Black African mothers' experiences of having their child diagnosed with Autism Spectrum Disorder

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Declaration

I Snenhlanhla Zikhona Mshengu declare that this study is my own work. Any work that is not my own has been cited and referenced accordingly. This study has not been submitted to any other university for any other degree or examination. This study is being submitted in partial fulfilment of a Master of Arts (Educational Psychology) degree.

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Supervisor's approval of this thesis for submission:

As the candidate's supervisor I have approved this thesis for submission.

Signed:

Mitchell

Dr. Carol Mitchell Date: 15 November 2019

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Abstract

In recent years there has been an increase in the prevalence of Autism Spectrum Disorder (ASD) around the world yet there has been little research aimed at understanding its implications in African countries. Due to the influence culture has on individuals' behaviour, beliefs and ideas, it is important to understand the way in which different cultures understand mental disorders. This study sought to gain an African perspective on the experiences black African parents had when their children had been diagnosed with ASD.

This study used a qualitative approach, using semi-structured interviews. Six participants were interviewed all of whom were black African mothers. The key findings of the study showed issues with education, finances as well as stigma. In addition, the study found that the average age of diagnosis for the children was four years old, which is half the predicted age of diagnosis of most African children. However, most of the parents in the study only sought a healthcare practitioner after a teacher had raised concerns. This appears to be in line with existing literature. Moreover, due to cultural belief systems black African parents sought interventions that were not within the scope of western medical practice such as traditional African healers and religious healers. Lastly, there appears to be a gap in not only community based awareness but also in healthcare policies that currently exist within South Africa.

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Definition of terms

- ASD: A pervasive neurodevelopmental disorder that affects an individual’s social, communicative functioning, as well as restricted repetitive patterns of behaviours and interests.
- BPS: The Biopsychosocial model recognises that mental health has biological, psychological and social influences.
- BPSS: A model that looks at mental health as being influenced by the BPS factors, however, it also includes a spiritualistic component that African individuals account for.
- Culture: The customs, behaviour, ideas and beliefs of individuals in a particular society.
- Parent: For the purposes of this study a parent is a biological/step/adoptive mother of a child or a primary caregiver.
- Alternative interventions: any intervention not involving western medical interventions.
- Traditional healer: any individual who is able to communicate with ancestors and uses African medicine to provide remedies. In addition, this may be someone with the authority to conduct traditional African rituals.
- Religious healer: an individual who communicates with a higher power such as God, and uses prayer to help heal an individual.
- *Impepho*: African plant that is dried and burnt in order to communicate with an individual’s ancestors.
- *Ufuzo*: a trait that is inherited from another family member. Usually present in multiple family members.
- *Ukuhlawula*: A practice in Nguni culture done when a child is born out of wedlock. A process of paying damages.
- Nguni: a group of people living in Southern Africa (Zulu, Swati, Xhosa and Ndebele).

Chapter 1: Introduction

1.1 Background of the study

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is characterized by impairments with social communication and restricted and repetitive behaviour (Sadock, Sadock & Ruiz, 2015). Recently there has been a global increase in the prevalence of ASD, with the Centre for Disease Control (CDC) in the United States of America (USA) realising a 15% increase in prevalence from 2012 – 2015 (Autism Speaks, 2018). According to Mokiti, Jonas, Schneider and de Vries (2019) no ASD prevalence studies have been conducted in Sub-Saharan Africa, including South Africa. There is currently a lack of knowledge and awareness regarding ASD in many African countries (Ruparelia et al., 2016). This may be due to ASD being previously thought to affect only individuals from western countries. ASD within Africa has not been an area of focus with little research being published. In the past 81 years, there have only been 47 studies that have been conducted in Africa on ASD looking at human participants (Abubakar et al., 2016). This is problematic as ASD may affect any individual regardless of geographic location. However, how it is perceived and understood may vary due to where an individual is located within the world.

In order to understand mental illness within the African context, it is important to take into account the philosophical assumptions of African people (Nwoye, 2015). This is because mental illness within the African context is understood differently and these assumptions have vast consequences for not only the people with ASD but for their families as well.

1.2 Problem statement

Culture has a strong influence on the way in which individuals interpret the world and their experiences. This is because culture shapes an individual’s knowledge, behaviour as well as their values (Kronenfeld, 1997). Due to the different cultures around the world, it may, therefore, be posited that there are just as many interpretations of phenomena that people may experience.

Within the African context, it is necessary to get an understanding of the experiences mothers with children with ASD have in order to clearly comprehend why certain treatments are chosen as opposed to others, as well as what meaning is attributed to mental illness. This is particularly important with ASD as many people still do not understand the disorder, both in western countries as well as Africa.

This study sought to understand the various experiences that black African mothers have had since their children were diagnosed with ASD. In looking at the experiences of mothers the aim was to get a comprehension of African understandings of ASD and how these affect diagnosis and interventions used.

1.3 Significance of the study

It is estimated that 1% of the global population is currently living with ASD (American Psychiatric Association, 2013). No prevalence rates have been established in Sub Saharan Africa, including South Africa (Mokiti et al., 2019). Currently many of the individuals that have been diagnosed with ASD are from developed countries; this may be due to several reasons, one such reason being unreported cases elsewhere in the world (Ruparelia et al., 2016).

Currently, little research has been conducted with regards to ASD within Africa. It is therefore important to conduct research that not only assesses prevalence but also experiences of living and caring for individuals with ASD, to gain an African perspective. In doing so the research could shed some light on the implications of raising a child with ASD in Africa. It may also lead to a better understanding of the resources available to children (and their families) living with ASD in developing countries. Due to many developing countries being deemed low-income countries not much attention is paid to mental health (Bakare & Munir, 2011). This leads to many of the available resources being designated to disorders that take a physical form and more visible nature. This is especially true in Africa where people still suffer from malaria and HIV/AIDS (Bakare, Bello-Mojeed, Munir, Ogun & Eaton, 2016). Illnesses, coupled with the poverty that many individuals face, may lead one to posit that mental health then becomes an aspect of health that many cannot afford to do anything about.

In a recent communication released by Autism Speaks (2018) the Centre for Disease Control and Prevention (CDC) in the United states of America (USA) reported a 15% increase in ASD prevalence from 2012-2015. It also highlighted that with increased awareness amongst minority groups in America there seems to be an increase in prevalence (Autism Speaks, 2018). It may be posited that the same could be true in other parts of the world; the increase of ASD awareness may increase prevalence. Moreover:

> Autism Speaks calls on legislators, public health agencies and the National Institutes of Health to advance research to help better understand the increased prevalence and the complex medical needs that often accompany autism…Autism Speaks also urges

> government leaders to advance policies that better provide individualized support and services in areas such as education, transition to adulthood, residential options and employment. (Autism Speaks, 2018, p.1)

It is evident from this communication that ASD research has become increasingly important as it is a mental health disorder that affects the individual during their whole life span. It may, therefore, be deemed a mental health issue as its prevalence is increasing over time whilst awareness and knowledge remain relatively low; this is especially true in African countries.

1.4 Purpose of the study

This study conducted interviews in an attempt to gain a better understanding of the experiences mothers have had since their child was diagnosed with ASD. The purpose of doing this was to allow the researcher to gain in depth information. Experiences mothers had were foregrounded, as it was hypothesized these would allow insight into the diagnostic process, familial relationships, communal relationships, African perspectives regarding ASD, alternative treatment options used as well as to gain some insight in the support that is given for children and families of children with ASD. This is not information that is currently exhausted in the available literature. In doing this the purpose of the study was thus to gain insight into African perspectives of mental illness.

1.5 Objectives of the study

The objectives of this study were to:

1. Gain a comprehensive understanding of black African mothers' experiences of having their children diagnosed with ASD
2. Gain knowledge on black African mothers' understandings of ASD
3. Explore differences in alternative understandings and treatments used by black African mothers before or after an ASD diagnosis within an African context

1.6 Research Questions

The main research question for this study was: What are black African mothers' experiences of having their child diagnosed with Autistic Spectrum Disorder?

The sub-questions were:

a) What alternative intervention avenues are used by black African mothers when a child is diagnosed with ASD?

b) What do black African mothers understand about ASD?

c) What aid is available for children with ASD in South Africa? Particularly in the black community (schooling/healthcare/social care).

1.7 Scope of the study

The sample population chosen in this study was black African mothers whose children had received a formal diagnosis of ASD, inclusive of pervasive developmental disorders (PDDs) if the child was diagnosed prior to 2013. No children in the study were however diagnosed before 2013. The study was limited in its location and only included mothers from Pietermaritzburg, South Africa. Six biological mothers of children with ASD participated in this study.

1.8 Overview of the study

This study consists of six chapters. Each chapter is briefly outlined below.

Chapter 1

This chapter has provided an overview of the importance of the study. Including background, statement of the problem, significance and purpose of the study, research questions and objectives, scope of the study, as well as the overview of the study.

Chapter 2

The literature that is relevant to this study is discussed in this chapter. It also includes the theoretical frameworks that have been used in order to understand the research topic in a more comprehensive manner.

Chapter 3

The methodology chapter reviews the processes that were used in obtaining information for this study. It includes research design methods, sampling, data collection, data analysis, validity and reliability of the study as well as ethical considerations.

Chapter 4

This chapter consists of the results. It provides the findings of the study whilst using excerpts from the data to illustrate the findings. These findings have been placed as themes that emerged during the data analysis.

Chapter 5

The discussion chapter reviews the findings of the study in light of the literature and theoretical frameworks presented in chapter two. Any new findings from the study are included in this chapter.

Chapter 6

Provides an outline of the study and its findings. Limitations of the research are also discussed and recommendations for future research are made.

Chapter 2: Literature review

2.1 Introduction

This chapter reviews Autism Spectrum Disorder (ASD) and the associated effects the diagnosis has on mothers who have had a child diagnosed with the disorder. Firstly, ASD is defined and the current diagnostic criteria are laid out. In recent years there has been a rise in the prevalence of ASD, contributing factors and theories surrounding this are discussed, as well as the aetiology of ASD. Due to the study focusing on the African context, the role of culture in ASD diagnosis is explored, and context and culturally specific research are reviewed. Lastly the experiences that African mothers have had is explored.

2.2 Definition and Diagnostic Criteria

2.2.1 Definition

Autism Spectrum Disorder (ASD) is defined as a pervasive neurodevelopmental disorder that affects an individual's social and communicative functioning (American Psychiatric Association, 2013). Individuals also display restricted repetitive patterns of behaviours and interests (American Psychiatric Association, 2013). The presentation of symptoms varies in each individual and these may range from mild to severe (American Psychiatric Association, 2013). Due to this, the level of support individuals will need over their life time will vary (American Psychiatric Association, 2013). The support required will, therefore, have a huge impact not only on the individual but also their family or primary caregivers.

2.2.2 Previous Diagnostic Criteria

The DSM IV (1994) classified several disorders under 'disorders usually first diagnosed in infancy, childhood, or adolescence'. However, these disorders could also be diagnosed in adulthood if diagnostic criteria were met (American Psychiatric Association, 1994). These disorders included pervasive developmental disorders: Autistic Disorder, Rett's Disorders, Asperger's Disorder, Childhood Disintegrative Disorder (CDD) as well as Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS).

DSM-IV-TR diagnosis was based on communication, social interaction, restrictive repetitive behaviour and intellectual functioning (American Psychiatric Association, 1994). The main difference in the diagnosis an individual would receive was based on the level of functioning as well as communication (American Psychiatric Disorder, 1994).

Pervasive development disorders (PDDs) were characterised by severe and pervasive impairment in communication and interaction skills as well as the presence of stereotypical behaviour, interests and activities (American Psychiatric Association. 1994). With the introduction of the DSM V all PDDs were merged together to form Autism Spectrum Disorder (ASD) (Sadock, Sadock &Ruiz, 2015)

2.2.3 Current Diagnostic Criteria

Currently, the diagnostic criteria that are used for ASD are stipulated in the Diagnostic and Statistical Manual 5 (DSM 5) (American Psychiatric Association, 2013). It is with the introduction of the DSM 5 in 2013 that pervasive developmental disorders were merged to form ASD (American Psychiatric Association, 2013).

The DSM 5 criteria are as follows:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):
    1) Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
    2) Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
    3) Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive)
    1) Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
    2) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
    3) Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

    4) Hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

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

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

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level. (American Psychiatric Association, 2013, pp. 50-51)

Clinicians are required to describe the level of severity of symptomatology as well as any comorbid disorders that may be present. This allows for individuals to receive the most effective interventions that are targeted at their symptoms.

2.3 Aetiology and Prevalence

The aetiology and the prevalence of ASD are still the object of current research and thus ideas regarding these change over time.

2.3.1 Aetiology

There are a variety of aetiological factors that are believed to result in ASD worldwide; however, these are not specific to any region. There is currently no known cause for ASD, however, there are hypotheses that healthcare professionals have regarding aetiology. Generally, it is believed that certain individuals have a genetic predisposition to ASD, and this is then further affected by environmental factors (Russell, Kelly & Golding, 2009).

ASD is a highly hereditary disorder with a sibling reoccurrence rate of 3 – 8% (Russell, Kelly & Golding, 2009). Gene studies have shown the contribution of genetic factors to ASD however these have been proven not to be enough (alone) to lead to individuals developing ASD (Russell et al., 2009). Some environmental factors that have been shown to contribute to individuals having ASD are advanced parental age and low birth weight (American Psychiatric Association, 2013).

Moreover, risk factors that are thought to contribute to ASD are exposure to dangerous chemicals during a child's development, viral infections during gestation, dysregulation of the immune system as well as a mother's exposure to psychosocial stress during pregnancy (Pisu, et al, 2019). Lay individuals also have additional hypotheses as to the contributing factors to ASD and these are measles, mumps and rubella (MMR) as well as the mercury found in vaccines (Russell et al., 2009). It must be noted that none of these have been proven to be a primary cause of ASD.

2.3.2 Prevalence

With the increase in ASD research and the need to gain more knowledge about the disorder, more information has become available. Previously it was believed that ASD occurred more frequently in white upper middle-class families, but the current epidemiological evidence indicates that the prevalence of ASD is the same regardless of race, ethnicity or country of origin (Tincani, Travers & Boutot, 2009). Thus, the likelihood of individuals having ASD is the same regardless of where they are situated in the world.

There has been an increase in the prevalence rates worldwide with Russell et al., (2009) stating a 556% increase in the United States of America. They continue to state that currently there is a greater prevalence of ASD than cancer and Downs Syndrome (Russell et al., 2009). Rutter (2005) states that there are currently between 30-60 individuals diagnosed with ASD per 10 000 individuals. According to Autism Speaks (2018), the CDC recognised a 15% increase in ASD prevalence in the USA over three years (2012-2015). Globally it has been established that ASD is unevenly distributed between sexes, with more boys being diagnosed than girls at a ratio of 4:1 (Sadock, Sadock & Ruiz, 2015).

Although little is known about the prevalence rates within African countries, Moolman-Smook, Vermoter, Buckle and Lindenberg (2009) argue that, since ASD has the same likelihood of affecting an individual, regardless of race and socioeconomic status, then the prevalence rates that have been established in western countries may be transferred to African countries as well. Currently, there have been no ASD prevalence studies that have been conducted in Sub-Saharan Africa, including South Africa (Mokitimi et al., 2019). Sadock, Sadock and Ruiz (2015) state that prevalence rates will differ according to the age groups in a given population as many children are diagnosed later than expected. This view provides for a more realistic view of prevalence rates within a given country.

It appears that ASD prevalence rates in non-western countries are still much lower that western countries. Samadi and McConkey (2011) believe that this may be due to a variety of reasons ranging from available healthcare resources to parents' failure to seek healthcare services due to the stigma that is attached to having a child with a disability. However, culture has been shown to play a role in ASD, ranging from diagnosis to familial experiences of the disorder. This is discussed in more detail below.

2.4 Research

Previously ASD was only thought to affect individuals from high resource and technologically advanced countries; this meant the exclusion of individuals from low income countries (such as those found in Africa). This has had a variety of implications in understanding ASD in non-western settings.

Currently very little research has been geared towards understanding ASD in the African context; however, there has been an increase in the past decade. In a systematic review conducted by Ababukar, Ssewanyana and Newton (2016) of literature from 1935 – 2016 only 47 studies were found suitable. Inclusion criteria were as follows: studies had to be empirical and conducted on humans; ASD had to be the main condition, and studies had to be conducted within sub-Saharan Africa (SSA). The majority of the studies were published between 2008 and 2016 with no studies published prior to 1974. During this time, South Africa and Nigeria produced the most research, each producing 25.51% and 11.23% studies respectively (Ababukar et al., 2016). This is evidence of the limited focus that has been placed on ASD research in Africa. One may posit that this is reflective of the importance (or the lack thereof) that has been placed on the disorder within the African context.

Due to the limited research that is currently available, the understanding of how ASD presents itself in Africa still needs to be investigated. According to Nwoye (2015), it is of utmost importance to view and understand mental illness within an African paradigm which encompasses the philosophical assumptions of African people.

However, Eurocentric research should not be disregarded, but the knowledge that may be gained from it cannot be transferred without taking into account the new context in which it is to be used. This is especially true when looking at mental illness "…Eurocentric perspective is not considered to be completely wrong; however, its explanatory power is limited, since its Bio-Psycho-Social (BPS) Model is unable to accommodate some aspects of the African experience of psychopathology or psychological illness" (Nwoye, 2015, p. 306). This is because the BPS model states that an individual’s illness is due to a combination of factors such as biology, psychology and the environment. It is therefore a combination of these three factors that lead to an individual displaying certain behaviours. It is in looking at mental illness in this way that mental illness causes may be understood and subsequently the appropriate interventions may be employed. In order to account for the African experience of psychopathology it is then important to make provision for the inclusion of the spiritualistic perspective to the BPS Model when dealing with African experiences of mental illness (Nwoye, 2015).

Understanding ASD and its consequences using the Afrocentric paradigm is crucial as the cultural and societal behavioural norms in Africa are markedly different from those in western countries. It may be posited that the failure to adequately incorporate an African understanding of ASD may have huge consequences when looking at the diagnostic and treatment process.

This is due to the large role in which culture affects individuals, not only in their understanding of themselves but also in how they view and understand their positioning in the world, mental illness and their experiences. This will be discussed further below.

2.5 Culture and meaning systems

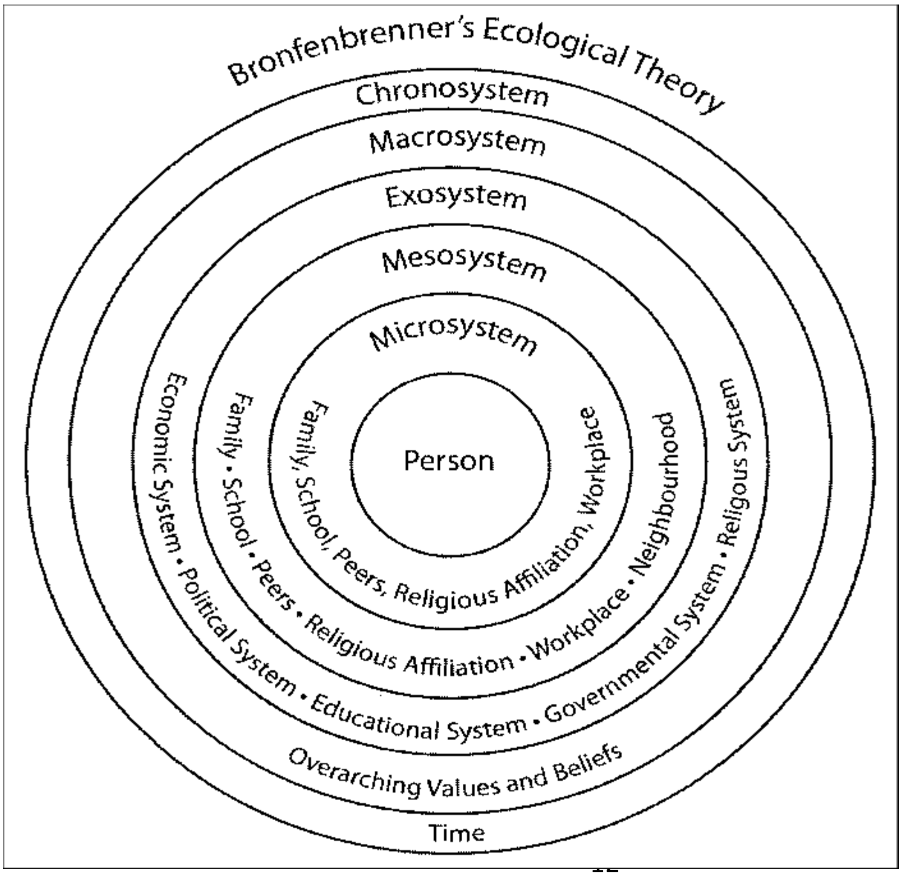
Collective representations are knowledge systems that are shared by groups and are inclusive of linguistic and cultural knowledge. It is these systems that determine a group’s and therefore an individual’s knowledge, values and behaviour (Kronenfeld, 1997). “It is the combination of shared experiences by shared minds in shared contexts and interactive and communicative interdependence that keeps these individual representations close enough to one another to function as single systems distributed across many individuals” (Kronenfeld, 2017, p. 37). Given these cultural ways of knowing, it follows that communities have created narratives, rooted in cultural beliefs, in order to understand the existence of disabilities. These understandings of disabilities lead to individuals viewing others with disabilities in culturally specific ways (Bunning, Gona, Newton & Hartley, 2017).

The culture an individual belongs allows individuals to not only behave in certain ways but to also give meaning via language that is used. Many bilingual individuals then may be seen as belonging to multiple cultures and are therefore able to switch among different cultural systems when events require them to do so (Kronenfeld, 1997). This is particularly interesting in a multicultural, multilingual country such as South Africa where many individuals not only adopt their own culture but others in different environments.

This means that an individual may experience one event and attribute multiple meanings to it depending on the cultural knowledge that they use at that time. The flexibility that this requires is dependent on the individual and their interaction with the group and their stake in it (Kronenfeld, 2017).

Bronfenbrenner’s ecological systems theory recognises the need to understand the individual in relation to the environment in which they interact, this is inclusive of their culture (Bronfenbrenner, 1979). Individuals and their views on disability are therefore a product of the multiple systems, proposed by Bronfenbrenner, interacting together. Bronfenbrenner recognises five systems: microsystem, mesosystem, exosystem, macrosystem and the chronosystem. The microsystem refers to the individuals and groups that immediately affect the individual (Paat, 2013). The mesosystem is the interconnections between the microsystems (Bronfenbrenner, 1979). The exosystem refers to the links between a social setting that an individual does not actively participate in and the individual’s immediate context; these may have an indirect influence on the individual (Bronfenbrenner, 1979). The culture in which the individual lives in is the macrosystem (Bronfenbrenner, 1979). Lastly, the chronosystem is comprised of sociohistorical circumstances and environmental events (Bronfenbrenner, 1979). *Figure 1* is an illustration of this system.

Figure 1



From “Moving “eco” back into socio-ecological models: A proposal to reorient ecological literacy into human developmental models and school systems” by Nick Stanger, 2011 (https://www.researchgate.net/figure/An-adapted-illustrated-model-of-a-Bronfenbrenners-Ecological-Theory-Adapted-from_fig1_285232380)

2.6 ASD knowledge and beliefs

ASD knowledge in Africa is currently limited in many spheres of society, ranging from lay individuals to healthcare practitioners. This may be due to a variety of factors which are not limited to the amount of research that is currently available as this is an area that is still being researched and other factors may arise.

In a report by Ruparelia et al. (2016), it was noted that at a conference with African country representatives there was a lack of ASD awareness in many of the countries. This led to many children receiving alternative diagnoses or no diagnosis at all. In Nigeria research found that ASD was believed to be caused by supernatural causes or a mother’s wrong doing (Ruparelia et al., 2016). These beliefs were not adopted by lay persons alone but also by healthcare practitioners in the country.

This was further reiterated in a study conducted by Gona et al., (2015) in Kenya; it was found that many parents and healthcare practitioners shared common beliefs as to what caused ASD in a child and how it would then be treated. Many of the participants indicated that ASD stemmed from supernatural causes such as witchcraft and evil spirits (Gona et al., 2015). The same sentiments were shared regarding treatment, where both traditional healers and medical practitioners were consulted in the treatment of the child (Gona et al., 2015). “The results further suggest that the socioeconomic status of people in this region is less relevant than the impact cultural beliefs and traditional practices have on the people” (Gona et al., 2015, pp. 10).

According to the White paper for Transformation of Health Systems in South Africa (Department of Health, 1997) it is imperative to understand mental illness using an approach that incorporates biological, psychological, social and cultural components of an individual’s understanding of the illness in order to provide a holistic treatment (Mavundla, Toth & Mphelane, 2009).

It may be posited that the lack of knowledge, in conjunction with cultural beliefs surrounding the disorder, may lead to many parents turning to alternative methods in order to gain assistance for their children. In Africa, it is common for parents to take their children to a spiritual or traditional healer for explanations and interventions for ASD (Bakare & Munir, 2016; Gona et al., 2015; Ruparelia et al., 2016). Although there is currently no literature on the effectiveness of the interventions, they should not be disregarded. Ruparelia et al (2016) state the need for the inclusion of traditional and spiritual healers in ASD management and support for the family. The bio-psych-social-spiritualistic (BPSS) model incorporated in the Afrocentric paradigm, therefore, allows for this inclusive process to take place as it allows mental illness to be treated and managed in light of the cultural beliefs parents and caregivers may have.

Moreover, there is a need for ASD awareness not only for healthcare practitioners but also for educators and communities. In terms of educators, awareness needs to be increased as many children only get diagnosed during these formal years. Educators not only need to be aware of symptomology and how it presents in African children but also how to manage the disorder. In a study conducted by Hutton, Mitchell and Van der Riet (2016) it was found that educators associated ASD with a lack of speech. This is consistent with research that has been published within the African context where a majority of the cases reported have been non-verbal.

With regards to communities, the need for awareness is vital. As African culture is based on collectivism, it is not unusual for extended family members or community members to assist with child rearing. Community based awareness may, therefore, lead to the earlier identification of ASD.

2.7 Assessment Tools

Due to the research that has been previously published, many ASD assessment tools have been developed for high income countries in the west. However, with the increase in knowledge and research over the past decade it has become resoundingly clear that assessments need to be developed for other cultures. This is due to different cultures having varying views of what is considered ‘normal’.

With regards to a disorder such as ASD, where the diagnosis is reliant on observation and clinical judgement, it is imperative to have assessments that take into account a particular culture’s behavioural norms. This is because social interaction and communication are socially constructed and therefore the norm in one society does not always align with that of another. Grieve and Foxcroft (2013) state that there is no culture-free assessment, but clinicians may be culture fair when using certain assessments as culture not only influences how individuals learn but also how individuals behave and think. Many of the assessments that are currently being used within the African context are being transferred to Africa with very few taking into account the cultural variabilities.

In a study conducted by Chambers et al. (2016) it was noted that cultural variations must be accounted for. For example, lack of eye contact is a symptom in children with ASD, however, it was noted that in the IsiZulu community a child's lack of eye contact with adults is considered normal and respectful, and as such when dealing with children of this cultural background eye contact must not be considered a symptom. This was further reiterated by another study conducted by Wilford (2013) in Durban, KwaZulu-Natal, South Africa, where it was found that the Autism Diagnostic Observation Schedule (ADOS) was not completely accurate in diagnosing Zulu children with ASD. This is due to cultural and socialization aspects, as ways of interaction and communication are culturally specific (Wilford, 2013). In addition, the socialization of Zulu children was markedly different from that of the Indian and white children. Zulu children were socialised to not be outspoken and interact in a 'confident' manner with adults (Wilford, 2013). Wilford (2013) also noted that in a country such as South Africa it is important to note who the clinician administering the assessment is due to the status that may be attributed to them, which would possibly change the interactional dynamics. Wilford (2013) argued that it is important to take all of the above into account when administering the ADOS in certain populations as it is based on qualitative observations, and these may be affected by a variety of factors and therefore skew the results if culture and socialization are not accounted for. Accounting for the cultural variations when making an ASD diagnosis is therefore important as it allows for a more valid diagnosis.

2.8 Age of Diagnosis

Currently, the age at which ASD may be diagnosed is between 12 and 24 months. However, different areas of the world have differing ages at which an initial ASD diagnosis is made. In a study done by Mandell, Ittenbach, Levy and Pinto-Martin (2007) in the United States of America (USA) the age of diagnosis was affected by race, and it was found that non-white children were more likely to receive another diagnosis, such as ADHD or obsessive-compulsive disorder (OCD), before a formal ASD diagnosis was made.

Munir and Bakare (2011) noted that children in Nigeria were more likely to receive an earlier diagnosis if the symptoms were severe enough. One of the first notable symptoms was a delay in communication and language, which prompted parents to seek medical intervention (Samadi & McConkey, 2011). In a study conducted by Franz et al (2018) it was found that 94% of the

ASD cases brought to a Western Cape tertiary paediatric clinic were non-verbal. It may therefore be posited that parents appear to seek help when there are language delays.

Moreover, Bakare and Munir (2011) noted that most ASD cases in Africa were only reported about children who were well above the age of eight. This is when children generally had their first practitioner visit and when formal education commenced (Bakare & Munir, 2011). This is relatively late when bearing in mind the ideal age for intervention. This was further reflected in another study conducted by Bakare and Munir (2016) who reported that children with ASD in Africa were diagnosed relatively late compared to those in high income countries. This was due to the fact that the identification at this age is more dependent on parents and close community since children have not started formal schooling at this stage (Bakare & Munir, 2016).

Currently, in South Africa, there are policies in place within the Department of Education to assist with the screening and placement of children with special needs. These are the Screening, Identification, Assessment and Support (SIAS) policy which provides for the access to quality education of vulnerable learners, as well as White paper 6 which recognises the need for inclusive education (Department of Basic Education, 2001; Department of Basic Education, 2014). As many children are diagnosed once they are at school going age it may be posited that these policies may assist in children being diagnosed quicker once they have entered the education system. However, it must be noted that within South Africa the national policies that have been put in place do not appear to be implemented at the provincial level (Mokitimi et al., 2019).

It must be noted that according to Sadock, Sadock and Ruiz (2015) late diagnosis is typically seen with children of average intellectual functioning and mild language delays as they may develop adaptive skills until social demands exceed their capabilities. In addition, if the identification markers of these children are not severe they may be easily missed (Bakare & Munir, 2016).

Early diagnosis is essential as it allows for interventions to be implemented earlier. In order for interventions to be the most effective literature suggests that interventions are started as soon as possible (Baron-Cohen et al., 2000). These vary from pharmacological intervention to psychosocial interventions. In treating the symptoms of ASD it is important to use both of these intervention techniques in assisting individuals with ASD (Weis, 2014).

2.9 Healthcare Resources

In many developing countries, such as South Africa, research has shown that there is a large delay in the diagnosis of ASD due to a variety of reasons. One of the most prominent is access to healthcare resources (Bakare & Munir, 2011). Many African countries have high rates of poverty and unemployment, which, when coupled with diseases that take a physical form, lead to mental health issues being made a low priority. This is evident not only in the research that has previously and is currently being published but also through the knowledge that healthcare practitioners have on disorders such as ASD.

There appears to be little focus placed on neurodevelopmental disorders within the healthcare system in South Africa. This may be seen when looking at the Department of Health website that lists a variety of mental disorders ranging from Attention Deficit Hyperactivity Disorder (ADHD) to Generalised Anxiety Disorder (GAD) with no mention of ASD and other neurodevelopmental disorders (Department of Health, 2019). This may be due to a variety of reasons beyond the scope of this research. The lack of focus on ASD in healthcare systems is a challenge in a time where autism prevalence is on the rise worldwide. The knowledge of the disorder itself is therefore crucial in early recognition amongst not only parents but also healthcare practitioners.

Due to many public health care facilities being overcrowded, under resourced and short staffed this may mean that many children may go undiagnosed. This may pose a huge problem considering that 96% of children living in South Africa rely on public health care facilities (Statistics South Africa, 2018). Due to poverty in South Africa, many parents cannot afford to send their children to private healthcare facilities.

Many healthcare facilities in low income countries are under resourced not only with tools but also with staff which may lead to non-physical disorders being unidentified. Ruparelia et al. (2016) recognise the need to develop simple and concise ASD screening tools that may be used in clinics and hospitals. They further suggest that these screening tools be administered on children during their 18-month visit, to healthcare practitioners, for immunisation (Ruparelia et al., 2016). This is may be posited to reduce the current age of diagnosis in African countries. Hugo et al. (2003) also recognised the issue of non-detection of mental illness in general practitioner visits as well as primary care facilities.

There is therefore not only a need to increase awareness in Africa but also a need for the development of new policies directed at neurodevelopmental disorders as well as culturally and contextually appropriate tools (Munir & Bakare, 2011; Ruparelia et al., 2016).

2.10 Parental experiences

Much of the research that has been conducted on parents' experiences does not consider the experiences of black African parents' having their children diagnosed with ASD. This is an important area to review due to the lack of knowledge that surrounds the disorder. Many people in Africa do not know much about mental disorders and their causes and subsequently, parents, amongst other factors, are generally said to be the cause of their child's mental disorder (Mthombeni & Nwoye, 2018). Understanding black African parent experiences would, therefore, provide invaluable insight into cultural meanings attributed to the disorder, alternative interventions as well as the impact the disorder has on the family.

2.10.1 Stigma

According to Byrne (2000, p. 65) "Stigma is defined as a sign of disgrace or discredit, which sets a person apart from others" (. It has been found that many parents within the African context are stigmatised by their communities due to having a child with ASD (Bakare & Munir, 2011; Costa, Steffgen & Ferring, 2017; Schlebusch & Dada, 2018). This may be attributed to not only a lack of knowledge but also cultural beliefs about the disorder (Bakare & Munir, 2011). Mavundla et al (2009) state that the biggest contributor to mental illness stigma is misinformation and this may be alleviated through community-based education.

The stigma that parents may experience is described as 'courtesy stigma' as it has a negative impact on the parents due to their association with a stigmatised child (Corrigan & Miller, 2004). 'Courtesy stigma' occurs when an individual is related to a stigmatized person and by extension, both are treated the same by society at large (Angermeyer, Schulze & Dietrich, 2003). Individuals experiencing this kind of stigmatisation from society may experience isolation, social exclusion, stereotypes and discrimination from those around them (Byrne, 2000). In addition, it may lead to feelings of shame, blame and secrecy (Byrne, 2000). Mavundla et al. (2009) state the stigmatisation experienced by primary caregivers of individuals with a mental illness is a primary contribution to the negative experiences they may report. In a study conducted by Wahl and Harmann (1989 as cited in Angermeyer et al., 2003) the relatives of mentally ill individuals reported having experienced courtesy stigma, which led to damage to their self-esteem, difficulties maintaining friendships, as well as finding a job.

This stigmatisation experienced by individuals (or their caregivers) may contribute to delayed help-seeking as well as noncompliance (Mavundla et al., 2009).

2.10.2 Parents' experiences of diagnosis

There are a variety of reasons (many of which have been mentioned above) that contribute to a parent's understanding of the diagnosis. Due to the understanding of ASD in Africa, it is important to take into account the parents' cultural beliefs when making a treatment plan (Mavundla et al., 2009).

As described above, the age at which a child may be diagnosed with ASD is dependent on a variety of factors such as healthcare resources, detection of symptoms as well as ASD knowledge. A study in France found that parents noticed developmental delays in their children around 18 months (Chamak, Bonniau, Oudaya & Ehrenberg, 2011). However, many paediatricians denounced fears and anxieties attributing developmental delays and behavioural problems to inadequate parenting (Chamak et al., 2011). Another study conducted in KwaZulu-Natal, South Africa found that many health care practitioners were unwilling to make an early diagnosis (Mitchell & Holdt, 2014)

Another factor that must also be accounted for is the parent's socioeconomic status. In a study conducted by Cohen and Miguel (2018) it was found that the parents' socioeconomic status had a high correlation with access to ASD services. In addition, the socioeconomic status provided a better understanding of whether individuals would have access to services than the severity of ASD symptomology (Cohen & Miguel, 2018). This has implications for South Africa where 94.1% of all children regarded as living in poverty were black Africans (Statistics South Africa, 2018). KwaZulu-Natal currently has the highest burden of child poverty within the country.

The diagnosis of ASD can have a huge impact on parents, not only in their understanding of the disorder but also in how to manage it. Abbott, Bernard and Forge (2012) conducted a study looking at parental experiences in the communication of the diagnosis to parents in the UK. The study found that most of the parents felt anxious before the diagnosis was given and were faced with information overload when the diagnosis was being communicated to them (Abbott et al., 2012). Abbott et al. (2012) also recognised the stress that affects parents during the diagnostic process and state that these feelings may continue long after the diagnosis has been made.

In addition, it is not unusual for parents to experience grief when their child has been diagnosed with ASD, this may include feelings of sadness, guilt and frustration (Gordon, 2009). These feelings have been found to stem from parents mourning the loss of the child they thought they had (Sicile-Kira, 2014). These feelings vary over time with parents, however, they have been found to be the strongest with parents of newly diagnosed children (Wayment & Brookshire, 2018). It must be noted that although these feelings are regarded as negative, they do act as a catalyst for parents and they give them the drive to be more proactive (Sicile-Kira, 2014).

Mavundla et al (2009) argue that in an African setting it is important to incorporate the cultural understandings of mental illness when educating parents after a diagnosis has been made. In addition, they recognise the importance of integrating traditional practices in treatment when these do not pose any harm (Mavundla et al., 2009). This provides for a more holistic treatment process that includes African culture.

2.10.3 Parents' experiences of treatment

In understanding the experiences that parents have, it is also of some importance to understand their reasons for choosing certain interventions over or in conjunction with others. This is particularly important in an African context where western models of treatment are not the only routes parents may take.

In South Africa the Traditional Health Practitioners Act, 2007 was established to regulate traditional health practices as well as protect citizens (Department of Health, 2008). This, simply put, became the recognition of traditional practices in South Africa. It is important as the understanding of mental illnesses also has cultural influences and therefore treatment.

The factors affecting which intervention may be chosen by a parent is the result of a number of factors such as: parental demographics, recommendations by health care practitioners, availability, cost, accessibility and effectiveness, to name a few (Wilson et al., 2018). It is therefore important to have ASD interventions that take into account certain factors, especially those that are more practical. Wannenbury and van Niekerk (2018) state that it is important to have ASD interventions that are financially feasible. Currently, many of the interventions cost more than an average South African can afford (Mitchell & Holdt, 2014).

Furthermore, in understanding assisting parents with which interventions are chosen health care practitioners must bear in mind the culture of an individual. Traditional or cultural practices must, therefore, be incorporated in treatment plans if a parent chooses to do so (Mavundla et al., 2009).

2.10.4 Wellbeing

Parental wellbeing has been found to decline significantly when a parent is raising a child with ASD. Costa et al. (2017) state that parents raising a child with ASD are at a greater risk of developing mental health problems, particularly depressive symptoms, than those raising children with no disorders. They argue further, that these parents have an increase in stress and a decrease in overall mental wellbeing. This is due to a number of factors such as stigma, marginalisation, isolation, lack of understanding from others, lack of support and financial strain. Stress that is felt by parents and families may also be dependent on the manner in which the diagnosis is communicated to them by healthcare practitioners and others (Abbott et al., 2012; Chamak et al., 2011).

Within the African context financial resources appear to be a major contributing factor in the decrease in wellbeing of parents raising children with ASD or a mental illness (Schlebusch & Dada, 2018; Mitchell & Holdt, 2014, Mavundla et al., 2009). In a study conducted by Mitchell and Holdt (2014) six of the seven mothers interviewed (middle class) had stopped working to provide full time care for their children with ASD. This may not be possible for low-income families, "For many low-income families, the expectations of not working, accessing therapy services and making adaptations to accommodate their child with ASD may be difficult to achieve" (Schlebusch & Dada, 2018, p. 36). Financial resources a family has consequences not only for the parent and child with ASD but the family as a whole.

Schlebusch and Dada (2018) argue that the positive and negative cognitive appraisals parents attribute to their children's ASD impact on their overall wellbeing. Positive appraisals have a more positive outcome and assist parents with adjusting to raising a child with ASD (Schlebusch & Dada, 2018). Cognitive appraisals of stressful life events shape the way in which individuals will react to them (Mikolajczak & Luminet, 2008). These interpretations of having a child with ASD are greatly influenced by culture and how an individual's culture defines disability (Schlebusch & Dada, 2018). Therefore, understanding culture and how mental disorders are understood may be beneficial in understanding parental wellbeing.

2.11 Summation

The aim of the literature review was to give a better understanding of ASD and the multitude of factors, within the African context, that affect diagnosis and parental wellbeing.

Considering the above, it is evident that there is a need to include Africa in ASD research. In doing this, western models should not be the only one used but rather the issues presented should be dealt with using Afrocentric perspectives of mental illness which emphasises the inclusion of culture in understanding, diagnosing and treating mental illness. The need to explore parental experiences of having a child with ASD is therefore important as it could go a long way to reveal a variety of factors that affect families in developing countries, particularly black people. It could be posited that with in-depth analysis of transcriptions obtained from interviews, one could gain an understanding of perceived causes, as well as, cultural and medical interventions of ASD within the black African community. Likewise, this research could lead to an understanding of the implications that may be present when a parent is raising a child with a mental illness.

Chapter 3: Methodology

3.1 Introduction

The following chapter presents the methodology that was used in this study. This includes the aim of the study, research questions, research design and sampling. The data collection process and its challenges are also discussed. In addition, the way in which data was analysed is explained. Lastly, the ethical considerations and issues that came about during the process of the study and how these were dealt with are discussed.

3.2 Research design and aim of the study

The aim of the study was to gain a holistic understanding of the experiences of black African mothers with children with ASD. This was inclusive of experiences leading to the diagnosis, during the diagnostic process, and after their children had received the ASD diagnosis.

In understanding these experiences the aim of the study was to get a view on the understandings of ASD in the black South African community; gain knowledge on how black mothers in South Africa understand ASD; as well as to explore the differences in alternative understandings and treatments used within the African context. In addition, the study sought to look at the available aid that is available for both children and mothers within South Africa.

In order to allow for the richest information to be obtained from the participants, a qualitative design was employed. The qualitative method used was semi-structured interviews that had open-ended questions. This format allowed for further exploration into themes that arose that were invaluable to the research (Hines, 2012). In addition, it ensured that individuals could fully discuss their experiences whilst the researcher immersed herself in these narratives (Hines, 2012). Additionally, interviews allow for new rich data to be extracted through thematic analysis, this is especially important in cases where there is not much available literature on a given topic (Hines, 2012).

A qualitative design was suited to this research as it allowed for the immersion of the researcher into participants' narratives in order to understand the social phenomena (Schensul, 2012). In addition, this allowed for an examination of the language used (and meaning given to words) when describing the experiences.

Moreover, a qualitative approach was the most suitable for this study as it allowed the researcher to gain extensive qualitative information. This was particularly important as it was the experiences that the mothers had that the researcher attempted to analyse and ultimately understand. A qualitative semi-structured interview also allowed for more data to be extracted where necessary.

A qualitative approach allowed the aims of the study to be met more efficiently, as many of the experiences that mothers had were explored deeply.

3.3 Sampling

3.3.1 Inclusion criteria

This study only interviewed black African mothers living within the Pietermaritzburg region, KwaZulu-Natal, South Africa (inclusive of the Greater Edendale Area). The term ‘mothers’ was used to include primary caregivers and legal guardians. However, all participants were biological mothers of the children. Only mothers who were caregivers at the time of diagnosis were considered as some questions involved experiences prior to the child’s diagnosis.

All mothers had a child formally diagnosed with ASD. For children diagnosed before 2013, using the DSM IV, they must have had a diagnosis of autism, Asperger’s syndrome or pervasive developmental disorder (PDD). These have been consolidated into Autistic Spectrum Disorder following the introduction of the DSM V in 2013 (American Psychiatric Association, 2013, p. xlii). No participant in the study had a child diagnosed prior to 2013.

All participants were English or IsiZulu speaking as these are the most spoken languages in the KwaZulu-Natal province (Statistics South Africa, 2011). Statistics South Africa (2011) recognises that 78% of the population speak IsiZulu as a first language and 13% speak English as a first language. The researcher is bilingual and was, therefore, able to conduct the interview in the participants’ preferred language, although many participants code switched.

3.3.2 Sampling method

In conducting this research three sampling methods were used; these are convenience, purposive and snowball sampling. Convenience sampling is the use of cases that are easily accessible (Neuman, 2014). In terms of the study only individuals living in Pietermaritzburg were used as the researcher was located there. Purposive sampling is used when sampling hard to reach populations that fit within a particular criteria (Neuman, 2014). All mothers within the study had to fit within the criteria specified in 3.3.1. Snowball sampling was also used as a means to recruit participants (Geddes, Parker & Scott, 2017). This type of sampling uses the networks that individuals are connected through in order to get access to other individuals (Neuman, 2014). Schools and organisations known to work with children with ASD were contacted by sending a letter (Appendix A). Organisations were selected based on their work with children that have ASD as well as their parents. A letter (Appendix A) was then sent to each school or organisation asking the principal or person in charge to make parents of children with ASD aware of the study to be conducted and to pass on the researchers' information (Appendix A) to those that would like to participate. The recruitment letter (Appendix A) was given to the interested parents and they had the option of contacting the researcher (contact information available on the recruitment letter).

Geddes et al. (2017) argue that snowball sampling is often used in research when recruiting hard to reach participants including those with serious illnesses. This was the case in terms of this research where not much has been studied about ASD in Africa and the relatively low known prevalence. Snowball sampling was therefore useful in the context of this study as it was posited that there would be very few people that would be found in Pietermaritzburg, as it is a smaller city, and the number would be substantially smaller when racial categorisation was employed. Therefore, snowball sampling proved to be useful as people within the group were closely affiliated as many of them had children that attended the same school. Although many schools and organisations were contacted, participants only came from two schools within Pietermaritzburg, one private and one public. Only one child within the study was not at school.

Only two mothers responded to the recruitment letter, another participant was referred to the study by another professional and this mother passed on the researchers' information to other mothers who would be interested in the study.

Initially, a sample of six to eight participants was proposed for this study. Robinson (2014) suggests that qualitative research using such methods should have between three and 16 participants. Due to the difficulty in finding participants for the study, only six participants were recruited. All participants were female biological mothers of the children. Although a seventh participant shared an interest in being a part of the study she was not interviewed due their child having not received a formal diagnosis from any healthcare practitioner. *Table 1* illustrates the details of the participants.

Table 1

Participants' demographic information

Mother Pseudonym	Mother Marital Status	Child Pseudonym	Child Gender	Child Age	Child Age at Diagnosis
Tina	Single	Njabulo	Male	10	5
Silindile	Married	Ziphe	Male	8	4
Thando	Single	Zothani	Male	7	3
Bathabile	Single	Ntsika	Male	7	4
Ntobeko	Single	Zama	Female	6	4
Asanda	Single	Nkululeko	Male	10	4

3.4 Data collection

The qualitative method used was a semi-structured interview that had open-ended questions. This format allowed for further exploration into themes that arose that were invaluable to the research. In addition, it ensured that individuals could discuss their experiences freely whilst the researcher can immersed themselves in these narratives. Interviews additionally allowed for new rich data to be extracted through thematic analysis, this was especially important as not much available literature was available (Hines, 2012).

Data was collected via an interview for all six participants. Questions that were asked during the interviews (Appendix B) were developed in a way to try and gain the most information from participants, inclusive of parental, familial and communal experiences. This allowed the researcher to gain a better understanding of how the ASD diagnosis not only affected the mother but also the family system. These questions also allowed for individuals to speak about experiences that went beyond the traditional BPS model of mental health diagnosis.

All participants were contacted telephonically and interviews were scheduled according to their availability. Interviews lasted approximately 40 to 90 minutes. All interviews were recorded and each participant had one interview. Interviews were recorded to allow continuous undisrupted communication between the researcher and the participants and to assist in the analysis of the data.

The interviews were conducted in various settings due to the demands of the participants' lives and travel difficulties. Two participants were interviewed at home, two were interviewed at work, one was interviewed telephonically and one was interviewed at the Child and Family Centre (CFC). The telephonic interview was conducted due to the participants' busy schedule and time constraints. All relevant information (consent form, recruitment letter and letter for psychological services) was then relayed and emailed to the participant. In conducting the interviews the participants had ensured that there were no disruptions both at home and at work. All interviews were conducted in a room with only the researcher and participant present.

At the beginning of each interview, participants were informed about what the study entailed, confidentiality and the option to withdraw from the study were discussed. The interviews were recorded using a Dictaphone. The telephonic interview was recorded using the researchers' cell phone as it allows for call recordings. Recording interviews ensured that the researcher did not miss anything, this is useful for the analysis process.

3.5 Data analysis

All interviews were recorded and subsequently transcribed for in depth analysis. All transcriptions were done by the researcher as she was bilingual and could write in both English and IsiZulu. The transcribed data was analysed using thematic analysis (Winston, 2012). This approach is used in qualitative data analysis and requires the researcher to interpret data sets through critical thinking, questioning and categorising (Winston, 2012). Smith (1992, as cited in Winston, 2012, p. 129) states that this form of analysis allows "for coding verbal materials to make inferences about characteristics and experiences of persons, social groups, or historical periods."

Thematic analysis allowed the researcher to extract common themes from the data. These then allowed the researcher to make appropriate inferences regarding the group in question as well as their experiences. In using thematic analysis, the researcher develops codes and themes that may be used in the understanding of the data that has been acquired (Winston, 2012).

In order to meet the trustworthiness criteria (which will be discussed later in the chapter), thematic analysis was conducted in phases as set out by (Nowell, Norris, White & Moules, 2017). These were familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report (Nowel et al., 2017).

3.5.1 Data management

In order to start the data analysis phase of the study all interviews were transcribed verbatim by the researcher through listening to the interviews and typing out was being said. All interviews were transcribed in their original languages. This was done by the researcher as she is bilingual and speaks both IsiZulu and English. Interviews in IsiZulu were then further translated into English to allow the researcher to work with the data in an easier manner. Data was then archived for later use.

3.5.2 Familiarisation and immersion

The researcher was able to familiarise with and immerse herself in the data through a variety of ways. Through the transcription process data became more familiar to the researcher. Thereafter the text was read and re-read several times in order to gain a meaningful understanding of the texts. In doing the transcriptions and reading them multiple times the researcher also reflected on the interviews and any key points were noted.

3.5.3 Generating initial codes

Once familiarisation had occurred initial codes were generated. This was done by highlighting important text and noting codes that had arisen. Once coding had occurred the coded data was extracted.

3.5.4 Searching for themes

In searching for themes across the data, the researcher familiarised herself with the data and extracted codes from it. This was done by re-reading the extracted data and tabulating them in order to get a better understanding of the emerging themes. *Table 2* is an example of the tabulation of codes and themes that arose during this process (participants names have been redacted).

Table 2

Tabulation of codes and themes

Support		
Family and Friends	[redacted]	And as a family and I mean when he's with his uhm dad's side they'll notice something that is you know different or is an improvement so ja, so I think they're they're very supportive
Family and Friends	[redacted]	But there is no one or who talks to me or speaks to me about it or or speak maybe with [redacted] mom sometimes maybe I speak to [redacted] mom but other times I see that Thabiso's mom she is single and I'm I'm married, it ends up not being the same that we give each other advice that isn't in line you see that?
None at all	[redacted]	No, because no one ever calls me to ask maybe how the child is, how is school going, how is he behaving now, what is he doing now, no on. Even my husband he doesn't even ask

3.5.5 Reviewing themes

Data that was initially extracted to form part of the themes was reviewed to determine if it fitted coherently. Any codes that overlapped into multiple themes were removed and allocated to the theme that accurately reflected the common meaning of certain experiences. Themes that had been generated but did not strongly convey the experiences of the participants were removed.

The initial data was then read again to ensure that no important information was left out. No other codes emerged during this process and therefore no other themes were generated.

Finally, the themes were then checked against existing literature and new emerging themes from this study were identified.

3.5.6 Defining and naming themes

Once the themes had been identified they were renamed in order to show what the theme was about. Themes were then organised into a chronological order to show how each fits into the experiences the mothers had before, during and after their children were diagnosed with ASD.

3.5.7 Producing the report

It is at this stage in which the data was then used to produce the results section that follows.

3.6 Validity and reliability

Validity looks at whether the research conclusions are sound (Van der Riet & Durrheim, 2006). It is therefore important to realise any potential factors that might affect the outcome of the research (Van der Riet & Durrheim, 2006). This is particularly difficult when research involves the interpretation of experiences (Van der Riet & Durrheim, 2006). It may then not be possible to establish such factors as different contexts will yield varying results.

Reliability looks at if the results obtained in a study may be repeated to yield similar results (Van der Riet & Durrheim, 2006). However, this is not always the case in qualitative narrative research. This is because peoples' experiences are perceived to change under different circumstances (Van der Riet & Durrheim, 2006).

Lincoln and Guba (1985) therefore suggested four alternative criteria that may be used to judge validity and reliability in qualitative research. These are credibility, transferability, dependability and confirmability (Trochim, 2006).

3.6.1 Credibility

Credibility looks at whether the findings of a study are believable from the perspective of the research participant. This study involved looking at the experiences participants had and therefore findings can only be deemed credible by them. The interview process allowed for the participants to speak about their experiences and are therefore assumed to be true as they are first-hand accounts of their stories. Moreover, in order to ensure credibility within the study, the use of thematic analysis was employed to allow for the experiences to be presented in a way that kept their meaning intact. Transcripts were also read thoroughly during this process, themes that emerged are discussed in chapter four with accompanying excerpts. In addition, the findings of the study appeared to be in line with that of other research.

3.6.2 Transferability

Transferability is the degree to which the results obtained from a study may be transferred to other similar contexts. This is done by the researcher to ensure that the assumptions and descriptions of the research context are described adequately.

In regards to this study, the research design may be transferable to other similar contexts. However, the results may not necessarily yield the same results as experiences are affected by the individual and the context in which they live. They way in which an individual interprets and deals with what is happening to them is dependent on a number of factors such as culture which plays a large role in beliefs and behaviours. These experiences may, therefore, change under varying circumstances which may not be possible to replicate. It may, therefore, be posited that this study may be transferable to other individuals of the Nguni cultures living in metropolitans.

3.6.3 Dependability

This aspect looks at how reliable the results of the study are. Therefore, this is to say that if the study was replicated in the exact same manner with the same participants, would the results be the same. In order to ensure this, a researcher must account for the changing context within the research.

Rapport was established with all participants before the interviews were conducted and this allowed the participants to speak openly with the researcher. However, it must be noted that some participants were reluctant to share experiences regarding traditional healers and this may be due to the researchers' age or perceived 'rank'. Results in this regard may differ if a traditional healer were asking the questions. However, the results in the study do appear to be in line with existing research.

3.6.4 Confirmability

Confirmability looks at whether other researchers would be able to use the same methods and yield similar results, and to what degree this would be true. This may be heightened by providing clear documentation of how the researcher interacted with the data.

For this study, this was ensured by the data that was used being collected by the researcher and transcribed verbatim. Inferences made were confirmed by the use of transcription excerpts. The analysis of the data is clearly described above.

Information regarding the experiences that participants had was assumed to be true as participants recounted them themselves in a language they were comfortable with. In addition, participants were not given time limits and were allowed to speak openly about their experiences. This was further ensured by the use of open ended questions. In doing all this the study aimed to ensure the trustworthiness of the study.

3.7 Ethical considerations

There are four principles that are important in all research and these are nonmaleficence, autonomy and respect for the dignity of the persons, beneficence and justice (Wassenaar & Mamotte, 2012). These are all considered within the elements of ethical research: collaborative partnership; social value; scientific validity; fair selection of participants; favourable risk/benefit ratio; independent ethics review; informed consent; ongoing respect for participants and study communities (Wassenaar & Mamotte, 2012).

3.7.1 Informed consent

All participants were briefed before the interview started on what participation involved as well as what the research intended to study. Participants were given information forms stating voluntary participation, potential risks, benefits and the right to withdraw from the study. Information sheets also gave available resources for participants should they feel overwhelmed by the research and need any form of counselling which could be provided by the Child and Family Centre, University of KwaZulu-Natal, Pietermaritzburg (Appendix C).

The HSSREC contact information was also provided on all information sheets for complaints regarding the researcher and their methods or should clarification be warranted.

Consent forms were also given to the participants stating the nature and extent of their consent as audio recordings were utilised. Consent was formalised by participants signing the consent form after having heard all the relevant information (See Appendix D). In terms of the participant which the telephonic interview was conducted, the consent form was emailed and signed by her before the interview was conducted.

3.7.2 Collaborative partnership

Collaborative partnership is essential in social science research to encourage the researcher to conduct research with the target community. Wassenaar and Mamotte (2012) emphasise that the researcher should not conduct research that has been extensively done on the desired target population. This research could be useful in providing an insight into alternative intervention methods used by mothers of children with ASD.

3.7.3 Social value

Emanuel et. al (2008, as cited in Wassenaar & Mamotte, 2012) state that the research conducted must address issues that are important and beneficial to society.

This study was done to generate knowledge. It attempted to explore the different cultural aspects involved when a child is diagnosed with ASD as well as the larger dynamics involved during this process.
In addition,social value was ensured by conducting research that has not been thoroughly investigated. As stated above, much of the available ASD research is aimed at developed countries and at identification and diagnosis. This research looked at black African mothers experiences of raising a child with ASD which is a topic that has not been exhausted in this area.

3.7.4 Scientific validity

"The design, sample, method and analysis of the study should be rigorous, justifiable, feasible, and lead to valid answers to the research question." (Wassenaar & Mamotte, 2012, p. 14).

In answering the research topic, a qualitative design was employed. This was done to enable the researcher to gain in-depth knowledge relating to the experiences faced by black African mothers whose child has been diagnosed with ASD. An interpretive approach was used as it allowed for the immersion of the researcher in the experiences of participants' narratives to understand certain social phenomena.

The sample was selected by convenience as the researcher was within the given location and because of the availability of participants.

3.7.5 Fair selection of participants

Fair participant selection was ensured as participants were selected because they are who the research question applies. Convenience sampling as stated above was the most appropriate method as the study was primarily being conducted for educational purposes (Wassenaar & Mamotte, 2012). Not all individuals who had children were sampled due to restrictions such as location. There were dificiculties in obtaining participants and therefore the sample size was also limited. Furthermore, as the letters were sent to schools it meant that only mothers whose children were of school going age were sampled.

3.7.6 Favourable risk/benefit ratio

"A favourable risk/benefit ratio requires the fair distribution of research burdens and benefits… There are two general issues to be considered in risk/benefit determinations: (a) the probability of the harm occurring, and (b) the anticipated severity of the harm" (Wassenaar & Mamotte, 2012, p. 16). As some of the issues discussed in the interviews elicited emotional responses from the participants; counselling was made available to all participants should they need it. Counselling was to be provided for by the Child and Family Centre, University of KwaZulu-Natal, Pietermaritzburg. However, no participants utilised this service.

Due to the sensitivity of some of the issues that were discussed, to ensure confidentiality of participants no names were used in the study as well as the interview, however, pseudonyms were used. No details that may make participants identifiable are accessible to anyone but the researcher and supervisor as all work conducted by the researcher is subject to supervision. This will further protect participants from harm.

All interviews were recorded and subsequently transcribed for in depth analysis. All interviews and transcriptions are kept on the researchers' laptop in an encrypted (password protected) folder and will be disposed of after a period of five years as per requirement.

Once the study has been completed participants will receive feedback through a summarised version of the study. Participants will also receive information booklets speaking about ASD and available resources for mothers and children.

3.7.7 Independent ethics review

This study was submitted for ethics review to the University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee (HSSREC) for approval before any data collection commenced (Appendix E). Ethics approval number HSS/0891/018D.

3.7.8 Ongoing respect for participants and study communities

Ongoing respect for participants was achieved by informing and allowing participants to withdraw from the study at any point should they wish to do so. In addition, confidentiality was maintained at all times by not disclosing participants' names or any other information that would make them identifiable to others. No new information arose during the study.

Participants will receive a brief report regarding the study and outcomes. These will be posted, emailed or delivered to the participants depending on their preference.

3.8 Summation

This chapter outlined the methodology that was used in this study. It detailed the aims, research design, sampling, data collection and data analysis that was used within the study. Challenges that arose were also discussed and how these were overcome. Due to the sensitivity of the experiences, special consideration was paid to the ethics surrounding conducting a study such as this. In conducting this study it was ensured that no harm came to the participants and if sensitive information brought up emotional difficulties, counselling was provided.

Chapter 4

4.1 Introduction

The following chapter is a presentation of the results that were obtained during the analysis of the data which was obtained from the interviews. These themes are presented in chronological order starting from pre-diagnosis to post-diagnosis. All names have been changed and pseudonyms are used for all mothers and healthcare practitioners mentioned in interviews. This includes hospital names and names of certain areas within Pietermaritzburg as some of the information is sensitive.

Certain IsiZulu words and phrases have been used in this chapter. Meanings have been written in brackets next to them. Although some meanings appear to be straight forward it is the connotations that come with them that has led to them being kept in isiZulu.

4.2 Demographic Information

All the participants were the biological mothers of the children and their primary caregivers. Five of the children were male and one was female. Their current ages ranged from six to ten years old. The average age at which the children had received a formal diagnosis was four years old.

4.3 Themes

Various themes emerged during the interview process, these are depicted in *Table 3*.

Table 3

Themes that emerged during the interview process

Pre-diagnosis	Diagnosis	Post-diagnosis
Signs and symptoms first noticed	Specialists consulted	Understanding of ASD
Knowledge before diagnosis	Age of diagnosis	Family perceptions
Referral source	Maternal feelings	Relationship difficulties
	Alternative people consulted	Stigma
	Sources of information	Maternal fears
		Challenges
		Medication
		Educating others
		Support
		Advice for other parents

4.3.1 Pre-diagnosis experiences

Mothers in this study reported many understandings of their child's delayed development mainly attributing it to *ufuzo* [inherited]. With many of the mothers, a delay was noticed however these were dismissed due to the belief that a child would improve with time.

4.3.1.1 Signs and symptoms first noticed

During the interviews, all the mothers in the study stated that the first sign they noticed that warranted concern was a lack of speech in their children. However, due to a lack of knowledge many believed that this developmental delay would improve over time as this was attributed to *ufuzo* [inherited] from the father's side of the family.

> *Yes, eh. In terms of speech. His speech was very much delayed, but we only thought eh it's a traditional thing, my brother also they would say he started speaking late and his father's side they will to say the other kids had late speech so... We did not think it's something that related to autism. We just said, thought that it's just delayed speech and a bit of hyperactivity but we we really didn't think that it was autism. (Tina)*

Tina expressed that regardless of concern over her son's speech these were put at ease by her family members, due to other children in the family who also exhibited delayed speech. Family opinions, especially from elders, are taken into consideration in child rearing within African communities as child rearing is not exclusively the mothers job alone.

> *I saw, it's when he's supposed to start talking, nothing, the child isn't speaking. But e e when he was at this age, when he was 6 months, 7 months, he used to like, he used to sing. Like baby talking. He used to sing saying this and that. When he now has to start baby talk, that he's trying to talk, nothing, nothing is coming out, nothing is coming out. (Bathabile)*

Bathabile had recognised developmental delays in her son, the most prominent one being a lack of speech.

One of the mothers Silindile expressed that her concern was the lack of speech however there was nothing physically wrong with her son which contributed to her confusion.

> *He didn't speak. 3 ½ years he had never said "mama", he didn't say "baba", he didn't even call one child in the house by name. He's just quiet but he's fine there's nothing wrong with him. (Silindile)*

Several mothers reported hyperactivity in their children as being another symptom that was noticed early on.

So, as well as she had a very a hyperactive behaviour as well. (Ntobeko)

Silindile was able to describe her son's inability to stay seated, which is one of the behaviours that hyperactive children may display.

> *He used to sit wherever he was sitting and maybe he didn't want to sit stable, he's in and out, in and out he kept going around outside and he didn't want maybe on a certain day he doesn't want to sit in the house. He'll keep going around the house outside that's it. (Silindile)*

Silindile was the only participant who reported sensitivity to food as a symptom, which she noticed.

> *You know he's choosey, he's picky when he eats, and he eats in his own way. He won't eat what you make him. (Silindile)*

In addition, Thando had become worried initially when her child had seizures and that prompted her to seek assistance.

> *He had fits and he didn't want to walk then at Edendale they told me that I must wait until he is 18 months then they will be able to do a CT scan, CT scan, MRI and ECG EEG ECG something like that. (Thando)*

4.3.1.2 Knowledge of ASD

The majority of the mothers had no knowledge about what ASD was before their children received a diagnosis,

> *I did not even know that there is a thing that is called autism first of all. I didn't even know that that thing existed and he also wasn't showing any signs of a sick person you see. (Bathabile)*

Although Asanda had heard of ASD she had no knowledge of it beyond its existence.

> *No, no, it was just I think I I I came across the name but not that I ever researched about it or anything like that. (Asanda)*

Tina was the exception, as she had knowledge due to family members and a friend's children who had received an ASD diagnosis.

> *I have a friend eh I I used to stay in Pretoria, so I have a friend who struggled for a while to have children and then eventually she did have kids, so both her sons were diagnosed with autism. Ja and within the family also there is an uncle of mine whose got a daughter who is autistic, so I had a roughly an idea of what autism is. (Tina)*

4.3.1.3 Referral source

Although many of the mothers noticed certain developmental delays many of them did not seek professional help until a teacher realised the need for a child to see a specialist. It was, therefore, the teachers who were the primary referral sources in many of the instances.

> *Cause there were a whole lot of complications about that school, so I took him to another school and then almost immediately like a month after he started at that school they picked up that, the teachers picked up that you know, that something was wrong. (Asanda)*

Due to her son's behavioural difficulties, Asanda had moved him to a different school. It is here where teachers realised that her son needed to be assessed.

> *We um the teacher the one, grade R teacher that was teaching him said it could be autism. We were like what is autism? (Ntobeko)*

Ntobeko's son was referred for assessment after one of his grade R teachers had noticed that he displayed ASD symptomology.

Silindile expressed that although the teacher had an idea of what it was, no one expressed to her what they thought may be the problem with her son.

> *Then at creche that's when they saw that the child uh uh he's not normal, he's not like other kids. So, then a teacher from Zimbabwe who works there so she knows about autism. So, they didn't tell me what is this, but they called me then they sat down with me and they had videos, they had taken videos showing how he behaves, what he does. (Silindile)*

In Tina's case although there was concern over her son at school they were unsure what the difficulty could be and had assumed he was deaf, due to lack of social communication and social interaction.

> *It was at school when I was trying to get him to school then they said no no no. They initially thought that he's deaf, he doesn't hear, and then but after obviously there being eh un having undergone a couple of tests then they said no its autism he can actually he will [hear] properly. (Tina)*

Bathabile was the only mother who had taken her child for assessment without the recommendation from a teacher as she had seen an overall developmental delay. At the time her son was not reaching developmental milestones at the expected rate.

> *I could say that I saw it myself sisi, I saw it myself. Cause as that time he hadn't started creche. He hadn't started attending creches, he hadn't started all of this. He had to do everything he had to, it was still steps that children do that he has to learn these steps that he all children have to learn, walking, talking, eating you see. And the way he was, you see, that's when I first noticed. (Bathabile).*

4.3.2 Diagnostic phase experiences

4.3.2.1 Specialists consulted

The mothers in the study had varying experiences in obtaining a diagnosis for their children. Many saw more than one healthcare practitioner before receiving a diagnosis, while others were referred to the appropriate specialists. This did not appear to be influenced by their access to resources but rather by what the referral source believed was the problem with the child.

One of the mothers, Thando, had been referred to a clinical psychologist through the hospital, however, she sought a second opinion after the initial diagnosis was made.

> *He was diagnosed at Edendale Hospital in 2014. Then I started, they gave me a letter and I started seeing the psychologist at the hospital, but I wasn't satisfied enough, and I ended up going to a private psychologist. Then they confirmed that no it is an interaction, it is an interaction autism. Yes. (Thando)*

Bathabile first consulted a speech therapist due to speech delays that her son was experiencing. It was from there where she was referred to other specialists for further evaluation.

> *It was there, there at the speech therapist that we found that actually there has to be further more testing on the child so that we know properly that he is autism. (Bathabile)*

Asanda had first consulted an occupational therapist before being referred to a paediatrician for further assessment.

> *They referred me to an occupational therapist who then assessed him and then they … and then they referred us to a a paediatrician who deals with autistic children. And ja, that's how ja. (Asanda)*

Silindile saw a variety of professionals before receiving a diagnosis. At first, she had taken her son to the hospital for tests and she was told he had no difficulties, this was later confirmed by her paediatrician. Upon hearing this one of her clients referred her to a specialist paediatrician who later referred her to a clinical psychologist and a speech therapist before her son received an ASD diagnosis.

> *Then at the hospital they did a lot of tests and they found that his brain is right uh everything is normal. Even his doctor Dr Y the paediatrician he couldn't see that the child… he signed and said the child is fine there's nothing wrong with him. The principal said no he's not fine. Then I called the doctor that's my customer and told her… Then she referred me to Dr Z. Ja. She gave me her card and she called her and asked her to make an appointment for me about the child. She also told me that the child is autistic what what. Then when I got to Dr Z., she started assessing him and did all those things. She referred her also to the to the clinical psychologist. You see and to the speech therapy then they came back and told me that the child is autistic. (Silindile)*

Ntobeko also had seen multiple specialists before obtaining a formal diagnosis. She had first consulted with a paediatric neurologist who then referred her to a speech therapist. It was then her colleague who suggested she take her daughter to an assessment centre where the diagnosis was made by a psychologist.

> *So, there was a concern and then we um we first went to a uh uh a what? Paediatric neurologist. Ok. She observed her and when did tests and then realised ukuthi she need speech therapy. So, um... so ok, so I don't know now but and then we had to take her for a formal assessment. Oh, so I talked about this like at work cause it*

> *was really bothering me you see and stuff like that. And a lady by the name of Joy that I work with, she um, she advised me... So, she suggested that I go to like a children's centre to have like a full assessment of what, like you know, just to find out what is wrong with my child… So, we booked there, and then that's when we discovered that she has autism. Ja. (Ntobeko)*

It is not unlikely for a child to be referred to multiple specialists before receiving a formal diagnosis. All the mothers had seen more than one healthcare practitioner, as well as traditional and spiritual healers, before receiving a diagnosis of ASD.

4.3.2.2 Age of diagnosis

The average age at which children received a formal diagnosis was four years old. Four of the children received a diagnosis at the age of four, one child received it at the age of three and another received a diagnosis at the age of five.

4.3.2.3 Maternal feelings

Mothers reported a variety of feelings when their child had received an ASD diagnosis and these ranged from sadness to denial. Many of these feelings appear to have been grounded in the inability to know how to cope with a child with ASD.

As one participant Tina described the feelings she had experienced at the time were similar to hearing that you have a terminal illness. She described going through the stages, which are those of grief, denial, anger, bargaining, depression and acceptance.

> *I think at first you go through the stages when more like you've got a terminal illness where you have denial you go through denial then you accept and then you live life moves on. But obviously it's a bit of a shock because you don't understand that the detail information around autism. I did not have that. I just knew that ok there is a condition called autism but to deal with it now was something new to me and the immediate family. So ja. It was shocking *laughs* (Tina)*

Many of the other mothers reported feelings of sadness and denial.

> *So it upset me a lot, a lot. But at the same time because to me if something happens I used to think that maybe there certain reasons that it is happening. (Bathabile)*

One mother noted that when she had received the diagnosis she was worried about the future of her daughter's education and social life.

> *I was kind of sad, yabo, cause I was thinking about the future and like socially like will she… how will she relate but like my worries were social lokhuzana [um this thing], socially how will she relate to her peers and you see the story with school like it's a huge thing for me. (Ntobeko)*

Feelings of being overwhelmed with the uncertainty of what they would be facing was also evident in a few mothers.

Ntobeko was particularly worried about how she could help her child as she didn't have enough information at the time.

> *Because it's over, overwhelming enough that ok my child is like this, then the next question is how do I help my child? (Ntobeko)*

Another mother Asanda expressed feelings of shame which have only been alleviated through her son receiving interventions and her receiving more information about the disorder.

> *It was very hard. It was very hard. But as I carry on attending, I'm a little bit healed and eh I accept him as he is. But it's not easy, sometimes he misbehave like I wish I can hide him but then I can't. (Asanda)*

Silindile expressed still struggling with her son's diagnosis at times and the burden the disorder has on her.

> *Ja, that is why I end up that I deal with all of it myself. Sometimes I wish that you know maybe if I could get admitted and I get admitted even at a particular hospital, so I can sleep or get something that can drug me you know? I just sleep. I sleep and rest. Rest from thinking, rest from about what to do, rest, but sometimes I say eyi, you shouldn't wish that cause God will just say let me take you, so you can rest forever. If you're on this earth you won't rest, you see. (Silindile)*

4.3.2.4 Alternative people consulted

In African culture, it is not uncommon for individuals to seek non-medical routes in trying to understand difficulties, especially those that are foreign to them. Some of the mothers had sought alternative explanations and interventions, however, a majority of those that had were not comfortable at first in sharing these. Two mothers had sought no other assistance with anyone other than medical practitioners.

4.3.2.5 Traditional healer

In seeking the assistance of a traditional healer many of the mothers reported that it was the wish of their children's father that certain traditional rites be performed such as slaughtering a cow as a sacrifice. Due to this, they could not elaborate on the processes that were done during the traditional practices. However, all the mothers reported no improvement in the symptoms.

As previously stated the family system in African cultures is very complex and younger people often consult elders when facing situations that they may not have adequate knowledge of. In doing this the elders' opinions are usually taken into account and implemented. Many Nguni people believe in *amadlozi* [ancestors] and therefore illnesses that affect family members often lead to *umsebenzi* [traditional practice] being done in order to appease the ancestors and ultimately healing the individual. This was the case with Asanda where her son's father's family had done *umsebenzi* for her son in order to assist him, however, she stated that there was no improvement in his symptomology.

> *Uhm but his dad was like no he's gonna be fine. And I'm like he's not talking bra* [brother] *and we should be worried and he's like no he's gonna be fine my family says that we just need to slaughter a cow or slaughter a I don't know slaughter something. So, you know what? Because I'm open-minded and I think our family is very open-minded and uhm irrespective of whether you know what we believe in, we should allow people to also you know, uhm practice their views or their understanding or their cultural beliefs or whatever so we allowed that to happen. When he went to his dad's you know it was an agreement that no its fine you are part of his family anyways you know? So, they did the ritual or whatever whatever whatever and then ja, so…but he was still autistic when he came back (laughs). (Asanda)*

At the time Thando's son was born she was engaged [*elotsholiwe*] to her son's father, therefore, according to Zulu culture the child belongs to his family. Traditional practices for her son would then be done by his family. Her son's father's family had then done the traditional practices needed but she also stated no improvement in her son.

> *Then with his father's family cause we aren't connected anymore and the time I wanted to do things with doctors they wanted to do traditional things and I allowed them to take him and do them for him, like things zamasiko* [traditions] *that they do*

> *and wagcaba* [traditional incisions] *and did everything but at the end of the day I saw that it isn't working for me. (Thando)*

Tina had consulted a traditional healer due to her son's symptoms and was then required to do a traditional ceremony in order to appease the ancestors. There was however no change in his symptoms.

> *They will say something about the ancestors, the rituals that you needed to do to appease the ancestors and all that. But to do all those things and nothing happens so ja. (Tina)*

Only one mother, Silindile, was told by a traditional healer that her son's behaviour was genetic and she could not be assisted further.

> *But with him, if he's crazy okay, maybe let me go to people and check what's causing it. Until I went home um home for me is in the Mpumalanga province. Then my mom took me to someone in Mpumalanga province and they spilt some bones sort of. So, she took me there. Then there the lady told me straight that what my child has it's like a a gene… it's like a gene she sees it as a gene from my family. The M family, where I am married. (Silindile)*

4.3.2.6 Religious healer

Three mothers had sought assistance from religious healers or priests, who prayed for their children. They reported no improvement in symptoms. It must be noted that these were the same mothers who had sought assistance from traditional healers. This may speak to the desperation mothers have in understanding the disorder and in improving the symptoms that their children present with.

Tina had consulted a pastor who had prayed over her son for a week. There was no change noted.

> *Uhm we had a pastor who… asked to come for about a week just to to pray for him and ja. (Tina)*

Thando addressed the desperation she felt in trying different avenues to help her son. Having seen no improvement with other interventions she sought the help of a priest who prayed for her son but ultimately it yielded no results.

> *Ja. First time I went to him [priest] is that he [Zothani] doesn’t want to walk, I did try traditional things… but not like eh. I took him to another man that they call baba Mkhize and he prayed and did all those things of his, and I wasn’t helped. (Thando)*

A priest had also prayed over Silindile’s son however no improvement was noted.

> *I once took him and went with him to baba Mkhize so but eh the point is he’s alive. He’s not sick. It’s just that he doesn’t speak. His problem is that he doesn’t speak. And at that time, we had not seen that his brain is slow because he was young. (Silindile)*

4.3.2.7 Information

During the time at which the mothers were receiving an ASD diagnosis for their children the information, they obtained as to what the disorder came from various places. Not all mothers believed that the healthcare practitioners had given them enough information as to what the disorder was, they, therefore, searched for this information elsewhere.

One of the biggest difficulties Ntobeko faced was not having enough information after her daughter was diagnosed. She believed that healthcare practitioners should have written material to assist mothers with what to do after your child has received an ASD diagnosis.

> *Cause I think the minute they tell you that your child ok this is the problem, at least maybe if they give you some kind of brochure or a little booklet that will explain like more information. OK so this is what autism is… where do you, where to from here, you see. (Ntobeko)*

Although Bathabile was able to get sufficient information she expressed not knowing how to live with an autistic child.

> *Yes, I did get the, an explanation about what I’m dealing with. But at the same time, knowing what you’re dealing with doesn’t, it doesn’t teach you that how I will be able to live with it. (Bathabile)*

Many mothers state that the majority of the information they got was through them googling autism and trying to find out more.

> *What helped me a lot with understanding autism is I was googling a lot, everything. I was I was checking everything. (Silindile)*

Due to Ntobeko not receiving enough information at the time her daughter was diagnosed she relied on Google to provide her with the necessary information

> *So, we started googling and then you know like google google tells you what autism is. (Ntobeko)*

Asanda received a lot of information not only from researching but also from her son Nkululeko's paediatrician, as well as the school which he currently attends. The school offers classes to better equip mothers and sends out weekly newsletters offering additional information.

> *…uhm either than school, the doctor the paediatrician and uhm ja besides that I think that's… ja, ja. (Asanda)*

Tina obtained most of the information she has from the different healthcare practitioners that her son had seen.

> *…because my son undergoes like weekly therapy with all the therapies that uhm he sees they always try to provide information whatever I mean I can ask them anything and then they will assist with Njabulo. (Tina)*

One mother noted having received most of her information from a specialist doctor and a psychologist.

> *…it's at the hospital and the psychologist at UKZN… honestly speaking the person who helped me understand the most was the neuro doctor, Dr M. (Thando)*

4.3.3 Post-diagnosis

The results obtained from the thematic analysis suggest that African mothers experienced a wide array of difficulties post diagnosis. These were not exclusively financial, they also included fears for their children's future, dealing with stigma and the change this diagnosis had made in their personal lives.

4.3.3.1 Understanding of ASD

Participants appeared to have the same understanding regarding ASD, although none of the participants could elaborate further than the disorder being a spectrum and children exhibiting different behaviours.

Tina's understanding of ASD was that it is a spectrum and each child will not present the same. In addition, she noted that it was a lifelong incurable disorder.

> *Ehm… that it's a… it's a condition… eh… which like it's a spectrum you ca… each and every child eh is not the same. They may all be diagnosed with ASD, but it doesn't mean that they will portray similar eh behaviour like for instance my child is not violent for instance, but you will find that another autistic child will display violent behaviour eh and that its not something that is… that can't be cured. You… it's a lifetime eh therapy that they need to undergo but its not like there's something that can cure them. So ja. (Tina)*

Another mother Bathabile recognised the differences in schooling children with ASD may have as well as the different behaviours they may present with:

> *There are others [autistic children] that are normal that you see that even if they have autism they go to normal schools they they they just become smarter than other children. Then there are others that are aggressive and have anger and everything and you can see that it's autism you see, it's actually worse… then there are others who are normal and in between. (Bathabile)*

This was reiterated by Thando, who said:

> *We have children and they are in like different autism, different autistic and they, you see that eish even though he has autism he's better than the other one. Other people are more like, you find that they don't know how to speak, they can't walk, you find that another one can do these things but the way they behave you see that ok. (Thando)*

4.3.3.2 Family perceptions

African societal living is based heavily on the community. What happens to a child is therefore not exclusively the mother's decision alone but also involves other key family members opinions. Therefore, receiving a diagnosis of ASD then affects the extended family as well as the immediate.

4.3.3.3 Reactions to diagnosis

Many individuals do not understand ASD as well as the longevity of the disorder. Many mothers reported that their families believed that the children would be fine as long as the mothers prayed for them to get better.

Due to the belief systems African people have the 'cure' to a disorder is generally assumed to lie within the spiritual realm. This was evidenced by Ntobeko's family who believed that her daughter Zama would develop speech if they prayed.

> *Like my family, I think you know us as black people we don't know what autism is. We can't just even relate, I can say it like that. So, they just say no Zama will be fine. Zama is ok…So even now like my sisters will call me and ask me like, how is she? Is she developing speech and they are like don't worry you'll see she will be right just pray, you see? No matter how much you pray unfortunately autism is autism, ja. (Ntobeko)*

There have been studies linking certain genes to ASD. Thando notes how her son's paternal grandfather recognised the likelihood of her son's disorder being genetic.

> *So, at his grandfathers they understand properly kaX that the child was born with their genes, cause their grandfather's younger brother had narcolepsy and he wasn't ok mentally. So, they understood a lot, more than his grandmother's family. (Thando)*

Tina's family was able to understand what the diagnosis meant because her child was not the first to be diagnosed with ASD within the family.

> *Uh. I guess they were ok with it no one has really said anything as I'm saying with the with the I'm staying with my mom so that's the immediate person who's always exposed to this autism… but the extended family I think they understand because as I'm saying there are other people in the family who… like my son was not the first in the family to be diagnosed so they do understand that this its autism. (Tina)*

4.3.3.4 Medication and special schools

One mother Ntobeko expressed the involvement of her fiancés family in raising her daughter Zama. This included whether or not she should be enrolled in a special school as well as whether she should be given medication (Ritalin). She states that her fiancé's mother (a healthcare practitioner) had expressed beliefs that Ritalin was only given to people *abahlanyayo* (crazy people) and special schools were for children *abajuza amathe* (who drool).

> *You know like her gran is a healthcare practitioner, so she was like no she can't go to a special… like she didn't understand what a special school was. She thought it a special school was for, there are children you see that are dyslexic only you see,*

> *and those that drool and stuff and those abakhubazekile [physically disabled]. She said no the child will copy the behaviour of the disabled children, I don't think it's a good idea. (Ntobeko)*

> *Yes, I remember that she [paediatrician] said it was Ritalin. Then her gran said no eyenhlanya [crazy people]. We give that to crazy people at work, my child will not be given that. (Ntobeko)*

It's important to note that these are the feeling many mothers also have especially in regard to Ritalin. The participants' perceptions of medication are discussed later in this chapter.

4.3.3.5 Relationship difficulties

The diagnosis of ASD appeared to have had major consequences for three participants. It is reported to have caused a breakdown in the relationships mainly because the fathers blamed the mothers for the child having the disorder.

For Thando her engagement ended after her son Zothani received the diagnosis of ASD. Her fiancé at the time questioned the child's paternity and this ended up in court proceedings. He currently only pays court mandated child support and has not seen his son in years. In addition, her son no longer visits his paternal family due to physical and emotional abuse inflicted on him.

> *I was actually living with his father [Zothanis] in Ashdown as he was in the process of lobola [?] when I was on maternity leave, then I had my child then after that, cause his father was in the process of lobola, we had queries and we ended up breaking up, cause he didn't understand what was going on with the child. We went to court and the hospital and they did DNA test because he didn't want to support my child. He said I just want expensive schools and all that. Then we found out that the child really is his. After that he paid R800. (Thando)*

Silindile reported that although her relationship had been rocky previously it had escalated after her son Ziphe was diagnosed with ASD. She stated that however, she was unaware if that was the cause in the decline of her marriage. Her husband has never asked about Ziphe's diagnosis nor have they ever spoken about it.

> *No. And no one… no one, even my husband, no I don't know with him. Maybe he was googling by himself and checking. We didn't even sit down and talk about it, to say this child, what is autism. We just see each other at the school. There are*

> *times at school that there are issues and it's like we are far apart from each other, so we had to… one day we ended up having to both go, then they started asking us about the child, so he says what he says, and I say what I say you know. But even to sit down then we are studying it together that oh this is why he does this, he will do this like this, or you know. No. (Silindile)*

All other mothers in the study were single mothers. The diagnosis of the child had no role in the breakdown of their relationships.

4.3.3.6 Stigma

Raising a child with any form of physical or mental disability may lead to the family of that child being stigmatised. The majority of the mothers reported experiencing stigma from the community in which they lived. This is with the exception of those mothers who lived in suburbs, stigmatisation they felt was from church members.

Thando described many instances where she felt stigmatised due to her son having ASD. She reported that at the rental she lived in, there were many times where the children of the others living within the same property go on outings together and her son was always excluded from these.

> *Sometimes if they go somewhere, like the people living in the yard, they don't invite me cause I've got an autistic child. They will take the other children and go with them but you'll find that me and my child will be left behind cause they know he misbehaves. But I've also just been like… I just take him if I realise that all the children that live here have gone somewhere, rather I take him maybe and we go somewhere in town just so he doesn't notice that all the others left. Why he hasn't been included. (Thando)*

The stigmatisation Thando experienced was also from the community she lived in. In the extract below she relayed a story of taking Zothani to town and the comments one woman made in a taxi.

> *Ja as he was in school in town for three years… sometimes you get into a taxi, people they're judging you cause they grab people, they scream and uh it was on one of those days he was wearing a diaper, it was 2016, and I went into the taxi and this lady is like "This child is too old to be wearing a diaper" you see it's like embarrassing. Sometimes you go to town with him and people are staring at you "Why is this child behaving like this?" wa wa wa they want an answer as if we are*

> *owing somebody an explanation for having a child with autism. *sighs* ja, it's not easy *laughs*" (Thando)*

Ntobeko and Silindile relayed that although they did not feel stigmatised by the communities in which they lived, the stigma they experienced was in their church communities where people did not understand why their children behaved the way the do and therefore judgement was passed onto them and their parenting skills. Both reached a point where they either changed churches or stopped attending Sunday services due to how they were treated within the church due to their children.

Silindile struggled with stigma at church which led her to leave services early many times. She described the emotional pain it had caused her.

> *Maybe where I almost saw was at church, the church I was at before they had that issue a lot you see. They saw him distracting them, he can't sit stable so much as you've introduced him that my child is not right so so but you see that they don't you see they just don't like it, he makes a noise, he disturbs them, they say it straight "give him a bottle" "How come you give such an old child a bottle" and all of that you see? Yoh yoh yoh! No with that one I used to cry a lot, with that one I used to just inside ja the church you'd see that no here you're getting irritated and I'd just leave and take my child and go. I'd go outside and phone his dad and say he must come back and fetch us, I'd take him and get out and leave." (Silindile)*

This was reiterated by Ntobeko who realised that she was stigmatised because of her daughter's behaviour.

> *I think I've experienced that, like I have experienced it in a place you couldn't imagine. Like I was at church, so Zama like like confined spaces she cannot do. So, this day it was full at church and like I wanted to go to church, so I went with her because I can't always leave her behind you see?... So, Zama is restless, she goes outside, she comes back in, I try to… So, with that up and down umama [older lady] was like "no this child" you see she was like "this child is disrespectful. This child is disrespectful, she doesn't listen". Eyi, you see with that I was almost in tears, you know the way she was shouting at me. (Ntobeko)*

Although Bathabile did not experience stigmatisation from her community she experienced it with her friends and family who did not want to babysit her son Ntsika due to him being autistic.

> *Um, ja ja because um, as much as Ntsika hasn't, doesn't misbehave, he doesn't have anything wrong with him they will use autism as a reason to not help me. Let's say maybe I want to go job hunting, can you just look after him for a while you see, weh, what if iyavuka lento yakhe? [what if this thing of his starts up] what if something happens? You see that? Like really kanti yini lento evukayo? [what is this thing that's starting up?]. (Bathabile)*

Asanda and Tina did not report experiencing stigmatisation from their communities, families or friends.

4.3.3.7 Maternal Fears

Many of the mothers within the study stated the same fears they had for their children. These were how their children would cope socially as they matured, education, independence and what would happen to their children once they died. These fears brought about feelings of sadness and excessive worry in many of the mothers.

4.3.3.8 Education

> *I was kind of sad, you see, cause I was thinking about the future… the issue with school like that's a huge thing for me.* (Ntobeko)

Silindile expressed worries in the type of education her child would receive. Although she realised that children with ASD could grow up to be independent and lead successful careers, her worry was rooted in the kind of education and interventions available for children with ASD in South Africa.

> *My biggest worry is the way they learn and are educated… cause one day I said if only I had money then I just go and live overseas cause overseas I can see that… they progress, they are lectures, others work the way they are, they get paid… they become a lot of things but this side I haven't seen that thing, I haven't heard about it as well, where are they, you know? Where are they? Where do they end up? What happens? (Silindile)*

This was similarly expressed by Thando who was worried about the education that her child was receiving at school and whether the teachers had the proper training and expertise to teach autistic children. Her son had been in a public special school for two years and she reported that he had regressed.

> *I think they're not fully… educated about autism. Cause when you find professionals in autism, they say a child with autism can write and when you get this side they say he doesn't want to write what can they do. Of which that person doesn't have time. (Thando)*

Asanda's fears were based on what school her child could attend as a teenager as there are not many schools that cater to autistic teens.

> *…it's a concern, that he's growing older now and the school he's in, as good as they are… when he's 13 he'll be forced to join elsewhere. You know. And I think that's a concern because now there aren't a lot of places for adults that have autism or rather schools for teenager. (Asanda)*

4.3.3.9 Social Adjustment

Two mothers raised a concern with social adjustment and how their children would cope in interacting with their peers. Silindile expressed worries when it came to Ziphe's teen years and establishing romantic relationships.

> *Cause I am worried that maybe he will go around sexually harassing people's kids you know? Maybe cause he won't be able to ask girls out. You see that? (Silindile)*

Ntobeko was mainly concerned with how her daughter Zama would relate to her peers and establish relationships with them.

> *I was kind of sad, you see, cause I was thinking about the future and that socially like will she be able… how will she relate? But like my worries were social things, socially that how will she relate with her peers? (Ntobeko)*

Bathabile was worried about her child's ability to create bonds in relationships, especially a bond with her which she felt she may never have with her son Ntsika.

> *So, will I ever have a child who I can communicate with and have that bond and understand each other… How am I gonna handle this? This is my first child. (Bathabile)*

4.3.3.10 Independence

One of the most prominent fears that mothers expressed was whether their children would be independent in future and if not, what would happen to their children after they had died. Worries were based mainly on whether those who will be the primary caregivers of their children will be able to treat their children the same way they have.

Tina voiced concerns about whether her son would be treated appropriately by family members who would have to care for him. Her worries were based on others finding her son to be a burden that would be placed on them.

> *So now you are stuck with this child and… this child has grown and uhm you know ja those are the things I worry that what happens post my existence. How is he… I have to think about family members eyi will they be able to treat him well enough when I'm no longer alive. (Tina)*

Bathabile seemed hopeless not only in not having the ability to ensure her children are well taken care of when she has died, but also hopelessness in not being able to do anything about her son's condition.

> *Am I going to be useless to them for the rest of my life? What happens when one day I don't wake up? What's gonna happen to them? Will I have done enough?... who will actually stay with these kids and understand them when I'm gone? What can I do? (Bathabile)*

Ntobeko expressed worries about whether her daughter would ever be fully independent.

> *Like and like for how long do I have to take care of her like when will she be independent. (Ntobeko)*

4.3.3.11 Challenges

As the mothers within the study came from different socioeconomic backgrounds their challenges varied, with some stating finances and others finding the right schools for their children.

4.3.3.11.1 Finances

Due to the interventions that children with ASD have to have, raising an autistic child becomes a financial obligation.

> *…just gonna spend because all therapies they come at a cost. Its different therapies and unfortunately, they have to go on a weekly basis. You can't say no my son is gonna see an O.T once a month. Its like weekly. So, you just need to dedicate their finances… (Tina)*

Silindile recalled a time where she struggled with getting her child to a clinical psychologist who specialised in ASD due to financial difficulties. She reported that she could only afford a cab from her home to the specialist and would have to walk the distance back *ebelethe* (put on her back) her son in order to get to taxis that would get her home.

> *…you find that the appointment is for around four. Can you imagine it's for around four. Taxi's don't go there. I don't have money to to take a taxi maybe to take a cab and take this child… I'd go and when I come back I think it's better if I take a cab going there cause it's uphill, then when I come back I just take the child and put him on my back… You know when I'm coming down by the show ground? It's already, already dark… I'm walking and crying the whole way until I get to the rank. I come back. I get home and I cry yhoo I cry I cry the whole night. (Silindile)*

Bathabile also expressed the difficulties in getting her son Ntsika to different specialists that he has to see, especially as she is unemployed and has no source of income other than the government social grant.

> *We have to go to speech therapy, go to audio, go to these things of theirs. Then we go to the doctor again and they refer you to someone else again… all of that costs money. I'm not getting any help from my family. The only money I get is the R400 [social grant]. (Bathabile)*

Thando's financial difficulties were based around finding her son Zothani a boarding school due to her having to work full time to pay for his needs. However, she cannot afford the fees required to put him in boarding school.

> *I can't afford to pay R2000 a month for him to stay in a boarding school. I can't afford it. (Thando)*

Ntobeko and Asanda stated no financial difficulties.

> *… I guess I'm lucky that I am able to actually afford his lifestyle and the kind of person that he is. (Asanda)*

4.3.3.11.2 Finding a school

Another challenge that mothers noted was finding the right school for their children to attend, one that would be able to cater to their needs which would also be easily accessible.

Bathabile's son was unable to find a school that was close to home and had to live with a relative as the only school that could take him was far from his home.

> *In January he needed to start school cause he's 6… We couldn't find one around here in town, we ended up finding one near Henley which is far you see… (Bathabile)*

Due to the limited number of schools, Tina had to be put on a waiting list in a government school. After having waited for a long time she subsequently had to take her son to a private school.

> *There's no facilities basically. Government they're always crowded. They they do have certain schools with autism units, but you stay in a… waiting list forever. (Tina)*

Asanda stated that her challenge was currently finding a school for her son to go to as a teen that would be appropriate for him and provide him with the same stimulation that he currently has at his school.

> *…to actually find uhm another place that will be able to stimulate and improve him. So that's a challenge for now. (Asanda)*

4.3.3.12 Medication

Many children who have been diagnosed with ASD are prescribed medications in order to improve symptoms. The most commonly prescribed medication within the study was Ritalin which aids with hyperactivity, four children had been diagnosed with ADHD. Risperdal which is an antipsychotic used in treating irritability in children with ASD was prescribed to two children. Tegretol is an anticonvulsant given to treat seizures, this was only prescribed to one child.

What is interesting with many of the mothers was the negative perception that was associated with Ritalin and not the other medication. Although the children had been prescribed the Ritalin it was not being administered to their children. The two excerpts below are an example of how the mothers perceive the effects of Ritalin on their children.

Although Ntobeko's daughter had been diagnosed with ADHD she does not currently give her the medication as she believes that it will make her daughter less responsive as if in a comatose state.

> *Maybe but because she is still young let's just wait until maybe she is like 7 years old then maybe we can say like medication. Because I don't want her at such a*

> *young age to start like you see be a person that is numb. Be numb for four days. (Ntobeko)*

Silindile worried about her son not interacting as much when he was given Ritalin and as a result, she stopped administering it to him.

> *… cause with us it's as if he sees a… ghost, the way he's behaving you can see that he's hiding himself, he's shutting down, he's always… it's as if he's… he's in a tin you see? He's closed off here… (Silindile)*

4.3.3.13 Educating others

Mothers in the study expressed feelings of frustration and a need to explain their child's disorder before people make any assumptions. Although Asanda does not speak about her son Nkululeko being autistic she does explain to people should the need arise. She expressed the challenges she faced in educating others and reducing the ignorance surrounding ASD.

> *I find it very challenging to actually try and reduce that whole ignorance thing you know… obviously I don't go around shouting "hey my son is autistic" but you know, it gets to a point whereby somebody asks about about it. I know it comes up a lot when someone will ask me, oh so what grade is he in now? If we're talking about my son. What grade is he in now? Obviously he's not in any grade because his school is specialized for autistic children you know. So that, that I need to explain okay he's not in a grade, okay but he's 10 years old what do you mean he's not in a grade? And then that's how the, you know the conversation will will will start off. (Asanda)*

Ntobeko expressed feelings of frustration of always having to explain their children's behaviour and the disorder to others.

> *… I cannot be explaining all the time that Zama has a problem… (Ntobeko)*

Thando noted that people made her feel obligated to explain her sons' behavioural difficulties to them.

> *… they want answers [for the child's behaviour] as if we are owing somebody that we have children with autism. Ja, it's not easy… (Thando)*

Silindile struggled with educating her mother about what ASD is and the effects it will have on the child, so she would explain by stating that her child is crazy. This seems to have been her only available explanation especially because her son Ziphe was not physically showing abnormalities.

> *But if you talk about autism she doesn't know what that is, you would have to say "mom the child mom it's that he's crazy" you know but theeee easy term to explain it to her about what the child has cause he's not sick and he doesn't get hospitalised. (Silindile)*

Tina stated that the people in her community are unaware of what ASD is and because of her family not interacting with others a lot she has not felt the need to explain it to her community.

> … they will know that there's a child who doesn't speak and it ends there but I think they don't know that what is the condition they just know that Njabulo doesn't speak. (Tina)

4.3.3.14 Support

A majority of the mothers within the study expressed difficulties of not having a support system from their communities as well as the government.

4.3.3.14.1 Emotional support

The only support Bathabile received was when her son Ntsika was very young, before the diagnosis. The support was from her mother, she, unfortunately, passed away and she has received no support since.

> *Support yes, I did. It was when he was young cause his gran, I did. But his gran apparently the sad part is that wasishiya (died) when he was one and then after ukusishiya (her passing) that was it. So, now whatever is happening with my child, whatever I'm going through, whatever I'm facing, whatever he's facing, whatever he he that needs, what can I say? I'm alone. I'm alone* (Bathabile)

Silindile stated that she had no support in her life.

> *But there is no one or who talks to me or speaks to me about it or or speak maybe… (Silindile)*

Tina and Thando had access to support groups for mothers with children with autism. Thando, however, could not attend the groups due not being able to take time off work to attend.

> *… I couldn't attend cause I have to be able to raise this child at the end of the day. I cannot take my days off to collect his medication as he has fits and then also go attend when they say they have groups… (Thando)*

Tina received support from a support group as well as her family and friends.

> *… immediately after he was diagnosed [the clinical psychologist] had organised a support group for mums who were like having autistic kids or recently been diagnosed with autism. So that support group really helped a lot as well as support around friends and family I would say. (Tina)*

Asanda received her support from family and friends.

> *And as a family and I mean when he's with his uhm dad's side they'll notice something that is you know different or is an improvement so ja, so I think they're they're very supportive. (Asanda)*

4.3.3.14.2 Government financial aid

In South Africa, a government grant is given to children with disabilities. Many of the mothers within the study do not receive this grant, only one mother (Thando) received it. Regardless of her being the only one receiving any government support she still believed that the South African government was not doing enough for autistic children. This was the sentiment all the other mothers shared.

> *Ja. No he's [government] not doing enough. Especially for autistic children. Unless you say a child is disabled straight then they say there's nothing they can do. But autistic children they got two legs, they got eyes, they got hands, they can do something… (Thando)*

Bathabile does receive a social grant for her son Ntsika however this is not specific to his disabilities, it is rather a grant to assist unemployed mothers.

4.3.3.15 Advice to other parents

As has been reflected in the study, mothers have varying experiences of their children being diagnosed with ASD and these bring forth strong emotions. Having reflected on their experiences and sharing their stories the mothers had advice to share with other parents who have just started this journey.

The most common advice the mothers shared was to offer love, support and to be patient with your child as they are also going through a difficult journey.

Ntobeko's advice was for parents to be patient and to find out as much information as they could to assist their children. She also expressed the need for parents to do all the interventions that may be recommended.

> *All I can tell them is be very patient… Be patient, like find more information and resources to help you… Try and get as more information as much as needed. As well as well as your child, support them, well everything that is recommended unfortunately you gonna have to do it. No matter how much it costs you, that doesn't matter. (Ntobeko)*

Asanda felt that the most important thing that other parents should do is to engage with people who are uninformed.

> *And y y you you know instead of shying away from your typical ignorance, stigmas and stuff from people. Challenge those people you kn kn kn know and it's so funny because once you as a black person say something about i-autism uhm you actually realize people have a bad perception about what what it means. And if if if if you are going to allow for abantu to continuously think that way, not only are you caging your child but you're caging yourself as well and the information you have to help the next person. (Asanda)*

Silindile believed the most important thing parents needed to do was to understand their children, especially their behaviour, and accept their children.

> *Cause another thing is being more educated about the child, that is how you will cope with them, you see, you will be able to live with them, you will be able to understand them, you will know that ok if they do this it's it's normal with autism you see. That Njabulo will stand, clap his hands in the house, he he he screams *screams*, it's normal with autism. Anyway, with autism he will do this. But for us who live like this you see it as an embarrassment, "what are you doing? What are you doing? Sit down, sit down" you see. To understand that no it's normal, what he's doing is normal to him and accept it. (Silindile)*

Thando stressed the need for parents to love their children more than they do and to accept them as they are.

> *They need a lot of love, more than being violent with them. They need a lot of love so we need to love them more. (Thando)*

Tina expressed the need for parents to understand the financial commitment that comes with raising a child with ASD.

> *… the financial aspect of it… they must just tell themselves that, they gonna spend. They just gonna spend because all therapies they come at a cost. Its different therapies and unfortunately, they have to go on a weekly basis. You can't say no my son is gonna see an O.T once a month. It's like weekly. So, you just need to dedicate their finances to try and assist their children or their child. Ja. (Tina)*

Bathabile stressed the need for parents to understand that there is nothing wrong with their children and for them to dedicate time to understand their children.

> *There is nothing wrong with your child. There is nothing wrong with your child. There is nothing wrong. It's just that, what can I say, the child needs more time, more understanding you see. More time, more understanding. If you put that in your mind your child will be alright, your child will be happy. (Bathabile)*

4.4 Summation

The aim of this chapter was to present the results of this study. The participants within the study had various experiences of having their children diagnosed with ASD. All of them sought out the aid of multiple practitioners before their children were able to receive a diagnosis. The diagnosis not only affected the children but the family as a whole. Many struggled with stigma, relationship breakdowns, finding appropriate schools, finances and various other factors. These, however, were not experienced to the same degree. The experiences they had are not exclusive to a certain period but it is something parents will have to go through their entire lives. This was evidenced by all the mothers expressing worry and fear for the future of their children. It is apparent from their experiences that it is crucial for parents to have a good support structure when dealing with everything that comes with raising a child with ASD. The mothers also expressed the lack of government support, access to education and schooling environments that would stimulate and assist their children, many had no evidence of this within South Africa.

It is also important to note that medical diagnoses alone are not enough. Traditional and spiritual healers were also consulted in a majority of the cases in order to help heal the children.

This was done in an effort to exhaust all other possible explanation for the causes. This is particularly important to consider within the African context.

Chapter 5: Discussion

5.1 Introduction

This chapter aims to answer the research questions set out in chapter one. This is done by reflecting on the findings of the study in relation to the appropriate literature as well as theory that was used regarding black African participants experiences of having their child diagnosed with ASD. Any additional findings that were evident in the study that were not reported in existing literature are also discussed. Lastly, this chapter reviews the limitations of this study and provides recommendations for future research.

5.2 Black African mothers' experiences of having their child diagnosed with ASD

The experiences reported by participants of having their child diagnosed with ASD ranged from the moment they had started developing feelings of concern to experiences they had with individuals around them.

5.2.1 Primary symptoms

The literature review explained that the symptoms that parents noted as a concern appeared to be different depending on where they were located in the world. This is because the behaviour that we exhibit is highly dependent on the way in which one is socialised and the culture in which they belong. In western countries eye contact and social withdrawal are one of the major symptoms that are looked at in the diagnosis of a child with ASD, as shown by the current diagnostic criteria. However, this is not the case within Zulu culture where eye contact with adults is considered rude and therefore not necessarily an ASD concern (Chambers et al., 2016). In terms of social withdrawal, it has been noted that Zulu children are not socialised to be outspoken and to interact in a 'confident' manner with adults, therefore, this symptom should be analysed with caution when diagnosing children (Wilford, 2013).

The findings of the study appeared to be in line with existing literature as not a single participant noted a lack of eye contact as an area of concern. In terms of social withdrawal, only one participant expressed this as a concern but it was not a major one.

One of the first symptoms noticed by parents of children with ASD is a delay in language and communication (Samadi & McConkey, 2011). All of the participants within the study noted a lack of speech as the primary symptom that caused unease. However, it must be noted that although this was a concern for the participants, only one sought medical attention. This is because the participants assumed the children were either slightly delayed and would improve over time or that the delayed speech was due to *ufuzo* [hereditary] and would also ultimately lead to the children acquiring speech with time. From an ecosystemic perspective

5.2.2 Referral and diagnosis

As previously stated, many participants expressed that they were concerned about their children's delayed speech, however, the majority of them had not sought out any medical assistance. From an ecosystemic perspective a child's development is dependent largely on the environments which they are in, and the interaction between these. The interaction between home and school, occurring at the mesosystem, may, therefore, be crucial in how early a child may be referred to a healthcare practitioner. Many children within the African context appear to only receive a diagnosis from the age of eight upwards, after a child has started going to school (Bakare & Munir, 2011). The children in this study had an average age of four years at diagnosis. In many of the cases, healthcare practitioners were only sought out when the child had started attending school due to the teachers' request. Although most of the teachers did not know what difficulty the child had, they did recommend that the children go to healthcare practitioners for an assessment. This was mainly due to the behaviour that the children were exhibiting at school.

Moreover, this current study found that multiple healthcare practitioners were consulted before a diagnosis was made; some of these were speech therapists, occupational therapists, clinical psychologists and paediatricians. The number of healthcare practitioners that each child had to see varied amongst the participants. It must be noted that a change in one system, such as the exosystem, may lead to changes in other systems that may have a great impact on an individual (Bronfenbrenner, 1979). This is to say that if the structures that have been put into place by governmental systems change it may then affect the individual. Thus, new policies focusing on neurodevelopmental disorders should be put in place in the African context, including the screening of children for ASD during their 18 month visit to a healthcare practitioner for immunisation (Munir & Bakare, 2011, Ruparelia et al., 2016). This could have a huge impact, potentially leading not only to earlier diagnosis, but also the reduction of the number of healthcare practitioners that have to be consulted before a diagnosis is made.

5.2.3 Feelings about diagnosis

The participants in this study reported having experienced different feelings upon hearing that their child had ASD. Some of these were sadness, denial, being overwhelmed, shame and grief. One of the participants described being given the diagnosis as the same as going through the different stages of grief where you experience denial, anger, bargaining, depression and finally acceptance. Many of the participants' feelings were rooted in not knowing how to cope with a child that has ASD. This was due to healthcare practitioners not giving them enough information about how to cope with a child that has ASD.

The findings of this study are in line with the existing literature. Keenan et al (2009) stated that parents felt like they had not received the relevant advice that they needed in explaining to them how to proceed after a diagnosis was made. In addition, the feelings of grief that parents experience may be seen as a way in which they mourn the loss of the child whom they thought they had, this has been found to be normal with many parents of children with ASD (Sicile-Kira, 2014; Wayment & Brookshire, 2018). The grief that parents feel may include feelings of sadness, frustration or guilt (Gordon, 2009).

Grief is regarded as being stronger in mothers whose children have been recently diagnosed (Wayment & Brookshire, 2018). However, this is not to say that the grief has completely been resolved by the time parents have reached the acceptance stage as it may return depending on the experiences they have in future (Sicile-Kira, 2014). Similarly, in this study all the mothers expressed that they had accepted their children now, nevertheless, they did note times where they felt sadness and frustration.

The grief that parents feel may act as a catalyst as it drives parents to find out more about the disorder and to be proactive (Sicile-Kira, 2014). Participants in this study stated that they felt the need to get more information about ASD after they had received the diagnosis.

The way in which African cultures view mental illness and its causes is important to understand as this may play a role in the grief mothers may feel when their child has been diagnosed with ASD. This is because the views that individuals have about mental illness are culturally and socially constructed, and it is these knowledge systems that form part of the macrosystem that ultimately affect the individual in various ways. A study done by Gona et al (2015) found that both lay individuals and healthcare practitioners in Kenya believed that ASD was caused by supernatural forces. This was the case with one of the participants where rituals were performed in order to appease the ancestors with the hope of alleviating ASD symptomology.

Due to the participants in this study having multiple knowledge systems, as well as being bilingual, it may be posited that these knowledge systems may allow for the grieving process to be moderated via the cultural or spiritual practices or the understandings of mental illness that these may give.

5.2.4 Stigma

Knowledge systems are collective representations that are shared by different groups, and these determine a group's behaviour. In understanding the stigma that individuals experience it is therefore important to bear in mind the culture in which they belong, and the beliefs that culture has about individuals with mental illness. According to Nwoye (2015), it is of utmost importance to view and understand mental illness within an African paradigm which encompasses the philosophical assumptions of African people encompassed at the macrosystemic level.

Many individuals in African countries do not have much knowledge about mental illness and their causes and thus sometimes the parents of the child with ASD are thought to be the cause of the illness (Mthombeni & Nwoye, 2018). Although many of the participants in this study did not express having felt blame from others they did experience stigma in a variety of contexts and this may be due to inadequate knowledge many individuals have about ASD within the African context.

Many parents within the African context are stigmatised by their communities due to having a child with ASD (Bakare & Munir, 2011; Costa et al., 2017; Schlebusch & Dada, 2018). The courtesy stigma that parents experience is due to their relation to the child with ASD and by extension, they are treated the same way as the child (Angermeyer, Schultz & Dietrich, 2003). Parents have noted having experienced isolation, social exclusion, stereotyping, discrimination and feelings of shame, blame and secrecy (Byrne, 2000).

The findings of this study were in line with the literature. Participants reported being isolated, socially excluded and discriminated against. This was done through others not inviting the participants out due to the behaviour of their children, as well as being judged and discriminated against by the members of the community. The participants believed the stigmatisation they felt was due to a lack of knowledge about ASD. From the data, it appeared that participants were shamed by others as their children's behaviour was attributed to their 'poor' parenting skills. Those participants that had not felt any stigmatisation had little contact with individuals outside their immediate and extended families.

5.2.5 Financial implications

Raising a child with ASD has major financial implications due to the various specialists they have to see as well as the constant interventions the child must undergo. Within the African context, financial resources appear to be a major contributing factor in the decline in wellbeing of parents raising children with ASD or a mental illness (Schlebusch & Dada, 2018; Mitchell

& Holdt, 2014, Mavundla et al., 2009). This may be due to the stress that is associated with the financial strain that many parents have to endure. The difficulty with finances around raising a child with ASD therefore not only affects the child in accessing interventions but also the family as a whole.

Participants in the current study also reported having felt financial strain in varying degrees. They also expressed the emotional toll that financial strain had on them in terms of causing stress. Financial strain appears to come largely from the money required for interventions as these require both taxi fare as well as money to pay the specialists themselves. Mitchell and Holdt (2014) reported that the interventions that are needed for ASD children currently cost more than the average South African can afford. This is a major problem as 94.1% of black South Africans are regarded as living in poverty (Statistics South Africa, 2018). It must be noted that even those mothers who were employed and earned a 'good' salary also expressed financial strain. It appears the financial implications of the interventions are similar across socioeconomic classes.

If mothers cannot afford the interventions or even to get to the various specialists on a weekly basis it could have major consequences for the child such as not having any intervention at all. Due to the high rate of poverty within many African countries, mental health is not a primary priority. An economic crisis may affect the development of the child, taking into consideration the time in which the family in question experiences this financial strain (Bronfenbrenner, 1979). In terms of the findings of the study, the financial strain felt by the family (microsystem) due to the economic system, and the lack of accessible healthcare resources (macrosystem) may lead to a child with ASD not accessing particular services and therefore affecting their development. It is therefore important to develop interventions that are financially feasible across the South African population (Wannenburg & Van Niekerk, 2018).

5.2.6 Cognitive appraisals

The cognitive appraisals that individuals have of their experiences have a significant impact on their overall wellbeing, this is especially true of mothers with children with ASD. As discussed above, many mothers expressed the stress and difficulty in raising a child with ASD. Cognitive appraisals of these stressful life events shaped the way in which individuals reacted to them (Mikolajczak & Luminet, 2008). These appraisals are therefore ultimately affected by the macrosystem that includes the culture to which one belongs (Paat, 2013). Parents' cognitive appraisals impact on their overall well-being, as positive appraisals have a more positive outcome and assist parents with adjusting to raising a child with ASD (Schlebusch & Dada, 2018).

The participants in the study appeared to have positive cognitive appraisals regarding their children as they stated the need to love, accept, understand and know that there is nothing wrong with their child. This is not to say that the participants did not experience any difficulties but they managed to react to these in a positive and productive manner that has been beneficial not only to them but also to their children.

5.3 Black African mothers' understanding of ASD

Currently, there is a lack of ASD awareness in many African countries (Ruparelia et al., 2016). This may be seen by the limited literature that has been published within the African context. From 1935-2016 only 47 studies in Africa were produced with South Africa producing 25.51% of these (Abubakar et al., 2016). This is due to ASD previously being thought to affect children from western countries (Tincani et al., 2009).

In order to gain an understanding of ASD, an African model of understanding is useful. Using an African paradigm in understanding mental illness allows for the philosophical assumptions of African people to be incorporated (Nwoye, 2015). This is because culture shapes the way in which we understand and interpret the world around us (Kronenfeld, 1997).

Four of the six participants in the study had no prior knowledge of ASD before their child was diagnosed. Of the two who had knowledge, one had come across the name of the disorder and another had family members who had previously been diagnosed. This is consistent with the literature where many countries have little knowledge regarding ASD and its causes.

After the children had been diagnosed with ASD, the participants stated that they had more knowledge and had researched the disorder. This was done mainly via Google. However, the knowledge that many of the participants exhibited was rudimentary and centered around the disorder being a spectrum and being permanent. The way in which mothers understand ASD has huge consequences when looking at the diagnostic and treatment process.

5.4 Interventions

In understanding the interventions that mothers seek it is important to understand what meaning they attribute to ASD as a disorder. Kronenfeld (1997) stated that bilingual individuals could be considered to belong to two cultural systems, and switch between the two when necessary. It may be posited that the use of multiple interventions, such as traditional, spiritual and western, speaks to the meaning systems individuals use at a given time. In addition, this may also be understood as a way in which mothers exhaust every possible treatment option when attempting to make sense of what is happening with their children.

5.4.1 Traditional interventions

Many of the participants in the study were from the Zulu culture, except for two who belonged to the Xhosa culture. These cultures are however similar and will, therefore, be regarded as such for the purposes of this study as they are both Nguni tribes.

According to Nwoye (2015), the Eurocentric perspective on mental illness does not take into account certain aspects of the African experience of psychopathology and this leads to it having limited explanatory power. It is therefore important to include a spiritualistic perspective to the western BPS model (Nwoye, 2015). Therefore, the meanings that individuals attribute to mental illness is dependent on their knowledge systems, which are affected by their culture; this determines not only their knowledge but also values and behaviour (Kronenfeld, 1997).

In a study conducted in Nigeria, it was established that many individuals (lay persons and healthcare practitioners) believed that ASD was caused by supernatural entities (Ruperelia et al., 2016). It is therefore important to take into account these cultural beliefs that individuals have when developing a treatment plan (Mavundla et al., 2009; Department of Health, 1997). This is important as both traditional healers and medical practitioners are consulted in the treatment of a child (Gona et al., 2015).

The findings of the study were consistent with the literature as four of the participants in the study stated that their children had received some sort of intervention from a traditional healer. After consulting a traditional healer, certain rites and rituals were performed in order to appease the ancestors. This was done in an effort to alleviate ASD symptoms and to get a better understanding of the disorder.

However, what is interesting with these findings is that overall (except for one participant) the route to seeking help from a traditional healer appears to have been initiated by the children's fathers. This may be due to a number of reasons which do not appear to have been discussed in the available literature. It may be posited that one of the most prominent ones may be that in South African Zulu culture, when the process of *ukuhlawula* (damages have been paid), as well as other rituals, have been undergone the child is seen as belonging to the father's family (S. Mkhize, personal communication, 28 October 2019). Many traditional practices would therefore be done by the father's and not the mother's as *impepho* (African plant) has been burnt for the child in at the father's family home (S. Mkhize, personal communication, 28

October 2019). This may speak to ideas and issues surrounding belonging and traditional practices, these are outside the scope of this study. Issues surrounding the child's belonging were not considered within this research, however, it appears that regardless of which family (maternal or paternal) a child belongs to, western interventions are not dismissed and are done in conjunction with traditional interventions.

Mavundla et al (2009) recognized the need to incorporate traditional practices into the treatment of individuals, providing it does no harm. All participants noted no improvement of symptomology in children after traditional rituals had been performed, and reported that they did not perceive these as harmful.

5.4.2 Religious interventions

Participants in the study not only used traditional interventions but also religious interventions. Three participants consulted priests and had them pray over their children. It appears as though this was used as a means to exhaust all options when trying to find a 'cure' for their children's diagnosis. However, none of the participants noted any improvement in symptomology after the priests had prayed over the children.

Although current literature does not appear to account for religious interventions in Africa, it may be posited that the same understandings of traditional practices may be applied in the same context. This is because of the view that a 'cure' may come from a spiritual entity (God) and thus the source of the disorder may be understood as having come from that same entity.

Although the source of the disorder differs from traditional beliefs (ancestors vs God) it must be noted that Nguni tradition does not denounce the presence of a higher entity such as God. Viewing the meanings systems allows for a better understanding of the interventions sought as both rely on a supernatural force to intervene.

5.4.3 Western interventions

All participants in the study were bilingual and could be said to have multiple meaning systems to draw on (Kronenfeld, 1997). As previously discussed, the participants sought multiple intervention avenues; however, they did not disregard western interventions that were available to them. Gona et al (2015) also noted that many parents consult both traditional healers and medical practitioners.

The participants in the current study made sure that all interventions that were suggested by the healthcare practitioners were adhered to. These were inclusive of both medical and psychosocial interventions. However, participants appeared to be hesitant when it came to giving their children Ritalin as there was a conception that it is not only for crazy people but also alters the children’s personalities. This appeared to be a shared belief amongst the participants and as a result many participants did not administer this medication to their children.

5.5 Resources for children with ASD in South Africa

5.5.1 Community

As discussed above, mothers with children with ASD have varying struggles, which have the potential to cause psychological distress. It is therefore important to provide them with the necessary support. Support from family has been found to be one of the positive aspects that parents experience (Fernańdez-Alcántara et al., 2016).

The majority of the participants in this study felt like they had no support and people to turn to when they were facing difficulties with their children. One mother expressed that at times she hoped to be admitted to the hospital to get a break from the difficulties of raising her son. Gordon (2009) recognised the frustration that parents with ASD children feel and noted how this feeling fluctuates over time. Two participants in this study had gone to support groups soon after their children had been diagnosed, but have stopped due to work responsibilities. Other support noted was from friends and families, however, this is also very low.

In addition, it appears that support from the broader communities that the individuals are a part of is little to none. Two participants noted how others stigmatise them and refuse to assist due to their children’s condition; this appeared to have emotional consequences as both participants were tearful when relating the stigmatisation and lack of support. The misinformation individuals in South Africa have about ASD may lead to an increase in stigma; this may only be decreased by community based education programmes (Mavundla et al., 2009). An increase in stigma appears to lead to a decrease in social support afforded to parents.

Those participants who had little support but did not note this as a difficulty for them also had little social interaction with individuals outside their immediate families. What is also important to note was that these participants also had higher incomes.

5.5.2 Government

There is an increased need to support the mothers and the families of individuals with ASD as the disorder not only has repercussions for the individuals themselves but for the family at large. This support should not be solely left to the extended family and community but should be inclusive of government structures as well. This is consistent with an ecosystemic approach where it is recognized that an individual does not operate in isolation but there are a variety of systems, both direct and indirect, that may affect their lives (Paat, 2013).

The exosystem is the social setting an individual is affected by, indirectly, that they do not actively participate in (Paat, 2013). Although mothers of children with ASD do not actively play a role in governmental structures the policies and information available to them through these do affect them. This is inclusive of health, education, social grants as well as access to the appropriate facilities.

Currently in South Africa there are policies that have been put in place to protect individuals. However, these do not appear to extend to those with neurodevelopmental disorders and their families. The policies that apply to this study include the White Paper for Transformation of Health Systems (Department of Health, 1997) as well as the Traditional Health Practitioners Act (2007). These however speak to the interventions that mothers may choose to use that do not necessarily align with the western model of intervening with ASD individuals.

Moreover, the participants within the study expressed their frustration not only with the process that they had to undergo in receiving a diagnosis but in also finding a school. The main issue was finding a school that had educators who were well trained and equipped to teach their children. Another concern was the long waiting list that the public schooling system had for special needs children. In addition, a major concern for most participants was not only finding a school for their children now, but also finding a school that their children could go to as teenagers as currently they were not aware of any. The SIAS policy is aimed at improving access to quality education for vulnerable learners (Department of Basic education, 2014) however, it involves a lengthy process that mothers have to undergo before a child may be placed into a special school.

The South African Social Security Agency (SASSA) provides a government grant for special needs children. However, only one participant in the study was receiving this grant even though others were also having financial difficulties due to their children’s disorder.

Moreover, when reviewing the Department of Health website there are a number of childhood disorders that are noted such as ADHD, however, ASD (or any other neurodevelopmental disorder) is not listed under disorders. This not only speaks to the amount of information available for lay persons but also to the need to increase awareness in all spheres of the society. There is an increased need in Africa to develop new policies that are geared towards neurodevelopmental disorders (Munir & Bakare, 2011; Ruparelia et al., 2016).

5.6 Summation

The aim of this chapter was to discuss the findings of this study in light of relevant research and theory. The participants in the study went through different journeys in getting a diagnosis for their children however these were similar in many aspects. Although it has been postulated that ASD knowledge is on the rise, many of the mothers had no prior knowledge of ASD before their children were diagnosed. The current knowledge that they had was basic and many expressed issues with access to information.

The support that is currently available for mothers in South Africa appears to be lacking, this is inclusive of communities as well as the government. It is therefore important for community based education programmes to be implemented in order to reduce negative experiences that mothers and families may have. Furthermore, policies focusing on neurodevelopmental disorders need to be put in place in order to assist mothers with children with ASD.

Lastly is has become increasingly apparent that the experiences mothers have are influenced by multiple systems that may be understood from an ecosystemic perspective. It is therefore not enough for individuals to rely solely on changes in the microsystemic and mesosystemic levels. Changes need to be made on every level in order to reduce negative experiences. However, this may not happen immediately for a continent that not only recently started having ASD awareness, but also one that has ‘more urgent’ matters to address.

Chapter 6: Conclusion

This chapter provides a brief summary of this study. Any new information arising from the study will also be discussed. In addition, this chapter will provide a discussion of the implications for practice, limitations as well as recommendations for future research.

6.1 Summary

This study sought to get an understanding of the experiences black African mothers have had since their children were diagnosed with ASD. Due to an increase in prevalence, it has become increasingly important to understand ASD and how it affects the family as African culture is based on collectivism.

Having looked at the results of this study it has become increasingly evident that the effects the disorder has on the family stem from multiple systems. From an ecosystem perspective, it is evident that the interaction between home and school in the mesosystem plays a major role in when a child's symptoms are identified and when they are referred to a healthcare practitioner. Available literature and this study show that children most often get referred to a healthcare practitioner when they have started attending school.

Moreover, both healthcare services and educational services within South Africa appear to not have developed policies that are targeted specifically to children with ASD. This affects many mothers as there are availability issues with the public schooling system. Mothers also expressed the need for children to be educated by well trained teachers and for there to be an availability of schools for teenage children with ASD.

There are large financial implications that raising a child with ASD come with and these cause strain on many mothers. Of the participants in the study only one was receiving government financial aid. Taking into account that ASD interventions are done regularly and may last their life time it is important to provide mothers with financial assistance regardless of their pay grade.

Lastly, it is evident that from a lack of information and community based awareness programmes the mothers have been subject to stigma which has reduced their wellbeing. It is therefore important to educate both professionals and lay persons about the causes of ASD and expected behaviours that an individual may exhibit. This may assist in reducing the stigma that many mothers have to face.

6.2 Contributions of the study

A few key findings of the study warrant discussion. Firstly, literature has shown that an African understanding of ASD may be different from that of the west, therefore, interventions may also vary. It is not unusual for black African individuals seek out help from a traditional healer when facing a disorder, this was reiterated in the findings of this study. However, the results of this study suggest that traditional practices are usually initiated by the fathers of children as opposed to their mothers. This may be due to various reasons which are discussed in chapter five.

Furthermore, it appears that the age of diagnosis for this sample was half of what is expected in South Africa where many African children are said to only be diagnosed after the age of eight. However, the early diagnosis that children in this study had may be due to them having started school at a much earlier age and therefore behavioural, social or communication difficulties were brought to their mothers' attention sooner.

6.3 Implications for practice

It has becoming increasingly important to take traditional African belief systems into account when treating individuals not only with physical disorders but also mental disorders. This has been accounted for under the White Paper for Transformation of Health systems which seeks to integrate traditional healers into the healthcare system in order to make the healthcare system more effective. However, when reviewing the results in the study it does not appear that this has been put into practice. Traditional healers that participants consulted with were not found via the healthcare system. It is therefore not enough to have policies in place without their implementation.

In addition, it is important for policies to be developed that are aimed at assisting children with ASD. Currently educational policies are for all special needs children with none dealing with ASD specifically. In addition, there is a need for focus to be placed on having schools that incorporate children with ASD as not all of them would fall at the same spot within the spectrum.

6.4 Limitations of the study

In conducting this study a few limitations arose. One of the limitations of the study is the number of participants that were sampled. This was due to the difficulty experienced in finding participants (as discussed in chapter three) only six participants were sampled. In doing this the findings may not be transferable to the larger African context, especially because of the different African cultures in South Africa. It is hoped that the results of this study may be transferable to black African mothers of the Nguni cultures as these are similar. In addition, due to the economic nature of the culture and the large majority of black African individuals living in similar conditions, it is hoped that the non-culturally based results of the study, such as stigma and age of diagnosis, may be transferred to other black African mothers.

Secondly, the participants in the study at times appeared to not be forthcoming with regards to traditional interventions that were done. Basic information was shared and this may be because of the researchers' age or perceived rank. Many of the participants were much older than the researcher and therefore in African culture it is common to withhold personal information from individuals that are younger. In terms of perceived rank, the information and recruitment letter had stated that the researcher is in progress of obtaining a master's degree. The stated education level may have led to participants not sharing as much information about traditional practices.

Although interviews provide in depth qualitative information, focus groups may have allowed for more information to be obtained especially in regards to traditional practices. Having a focus group may have made the participants more forthcoming about sharing information that is private. In some cases it may also have allowed for participants to remember certain aspects when hearing others speak of their own similar experiences.

6.5 Recommendations for future research

Having looked at the limitations and the results of the study it is recommended that future research be aimed at understanding the financial implications of having a child with ASD with a particular focus on low to middle income families as a majority of South Africans live below the poverty line.

In addition, research should be geared towards analysing the integration of western, traditional and spiritual interventions that are used by individuals and how these sectors may collaborate in order to provide a cohesive intervention plan for ASD individuals. Culture and religion is an important aspect in many South Africans lives and this may lead to interventions being done simultaneously as opposed to delaying one due to another.

Moreover, a study looking at the conceptions that black Africans have surrounding medication given to children should be done in order to increase understanding and to possibly assist with the issue of non-compliance.

Lastly, it appears that education for ASD children has not been a core focus and remains a primary issue for many mothers. A study looking at the education available for ASD individuals is important as it may help in understanding what future prospects are available for black African children with ASD.

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- Appendix D: Informed Consent Forms
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Appendix A

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Recruitment Letter

Dear Principal/Head of Organisation

My name Snenhlanhla Zikhona Mshengu and I am currently a student at the University of KwaZulu-Natal, Pietermaritzburg. I am in the process of obtaining my Masters degree in Educational Psychology. As part of my course work I am required to complete research for my thesis. The topic I intend to research is “Black African parents’ experience of having their child diagnosed with Autistic Spectrum Disorder”.

I am contacting you because of the proximity you have to parents who have children that have been diagnosed with autistic spectrum disorder. I would like to request that you pass on my details to any parents or caregivers that would be interested in participating in my study. Inclusion criteria for participants is being black African; having a child that is already diagnosed with autistic spectrum disorder (including autism, Asperger’s syndrome and pervasive developmental disorder); living in Pietermaritzburg (including the greater Edendale area) and English/IsiZulu speaking.

All participation by parents or caregivers is voluntary and would require one interview that would last 60-90 minutes.

Please forward my details to any parents that would be interested.

Kind Regards
Snenhlanhla Zikhona Mshengu
Email: [redacted]
Cell: [redacted]
Supervisor: Carol Mitchell
Email: [redacted]

Appendix B

Interview Schedule

1. Did you have any knowledge about ASD before your child received a diagnosis?
2. Did you notice anything different about your child prior to the diagnosis?
3. Was your child referred for further evaluation/testing by anyone such as teachers or doctors or did you recognise the need for evaluation?
4. At what age was your child diagnosed?
5. Who made the diagnosis?
6. How did you feel about the diagnosis when you received it?
7. How did you understand what ASD was after the diagnosis?

a) Did it have any cultural or religious meaning for you?

8. How did the family react upon hearing about the diagnosis? (immediate and extended)
9. Did you or your family have any cultural or religious beliefs about what caused the disorder?
10. How has the community in which you live behaved towards your child, you or your family?
11. Did people have opinions about whether or not your child had ASD?

a) If yes what were they?

12. Had you taken your child to anyone other than a medical practitioner for help before or after the diagnosis such as a traditional healer or priest?

a) If yes who?
b) Did they give an alternate explanation for the child's illness?
c) Did they suggest any forms of medication or treatment?
d) If yes to (c) were these helpful?

13. Have any cultural or religious rights been performed to assist the child in any way?
14. Was there any help offered to you by anyone (individual/community/organisation/government institution) to help cope with raising a child with ASD?
15. Was there sufficient information provided to you about what ASD is and how to help your child with living with it?
16. Are there any interventions that have been implemented in helping your child?
17. What have been your biggest challenges since your child was diagnosed with ASD?
18. Do you believe there is enough support being provided to you and your family? (government, extended family, community)

19. What do you think could have been done differently to help your child prior and after diagnosis?
20. Is there any advice you would give to other black parents that have a child that has been recently diagnosed with ASD?

Appendix C

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19 March 2018

To whom it may concern

This letter serves to provide the assurance that should any research participant interviewed by Ms Snenhlanhla Mshengu (Psychology masters student) require psychological assistance as a result of any distress arising from the research project titled: ***"Black African parents' experiences of having their child diagnosed with Autistic Spectrum Disorder"***, the service will be provided by Psychology Masters students and/or intern psychologists at the Child and Family Centre, University of KwaZulu-Natal, Pietermaritzburg Campus. It is acknowledged that Ms Mshengu's project is under the supervision of Dr Carol Mitchell. The rate per session is R200.

Yours sincerely,

Dr Phindile L. Mayaba
Director: Child and Family Centre
University of KwaZulu-Natal
Pietermaritzburg Campus

CHILD AND FAMILY CENTRE
School of Applied Human Sciences
Discipline of Psychology

Postal Address: Private Bag X01, Scottsville, Pietermaritzburg 3209, South Africa
Telephone: +27 (0)33 260 5166/6368 **Email:** mayabap@ukzn.ac.za **Website:** psychology.ukzn.ac.za
Founding Campuses: 🟥 Edgewood 🟧 Howard College 🟨 Medical School 🟩 Pietermaritzburg 🟦 Westville

Appendix D

Informed Consent

Information Sheet and Consent to Participate in Research

Date: 25/06/2018

Greetings Parent

My name is Snenhlanhla Zikhona Mshengu from the University of KwaZulu-Natal Pietermaritzburg. I am a Psychology Student (Masters, educational psychology).
Email: [redacted]
Cell: [redacted]

You are being invited to consider participating in a study that involves research that will be looking at the parental experiences of black African parents who are raising a child with autism spectrum disorder (ASD). The aim and purpose of this research is to get a better understanding of the experiences black parents have had with raising a child with ASD. The study is expected to enrol about 7 parents. All parents in the study will be from Pietermaritzburg (including the greater Edendale area). It will involve interviews with each parent and last between 60-90 minutes to get in-depth information. The duration of your participation if you choose to enrol and remain in the study is expected to be for the length of the interview (60 – 90 minutes). The study is not funded by any organisation or private persons.

The study may involve the following risks and/or discomforts: speaking about and exploring personal and family experiences (past and present). We hope that the study will create the following benefits: increased information in how black African parents experience raising a child with ASD and hopefully this research will be useful in showing the need of dealing with African problems in an African way. There will be no direct benefits to the participants.

It may be a little difficult for you to talk about your experiences. If you need to access counselling after our interview you can contact the Child and Family Centre at the University of KwaZulu-Natal, Pietermaritzburg Campus (Tel: 033 260 5166)

This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (approval number: HSS/0891/018D).
In the event of any problems or concerns/questions you may contact the researcher at
Snenhlanhla Mshengu
Cell: [redacted]
email: [redacted]

Supervisor - Dr Carol Mitchell
Tel: [redacted]
email: [redacted]

or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557- Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

Participation in this research is voluntary and participants may withdraw participation at any point. In the event of refusal/withdrawal of participation the participants will not incur penalty or loss of treatment or other benefit to which they are normally entitled.

If a participant no longer wishes to participate they may withdraw from the study and email to be sent to the researcher stating withdrawal from study (no reason is needed).

Interviews will be held in the interview rooms in the Psychology building on Golf Road in Scottsville, Pietermaritzburg. Participants would have to provide their own transportation to the venue. However, if participants cannot make it at any point an alternative venue would be used that would ensure privacy.

Confidentiality of all participants will be strictly kept at all times. Names will not be used in the study but rather pseudonyms. Any information that would make the participant identifiable will not be revealed. All interviews will be transcribed for research analysis purposes and recordings will be kept on the researchers' laptop in an encrypted (password protected) folder and will be disposed of after a period of five years as per requirement. Disposal will be done professionally ensuring removal from hard drive as well.

CONSENT

I ____ have been informed about the study entitled Black African experiences of raising a child with Autism Spectrum Disorder by Snenhlanhla Zikhona Mshengu.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed that there will be no compensation and counselling will be available at the Child and Family Centre (CFC), University of KwaZulu-Natal, Pietermaritzburg Campus; should I need it.

______________________ ______________________

Signature of Participant **Date**

Additional consent,

I hereby provide consent to:

Audio-record my interview / focus group discussion YES / NO

______________________ ______________________

Signature of Participant **Date**

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at:

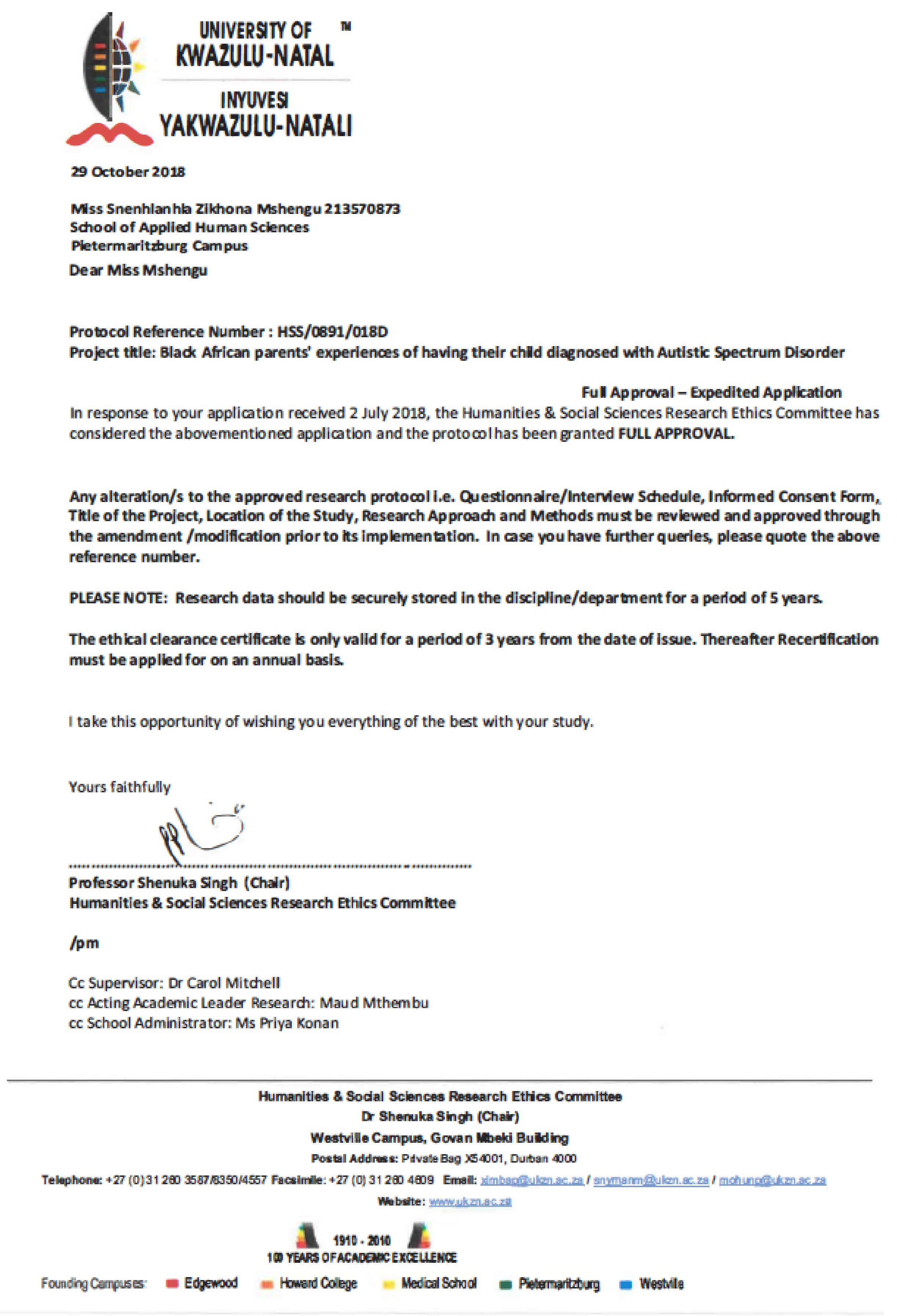
Email: [redacted]

Cell: [redacted]

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557 - Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

Appendix E



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29 October 2018

Miss Snenhlanhla Zikhona Mshengu 213570873
School of Applied Human Sciences
Pietermaritzburg Campus

Dear Miss Mshengu

Protocol Reference Number : HSS/0891/018D
Project title: Black African parents' experiences of having their child diagnosed with Autistic Spectrum Disorder

Full Approval – Expedited Application

In response to your application received 2 July 2018, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

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

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

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

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

Yours faithfully

....

Professor Shenuka Singh (Chair)
Humanities & Social Sciences Research Ethics Committee

/pm

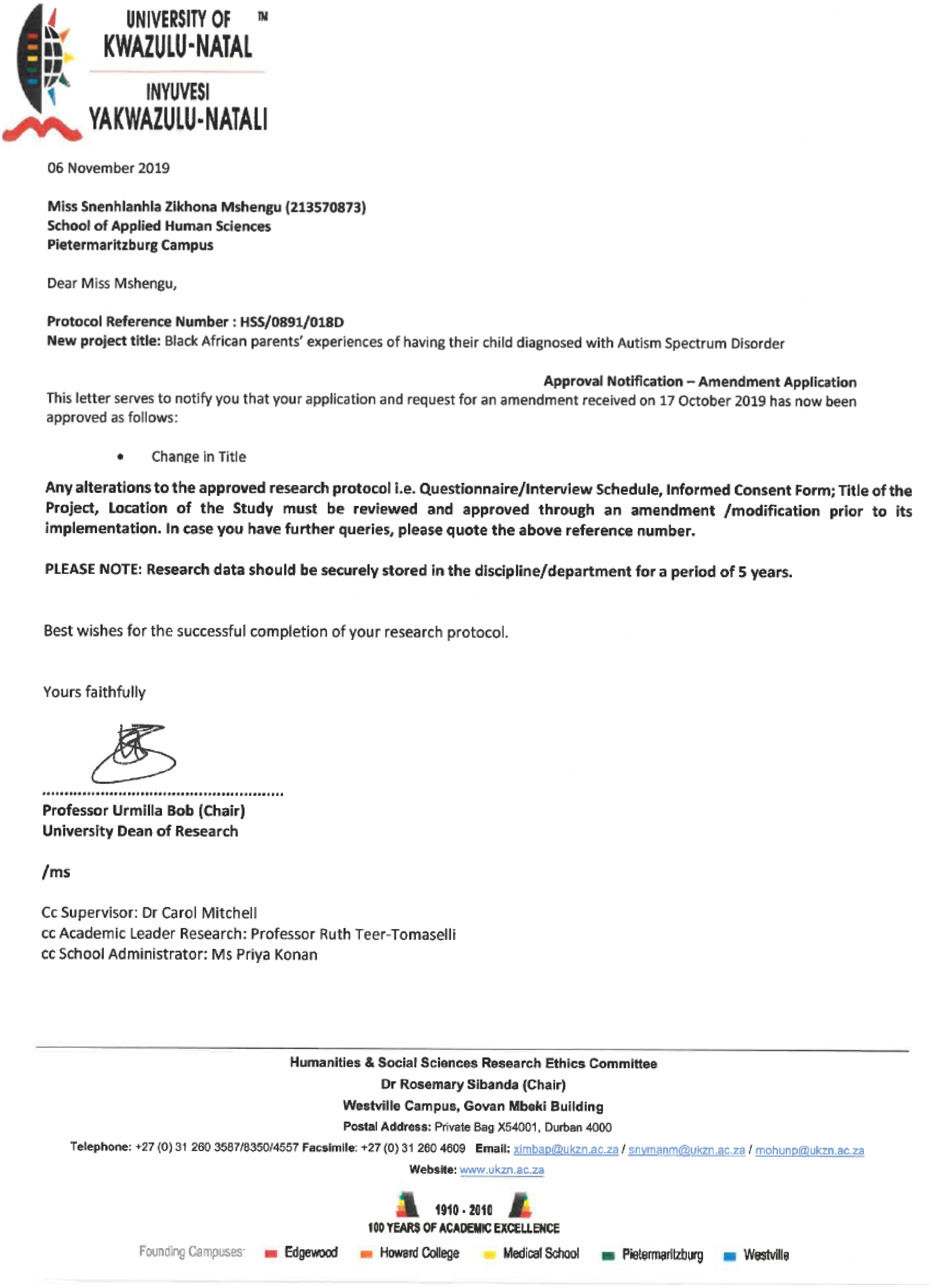
Cc Supervisor: Dr Carol Mitchell
cc Acting Academic Leader Research: Maud Mthembu
cc School Administrator: Ms Priya Konan

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0)31 260 3587/8350/4557 **Facsimile:** +27 (0) 31 260 4609 **Email:** ximbap@ukzn.ac.za / snymanm@ukzn.ac.za / mohunp@ukzn.ac.za
Website: www.ukzn.ac.za

1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: 🟥 Edgewood 🟧 Howard College 🟨 Medical School 🟩 Pietermaritzburg 🟦 Westville

Appendix F



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06 November 2019

Miss Snenhlanhla Zikhona Mshengu (213570873)
School of Applied Human Sciences
Pietermaritzburg Campus

Dear Miss Mshengu,

Protocol Reference Number : HSS/0891/018D
New project title: Black African parents' experiences of having their child diagnosed with Autism Spectrum Disorder

Approval Notification – Amendment Application

This letter serves to notify you that your application and request for an amendment received on 17 October 2019 has now been approved as follows:

- Change in Title

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form; Title of the Project, Location of the Study 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.

Best wishes for the successful completion of your research protocol.

Yours faithfully

……………………………………………………

Professor Urmilla Bob (Chair)
University Dean of Research

/ms

Cc Supervisor: Dr Carol Mitchell
cc Academic Leader Research: Professor Ruth Teer-Tomaselli
cc School Administrator: Ms Priya Konan

Humanities & Social Sciences Research Ethics Committee
Dr Rosemary Sibanda (Chair)
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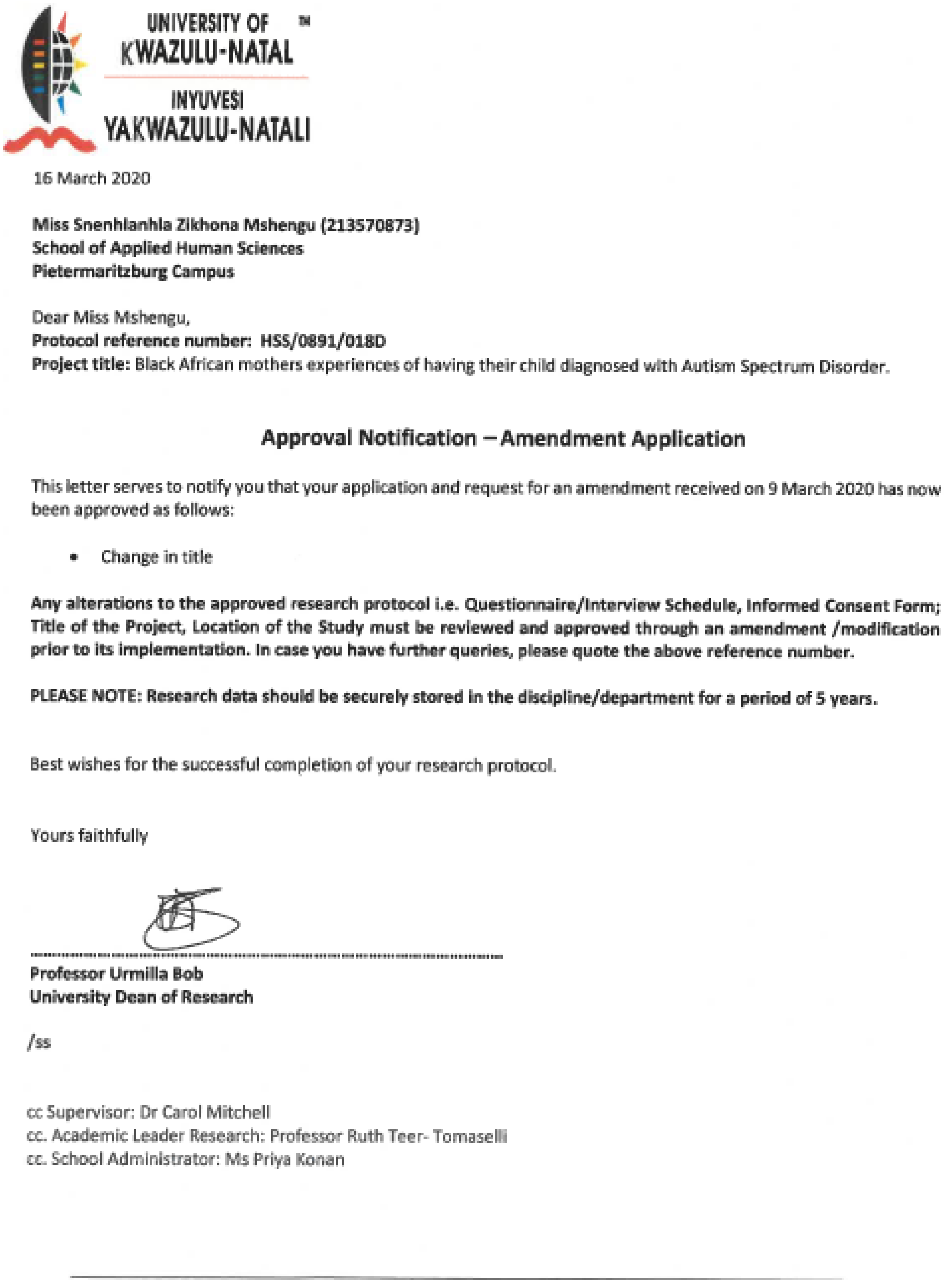
Website: www.ukzn.ac.za

1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville



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16 March 2020

Miss Snenhlanhla Zikhona Mshengu (213570873)
School of Applied Human Sciences
Pietermaritzburg Campus

Dear Miss Mshengu,
Protocol reference number: HSS/0891/018D
Project title: Black African mothers experiences of having their child diagnosed with Autism Spectrum Disorder.

Approval Notification – Amendment Application

This letter serves to notify you that your application and request for an amendment received on 9 March 2020 has now been approved as follows:

- Change in title

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form; Title of the Project, Location of the Study 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.

Best wishes for the successful completion of your research protocol.

Yours faithfully

Professor Urmilla Bob
University Dean of Research

/ss

cc Supervisor: Dr Carol Mitchell
cc. Academic Leader Research: Professor Ruth Teer- Tomaselli
cc. School Administrator: Ms Priya Konan