).

- The audio-recordings from the discussions held with parents were transcribed verbatim, as accurately as possible.
- The scores and results from each child's ADOS assessment were tabulated.
- Detailed reports were generated for each of the children. The reports comprised of a thorough background history that was obtained from the parents, along with observations and results from the ADOS assessment. Clinical details, about the birth, age at developmental milestones, early symptoms of ASD, and problematic behaviours, were transferred onto an Excel spreadsheet. The tabulated data was then analysed and interpreted.
- Information from the school files was recorded onto spreadsheets and managed systematically.
- Calculation of the means and standard deviation scores are included in the tables that appear in the Results Chapter to enable the reader to obtain an overall view of the cases and findings from individual cases.

Since thematic analysis is considered a flexible and useful approach for qualitative research, this method was selected to analyse, identify and report patterns in the transcripts, from the discussions held with parents (Braun & Clarke, 2006). The thematic analysis involved reading all of the transcripts to become acquainted and familiarised with each aspect of the data (Braun & Clarke, 2006). After that, initial codes were generated by highlighting

potentially interesting or meaningful parts of the text such as descriptions of the early manifestations of ASD, and experiences of raising a child with ASD using coloured markers. The third phase, according to Braun and Clarke (2006), involved sorting the codes that capture the essence of the text into possible themes. This required the researcher to make careful, intelligent decisions about “what the data was saying” (Rule & John, 2011, p. 77). The next stage involved reviewing the themes by exploring the codes in greater depth and creating themes or sub-themes (Braun & Clarke, 2006). Ongoing analysis and refinement of each theme were completed to define and clearly name the themes (Rule & John, 2011). The last phase of analysis involved identifying the best extracts that related to parental experiences of raising a child of African ancestry with ASD. Finally, the data from all sources were incorporated into the themes during the write-up of results, assisting the author to make sense of the overall case of ASD in a sample of African children (Baxter & Jack, 2008).

4.6.1. Establishing validity and reliability.

Guba (1981) suggests that in qualitative research trustworthiness is an alternative to validity and reliability. He further proposes that trustworthiness can be established by achieving a level of credibility, transferability, dependability, and confirmability (Guba, 1981).

Credibility refers to the extent to which this case study captured the essence of ASD in African children of African ethnicity (Guba, 1981). The researcher aimed to provide enough details about the cases so that readers of this research can assess the validity or credibility of the study (Baxter & Jack, 2008). Credibility was further established by including the researcher’s observations of African children with ASD completing the ADOS.

Triangulation or the use of multiple sources of data was a useful method to establish the credibility of the study.

Since it may be difficult to generalise the findings from six case studies to a larger population, *transferability* was not the purpose of the study (Baxter & Jack, 2008). Instead, Guba (1982) suggests that research should provide thick descriptions of the case and context. Thus, the aim of the study was to achieve a level of transferability by assisting readers to understand the findings and conclusions (Rule & John, 2011).

Dependability considers whether the findings would be similar if repeated (Baxter & Jack, 2008). Guba (1981) argues that dependability is difficult to establish due to case studies

relying on real-life settings. Nevertheless, the co-supervisor of this study challenged assumptions at each stage of the data analysis, thereby adding to the rigour and consistency of the research (Smith & Firth, 2011).

Confirmability involves acknowledgement of the study's limitations and the researcher's influence on the participants input (Rule & John, 2011). While conducting these case studies, greater insight and understanding was gained into African children with ASD. However, there is still a broad range of data that could be interrogated further.

4.7. Additional Ethical Considerations

Ethical considerations in each stage of the research served the purpose of protecting the interests of the children and their parents. As mentioned, the children were vulnerable hence every attempt was made to protect the children by implementing the following measures:

- The children's assessments were administered in a secure, private setting.
- Informed consent was obtained in writing from the parents and written or verbal assent from the child where possible, given the nature of ASD, before the assessment.
- After the researcher's introduction to the child, the researcher obtained verbal assent for the assessment and the video recordings.
- The researcher carefully explained to the parents the option to withdraw at any time by using unsophisticated language and ensured an isiZulu speaking translator was available, should the need arise.
- The provision was made for a participant, to discontinue the process if they felt reluctant or uncomfortable, at any time. If participants chose to withdraw from the study, there would be no adverse consequences.
- Children's assessment forms were kept under lock and key in the supervisor's office, with no information linking the forms to the project itself.
- No identifying information appears in any of the findings or reports.
- All collected data will be kept under lock and key, in the supervisor's office, for the required five-year period. Only the supervisor will have access to the key. Written documents will be shredded, and video data incinerated once the time has elapsed

Chapter 5

Results

5.1. Introduction

This study sought to understand how ASD manifests in a small group of Black African children in KZN. In order to develop this understanding parents of children with ASD were interviewed and the ADOS was administered to the children. Using case study methodology, the objectives of the study were to (i) identify the early features of ASD that African participants detected, (ii) explore the parents' experiences of raising a child with ASD in an African culture, (iii) gain an understanding about the way in which aetiology of ASD is understood, and (iv) gain insight into the way African children respond to the activities on the ADOS.

In presenting the findings from the multiple case studies, Chapter 5 is divided into two sections.

- The first section describes the six cases (see Table 2). A brief overview of the families' demographic information is provided in Table 3 and the discussion offers a general sense of their circumstances.
- The second section identifies the three main themes that emerged. The themes are discussed in relation to the commonalities and differences identified across the six cases (see Figure 1). In this section a discussion of the observations of the ADOS are included in the themes, where relevant.

5.2. Participant Information and Demographics

The demographic details of the participants are provided in Table 2. The families in the study originate from Zulu, Xhosa and Swahili ancestry and all reside in the KwaZulu-Natal Province of South Africa. Two of the participants were married to spouses from different ethnic backgrounds. The parents of the twin boy children, were refugees from central Africa and their sons were conceived shortly after arriving in South Africa. It was only after most of the data had been collected that the researcher realised that the twin boys had never formally been diagnosed, a phenomenon that is not unusual in a resource-scarce country such as South Africa (Elsabbagh et al., 2012).

In five of the six case studies, the parents had been cohabitating for over ten years. Khaya's mother was the only single parent in the study. She had not had contact with Khaya's father for 8 years nor received any financial contributions towards his care. Khaya's mother helped her son in class as a teacher-aid but relied on his disability grant as her only source of income.

The children in this study ranged in age from six to eleven years (see Table 2) and were recruited from five English medium public schools located in urban areas. One of the schools was a remedial school that followed a prescribed curriculum while the other four catered for learners with special education needs (LSEN) from low-and middle-income groups. 83% of participants had obtained their senior certificate (indicating success in their Grade 12 examinations). Neither Siyabonga's father nor the mother of the twin boy children had obtained this level of education. Having successfully completed secondary education, two of the participants had obtained undergraduate degrees, and two more were currently studying part-time towards undergraduate degrees.

The maternal ages at birth, ranged from 20 to 33 years old (see Table 2), whereas paternal ages ranged from 21 to 44 years of age. Siyabonga's father was significantly older at 44 years of age. Themba's mother was currently the sole provider of the family, as although his father was reported as having worked within the legal profession for 17 years, he was currently unemployed due to alcohol addiction. Two of the mothers cared full-time for their children at home.

Four of the seven children were firstborns and none of the children's siblings were reported to present with features of ASD. Six of the children in the study lived in urban areas while Khaya lived in a peri-urban area. Themba and Vuyo's parents had medical aid, which means that they were able to access private medical facilities.

As summarised in Table 3, most of the mothers in the study reported an uncomplicated pregnancy. Five of the children were delivered via emergency caesarian section since two of the children were overdue, and the twin boy children, delivered before 40 weeks, were breech. The average age of walking was estimated to be 13 months. However, toilet training was delayed in about half of the cases and the onset of speech was significantly delayed in six of the seven participating children. In the fraternal twins' case, Bongani presented with

prominent dysmorphic features (i.e., short in stature, short neck, broad nasal bridge and low set small ears). His brother, on the other hand, did not present with any dysmorphic features.

Table 2

Participants' Demographic Details

	Themba	Khaya	Sipho	Vuyo	Bongani + Bafana	Siyabonga	M
Age of Child (Y,M)	10,8	9,6	11,4	6,7	8,1	10,8	9,3
Mother	Xhosa	Zulu	Xhosa	Zulu	Swahili	Zulu	
Father	Zulu	Zulu	Zulu	Zulu	Swahili	Zulu	
Marital Status	Married	Single	Married	Married	Married	Married	
M Education	Nursing Diploma	2 nd Year Technical	Matric	No matric	No Matric	Matric	
F Education	BA Law	Matric	Police college	Matric	B Com	Matric	
M Employment Status	Hospital Director	Unemployed (T/A for son)	Manager	Housewife	Housewife	Teacher Aid	
F Employment Status	Legal profession Unemployed	Manager	Policeman	Manager	Barber	Self-employed	
M Age at Birth	29	26	20	23	24	33	25,6
F Age at Birth	33	31	21	35	32	44	32,6

Note. (Y,M) = year, month; M = Maternal; F = Paternal; T/A = Teacher Aid; Age at birth of child.

Table 3

Birth and Developmental Details

	Themba	Khaya	Sipho	Vuyo	Bongani Twin	Bafana Twin	Siyabonga	M
Pregnancy	No difficulties	No difficulties	No difficulties	No difficulties	Breech	Breech	Stressful pregnancy	-
Birth	NVD Pethidine	C-Section Overdue	NVD Full-term	C-Section Overdue	Emergency C-Section	Emergency C-Section	Emergency C-Section	-
Birth weight	3,5 kg	3,81 kg	3,5 kg	3,2 kg	2,55 kg	2,16 kg	Unknown	-
Walked (Y,M)	1,2	1	0,8	1	1,3	1	1,6	1,2
First words (Y,M)	2	8	8	1,6	Nonverbal	5	8	5,4
Toilet Trained (Y)	5	Unknown	1	3	5	5	3	3,7

Note. Y = year; M = months.

5.3. Introduction to themes

In this section, the focus shifts to the discussion of the themes that were identified in this study. The three main themes and various sub-themes that arose during the data collection and thematic analysis of transcripts are represented in Figure 4. Overall, the main objective was to investigate Black African parents' perceptions and experiences of raising a child with ASD in an African cultural context. This chapter concludes with a brief account of the children's responses to particular ADOS tasks and results of the ADOS. Here the overarching objective was to investigate how Black African children respond to the activities and tasks/presses in the ADOS.

Figure 4. The main themes and sub-themes

Theme 1 The parents' growing realisation and recognition of ASD symptoms	Theme 2 African belief systems that influenced the parents' understanding of ASD	Theme 3 Parents' descriptions of ASD symptoms
<ul style="list-style-type: none"> • Nothing unusual detected during infancy • Recognition of developmental delays • Searching for answers: The journey begins • Encounters with medical and allied facilities • Age of ASD Diagnosis. 	<ul style="list-style-type: none"> • Effects of possible acculturation • Cultural and other beliefs accounting for atypical development • Traditional cultural rituals • Medical and allied help-seeking and intervention 	<ul style="list-style-type: none"> • Insistence on sameness • Sensory input and unusual exploration of objects • Lack of risk awareness: impaired prediction • Hyperactivity and self-injurious behaviours • Problematic behaviour arising in social settings • Judgement from society • Unusual eye contact

Most of the mothers in the sample reported experiencing uneventful pregnancies. Only Siyabonga's mother mentioned having a stressful pregnancy after discovering her husband's affair around one month into her pregnancy. Similarly, the parents indicated that their infants made good progress during their first year of life, and it was only after the first birthday that initial parental concerns, about some aspect of their child's development, arose. Most of the participants recalled first seeking advice from close family members on detecting concerning behaviours in their children. Thus, the first step in the participants' journey towards confirming a diagnosis of ASD, was the recognition of a problem. The first theme considers the participants' growing recognition of symptoms such as delayed speech and language development, along with socialisation difficulties and follows the path towards establishing a diagnosis of ASD. Furthermore, the participants experienced a protracted medical help-

seeking process and consulted several healthcare professionals. When a diagnosis was not forthcoming, most of the parents expressed growing frustrated and two of the mothers resorted to conducting their own investigations, before a diagnosis of ASD was finally confirmed.

In the second theme, African cultural belief systems were found to play a key role in the way that African parents gained an understanding of the atypical behaviours that characterise ASD. According to African cultural understandings, the participants first sought advice from the elders of a community and followed the recommended African cultural interventions such as rituals in an effort to repair their child's difficulties. The discourse from community members, identified in this study, around blame and bad parenting is also discussed. Some parents reported receiving criticism from community members regarding their child's problematic behaviour in social contexts. The final theme investigates the atypical behaviour that was commonly mentioned by the participants, and focuses on the problematic and challenging aspects of raising a child with ASD.

5.4. The journey towards diagnosis: Moving towards the identification of ASD.

Parental recognition of atypical development was found to occur in a progression of stages leading towards the confirmation of ASD (see Figure 5). The first stage represents the phase after birth in which the parents believed that their infants were developing appropriately; the second phase describes the parent's realisation that there was a problem and the final stage discussed the beginning of the parents' journey with the medical processes.

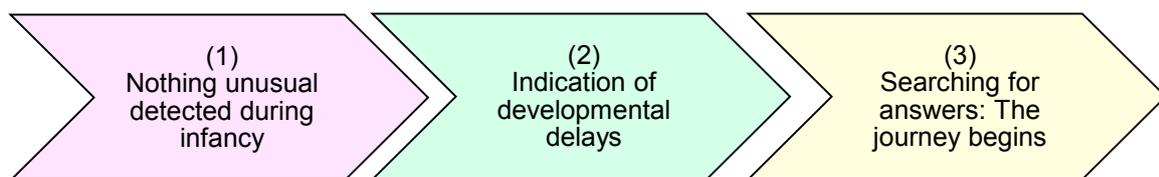


Figure 5. The stages leading up to a diagnosis of ASD.

5.4.1. Nothing unusual detected during infancy.

Overall, parents were found to experience their child's early development as normal, suggesting that they had some knowledge of expected child development patterns. Only the twins' mother expressed being concerned about Bongani's webbed neck (a physical feature, not related to ASD) in the first twelve months. Sipho's mother described her infant as a

“cuddly and happy baby.” All parents, bar the twin’s mother, did not observe anything unusual about their sons’ development during the first two years of life.

When he was a baby he was fine, he was just normal. (Themba’s mother, Interview 1)

We didn’t notice anything and when we did we thought Vuyo was going to come right. (Vuyo’s father, Interview 4)

Siyabonga’s mother’s mentioned feeling confused and surprised, when she noticed her son had problems around 3 years old after appearing to develop appropriately (see Table 4).

Siyabonga was ok before that. I don’t know if something happened along the way? I still don’t know what happened to change him? (Siyabonga’s mother, Interview 7)

Khaya’s mother did not detect anything unusual in the first few years of life. However, with hindsight, she recalled,

Khaya cried and held his hands over his ears when everyone sang Happy Birthday to him at his first birthday. (Interview 10)

It seems for these parents, concerns about atypical development only arose only after their child’s first year of life.

5.4.2. Recognition of developmental delays.

The second stage in Figure 5 arose when many parents mentioned that they had identified concerns about their child’s delayed development.

Delayed onset of speech-language.

The first symptom that was found to concern participants was a delay in speech-language development, ranging from age 18 months until 42 months (M=27 months) of first concern (see Table 4). Bongani and Bafana’s mother grew concerned when her sons could not say, “Mama” when they were 18 months of age.

When my children did not start speaking, I thought that it was my fault because I was speaking Swahili to them at home. I thought that they did not understand me so I started speaking to them in English. (Bongani and Bafana’s mother, Interview 8)

For Khaya's mother, the late onset of speech-language became evident when she compared her son to his peers,

Other children were talking but Khaya was not, so that worried me. (Interview 10)

When Themba was 2 years old, he could not really talk to me, but I could see that other boys his age and younger were talking and doing things that Themba could not do. (Themba's mother, Interview 1)

Sipho's parents were the only participants in the study to report a regression in their son's development,

Sipho was doing well until he started school when he was 2 years old. After he had been at the school for a few weeks, he lost his speech and did not talk. (Sipho's mother, Interview 5)

Two of the children in the study were verbal, at the time of testing, while four remained nonverbal with fewer than ten words in their vocabulary (see Table 5). During the ADOS administration, Bafana was observed to use phrase speech (i.e., the ability to use two to three-word sentences) and he largely communicated in gibberish. Khaya used five different words, and Bongani only squealed. The majority of children in this sample presented with severe speech delays.

Several speech peculiarities, not mentioned by parents, were identified during the ADOS administration. Two of the children were found to speak with accents. Themba spoke with an American accent and used the term "yeah" instead of yes while Sipho spoke with an Indian accent. Since isiZulu or Xhosa are these children's respective first languages, their parents may have overlooked this peculiarity since these accents may appear more pronounced in the English language. Interestingly, during testing Vuyo and Siyabonga combined some isiZulu and English words in sentences such as "funa toy" (want toy).

Table 4

Key Time Points of the Diagnostic Process

	Themba	Khaya	Sipho	Vuyo	Twin Bongani	Twin Bafana	Siyabonga	M
Present Age (Y,M)	10,8	9,6	11,4	6,7	8,1	8,1	10,8	9,3
P/Concern (Month)	24m	42m	24m	27m	18m	18m	36m	27m
Diagnosed By	Assessment Centre	Research Psychiatrist	Assessment Centre	State psychiatrist	Formally undiagnosed	Formally undiagnosed	Private psychologist	
Age of Diagnosis (Y)	6	6	6	5	8	8	7	6,6
Time until Diagnosis	4	2,5	4	2,8	6,5	6,5	4	4,3
Comorbid Diagnosis	-	ADHD	-	ADHD	ADHD	-	ADHD	
School Enrolment	5	8	7	5	8	8	7	6,9

Note: Y,M = year, month; P/concern = First parental concern, Time until diagnosis = From parental first concern until diagnosis.

Echolalia.

Interestingly, the parents who noticed echolalia did not perceive it as a problem. Themba's mother commented,

He repeated what other people said, over and over again. Even though Themba could not talk to me or construct a sentence, he could recite words from an advert on TV, but he could not talk to me. (Themba's mother, Interview 1)

Vuyo's father had considered his son's echolalia positively. He believed that his son was "very good at cramming" (i.e., possessed good memory abilities such as being able to repeat lines from television programmes). Although not described by the other parents, immediate echolalia and repetition of speech were noted in Khaya who frequently imitated the sounds of the toy cell phone and Bafana, who repeated the author's phrases during the ADOS assessment.

Social difficulties.

The second symptom of ASD found to concern participants was a lack of social interaction. The parents in the study were concerned when their child was not interested in playing with other children. Hence, playing alone was perceived to be unusual behaviour. For example,

When Khaya was not playing with other children, I noticed that there was something wrong. He did not even want to play with his cousin who lives in our house. (Khaya's mother, Interview 10)

Siyabonga did not play a lot. He wanted to be alone and play by himself. That's when I thought there may be a problem? Even when children came to visit, he did not want to play with them, he wanted to be alone. (Siyabonga's mother, Interview 7)

Themba's mother remembered feeling embarrassed when visitors arrived and her son hid behind the couch, or would not share his toys. During the ADOS, Vuyo demonstrated reduced engagement when the tester tried to engage him in play and he turned his back on her, preferring to play alone. Vuyo's parents confirmed that he had not played with the other children at preschool. A lack of shared social play is a characteristic often associated with children on the autism spectrum (APA, 2013).

5.4.3. Searching for answers: The journey begins.

The final stage in Figure 5 refers to the time when parents sought guidance about their child's developmental delays. When initial concerns arose, four of the six families sought counsel from close family members, and in return received reassurance. For example, Siphó's maternal grandmother was a nurse and felt that Siphó's regression in speech resulted from him changing schools.

My mother-in-law told me that Themba would grow out of his problems and not to worry. She also said that his Themba's father had taken a long time to talk and was very quiet. His father had not wanted to play with other children when he was young. (Themba's mother, Interview 1)

Themba's mother sought further advice from her colleague,

I suspected something when he was about 2 years old. I spoke to a doctor I know and he said that I was reading too much into this. The doctor said, "You know that boys are lazy and take a long time to do things." (Interview 1)

5.4.4. Encounters with medical and allied facilities.

Interestingly, in four of the six cases, speech delays were identified as the motivating factor for seeking medical advice. The participants' financial resources determined where they went to obtain medical assistance. Those on private medical aids went to private paediatricians while the other families approached local clinics or state hospitals. State hospitals seemed to conduct visual screening tests, speech therapy assessments, O.T assessments, and C.T scans. Every child in the study was assessed audiometrically by speech and language therapists, early in the help-seeking process, before the diagnosis of ASD was confirmed. Thus, speech therapists were found to play a critical role in identifying young children at risk of ASD. A report by a speech and language therapist in Bongani and Bafana's school file noted features of ASD in both of the children.

Confirming a diagnosis of ASD through healthcare professionals in KwaZulu-Natal was reported to be immensely frustrating. Participants consulted several healthcare professionals, even the two parents accessing private medical care, and all parents explained growing

disillusioned and despondent. However, it is often necessary to consult several healthcare professionals to rule out ASD through a process of elimination.

When Siyabonga was 3 years old, I thought that there may be something wrong, so I took him to the clinic. I told the sister that he hadn't said any words yet. She wrote me a letter for the hospital. That hospital sent me to another hospital... The professionals just didn't understand what was going (Siyabonga's mother, Interview 7)

Siyabonga's mother mentioned waiting for up to six months, between consultations in state hospitals. Overall, participants often described feeling confused and helpless during the help-seeking process. Vuyo's father remarked, "Frustration was the main thing" when a diagnosis was not forthcoming. Two of the mothers described taking matters into their own hands and conducting research over the internet to find out what was "wrong" with her son.

Television documentaries featuring children with ASD proved to be particularly insightful for Siphon and Themba's mothers who first learnt about ASD on the Oprah Show.

I only heard about autism for the first time when I saw it on Oprah (Themba's mother, Interview 1)

Nevertheless, both mothers mentioned feeling relieved on discovering that other children presented with similar features to their sons. The new knowledge appeared to empower and motivate these mothers to pursue a diagnosis of ASD for their child. Hence, television documentaries played an important role in educating and normalising the symptoms of ASD for these mothers.

5.4.5. Age at diagnosis of ASD.

Although the parents' first concern arose at an average of 27 months, the mean age at diagnosis was calculated to be 6 years 6 months of age (see Table 4). Therefore, parents waited an average of 4 years 5 months for a diagnosis of ASD to be confirmed. In hindsight, the age of the child, at first contact with a healthcare professional would have been useful to obtain since this may have shed light on the length of the medical process.

The participants felt that they had received little feedback, psychoeducation, advice, or support from healthcare professionals at the time of diagnosis. In addition, Vuyo's father mentioned his son not receiving a diagnosis of ASD. However, a report in Vuyo's personal school file from a state psychiatrist, confirmed the diagnosis of pervasive developmental disorder- not otherwise specified (PDD-NOS). It seems that Vuyo's parents had received little information about their son's diagnosis. Furthermore, only the two mothers who had viewed the television documentary had heard of the term autism before a diagnosis was confirmed. Additionally, participants mentioned that they felt to blame for their child's disorder, suggesting that health professionals had not explained the aetiology of ASD at diagnosis.

I had never heard of autism before (the diagnosis) and I still didn't know what it is.
(Khaya's mother, Interview 10)

In conclusion, the first theme indicates that the participants detected the core symptoms of ASD and were concerned about their child's delayed speech development and limited social interaction. Nevertheless, it became clear over the course of interviews that each family had experienced disappointment, heartache, and hardship along the way to establishing a diagnosis of ASD for their children.

5.5. Cultural Influences

Traditional African beliefs were seen to influence the participants' understandings of ASD and the choice of interventions. Important aspects that arose and seemed to influence the participants' belief systems are depicted in Figure 6. The participants' traditional cultural views may have been influenced by formal education and growing more modernised when living in urban areas. Thus, the influence of Western beliefs may have resulted in several participants expressing that they had grown relatively detached from their traditional beliefs before the birth of their child. In fact, two of the fathers referred to having "modern" views towards child rearing, compared to their parents' generation, and described a more child-centred, less authoritarian approach to raising a child. However, when participants realised that their child was not following a typical developmental path, several parents mentioned seeking advice from the elders in a community.

5.5.1. Effects of possible acculturation.

Although several parents expressed that they were sceptical about the healing ability of rituals, the majority of participants described feeling distraught about their child and attempting traditional African interventions. In retrospect, several parents recalled feeling pressurised by the elders to perform traditional rituals. It seems that the participants followed a natural process of implementing the advice from people that they respected and trusted in the hope that the recommendations would benefit their child.

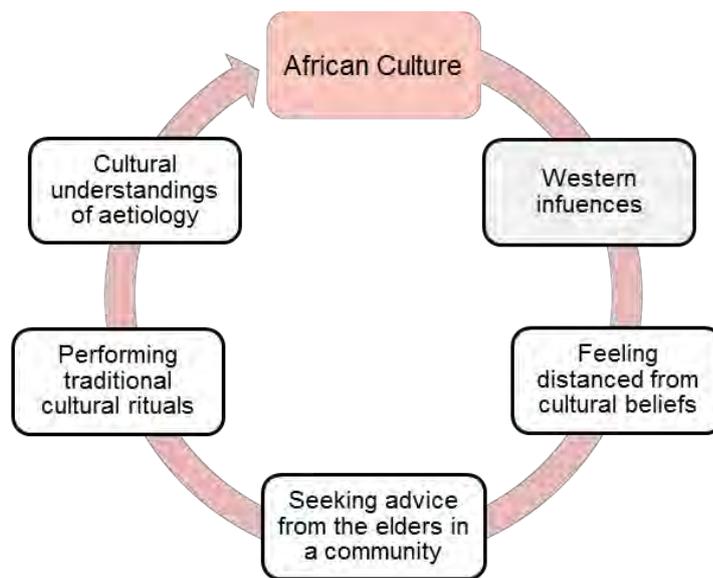


Figure 6. The overarching importance of African culture.

Observations from the ADOS administration revealed that the majority of children in this sample had severe deficits in verbal and nonverbal social communication skills (see Table 5). The children rarely initiated social interactions, unless it was to meet their own need. Similarly, Themba was the only child who made eye contact with his mother during the assessment in order to share interest in an object.

All three fathers described feeling eager to develop close relationships with their sons. The desire to be involved in child rearing seemed to stem partly from not having an opportunity to enjoy close relationships with their own fathers, and also from a belief that children raised by supportive fathers are more successful. Vuyo's father reasoned,

We need to come closer to our children if we want to see them getting somewhere
(Interview 4)

Sipho's father was afraid of not being involved in his child's life for the following reason:

When we were growing up, my parents believed in the saying children must be seen and not heard. This was the reason that my mother did not notice my younger brother was not talking or playing with others when he was growing up. (Sipho's father, Interview 6)

Nevertheless, when the children were around 3 years old, the fathers described feeling disappointed in their sons and blamed themselves for failing in their parenting role.

I even find it difficult to relate to him because he answers with a yes or no. Even if you ask him about school, he can't tell you what's going on. So you basically end up not knowing what's going on. (Themba's father, Interview 3)

It is suggested that the children's communication difficulties and inability to engage with others resulted in fathers feeling distanced or even rejected. It is possible that difficulties relating to their children made the fathers feel that they had not been able to develop close relationships and that the fathers had failed.

5.5.2. Cultural and other beliefs accounting for atypical development.

The elders in a community were found to play an advisory role to the participants. Thus, the elders interpreted a child's problems, based on traditional African understandings that the parents had done something to anger or upset ancestral spirits. For example, not introducing a child to ancestral spirits during the amagobongo ritual. Since several participants expressed feeling relatively detached from their traditional beliefs most of the children were reported not to have undergone the prescribed ceremony. A variety of opinions were expressed about the importance of performing traditional rituals. For example, Themba and Sipho's mothers, of Xhosa ancestry, doubted the healing ability of their husbands' Zulu rituals. Nevertheless, both mothers were willing for their child to participate. Siyabonga's mother, of Zulu ancestry, encouraged her son to participate in a ritual.

Its culture, we needed to do the ritual because we had a problem with our son, and we did not know if his problems came from not introducing him to the ancestors. (Siyabonga's mother, Interview 7)

In contrast, Vuyo's father felt pressurised to try cultural rituals and feared being ostracised by the community.

The community puts you in a corner in such a way that you don't have a choice, you have to try all these traditional things. (Vuyo's father, Interview 4)

Khaya's mother was the only parent to consult with a traditional healer. However, she was traumatised when a sum of R3000 was demanded in exchange for resolving her son's problems. In four of the six cases, traditional African rituals were followed before seeking medical intervention.

5.5.3. Traditional cultural rituals.

A variety of explanations were provided to account for their sons' ASD. In four of the children, autism was seen to originate from failing to perform a ritual to introduce their child to ancestral spirits. Other reasons included (i) high maternal stress during pregnancy brought on by a husband's extramarital affair, (ii) the administration of pethidine during labour, (iii) intrauterine foetal trauma, (iv) marrying someone from another African tribe, and (v) not paying "initiating fees" (pre-dowry fees) before marriage.

Interestingly, none of the parents raised the possible link between their child's difficulties and possible hereditary factors. In fact, it was only after the researcher specifically enquired about speech, language or developmental delays among family members, that several participants identified relatives with similar features. For example, Themba's father identified his nephew who only started speaking when he was 6 years old while Siphos father mentioned,

Sipho is exactly the same as my younger brother who only spoke when he was 5 years-old. My brother was a loner who did not have friends. (Interview 6)

5.5.4. Medical and allied help-seeking and intervention.

Seeking medical advice was found to be delayed in this study. Some parents believed that a child's difficulties would resolve over time while others first attempted traditional interventions.

At 2 and-a-half years, Vuyo hadn't started speaking, but we were not worried. The child was going to come right, and I went as far as doing all this traditional stuff. (Vuyo's father, Interview 4)

At the age of 4, Khaya was not playing with other children.

I noticed that there was something wrong but I didn't take action; I just thought it would be ok. (Interview 10)

Vuyo's father further expressed a belief that the ancestral spirits were in control of his son's problems hence nothing could be done.

Vuyo's problems were not in our hands. We had to wait there was nothing we could do as it was in the ancestors' hands. (Vuyo's father, Interview 4)

5.6. Characteristics of ASD Described By The Participants And/Or ADOS

Observations.

In addition to the first symptoms that concerned the participants (described in 5.3.1), they also described a wide variety of problematic behaviours that were especially challenging to manage. Even in the most resourced parts of the world, when a child's development does not seem to be following a normative pattern, parents do not usually start thinking of a disorder, rather they are largely unaware that the atypical behaviours could be associated with ASD (Matson & Goldin, 2014). Furthermore, one of the behaviours (impaired prediction) initially identified by the participants, is not included in the DSM-5 diagnostic criteria but is frequently reported in children with ASD (Wing et al., 2011).

Since the first edition of the ADOS assessment was developed using DSM-IV-TR (APA, 2000) criteria, some symptoms will be mentioned in relation to this edition, while other symptoms will be referred to using the DSM-5 (APA, 2013) publication. Of the five behaviours appearing in Figure 7, only abnormal eye contact was not mentioned by parents but it was observed during the administration of the ADOS. The participants identified two symptoms of ASD that fall under the DSM-5 diagnostic criterion of restricted, repetitive patterns of behaviour or activities. The insistence of sameness was raised by five of the seven parents. In particular, children were reported to be extremely selective about their choice of food, and often non-negotiable about specific preferences. The second symptom was hyper-or hyporeactivity to sensory input. According to participants, some children

explored objects using smell and touch and/or were unusually sensitive to certain sounds, tastes and textures.

The third behaviour, impaired prediction, is excluded in both the DSM-IV-TR and DSM-5. However, prominent researchers in the field of autism believe it to be a significant feature of ASD (Wing et al., 2011). The fourth symptom discussed is Attention Deficit Hyperactivity Disorder (ADHD), which commonly occurs in 30% – 60% of children with ASD (Wilkinson, 2014). However, ADHD is not considered a symptom of ASD (Bacalman et al., 2009). Four of the children in the sample had their diagnoses of ADHD confirmed by medical practitioners (see Table 3). The last characteristic, the occurrence of abnormal eye contact, is a criterion for ASD under deficits in nonverbal social communication domain in the DSM-5 (APA, 2013). The presence of unusual eye contact was observed during the ADOS assessments but was not raised by the parents. At the conclusion of this theme, a brief summary of the results from the ADOS, and some of the children's responses to activities are included.

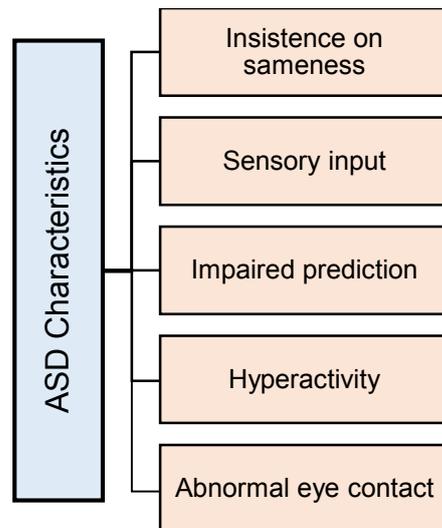


Figure 7. Identified characteristics of children with ASD.

5.6.1. Insistence on sameness.

The ASD-related behaviours of the insistence on sameness and inflexibility of routines were raised by parents and confirmed by observations of the children. The participants described their children's strict adherence to routines, even if these seemed to serve no purpose. For

example, Themba insisted on his mother travelling the same route every day. All participants remarked on their child repeatedly watching the same programme on television.

Siyabonga plays the Spiderman DVD the whole day, over and over again (Siyabonga's mother, Interview 7)

If Siphos was not in bed by 7 o'clock, all hell broke loose and he would fly into a rage (Siphos's mother, Interview 6).

Mealtimes were found to be particularly frustrating and exhausting for participants. The general consensus was that their children were extremely "fussy eaters."⁵

Siphos was exclusively breastfed until 3 years old because he refused to eat solids. When he started eating custard, porridge, and oranges, he would not eat anything else! (Siphos's mother, Interview 6).

The children were reported to present with an array of food selectivity.

Siphos chooses the kind of food that he eats. He doesn't eat any food with colour so he won't eat food that is green in colour, he never liked food that is red in colour but now that he is 11 years old, he has started warming up to red food (Siphos's mother, Interview 5)

While Themba reportedly ate only liquidised food until he was 5 years old, Vuyo enjoyed eating entire lemons, including the skin, and Bongani refused to eat curry and rice if they touched on a plate. When a child's food preference was not offered, the child would apparently resort to a tantrum. Thus, a child's food selectivity was found to be particularly problematic to manage.

Khaya hits the side of his legs with his hands and takes his pants off. Sometimes he tries to hit me with his head and other times he lies down and carries on screaming and hitting his legs. (Khaya's mother, Interview 10)

⁵ Fussy eating can be regarded as a feature of sensory defensiveness associated with ASD but is described in the DSM-5 as "eating the same food every day" under the insistence on sameness.

A general trend among children during the administration of the ADOS was a difficulty in transitioning from one activity to another. For example, four of the children tended to become attached to certain toys, hence redirecting their attention to the next activity became very challenging. In particular, children were attracted to the musical toys, which needed to be removed before transitioning to the next task. The resistance to change is also a feature of insistence on sameness (Sevin, Rieske, & Matson, 2015).

5.6.2. Sensory input and unusual exploration of objects using the senses.

Several participants described their child's sensitivity to certain sounds, a behaviour which was generally regarded as most unusual and had led to them feeling greatly concerned. As with many children with ASD, the children would hold their hands over their ears when there was a loud noise and at times react as if afraid (Matson & Goldin, 2014).

He will hold his ears if someone starts screaming (Siyabonga's mother, Interview 7)

According to his parents' Vuyo reacted in this manner when he heard thunder. Similarly, he seemed to be especially sensitive to low -frequency sounds during the ADOS. Vuyo was observed holding his hands over his ears when he heard the barely audible sound of the bubble machine. Auditory defensiveness created difficulties for some of the children. Being shouted at, was likely to create distress and the child was unlikely to interpret being shouted at as a reprimand to alter behaviour. This created difficulties if teachers shouted at the children.

Once you raise your voice, he won't be able to do anything. (Sipho's mother, Interview 5).

The participants also described how their children took an unusual sensory interest in certain things. For example, Sipho's mother was distressed when her child started to sniff food before eating and sniff various other objects. Resistance to certain textures was seen when Vuyo refused to wear certain items of clothing.

Observations from the ADOS confirmed that five of the children presented with unusual interests in sensory aspects of their environment. The children were observed to overly smell or touch objects by (i) rubbing a toy against their cheek or lips, (ii) smelling a candle and sponge, and (iii) using their cheek to pop bubbles. Additionally, Vuyo physically jumped

away from the examiner's touch and appeared tactile defensive, confirming what his parents had mentioned.

5.6.3. Lack of risk awareness: Impaired prediction.

Relying on public transport such as taxis was reported to be particularly stressful, especially with children who were more hyperactive, and thus more unpredictable.

Khaya didn't want to go in a taxi. I had to hold him tight all the time. If I let him go, he would run away when the taxi stopped. (Khaya's mother, Interview 10)

Siyabonga was fearless and was not scared of anything. He wasn't even scared of anything dangerous! He just went and touched things if you were not near him. I am afraid that he will get hurt. (Siyabonga's mother, Interview 7)

Similarly, Khaya's mother thought her son had, "no sense of danger" after he was knocked over by a car at 8 years of age when he ran into the road. Fortunately, he was not injured. The participants were particularly distressed about managing a child who seemed fearless and unpredictable. Observations of parent-child interaction confirmed this as the parents were generally hypervigilant, continually checking on their child's safety. Themba's mother was the only parent who was not continually observant of his behaviour. He had a younger sister whom his mother relied on to watch over him. His sister was present at the sessions and they sister played well together. Themba was generally a very well behaved and compliant child.

5.6.4. Hyperactivity and self-injurious behaviours.

Four of the children in the study had been diagnosed with ADHD (see Table 4). This added a layer of complexity to managing their children. Siyabonga's mother aptly summed up her son's hyperactive behaviour:

Siyabonga didn't want to sit down. He wanted to be all over the place! When you stopped him doing one thing, he started doing something else! (Interview 7)

Both Siyabonga and Vuyo's parents had noticed an improvement in their sons' behaviour after being prescribed methylphenidates. The antipsychotic medication that had been prescribed for Khaya's hyperactivity and Bongani's self-injurious head banging behaviour

were not considered by their mothers to have had the desired effect or led to any improvements.

During the administration of the ADOS, Khaya and Bafana's hyperactive behaviours were difficult to manage as they frequently left their chairs and attempted to remove toys from the storage box. Bongani and Vuyo were particularly difficult to engage in activities. Similarly, the participants reported that ADHD symptoms were particularly challenging to manage in the home context.

5.6.5. Problematic behaviour arising in social settings.

In five of the six mothers, regular church attendance was important. However, their child's worst behaviour, such as tantrums, tended to occur during the services. Although participants may have been more aware of their child's behaviour during formal social situations, trying to manage a child's dysregulated behaviour was highly stressful and significantly contributed to Themba's mother feeling that she was being judged as a 'bad mother'. Several mothers described feeling especially exasperated and socially judged at church.

Themba would start crying and rolling around in church. I could not contain him. If I went outside, he would start to calm down (Themba's mother, Interview 1).

When Siyabonga was 3 years old, he screamed in church when the people started singing. I sat at the back so when he started screaming, I could take him out so it wouldn't disturb the church. When he had settled down, I could go back in ... Other people said to me, he does not look like he has a problem (Siyabonga's mother, Interview 7).

It is a problem taking Vuyo to church as he walks in and out. The pastors are beginning to understand but, no (pause) the problem is the congregation they don't understand (Vuyo's father, Interview 4).

Church members apparently commented on the children's "bad behaviour" that was perceived to stem from the parents' lack of discipline. Although a church environment is considered a place where there is acceptance of others, a lack of tolerance and understanding by members of the congregation was reported and this left participants feeling more isolated and unable to access support even through their spiritual beliefs. Children with ASD may not have physical markers of disability such as children with Down syndrome (Wilkinson, 2014).

Thus, members of the public seemed to expect children with ASD to behave like typically developing children. The participants were deeply hurt and ashamed that others believed their child was undisciplined and that they had failed as parents.

5.6.6. Judgement from society.

Following on from the issue above of the child appearing to be a typically developed child, raising a child with ASD was enormously challenging for these participants. Overall, participants felt that community members and the general public lacked knowledge of the symptoms of ASD and had little understanding of what it was like to cope with a child on the spectrum.

You would hear people in shopping centres say, Ooh if that was my child I would just smack him. (Sipho's mother, Interview 6).

Comments from the community members resulted in parents feeling that they were "not disciplining," or "not smacking or hitting" their child enough. The parents experienced discourses of blame that resulted in many parents feeling that they were incompetent as parents. Some parents admitted to using more and more forceful discipline even though they were aware that the usual disciplinary techniques were ineffective with their children. The lack of tolerance and understanding expressed towards children with ASD, seemed particularly hurtful and participants possibly felt stigmatized.

When they see the child, they look at the parent and think, Ok, so there's no discipline here, the child is not disciplined. It was like a learning curve all the time ... Frustration was the main thing. Even now, people do not know what we are going through (Vuyo's Father, Interview 2)

Outings with a child who lacks an understanding of social norms was especially difficult and presented enormous challenges for participants.

I took Khaya (6 years old) to KFC. He just went up to a woman who was eating her meal at a table and took a piece of chicken off her plate, and started eating it! I didn't want to take him out with me again after that I was so ashamed (Khaya's mother, Interview 10).

Several participants reported that it was easier to stay at home while others introduced increased discipline measures.

I beat Themba a lot as I was trying to be this good mom who was disciplining my child. (Themba's mother, Interview 1).

One set of parents, thought that their child was defiant and obstinate when he refused to talk,

We thought Vuyo was the problem, so we stopped talking to him, and we used to smack him a lot every time he didn't talk, we used to smack him. (Vuyo's father, Interview 2).

In hindsight, these participants regretted punishing their children.

No amount of discipline would have helped! (Themba's mother, Interview 1)

Society's expectations of children's obedience meant that the participants believed they had failed in their role as parents. While the general public in KZN may be relatively uninformed about the symptoms of ASD, the discourse around obedience of children seemed to influence the parents in believing that they had not disciplined their child enough.

You feel angry because people don't understand what's going. I wish the community could be taught how to respond to children with autism. (Vuyo's father, Interview 2)

Interestingly, both Vuyo and Siphos fathers highlighted the need for society to become more informed about ASD in order to understand and tolerate the behaviour of children on the autism spectrum.

5.6.7. Unusual eye contact.

Although poor eye contact was not mentioned by participants, three of the children presented with a fixed gaze and did not make use of eye contact to communicate social intent during the ADOS. Siphos had little-sustained eye contact, but curiously glanced at the examiner while her head was bowed. This averting of his eyes could have been interpreted as the culturally prescribed method of demonstrating respect towards an adult.

In summary, managing problematic behaviours associated with ASD appeared to be exceptionally challenging and stressful for the participants. In particular, ADHD symptoms, unpredictable patterns of behaviour, as well as feeding difficulties were found to be the most problematic characteristics of ASD. An indirect effect of some features of the child's atypical behaviours was social judgement. This led to the parents believing that they were 'bad parents' who could not discipline their own children effectively. In addition, the perceived

social ostracism, led to some parents trying harder to enforce rules by being more punitive or by withdrawing attention. A further indirect effect was that the participants found it more difficult to access social and spiritual support as they were deemed to have naughty children.

5.7. Further Results and Observations from the ADOS Assessment.

There were several reasons for administering the ADOS in this study (i) to investigate whether the ADOS algorithms would confirm a child's diagnosis of ASD; (ii) the observation of the child enabled the researcher to contextualise information obtained from the parent interviews and other collateral sources; and (iii) to investigate how African children responded to tasks or presses on an instrument designed and tested in the US and UK. The inclusion of the ADOS provided a valuable opportunity to evaluate and examine behaviour and responses to individual tasks and note behaviour not mentioned by the parents. For example, none of the parents mentioned hand flapping in their children, a feature that was observed in Khaya, Vuyo and Bafana.

Overall, the birthday party activity in the ADOS received the most favourable reactions. Children were noted to spontaneously engage during the administration in this social routine. (i) Khaya danced when Happy Birthday was sung and spontaneously shouted, "Hooray, hip-hip-hooray," (ii) Vuyo imitated lighting the candles and cutting the Play-doh birthday cake, (iii) Bafana spontaneously pretended to blow out the candles and sang Happy Birthday, (iv) Siyabonga instinctively placed the candles on the Play-doh cake, and (v) 11-year-old Siphon intrigued by the doll that is introduced as part of the activity. Both Siphon and Khaya flicked the doll's eyelids, an action that is recorded and coded on the ADOS, as repetitive interests or stereotyped behaviour.

The bubble activity generally received positive responses. Only Khaya was noted to be initially anxious but the other children were delighted on seeing the bubbles. The balloon task was also well received even though the majority of the children were noted to respond by holding both their hands over their ears while the balloon was being inflated. Similarly, the parents mentioned this type of behaviour in relation to their child's auditory sensitivity.

In contrast, the introduction of the plastic frog in tasks was not well received. Vuyo jumped off his chair in fright when the frog was introduced while other children appeared fearful and apprehensive. The frog may not be appropriate to include in the ADOS with African children

due to the fear it invoked in many of the children. In contrast, the white toy rabbit received little attention with four of five children, ignoring its appearance and seemed unfamiliar with this type of animal.

During the ADOS snack activity, the children did not request more juice or food. It is unknown whether African children are not socialised to request more food or whether the children did not like the food offered to them. Two of the children referred to “Colgate” instead of toothpaste during the demonstration activity, a phenomenon frequently encountered in African people. During this demonstration activity, most children were unable to integrate verbalisations with gestures, electing to do one or the other, often depending on their level of verbal acuity.

The children who were administered the *functional and symbolic imitation* task (in Module 1), displayed some features of creative or imaginative play but seemed surprised when an adult participated in play with them. It may be that these children were unfamiliar with adults engaging them in play with toys.

The results from the ADOS assessment appear in Table 5. The play, imagination/creativity and stereotyped behaviour/restricted interest domains are scored but are not included in the final score (Lord, 2008). On the communication domain, all of the children achieved a score equal or above the ADOS autism cut-off of four. All children also exceeded the cut-off score of seven for autism on the reciprocal social interaction domain. The results from the combination of the communication and reciprocal social interaction domains indicated that all children scored above 12, which is the ADOS cut-off for autism. Each of the children’s three domain scores meets an ADOS classification of autism. These scores serve to confirm their inclusion in the study.

ADOS Results

	Themba	Khaya	Sipho	Vuyo	Bongani	Bafana	Siyabonga
Age	10y 8m	9y 6m	11y 4m	6y 7m	8y 1m	8y 1m	10y 8m
Verbal ability	Verbal	Non-verbal	Verbal	Non-verbal	Non-verbal	Phrase speech	Phrase speech
Module	3	1	2	1	1	1	2
Communication	4	9	6	4	4	8	4
Reciprocal Social Interaction	10	13	10	13	14	14	12
*Communication Social Interaction	14	22	16	17	18	22	17
Play	-	3	-	3	4	3	-
Imagination / Creativity	1	-	1	-	-	-	2
Stereotyped behavior Restricted Interests	0	5	3	0	3	1	2

Note. *= ADOS autism cut-off is 12, and the autism spectrum cut off is 7. Phrase speech = Verbal expression largely consists of echolalia or three-word phrases

Overall, the ADOS was a valuable instrument with which to observe behaviours associated with ASD. Although the activities in Module 1 are developed for young children over the age of 30 months, due to the significant speech delays (see Table 5), several children were administered Module 1. Nonetheless, the children responded with appropriate interest to most of the toys and activities that were intended for younger children. Furthermore, the ADOS confirmed a diagnosis of ASD in all of the children.

Chapter 6

Discussion

The main findings in the previous chapter were informed by six cases each comprised of African parent/s raising a child with ASD in the South African context. The clinical observations and results of the seven African children (the twin boy children were combined into one case) who completed the ADOS assessment were included in the findings along with relevant information from personal school files. After comparing this small sample with KZN demographics, this discussion chapter is organised according to the main research questions and then compared to the available literature when seeking consensus with the existing findings or differences encountered in this sample.

The participants described their experiences of raising a child with ASD as fluctuating over the course of time, almost like being on a roller coast ride in which many challenges emerged with little support or understanding from others. Each family had faced immense hardships and heartache, and their lives had been dramatically impacted by living with a child diagnosed with ASD. While some participants hoped to share their experiences so that other South African parents in similar circumstances may benefit, most participants expressed sheer relief at finally being able to share their stories, hopes, and fears with researchers' familiar with this disorder.

6.1. Identifying the Early Manifestations of ASD

The majority of participants proudly described their child's development during infancy as following a typical pattern with nothing abnormal being detected, before the gradual awareness of a developmental delay (with speech delay and difficulties with peer group interaction being the two major delays initially identified by the participants). This is consistent with the literature that describes parents having believed that their child was developing well, and then experiencing difficulty establishing the exact cause of their child's difficulties before the age of two years (Matson & Goldin, 2014). Similar to parents globally, these participants found that the emergence and recognition of a child's symptoms of ASD occurred in stages (Jones, Gliga, Bedford, Charman, & Johnson, 2014; Matson & Jang, 2014).

The thought that their child was not developing typically was reported to be exceptionally confusing and distressing for the participants in this study. As little is known about ASD, in KZN, the participants did not associate the patterns of atypical behaviour or “something was not quite right,” with ASD (Matson & Goldin, 2014).

Other studies concur that an early indication for parents that their child was not developing typically occurred when parents compared their child to typically developing peers (Turygin et al., 2014), whose abilities were developing at a faster or more typical rate (Matson & Jang, 2014). Furthermore, the finding that African parents turned to close family members or friends for advice, when concerns first arose, is also consistent with the literature (Tway, Connolly, & Novak, 2007).

A child’s delayed or lack of speech development was reported to be particularly distressing for these participants and was found to be the first symptom to concern parents. Likewise, parents worldwide first detect limited communication skills in young children with ASD (Hess & Landa, 2012; Kozlowski et al., 2011; Turygin et al., 2014). Developmental milestones related to speech are especially difficult to define, so it is not unusual for parents and professionals to know when to become concerned, and when to believe that their child’s speech will improve over time (Wallace, Berkman, Watson, Coyne-Beasley, Wood, Cullen, & Lohr, 2015). A recent systematic review has argued the benefits and difficulties of screening for speech delays in children under five years of age (Wallace et al., 2015).

Several studies in the US, have reported the average age of first parental concern to arise at 24 months (CDC, 2012; Landa, 2008; Zwaigenbaum et al., 2009). According to this study, the average age of first parental concern (27 months) was estimated to occur three months later than parents in the US. Of course, the small sample size decreases the value of mean estimates but suggests a greater tolerance towards delayed speech acquisition. There are several potential reasons that could account for or refute this pattern: (i) Western countries are receiving greater media attention about ASD in recent years due to concerns over the rising prevalence of the disorder (Elsabbagh et al., 2012). Thus, increased awareness and understanding of autism, by the general public may account for the earlier recognition of ASD symptoms by parents (Jang et al., 2014). (ii) On the other hand, one might argue that the higher level of education in these participants may mean they were able to recognise concerning symptoms relatively earlier due to an increased awareness of developmental delays in early childhood (Moh & Magati, 2012; Springer et al., 2013). (iii) Another

potential reason for an earlier age of parental concern is that six of the seven children in the sample were considered to have more severe forms of autism, which is easier to detect, although this is also associated with a poor prognosis (Matson & Goldin, 2014). Finally, it is interesting to note that the literature suggests that there is little racial or ethnic difference regarding when parents first become concerned about their child's atypical development (Jang et al., 2014).

A regression of language and social skills at 24 months was reported in one child in this study. Research in Western countries predicts that approximately 25% of children diagnosed with ASD regress around the second year of life, after apparently developing normally (Bölte et al., 2013; Landa, 2008; Lord & Bishop, 2010; Zwaigenbaum et al., 2009). Thus, the age of regression reported by the participant in this study is consistent. Of concern, was the finding that two of the parents reported significantly later times, 36 and 42 months of age, at first concern. This can partially be attributed to the fact that they had been reassured by family members that there was nothing to worry about in relation to the delayed speech development.

The second area of concern for the participants was a lack of social interaction. In particular, a child playing alone in the company of other children alerted the participants to their child's atypical development. In contrast, parents from Western cultures tend to overlook difficulties in peer group interaction in young children (Mandell & Novak, 2005). In fact, parents in the US are unlikely to raise concerns about social functioning before 36 months of age (Hess & Landa, 2012). Children in Western countries are more likely to be raised in nuclear family units, resulting in reduced contact with other young children before attending preschool (Ghaziuddin, 2010). However, children raised in African cultures tend to have more exposure to other children, even during infancy, leading to parental recognition of concerning features related to socialisation (Daley, 2004).

Despite this study's exploratory nature and small sample size, the type of first concerns noticed by these African parents may offer insight into the issues that are likely to be raised in consultations with health professionals. Furthermore, the fact that these parents identified core features of this developmental disorder suggests that the core symptoms of ASD present similarly across cultures (Matson et al., 2012).

6.2. African Parents' Experiences of Raising a Child with ASD in the KZN Context

6.2.1. Moving towards a diagnosis of ASD.

Undoubtedly, the journey towards confirming a diagnosis of ASD was viewed by participants to be emotionally exhausting, traumatic, and frustrating. Similarly, the literature reports the time leading up to a diagnosis of ASD to be one of the most emotionally distressing aspects for parents of children with ASD (Moh & Magiati, 2012). Participants accessing state medical care mentioned experiencing lengthy waiting periods between healthcare professionals while all participants in this study consulted several professionals (on average four and a half practitioners) before confirming a diagnosis of ASD. Matson and Goldin (2014) also found delays in reaching a diagnosis, resulting in an advanced age of diagnosis. Delays in diagnosis place incredible stress on parents (Matson & Goldin, 2014).

In this study, none of the children was diagnosed with ASD on first contact with a medical practitioner. Speech and language therapists were found to have early contact with every child in the sample. Speech and language therapists play a fundamental role in the early investigation of children at risk for ASD. Auditory assessment is a pre-requisite before a diagnosis of ASD can be made (DSM-IV TR, APA, 2000). However, delays in diagnosis have been attributed to healthcare professionals failing to recognise the early signs of autism as well as not conducting routine screening tests (Self et al., 2015). In this study the diagnostic confirmation was made later by paediatricians, psychologists and psychiatrists, who often worked with university-based clinics, in academia. Speech and language therapists play a critical role and are clearly part of an appropriate multi-disciplinary team when working with children at risk of ASD.

Although Western countries have created an awareness of ASD among parents and professionals through increased media attention (Lord & Bishop, 2010; Reaven et al., 2008), public awareness of ASD has been reported to be low in South Africa (Bakare & Munir, 2011a). Evidence from this study highlighted the significant role that popular media played in informing and educating parents of African ethnicity about ASD. Television documentaries proved to be most effective. Another KZN study also found that African parents of children with ASD gained knowledge and awareness of autism through magazines and television documentaries (Madlala, 2012). Likewise, popular media is proposed to be a powerful medium through which to raise awareness of autism in South Africa (Chaggan,

Karim, & Wallace, 2012). Given the lifelong nature of this neurodevelopmental disorder, an increased knowledge of early warning signs often referred to as the ‘red flags’ may help to improve early identification of children at risk of ASD (Springer et al., 2013).

In summary, these findings suggest that the general public in KZN was generally unaware of the symptoms that characterise ASD. Also, delays in seeking advice from healthcare professionals seemed to arise from traditional African beliefs about mental health disorders, as well as the implementation of cultural rituals before seeking medical advice. Elders of communities are well-placed to assist parents in KZN to identify early warning signs of ASD and assist in finding appropriate channels through which to seek support.

6.2.2. Confirming a diagnosis of ASD.

The CDC (2012) aims for children to have an accurate diagnosis of ASD by 3 years of age, even though the average age at diagnosis in the US is about 4 years of age. This study revealed that the average age of diagnosis was 6 years 6 months. In contrast, a recent study in the Western Province of South Africa, by Springer et al. (2013) reported the age at diagnosis to be 3 years 5 months, highlighting a large age disparity between the two studies. An explanation may be that significant health inequalities are present across all provinces, with marked variation in access to healthcare that may contribute to a late diagnosis of ASD (Elsabbagh et al., 2012). Additionally, the Western province study was conducted in a hospital setting and children may have had access to practitioners with a greater knowledge of ASD, as these are often associated with medical training facilities.

A recent Gauteng study has reported the age of ASD diagnosis to be 6 years 4 months (Van Biljon et al., 2015). Thus, children in the present study were found to be only two months older at diagnosis. However, both studies reveal a marked delay in diagnoses. Matson and Goldin (2014) found the long periods between initial concerns and a diagnosis of ASD to be related to significant parental stress, feelings of confusion and helplessness; and Guinchat et al. (2012) attributed the delay to high levels of dissatisfaction with medical services.

One of the consequences of a delayed diagnosis was that children did not have an opportunity to start school at a young age. After a few months of school entry, participants noticed a significant improvement in their children’s speech and language, even when a child first entered school older than 6 years of age. Therefore, early school entry was seen to positively

impact a child's speech and language, but in case 'better late than never' pays off. A Gauteng study proposes that a mother's low educational level was associated with a child entering school at an older age (Van Biljon et al., 2015). In contrast, this study found little association between the mother's levels of education and their children's age of school entry. A possible explanation is that it was more difficult for parents to find a school placement in KZN due to limited LSEN facilities. South Africa has only nine public schools that are dedicated to children with ASD hence an estimated 135, 000 children with autism are not receiving the necessary specialised education they require (Bateman, 2013).

This study also confirmed the lack of knowledge about ASD amongst the general public in KZN, with the participants only becoming aware of autism after their child's diagnosis. Madlala (2012) also found in her study that African parents in KZN were unfamiliar ASD before hearing their child's diagnosis. Both this study and Madlala's (2012) study found that participants were frustrated by the lack of information and guidance provided by healthcare professionals in KZN, during the diagnostic process (Madlala, 2012). Moh and Magiati (2012) reported that parents value knowledge about ASD especially at the time of diagnosis, as the information helps them to make sense of the disorder and feel more satisfied when they are given an opportunity to ask questions. Many practitioners refer parents to the Autism South Africa website to enable them to become more informed.

Early identification and effective treatment of the core symptoms of ASD can improve the long-term outcomes for young children with ASD (Matson et al., 2011; Wilkinson, 2014). Thus, children who receive late diagnoses are at a significant disadvantage. Therefore, there needs to be a greater effort to discriminate early in life between a child with ASD and other at-risk children in South Africa (Ozonoff, 2010). There is also an urgent need for routine screening tests of all children to be conducted at 18 and 24 months of age (Soto et al., 2015). Furthermore, young children with delayed developmental milestones, birth defects, epilepsy and challenging behaviours should be noted as a group at risk for ASD in South Africa (Matson et al., 2012). Some researchers propose that autism screening tests should rather be specifically developed to identify children with ASD from an at-risk population instead of the general population of children (Soto et al., 2015).

There is an urgent need for awareness of ASD in KZN amongst healthcare professionals. In particular, it is suggested that speech and language therapists remain well informed of the latest advancements in ASD research, as they are often the front-line professionals to assess

children with delays in speech development. It is also critical that relevant healthcare practitioners receive training that is developed and tailored to the requirements of African communities (Elsabbagh et al., 2012).

6.2.3. Discourse from community members around bad parenting.

Related to the lack of awareness of ASD by community members, the participants described experiencing discourses of blame and stigma in social situations around their child's difficult behaviour. This significantly contributed to the participants feeling unsupported and stigmatised as bad parents. In the absence of physical markers of disability or disorder, children with ASD were extraordinarily challenging regarding their adapting to unfamiliar or unstructured settings (Turygin et al., 2014). All children find it difficult in unfamiliar and less structured settings, at least, up to the age of four years, but children with ASD find variations from sameness especially distressing (Wilkinson, 2014).

Cultural groups hold particular views and frames of reference that shape their understandings of specific circumstances (Mandell & Novak, 2005). Also, social norms may dictate what behaviour is appropriate for certain settings. Hence, it may be normative for church members to assume that a 4-year-old child would be relatively contained and quiet in a formal church setting. Thus, community members tended to regard these children as unruly, defiant, and disobedient. Similarly, other studies have found that community members do not tolerate a child's challenging behaviour but instead view it as problematic (Hebert & Koulouglioti, 2010).

In addition, the reported criticism by community members impacted the parents' self-efficacy in relation to their parenting abilities. The way in which parents were seen to evaluate their self-worth may be explained by the developmental niche theory. Cultural beliefs and values are suggested to strongly motivate parents into believing that there are "right" or "normal" ways to think or act, according to African belief systems (Harkness & Super, 2000). Within African American families, an extremely high value is placed on respecting, obeying, and learning from elders in the kinship network and community (Willis, 1992). This is related to the high value for interdependence and respect with African worldviews (Mkhize, 2004) In other words; these participants assessed their child's challenging behaviour in social contexts, according to cultural expectations of "normal" behaviour. Since obedience by children is valued and emphasised in African cultures (Mkhize, 2004), the participants may have thought

that poor parenting skills resulted in their child's problematic behaviour. Likewise, parents of children with ASD have been found to possess a decreased belief in their ability to parent their child effectively (Karst & Van Hecke, 2012).

Therefore, society's worldviews diminished the parents' confidence in their abilities to rear a child with ASD. Furthermore, participants resorted to harsher means of discipline such as "smacking" or "beating" as a way of trying to make their children compliant and "be this good parent." Similarly, other parents of children with ASD have been found to feel that their discipline is inadequate and ineffectual (Tincani et al., 2009), and have described feeling utterly powerless regarding their child's challenging behaviour (Mulligan et al., 2012).

An implication of these findings is that the general public, in this region of South Africa, were unfamiliar with the behaviours that characterise ASD. This is consistent with international research that has clearly demonstrated the benefits of raising awareness of ASD in the general public and medical practitioners (Twyo et al., 2007). In fact, children living with ASD face major challenges particularly when there is low public awareness of the disorder, and this results in greater stigmatisation (Bölte et al., 2013). Moreover, the participants feared discrimination and stigmatisation within their communities. Many families in LMIC have been found to struggle with the stigma of having a child with ASD and this increases parental stress (Wallace et al., 2012).

Several participants explained that they preferred to stay at home to avoid contact with the general public. Similarly, a child's challenging behaviours may lead to parents becoming isolated in their communities (Pisula, 2011). South African researchers calling for greater awareness of ASD have noted that society's attitudes towards children with ASD needs to be de-stigmatised so unnecessary suffering about social rejection can be avoided (Chaggan et al., 2012). Participants in this study further expressed a desire for society's views to become more tolerant towards children with disabilities. Thus, the perceived culture of blaming children's problematic behaviour on poor parenting skills needs to be replaced with promoting autism awareness, understanding, and acceptance, as well as support for parents (Chaggan, Karim, & Wallace, 2012).

6.3. Understanding ASD from a Cultural Perspective

Undoubtedly, the participants in the study were influenced by urbanisation, modernisation, formalised education, and the adoption of Christian beliefs. Similarly, several participants were of the opinion that before the birth of their babies, they had distanced themselves from their traditional African practices. However, once they had noticed the atypical development in their child and had sought advice from elders, they were willing to perform the required rituals and revert to more traditional beliefs. Thus, cultural beliefs impacted on the way that African parents interpreted the symptoms of their child's autism (Tincani et al., 2009).

This was evident in the manner in which the participants worried that their own perceived wrongdoings had been the cause of their children's difficulties. In particular, upsetting the ancestral spirits by marrying someone from another African tribe or failing to conduct traditional rituals to introduce their child to ancestral spirits were cited in this study as potential causes of the atypical development. The cultural views expressed by the participants were similar to those expressed by Indian parents who believed that transgressions in their previous life could have resulted in their child's autism (Ravindran & Myers, 2012). Similarly, a Nigerian study found that 26% of their healthcare workers believed that the aetiology of ASD was linked to supernatural causes (Bakare & Munir, 2011b).

Rituals are extraordinary practices performed by the living for the spiritual world (Assatashakar, 2014). These are communal religious practices performed for a special purposes like rites of passage, appeasement, divination and sometimes for special needs or request of ancestors. Rituals revive the ancestors, which also mean the relationship between the physical and the spiritual worlds. In these religious gatherings, the community participates in various forms of worship, through which unity and healing are achieved for the family and the community.

Within the African worldview, many disorders and difficult life circumstances are considered to be forms of punishment for wrongdoings, with these beliefs being associated with intense feelings of guilt in parents (Mkhize, 2004; Ross, 2007). The participants expressed immense shame and guilt for their child's ASD. Hebert and Koulouglioto (2010) found that parents who viewed their child's ASD as a form of punishment for their own wrongdoings tended to develop increased guilt and a negative appraisal of the situation. These authors also found

that parents across the world hold a variety of beliefs about the causes of ASD, including perinatal circumstances, as well as environmental, genetic factors. Similar explanations (stress during pregnancy and the use of pethidine during labour) were identified in this study. Although the exact cause of ASD has yet to be determined, genetics are regarded as a significant aetiological variable (Matson & Goldin, 2014). Twin and family studies propose that ASDs have a heritability of approximately 90% (Rutter, 2011). Importantly, none of the participants in this study related their child's ASD to hereditary factors, and a possible explanation may lie in the fact that family members may not have received a diagnosis for their difficulties. Furthermore, Western medicine tends to attribute biological factors to disorders while traditional African views tend to associate disorders to arise from social, natural, or spiritual disturbances (Mkhize, 2004; Ross, 2007). Nevertheless, the participants' traditional African beliefs influenced their views about aetiology more than Western views.

An important implication of this finding arises when African parents consult health professionals and fail to mention, or are unaware of, hereditary factors. Some participants identified family members with delayed speech development and personality factors similar to a child but this was a response to questions and did not seem to be considered an important link. Therefore, health professionals may need to inquire specifically about familial links such as language delays, and social difficulties when conducting clinical intakes with African parents of a child at risk for ASD.

Elders of a community were reported to play an important advisory role, assisting participants to identify past wrongdoings. Since the children's difficulties were attributed to the punishment of the parental families, spiritual factors, and superstitious beliefs, treatment approaches have been found to include the use of prayer, natural substances, and rituals to restore harmony and equilibrium (Mkhize, 2004; Ross, 2008). Thus, in accordance with African belief systems, the elders of a community reportedly advised the participants to perform traditional rituals to appease the ancestral spirits and repair their child's difficulties. Given the fact that community elders are geographically available and generally held in high esteem, they appear ideal candidates to be trained in identifying potential risk factors for ASD. The potential for collaboration between the elders and healthcare professionals may also warrant further investigation with a view to assisting parents to identify risk factors associated with ASD. Further support and guidance regarding referrals to appropriate healthcare professions may also be of benefit.

In particular, parents of Zulu ancestry expressed a belief that ancestral spirits were in control of their child's problems and the only way to resolve a child's difficulties was through performing appeasement rituals. Since the participants expressed a belief that their child's condition resulted from spiritual causes, linked to their wrongdoings, the only solution to a child's problems is believed through restoring spiritual harmony with the ancestral spirits (Ross, 2008). Another motivating factor for parents conducting rituals, after feeling distanced from traditional African views, may be due to the fear of stigmatisation. Fear of stigma has been reported to influence the help-seeking behaviour of South Africans (Sorsdahl et al., 2009). Strategies to improve pathways towards deep collaboration between mental healthcare in Africa must include innovative programmes aimed at fostering on-going dialogue between medical services and these key community-based providers who hold and maintain the community's spiritual well-being (Burns & Tomita, 2014).

These participants had also been advised by community elders and their own family members that over time their children's difficulties would resolve on their own. Similar views have been expressed by parents in India who following advice from elders waited for their child's problems to resolve (Daley, 2004). Similarly, parents in Korea were found to trust that their child would outgrow his/her problems (Kim, 2012). Quilendrin et al. (2015) suggests that most parents wait in the hope that their child's development will eventually catch up to their peers. Of concern, is the implication that traditional African beliefs, such as waiting for a child's symptoms of ASD to resolve with time, may lead to a delay in early identification and commencement of intervention. Furthermore, the present study found, in accordance with results from a KZN study of African parents of a child with ASD, advice from healthcare professionals was only sought once traditional interventions were unsuccessful (Madlala, 2012).

6.3.1. Perspectives of challenging symptoms arising in children with ASD.

Children with ASD are a clinically heterogeneous group who present with varying degrees of severe language impairment, various comorbid disorder (most notably ADHD), intellectual impairments, global developmental delays, and challenging behaviour (Springer et al., 2013). The most frequent complaints from participants in this study were language delays, difficulties with peer group interactions, comorbid ADHD in four children, an inflexible attitude towards food, and unpredictable, risky behaviour. In contrast, primary caregivers in the Western Cape complained most frequently about stereotypical movement followed by

hyperactivity and then sleep disturbance (Springer et al., 2013). It is not surprising that problematic behaviours were experienced as extremely exhausting and challenging to manage.

In five of the six cases, 'fussy eating' was raised as a problematic feature of ASD. Although it has been hypothesised that parents from LMIC who have food insecurity may be more aware of their child's feeding difficulties (DeWeerd, 2012), it seems that medical problems associated with eating, commonly occur in children with ASD, leading to avoidant-restrictive food intake problems (Rutter, 2011). In addition, previous studies have established that food selectivity is amongst the most frequent behaviour problem for children with ASD, especially regarding the texture and taste of food (Postorino et al., 2015). There is little doubt that the management of mealtime behaviours was found in other studies to become a major stressor that negatively affected the quality of family life (Postorino et al., 2015). However, there is little information about why food selectivity is so prevalent among children with ASD (Postorino et al., 2015), although it is regarded as reflective of sensory defensiveness and may indicate difficulties with sensory processing (Williams, Dalrymple, & Neal, 2000).

Restrictive, repetitive behaviours, the second criterion in the DSM-5 for a diagnosis of ASD, often manifest as insistence on sameness (APA, 2013). Although there is no clear indication in the literature on the definition for "insistence on sameness," the term seems to refer to a rigid adherence to routines and a strong resistance to change (Sevin et al., 2015). The participants found that their children reacted badly when there were changes in routines such as following a different route to school or changes in bedtime. During the ADOS administration, children were observed to have difficulty transitioning from one task to the next. Children who present with an insistence on sameness, have been found to experience difficulty transitioning between activities (Sevin et al., 2015).

Not surprisingly, a child's unpredictable behaviour was described to be very challenging and problematic for parents to manage, as well as create tremendous responsibility for parents by placing a child in dangerous situations (Wing et al., 2011). This unpredictable behaviour meant that children engaged in risky behaviours. For example, one child in this study was knocked over by a motor vehicle. Impulsive, unpredictable behaviour also caused highly embarrassing situations, when a child helped himself to food from a stranger's plate in a restaurant. A decreased ability to predict consequences has been proposed as a fundamental problem underlying ASD but is not included in the diagnostic criteria in DSM-5 (Wing et al.,

2011). Several researchers propose that it is very challenging to accurately identify the most important criteria needed for an ASD diagnosis due to the heterogeneity of the disorder (Matson & Jang, 2014).

However, a pervasive negative attitude accompanied by extreme meltdowns was not especially mentioned by the participants in this study as amongst the more problematic behaviours. Some participants described that ‘all hell would break loose’ if there was a disruption in routine and another described obstinance in church settings. The lack of prominence given to meltdowns may be due to a number of factors: participants fear of being harshly judged as bad parents, their having resigned themselves to not over-reacting to bad behaviour as this could escalate at a rapid rate, or that meltdowns were not regarded as part of the presentation of ASD in their children.

Matson and Goldin (2014) describe ADHD as a frequently occurring comorbid disorder that complicates and exacerbates other challenging behaviours. It has further been found that children whose parents’ expressed concerns about developmental delays and challenging behaviour were less likely to be diagnosed with ASD than those whose parents who expressed concerns related to speech and language deficits (Turygin et al., 2014). Due to the presence of tantrums in many children with ASD, this poses a question about a comorbid disorder of Oppositional Defiant Disorder (ODD) (Mayes, Calhoun, Mayes, & Molitoris, 2012)(ODD). ODD can be a strong differential diagnosis but there is still uncertainty about as ODD can be a comorbid disorder with ASD (Mayes et al., 2012).

6.4. Responses to the ADOS Assessment

The children’s responses to the activities and general relevance of the ADOS tasks from an African cultural context relates to the final research question. Although the test authors and Autism Speaks have made concerted efforts to bring the ADOS to this country for research purposes, it has been largely unavailable and absent in community settings in South Africa (Elsabbagh et al., 2012). The high cost of the instrument in South Africa may make the ADOS unaffordable for many health practitioners. Likewise, clinicians may also be deterred by the length of time needed to complete the extensive training to achieve the level of expertise that is needed to competently administer the ADOS (Grodberg, Weinger, Kolevzon, Soorya, & Buxbaum, 2012). Despite the ADOS being an expensive and highly resource-intensive tool, it yields rich data and systematic information (Elsabbagh et al., 2012).

Overall, the ADOS activities administered in this study were found to provide an effective opportunity through which to evaluate African children's behaviour and the instrument was able to confirm a diagnosis of ASD in the children. Although children with ASD across the world present with similar core features (Matson, Worley, et al., 2012), parents may identify symptoms according to their cultural beliefs (Mandell & Novak, 2005). Furthermore, the process of socialization in African cultures may mean that some features of reciprocal interaction and speech and language may not be identified as atypical in African children. In this regard, participants in this study did not report their child's lack of eye contact. An explanation may be that the avoidance of eye contact in traditional African cultures is considered a sign of respect (DeWeerd, 2012).

Several children were observed to experience sensitivity to certain sounds such as the bubble machine during the administration of the ADOS. Likewise, enhanced sensitivities are common among children with ASD (Wing et al., 2011) and hypersensitivity to auditory input is now included in the DSM-5 criteria (APA, 2013).

These children responded spontaneously to the pretend birthday party activity in that they were familiar and able to engage in pretend play by singing, blowing out candles, shouting or clapping hands. This finding contradicts the suggestion that even typically developing children in rural areas of South Africa may not be familiar with the birthday party custom (DeWeerd, 2012).

Blowing bubbles and inflating the balloon were well received by the children in the study. Likewise, nonverbal children were found to engage well with the musical toys. The children were generally afraid or wary of the frog and were not especially interested in the white rabbit. This may be an indication of a need to adapt some of the toys used in the ADOS to the South African context, and this is in addition to adaptations need in linguistic translations (Soto et al., 2015). Thus, animals that are more appropriate and culturally recognisable may be a consideration for future adjustments to the ADOS with African children.

Assessments need to take into account the specific cultural values and factors in this country that influence ASD manifestations. Emphasis should also be placed on developing screening and diagnostic measures for older nonverbal children and children (beyond ages one to three years). Culturally appropriate screening and diagnostic tools need to be adapted to the

African culture and isiZulu language to reduce false positive and false negative diagnoses (Soto et al., 2015).

Research into the aetiology of ASD is evolving quickly (Matson & Goldin, 2014), with interesting advancements in neuroimaging and genomics that are predicted to be the next focus of assessments globally, and may rapidly improve the current diagnostic methods (Matson & Jang, 2014). Nevertheless, identification of functional impairments may prove to be more helpful than these potential methods to assist with diagnosis.

Chapter 7

Conclusion

7.1. Limitations

Several important limitations to this study need to be noted. Firstly, since children in the study were primarily recruited from public LSEN schools in urban areas, children living in rural areas and/or from financially more disadvantaged backgrounds were largely excluded. Secondly, the professionals responsible for recruiting the African parents for the study may have based their selections on children in which ASD was very clear. Thirdly, parents with little support or resources may have been overlooked for selection. Since most of the participants were relatively well educated, participants from a range of educational backgrounds were excluded and this may have influenced the findings in this study. Finally, reliance on parental recollections may mean that some details of their child's development were not accurately recalled (Ghaziuddin, 2010).

7.2. Recommendations for Future Research

Despite these limitations, the findings of this small explorative study may have important implications. Many questions remain unanswered about this complex neurodevelopmental disorder. An overall trend has been reported that very few fathers of children with ASD have participated in research studies (Braunstein et al., 2013). Since the present study found that the fathers provided important input regarding raising a child with ASD from male perspectives, their involvement was considered to be invaluable. Hence, further research involving fathers' perceptions of ASD in their children may be worthwhile. Given the benefits of early diagnosis, more research into the ADOS is urgently needed to develop culturally fair diagnostic assessments that can accurately identify symptoms of ASD in children of African ethnicity. Lastly, empirical research focusing on determining early parental concerns and the way in which the symptoms of ASD are expressed by African parents will help inform health professionals about the manner in which concerns are expressed and communicated.

Further research into the age at first evaluation by a healthcare professional to the time of diagnosis is necessary to investigate racial/ethnic disparities in South Africa in autism diagnosis. Likewise, clinicians and researchers should explore the cultural differences on

mental health issues to determine perspectives on help-seeking in relation to the kind of support/advocacy needed for an African cultural context (Jang et al., 2014). Lastly, more research, support, and education are required to remove racial/ethnic differences in ASD diagnosis and treatment and increase positive outcomes for all affected young children (Jang et al., 2014).

7.3. Reflexivity

Reflexivity refers to an exploration of how the researcher influenced and informed the research study. In particular, personal reflexivity points to an understanding of how the researcher's values, experiences, and identity shaped the research. In this study, my identity as a Caucasian South African female student of middle socio-economic status may have created some barriers especially for the participants and the children who were less familiar with engaging with Caucasian members of the population. This was probably more relevant to the children, as the parents generally relaxed into the interviews quickly feeling both relieved and motivated to share their experiences. The positive response received from participants was most encouraging. Since one of my close friends had a child with ASD, I have become fascinated in ASD. When I was interviewing the participants or working with the children, I was struck by the numerous commonalities in the African participants and my friend's experiences of having a child with ASD. Issues of power also need to be raised as a potentially intimidating factor: as a Caucasian woman from a University, it is possible that some participants were intimidated. Since I became aware of this, I tried to relate as an equal with the participants whenever possible. Although most of the participants were fluent in English, I am not fluent in any indigenous languages and this may have created a difficulty for the participants. Reflexivity also means reflecting on the ways in which my perspectives and experiences impacted upon my analysis of the data and the thematic analysis that I conducted. Thus, in order to address these issues of reflexivity, I kept detailed notes and audio recorded the research procedure in order to determine how the research took place and what assumptions informed my analysis of the data.

7.4. Overview

Despite the reported increased awareness of ASD in LMIC around the world (Wallace et al., 2012), African parents in KZN were unaware of ASD before hearing their child's diagnosis. Furthermore, these findings indicate that African parents identified the core features of ASD

in their children (deficits in social skills, communication and repetitive, restricted patterns of behaviours) along with problematic behaviours (food selectivity, hyperactivity and limited prediction) but with lack of awareness of ASD, they were not able to make sense of the manner in which children behaved (Matson & Goldin, 2014).

Since ASD is most accurately diagnosed over time and across various settings, a multidisciplinary team approach, incorporating different healthcare professionals is critical. Thus, professionals have a responsibility to remain informed about latest research in the rapidly developing field of ASD, in order to correctly identify risk factors associated with this disorder. Furthermore, scientific information needs to be provided in a way that conveys respect for cultural beliefs and values to develop holistic views of ASD (Ross, 2007).

Knowledge about the potential warning signs of ASD would probably be best received through the use of television documentaries to develop a greater awareness of early risk factors or warning signs in young children. Additional awareness campaigns and workshops held in community settings for elders may assist in the recognition of the early risk factors associated with ASD, and possibly reduce stigma and misinformation surrounding autism (Wallace et al., 2012).

In conclusion, the findings from this study may contribute to the limited information available of African children with ASD in South Africa. Furthermore, the manifestations and descriptions of features of ASD, by African parents, may help to inform health professionals about the symptoms that African parents are likely to report in consultations with health professionals.

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Appendices

Appendix A: Ethical Clearance



18 March 2014

Ms Michelle Dixon (210523179)
School of Applied Human Sciences - Psychology
Pietermaritzburg Campus

Protocol reference number: HSS/0343/012M
Project title: Exploring Autism Spectrum Disorders in Black South African children using multiple case study methodology

Dear Ms Dixon,

Approval - Change in Degree

I wish to confirm that your application in connection with the above mentioned project has been approved.

- It is noted that you have now registered for a Master of Social Science by Coursework.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the discipline/department for a period of 5 years.

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

Best wishes for the successful completion of your research protocol.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

cc Supervisor Mr Nicholas Munro
cc Academic leader Professor D Wassenaar
cc School Admin. Mr Sbonelo Duma

Humanities & Social Sciences Research Ethics Committee

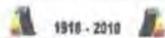
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Appendix B: Letters to principals

The Principal,
XXXXXX School
P.O. Box XXXX
Durban



Per electronic transmission: XXXXXXXXXXXXXXXX

Dear Mr/Mrs XXXXX,

KwaZulu-Natal Autism (K-ASD) Study

Seeking permission to conduct research at your school during 2012.

Thank you for taking time out of your busy schedule to meet with us. These are the details of our study. We are requesting your permission to use XXXXXXX Special School as a site for data collection in the first half of 2012, if at all possible. We understand that you and your staff are extremely busy and are sensitive to the extra work this may require. It is however, a large study involving the standardisation of the Autistic Diagnostic Observation Schedule (ADOS) for South African children. You are possibly aware that the ADOS is now regarded as the “gold standard” for the diagnosis of autism, and so we hope to be able to standardise this assessment schedule for children in our country and on our continent. The Principal Investigators in this study are Dr Shuaib Kauchalis (Department of Paediatrics & Child Health, University of KwaZulu-Natal), Dr Beverley Killian (School of Psychology, University of KwaZulu Natal) and Dr Meera Chhagan, (Maternal & Child Health, University of KwaZulu-Natal).

We would require the collaborative efforts of your occupational therapist on the study. This is an experimental design, thus we ideally would like to assess two groups of children, from 6-11 years of age who will be matched according to age, race, language and gender. One group being those children with Autistic Spectrum Disorder, who will be matched to a control group of children without this disorder and who have other needs for special education. The aim is to assess the children using the ADOS screening test and to ascertain whether it accurately screens for ASD or whether it shows false positives/negatives among SA children. We intend to conduct a double blind study meaning that at the time that the ADOS is administered, we do not want the researchers to know the diagnosis of the child concerned.

It will require the collaboration of key staff members who will allocate the two researchers 6 children to assess. The researchers’ involved namely, Aurene Wilford and Michelle Dixon teachers themselves and between them have twenty years of experience. They will video record the administration of the ADOS in the child’s home language.

We ideally would like to test 3 students who present with ASD in varying degrees, across race, age, language and gender and compare them to 3 students who are matched according to race, age, language and gender, yet do not present with ASD. Each assessment session will take between 40 minutes - 1 hour.

We understand the ethical ramifications of testing children, and will thus require written informed consent from each parent whose child is involved as well as the assent of the child concerned. Should you agree to our using XXXXX Special School as the site for this research, we will provide you with copies of the informed consent form. We shall provide all forms and are asking that your staff simply assist with some of the administration tasks: e.g. sending out forms, collecting them on completion and organizing the room in which we shall do the assessments. Every session shall be recorded for research purposes. Ethical approval for this study has already been granted by the UKZN ethical review committees.

Should your psychologists and other staff be interested, we are willing to train them in the use of this assessment tool. We would also like to make a meaningful contribution to both the parents and staff of the school in terms of their understanding of ASD.

We understand the pressures of school life and the probability that you are inundated with requests for research studies, which places added stress on your staff members. Nevertheless, we realize the uniqueness of your school learner profiles.

If you have any questions regarding this study you can contact Michelle Dixon on her email: xxxxxx Aurene Wilford on xxxxxxxxxx, alternatively Dr. Beverley Killian can be consulted on her email: xxxxxxxx.

Thank you for taking the time to consider our proposal.

Yours faithfully,

Michelle Dixon

Aurene Wilford

Beverley Killian (PhD)

Masters Student

Masters Student

Supervisor

School of Applied Human Sciences

Postal Address: Private Bag X01, Scottsville, Pietermaritzburg3209, South Africa

Telephone: +27 (0)33 260 5166 **Facsimile:** +27 (0)33 260 5363 **Email:** whitemanc@ukzn.ac.za **Website:** psychology.ukzn.ac.za

Founding Campuses : Edgewood Howard College Medical School Pietermaritzburg Westville

Appendix C: Second Letter to Principals

The Principal,
 XXXXXXX School
 XXXXXXX
 Pietermaritzburg



Per electronic transmission: XXXXXXXX

Dear XXXXXXXXXX

KwaZulu-Natal Autism Study
Seeking permission to conduct research at your school

Thank you for allowing us to conduct ADOS assessments with pupils from your school, your support is greatly appreciated. We are seeking permission to conduct further research involving African parents and their children diagnosed with ASD from your school. Not much is known about ASD in South Africa, particularly in the African culture. We are very interested in researching what symptoms of ASD are identified by African parents in the early developmental years and what African parents experience when raising a child with these special needs. We would like to observe and assess the identified children on the Autism Diagnostic Observation Schedule (ADOS), if they have not had an ADOS assessment with us. Furthermore, we would like to conduct three separate interviews with the parents/caregivers. Each interview will be approximately an hour in duration and will be audio taped for record purposes but the identity of the parents and child will be kept confidential.

We are looking for one or two boys and girls with African ancestry in the 6 - 11 year age group, with a clinical diagnosis of ASD, for the study. We are asking for your assistance to identify participants who fit these criteria and to discuss the proposed research with their parents. If the parents agree to participate in this study then please can you pass my details on to them so we can arrange an interview with them?

If at all possible, we would like to conduct the interviews with parents in a room on your premises.

Additionally, we would like your permission to release the child's school file containing confidential information once we have obtained written informed consent from the parents.

Yours sincerely,

Michelle Dixon
 Masters student

Dr Beverley Killian
 Supervisor

School of Applied Human Sciences

Postal Address: Private Bag X01, Scottsville, Pietermaritzburg3209, South Africa

Telephone: +27 (0)33 260 5166 Facsimile: +27 (0)33 260 5363 Email: whitemanc@ukzn.ac.za Website: psychology.ukzn.ac.za
 Founding Campuses: [red] Edgewood [yellow] Howard College [green] Mcedweni School [purple] Pietermaritzburg [blue] Westville [orange]

Appendix D: Parent Consent and Child Assent Forms.



UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

Dear

You and your child are invited to participate in a research project about African children diagnosed with Autism Spectrum Disorders (ASD). Since little is known about this topic, it is hoped that the study will provide some useful insights. My name is Michelle and I am a psychology Masters student at UKZN with ten years education experience. I will be conducting this study with my supervisor Dr Killian.

Firstly, we are asking for your consent to participate in this study and for your consent for your child to participate in this study. We are also asking for your child's assent. We would like to meet with you and answer any questions that you may have. After this, we would like to conduct in-depth interviews with you about your child's developmental history, and how you have experienced raising a child with this special need. We would also like to record important details about you and your child's life.

Secondly, we would like to observe your child either in their school or home environment and administer the Autism Diagnostic Observation Schedule (ADOS) with them. ASD tends to be very difficult to identify and the ADOS is presently the 'gold standard' for the diagnosis of ASD. It comprises of a variety of activities that children usually find enjoyable. The assessment process will be about forty-five minutes. With your permission, the assessment will be video recorded for record purposes and will be viewed by relevant professionals involved in this study. We would also like to conduct two questionnaires with you. We can ask you the set of questions or you can complete the questionnaires on your own. We are happy with which ever procedure you prefer. Additionally, we require your permission to view your child's individual school file to validate our research.

Lastly, we will meet for a feedback session where we will discuss your child's ADOS results. Thus, we request that you meet with us for two interviews at the start of this process, and a further follow up interview after this. We would also like to see your child for about an hour. In total, we anticipate that your times with us will amount to about five hours.

We have secured the services of a trained social worker to assist with translation of isiZulu, if needed. There will be no remuneration in cash or kind for participation in the project, but it will be a privilege for us to work with you and your child.

Both your identity and that of your child will be kept confidential and no identifying information will be included in the completed research reports. A coding system will be used to ensure both you and your child's confidentiality. You may withdraw from this study at any time and neither you nor your child will experience any adverse effects from such withdrawal or refusal.

I look forward to working with you and your child.

Thank you for your participation,

Michelle Dixon
Masters student

Dr Beverley Killian
Supervisor

School of Applied Human Sciences

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Telephone: +27 (0)33 260 5166 **Facsimile:** +27 (0)33 260 5363 **Email:** whitemanc@ukzn.ac.za **Website:** psychology.ukzn.ac.za
Founding Campuses: Pietermaritzburg, Durban, Richards Bay, Westville

SECTION A: CONSENT OF PARENT OR CAREGIVER

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

I, _____ (Full name of parent/ caregiver),
Hereby confirm that I understand the contents of this informed consent letter and the nature of the research project.

I consent to taking part in the research and understand that:

- The process will take approximately five hours, spread over two weeks.
- At each interview there will be a co-researcher present to help with translation and other information.
- All interviews will be audio-recorded for research purposes.
- My child will participate in the ADOS assessment and will be video-recorded during this assessment.
- The researcher will have access to my child's personal school file.

Signature of parent

Date:

Cell phone number

Email address:

SECTION B: ASSENT OF CHILD

My parent has explained that I will meet someone and I will do an assessment.

Name of child

Printed name or thumbprint of child

Child's date of birth

School and Grade

SECTION C: ADDITIONAL CONSENT/ASSENT TO (VIDEO THE ASSESSMENT) AND (AUDIO TAPE THE INTERVIEW)

I hereby agree to the video recording of my child during the ADOS assessment and to the audio recording of the interviews that I participate in, for record purposes. I understand that no personal identifying information or recording will be released in any form.

Signature of parent

Printed name or thumbprint of child

School of Applied Human Sciences

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Telephone: +27 (0)33 260 5166 Facsimile: +27 (0)33 260 5363 Email: whitemanc@ukzn.ac.za Website: psychology.ukzn.ac.za

Founding Campuses: igewood ard College School Pieterm burg Westville

Appendix E: Parent Interview Schedule

Participant No:	Child's Name:
Date of Birth:	Male/Female:
School:	Class: Grade

1. Ethnicity of child: _____ Mother: _____ Father: _____
2. Mother's name/age: _____
3. Father's name/age: _____
4. Mother's education/occupation: _____
Father's education/occupation: _____
5. Siblings: _____
Sibling's grades/difficulties at school: _____
6. Health of family and extended family members: _____
7. Planned pregnancy? _____
8. How did you feel about the pregnancy? _____
9. Were there problems during your pregnancy? _____
Anything significant during pregnancy– stress: _____
10. Age of parents at birth: M): _____ F): _____
11. Induced or spontaneous labour: _____
12. Type of birth? _____
Apgar: _____ Birth weight: _____
Full term/ Prem: _____
Experience of new-born? _____
13. How did your baby settle into the home?
Sleeping and feeding? _____
Baby's temperament (easy / difficult / slow to warm): _____
14. First year of your child's life? _____
15. Developmental milestones:
Sitting _____ Crawling - on knees? _____
Standing _____ Walking _____
First words _____ Sentences _____
Gestures/pointing _____
Comprehension _____
Development in comparison with others: _____
Co-ordination (fine/gross): _____
16. Fathers involvement with infant: _____
Child minders role: _____
Quality of relationship with sibling/s: _____
17. What about the second year? _____
18. What were the first things that you noticed about your child that were not quite right?
Mother: _____

- Age of child: _____
 Father: _____
 Age of child: _____
19. Age toilet trained? (out of night nappies): _____
20. Any feeding eating problems? _____
 Hearing tested: _____ Eyesight tested: _____
 Specialists that have been consulted: _____

 Present medication: _____
 Sleeping patterns: _____
21. First diagnosed by: _____
22. Age of child at first diagnosis: _____
23. Has anyone in your family had autism? _____
24. Any extended family members that have had difficulties? _____

25. Did you know anything about autism before your child was diagnosed?

26. Do you follow the traditions of your culture? _____
27. Have you consulted a traditional healer/sangoma? _____

28. Have you performed any cultural rituals? _____

29. How does your community view autism? _____

30. Are there any other children in your community with autism? _____

31. Does your child have any friends at school or in your neighbourhood? _____

32. What are your child's interests/activities/sports? _____

33. How is your child doing at school? _____

34. Concentration: _____
 Reading: _____
 Language: _____
 Maths: _____
35. What has it been like for you as an African parent raising a child with autism?

36. What is the most difficult aspect about raising a child with ASD?

37. What symptoms of ASD do you find are the most challenging?

38. What happens to the children in your community that are not diagnosed with ASD?

39. Do you have anything else that you would like to add?

40. Any questions? _____

Appendix F: Turnitin Report

The screenshot shows a Turnitin report interface. The main content area displays the title and author information of the submitted work. On the right, a 'Match Overview' sidebar lists 11 sources with their respective similarity percentages. The total similarity score is 11%.

Submitted Work Information:

- Title: Exploring Autism Spectrum Disorder in African Children Using Multiple Case Study Methodology
- Author: Michelle Glenise Dixon
- Student ID: 210523179
- Supervisor: Dr Nicholas Munro

Match Overview:

Rank	Source	Similarity
1	Submitted to University... Student paper	1%
2	www.goldlearningcentr... Internet source	1%
3	Comprehensive Guide... Publication	1%
4	Submitted to University... Student paper	1%
5	146.250.128.141 Internet source	<1%
6	scholarcommons.usf.edu Internet source	<1%
7	etd.isu.edu Internet source	<1%
8	Encyclopedia of Autism... Publication	<1%
9	Matson, Johnny L., an... Publication	<1%
10	www.natane.net Internet source	<1%
11	www.science.gov	<1%

Report Summary: 11% Similarity