

African primary caregivers' understanding and experience of having a child with autism

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DECLARATION

I declare that this thesis is my own work. All citations, references and borrowed ideas have been duly acknowledged.

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ABSTRACT

Autism Spectrum Disorder (ASD) largely remains an unknown form of neurodevelopment disorder, despite the global trend of increasing prevalence. South Africans, in general, have little awareness and knowledge about this relatively rare form of neuro-developmental disorder which could so easily be misunderstood due to the major areas of difficulty experienced by children with ASD. The aim of this study is to explore African parents' experiences in relation to having an atypically developing child who is eventually diagnosed with ASD. A qualitative approach was adopted in this study, so that the researcher could gain a "rich" description of the participants' experiences of raising a child with ASD. The pathways and steps taken to arrive at this diagnosis and their reactions to the diagnosis were a central aspect of this research. Eight black South African parents (mothers and fathers) of children who have been diagnosed with ASD, were interviewed to ascertain their understanding of their both typical developmental patterns and their child's atypical development, the experience of getting the diagnosis and the experience of how raising a child with ASD has been and is for them as African parents. The data obtained was analysed using thematic analysis. The results suggested that African parents experience and understanding of ASD is largely influenced by their frames of reference. Further, the parents turned to their traditional beliefs when faced with challenges. However, other interventions such as religion and finally the western practices were explored by the parents. This study therefore concludes that the African parents understanding and experiences of raising a child with ASD is initially influenced by the parents cultural frame of reference and later by western exposure.

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List of terms

Various terms used repeatedly throughout this dissertation are defined below:

1.1. Definition of ASD

Autistic Spectrum Disorder (ASD): The criteria used to both understand and diagnose this disorder are based on the DSM IV-TR (APA, 2000) definitions and criteria for Pervasive Developmental Disorder. The writer is aware that major revisions to the understanding of the Pervasive Developmental Disorder, of which ASD forms a subset, are anticipated in the DSM-V.

1.2. Primary Caregivers

For the purpose of this study, at the stage of sampling for participants, the term ‘primary caregivers’ was used to refer to mothers/fathers/grandparents/guardians of children with ASD, who serve as parental figures and are responsible for the daily care of the child. However, only biological parents who were raising children with ASD were part of the final sample. In the study the term ‘parents’ is used to specifically to the parents within the given cultural group; i.e. African parents.

1.3. Typically developing children

This term refers to children who are developing ‘normally’ according to society’s understanding and norms. Generally the term is used when comparing a typically developing child with a child on the autistic spectrum (Rieffe, Terwogt & Stockmann, 2000).

1.4. Atypically developing children

Atypical children refer to those who have delayed development in accordance to their age appropriate development (Rieffe *et al*, 2000). In this study, this is ascertained according to the normative understanding of the parents themselves. Thus, it is a subjective reference point used by the parents.

1.5. Gender:

In this study, a child with ASD is referred to using masculine pronouns. ASD occurs more frequently in boy children. Mubaiwa (2008) states that the ASD male predominance in South African children is 4:1, reason for these rates is unknown. Results confirmed this as all children were boys.

Chapter One: Introduction

The international prevalence of Autistic Spectrum Disorder (ASD) is reported to have been steadily increasing over the last two decades (Kauchali, 2008). Although initially ASD had been thought to have a much higher prevalence in American and European countries, this neurodevelopment disorder is now recognised to occur in all countries, cultures, across genders, and socioeconomic groups (Mash & Wolfe, 2007). However, there is still a dearth of literature about the way in which ASD manifests in African children and a lack of literature detailing how parents understand this particular form of developmental disorder.

Various descriptions and prevalence rates of ASD will be explored before examining the specific issues that parents face in understanding the nature and cause of their child's difficulties when their child has ASD. In South Africa in particular, ASD remains little understood, despite the recognition that it is increasingly becoming diagnosed across all cultural groups (Kauchali, 2008).

The critical role of parental care-giving and the ways in which culture forms and creates meaning for both parents and children will also be considered. African epistemologies are rich in their considerations of child well-being (Harvey & Rauch, 1997); and so this study will explore the literature on how African parents experience and react to having a child who seems to be following an atypical path of development. The study will then consider the ways in which African parents experience and react to a child who manifests ASD symptoms, and who may eventually be diagnosed with one of the Autistic Spectrum Disorders. Various studies have been conducted in determining how parents become aware of and understand ASD.

The core aim of this study is to gain cultural sensitive insight into African parents' understanding and experience of raising a child with ASD. Although most traditional societies are in the process of some form of transition, it was thought that for many South African parents, their cultural background may be a pivotal reference point in shaping their way of thinking and being as parents of atypically-developing children; and specifically children with ASD.

1.1. Research questions

The aim of this research was to explore the African parents lived understanding and experiences of raising a child with ASD. The research questions of the study were as follows:

- What experiences do African parents have before and after their child is diagnosed with ASD?
- How (if) do African parents relate their understanding and experience to their culture? Is there a cultural link?
- What (if any) cultural interventions have been used.

1.2. Thesis layout

Chapter One, Introduction: This chapter will introduce the topic of the thesis.

Chapter Two, Review of literature: The second chapter presents and discusses the literature available and relevant to the study.

Chapter Three, Methodology: In this chapter the methodology utilized in the study will be elaborated and explored further.

Chapter Four, Results: The results of the data collected will be presented in this chapter.

Chapter Five, Discussion: The discussion of the results in collaboration with literature will be in this chapter.

Chapter Six, Conclusion: The concluding remarks regarding the study, implications of the study, future recommendations and final remarks will be highlighted in this final chapter.

References: All references used in this thesis will be listed in this chapter according to the APA guidelines.

Chapter Two: Literature Review

For most parents worldwide, the experience of raising a child is considered challenging and fulfilling. It is unfortunate however that at times, this experience is threatened by inexplicable circumstances and health complications. Children are increasingly faced with lifelong developmental disorders such as Autism Spectrum Disorder (ASD), that usher great complexity into their young lives. For the parents of these children, this is a particular challenge as they struggle to comprehend their own experiences and the nature of the disorder. The focus of the following literature review will be on the understandings and experiences of African parents raising children with ASD.

2.1. ASD description and diagnosis

ASD is a pervasive developmental disorder, which amongst others most classified as Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) includes Asperger's Syndrome; Rett's Syndrome; Childhood Disintegrative Disorder (APA, 2000) (see Table 1). Primarily, ASD is characterized by a difficulty in relating to others; lack of communicative speech; disturbed motor behaviours; occasional intellectual impairment; and demands for sameness in the environment (Nevid, Rathus, & Greene, 2005). Children with ASD appear to be in their own world, despite parental efforts to engage (Nevid *et al.*, 2005). For the purpose of this study, ASD will be defined by using the DSM-IV-TR diagnostic criteria (see Table 1).

ASD occurs across a spectrum that identifies the experiences of the child concerned. DSM-IV-TR (APA, 2000) states that the diagnostic criteria for ASD lay particular emphasis on the absence of normal development in two areas and the presence of atypical behaviour. Children with ASD have impairment in social interaction, as well as impairment in communication. There is also the presence of abnormal behaviour in the form of restricted, repetitive and stereotyped patterns of behaviour, interests and activities (Mash & Wolfe, 2007). Social impairment for children with ASD refers to their difficulty in relating to others. This difficulty manifests from a young age, where there are deficits in crucial skills for early social development.

Table 1. Features of DSM-IV-TR Diagnostic Criteria for ASD

- A.** Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
-

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

- (a) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- (b) failure to develop peer relationships appropriate to developmental level
- (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- (d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

- (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- (c) stereotyped and repetitive use of language or idiosyncratic language
- (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (c) stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

These deficits are key areas of normal social development such as: a lack of social and emotional reciprocity; unusual nonverbal behaviours such as atypical facial expressions; lack of eye-to-eye gaze; awkward body postures; lack of gestures to regulate social interaction; lack of interest and/or difficulty relating to others (especially other children); and a failure to share enjoyment and interests with others (Mash & Wolfe, 2007).

Communication impairment is also evident in early development and tends to persist. The child will display serious abnormalities in communication and expressive language (Moh & Magiati, 2012). One of the signs of language impairment is the inconsistent use of early preverbal communications; for example, a child with ASD may take the parent's hand, using it as a tool to show what he wants if it is out of reach, in preference to using vocalization (Charman, 2002). Primarily children with ASD display profound impairments in the normative use of language in social and communicative contexts. They also show verbal and nonverbal deficits that reflect a basic failure to recognise the thoughts, feelings and intentions of other people (Mash & Wolfe, 2007).

Children with ASD also present with repetitive and stereotypical behaviour and narrow patterns of interest. For example, they may have habits such as: rocking body movements; flapping their hands and arms; or unusual finger movements near the face or eyes. These stereotyped behaviours may occur when the child is not explicitly directed to engage in another activity; suggesting a possible deficit in the ability to initiate activity on their own (Mash & Wolfe, 2007). They may also manifest stereotypical behaviour particularly in unpredictable or demanding situations (Charman, 2002).

2.2. Prevalence and epidemiology

Prevalence rates have undoubtedly increased in across a wide array of cultures over the years (Ametepee & Chitiyo, 2009). Although the incidence of ASD in both Africa and the world at large is increasing at a rapid pace, there remains the challenge of determining the rates of increase. There is no doubt that the lack of knowledge about the disorder in society in general, as well as amongst health practitioners in particular, leads to a difficulty in determining the prevalence rates for this neurodevelopment disorder (Ametepee & Chitiyo, 2009). In the past, research claimed that ASD was mostly prevalent in only certain areas of the world; however this assumption has been refuted in empirical literature.

There have not been studies that indicate an association between ASD and culture, neither have there been any that suggest a link between socio-economic status and ASD. No studies indicate an association between ASD and culture or race or ASD and socioeconomic status has been found (Sadock & Sadock, 2007). This implies that this disorder knows no culture, race or status, as any family may find themselves faced with challenge of raising a child with ASD. On the other side, studies have indicated that ASD occurs more frequently among boys than girls, and that girls with ASD are more likely to have severe mental retardation (Sadock & Sadock, 2007).

In South Africa, there is an increased awareness of the incidence of childhood neurological and developmental disabilities, while there remains a limited understanding of developmental disorders particularly ASD (Kauchali, 2008). The fact that the “data available from clinical case registries in large academic facilities has gone unpublished, leaves no data on the prevalence, causes, risk factors and intervention models for ASD in South Africa, and because of this misfortune, ASD has received diminutive attention as public priority” (Kauchali, 2008, p. 5). Research indicates that ASD exists worldwide among all cultures, races and groups (Mubaiwa, 2008). Parents and children from non-dominant cultures in a given society are however faced with triple-layered problems: they are culturally different; they may be linguistically different; and they have exceptionality that is shot throughout with unique behavioural repertoires (Trembath, Balandin & Rossi, 2005).

Apart from Lotter’s (1978) studies in six African countries, few studies about ASD in Africa have been published; and the samples in the published studies are not representative of children in Africa, again making it tricky to verify the prevalence rates (Ametepee & Chitiyo, 2009). Khan and Hombarume (1996) study examined and documented the existence of ASD behaviour among children with mental retardation in Zimbabwe. Studies like this serve as an example of how previous research has struggled to conduct studies that will yield representative results about the prevalence rates of ASD in Africa (Ametepee & Chitiyo, 2009).

Another challenge is that of epidemiology, and one of the reasons for the lack of epidemiological data is a result of the fact that ASD is not well understood; especially from a cultural perspective (Kauchali, 2008).

Parental understanding of developmental disability is a critical link to accessing health care, such that if the parent does not have an understanding of development and does not consider their child as having a medical or neurological problem; this could then cause damage to the child and a failure to access professional services. This also suggests that there may be more children with ASD than that which has been researched or exposed.

Logically, parents should initially take the child to a primary health care service for assessment and appropriate intervention. Such self-referral and accessing of services would result in more accurate data. In addition, understanding is even more crucial for the health care providers who assess and treat the child, but unfortunately, because of limited knowledge, some children with ASD stand the chance of being misdiagnosed as having another form of developmental disorder or impairment. For instance, a child with ASD may be considered to be mentally retarded; as having a hearing or speech impairment; or some other form of difficulty other than ASD (Kauchali, 2008).

Various cultural groups may have different views and beliefs about the etiology and prognosis of ASD or other developmental milestones that their child may present with (Ertem, *et al.*, 2007). Ertem *et al.* (2007) state that some parents believe their child's ASD is caused by or linked to gastrointestinal function; and/or due to toxicity from heavy metals. Currently, Western medicine has suggested significant factors such as exposure (before or after birth) to drugs, vaccines, infections, heavy metals, and physiological abnormalities that affect the gastrointestinal tract and immune system (Jack & Kaye, 2003).

However, the precise cause of ASD has yet to be found. At present, the overall consensus is that genetics and biological factors are the most likely causes of ASD. However, Ametepee and Chitiyo (2009) have found that there is a link between ASD and some of the infectious diseases in Africa. Mankoski (2006) conducted a study in which revealed that severe malaria, when contracted in the first few years of life, can become a possible cause of ASD. If accurate, this conclusion leaves Africa with a profound need for further research.

With prevalence rates and frequency of diagnosis increasing, more children are going through assessment and are diagnosed with ASD (Mubaiwa, 2008). Having found that there are differences in cultural groups' perception of ASD; culture should be a core factor when establishing correct prevalence rates worldwide (Weru, 2005). Hence, the study focuses primarily on the parent's culturally-embedded understandings and experiences around ASD.

2.3. Cross-cultural factors of ASD

Marsella (2003) suggests that culture greatly influences one's construction of self, along with one's understanding and interpretation of reality. Further, this then explains how and why developmental disorders are understood differently across cultures (Marsella, 2003). This understanding becomes inseparable from the holistic experience of culture. According to Lopez and Guaranaccia (2000), developmental researchers give attention to the possibility that culture shapes the type and extent of problem behaviours in children, and the way such behaviours may be expressed or observed. This view has been strongly endorsed by the World Health Organization, which also recognises the centrality of culture in understanding the way in which disorders manifest and are understood (Lopez & Guaranaccia, 2000).

As much as cultural groups may have diverse understandings, this does not rule out the possibility that the behaviours exhibited by a given child are characteristics of ASD. Weru (2005) highlights that among African children, there is not much 'flapping of hands', elaborate ritual play or self-injurious behaviour; whereas the more common behaviours across cultures are carrying objects, and the banging and twisting of objects (Weru, 2005). This suggests that there is a framework that accepts certain behaviours in a given culture and not in another; and also that some of the ASD characteristics may be more prominent in a given group than in another.

It is assumed that the different symptoms and developmental features of children with ASD result from differences in adult tolerance, child-rearing practices, and expectations for children's behavioural problems (Weru, 2005). Nonetheless, these findings need further investigation in different cultures and contexts; and the explanations that have been offered by Weru (2005) should be further explored. Another study (Lotter, 1978) also alludes to the possibility of certain stereotypical behaviours such as hand flapping, self-aggression and rocking, being uncommon in African culture. In addition, a recent study by Mankoski (2006) confirmed that certain ASD behaviours known to be common in Western culture may not be as common in African culture (Ametepee & Chitiyo, 2009). However, with the scarcity of comprehensive studies on ASD among African cultures, it may be too soon to reach such a conclusion.

2.4. Parents' experiences with ASD

In understanding how parents from various cultures raise and experience their children with ASD, child-rearing practices themselves should be considered; particularly in terms of how these may vary from parent to parent and across cultures. Ogbu (1981) states that child-rearing is the process where the parent and/or other caregivers transmit life lessons through which children gain, the prior existing competences needed in life, and that this process informs us of how the prior existing cognitive, linguistic, social emotional and practical competencies are transmitted and acquired. However, the study of the range and nature of the cultural tasks requiring these competencies, provides us with the knowledge of why a given range and form of such competencies exist at all within the population (Ogbu, 1981).

Cultural groups and parents may have certain practices they regard as priority, and these may influence how they experience their children and how they relate to ASD. In Kenya, Gusii African mothers as well as middle class western cultural models of child care include a moral direction, a pragmatic design, and a set of conventional scripts for action that shape development (LeVine, Dixon, LeVine, Richman, Leiderman & Brazelton, 1994). LeVine *et al.* (1994) state that Gusii mothers have a Paediatric cultural model emphasizing infant protection from mortality and other threats through use of soothing by reacting to infant distress instantly and by modulating infant excitement. This pattern decreases over the first thirty months of life (LeVine *et al.*, 1994). In contrast, the western Pedagogical cultural model emphasizes active engagement and social exchange through use of stimulation and protoconversations (LeVine *et al.*, 1994). These mothers respond to babbling and provide elicitation frames encouraging excitement, questions and giving verbal praise, which increases over the first thirty months of life.

This in turn influences the way a Gusii parent as compared to the western parents may experience ASD. They do not easily take note of the lack of eye contact, and may consider it normal if the child avoids eye contact or has delayed speech (LeVine *et al.*, 1994). These two aspects of delayed speech and lack of eye contact are significant symptoms in the onset of ASD (Mash & Wolfe, 2007).

A study comparing Chinese parents and American parents found that firstly, Chinese parents tend to control their children more, as the idea of parental authority is still greatly valued (Lin & Fu, 1990). Secondly, Chinese parents are somewhat less expressive and affectionate; they emphasise family harmony through emotional restraint - especially fathers, who are emotionally less involved with their children. These parents also, thirdly, avoid encouraging independence, rather choosing that the child learn his “place” in the social order. Lastly, Chinese parents emphasise the value of academic achievement, which is regarded to be a reflection on the entire family or community (Lin & Fu, 1990). The Chinese seem to have childrearing practices in common with African cultures, notably in the practice of parental authority; limited affection; less encouragement of being independent; and more collectivism and encouragement for family or community representation (Lin & Fu, 1990). These practices may then impact on the parents experience of ASD in their child, where again early signs and delayed milestones may be missed.

Interestingly in China, children with ASD were not diagnosed until 1982, when Dr. Tao Kuo-tai diagnosed the first eleven children known to have the disorder (McCabe, 2007). Although many countries are developing their knowledge of ASD, it is still found that in countries such as China, not every doctor is familiar with this disorder; and this increases the number of children whose diagnosis is delayed (McCabe, 2007). In the current study, the lack of knowledge regarding psychological and psychiatric disorders among general practitioners was evident. However for those fortunate enough to be in countries where prompt diagnosis is possible, it does not mean things are any easier as the struggle of adjusting and raising the child with ASD remains significant.

In African culture, children in the adolescent stage are seen as playmates that are more appropriate for babies than parents, who are often involved in other chores and responsibilities (LeVine *et al.*, 1994). Therefore, it is common practice for children as young as three years of age to monitor their sibling’s activities and teach them daily task, encourage stimulation and develop valuable social skills in the toddler (Keller, 2003). These early experiences actually shape neurological and psychological development; and the emotionally stimulating experiences with other children are the basis for the self-organization of the developing brain (Keller, 2003). Given the cultural practices utilized to raise children, the understanding and experience of ASD is influenced, affecting broadly the experiences encountered in the process of obtaining a diagnosis for the child with ASD.

2.4.1. Diagnosis stages and experience

The outline for the stages in diagnosing ASD is: to screen; conduct a comprehensive diagnostic evaluation with use of standardized interviews and observational assessment tools; to be conducted by medical professionals with relevant training in diagnosis and management of ASD (Osterling & Dawson, 1994). The first step towards the diagnostic process is for the parents to recognise that there is a difficulty with the child; bearing in mind that this is a complicated identification process for parents and those involved. Importantly, ASD should be differentiated from one of the other developmental disorders such as mental retardation syndromes and developmental language difficulties (Sadock & Sadock, 2007). Often it is difficult to make the diagnosis of ASD because of the overlapping symptoms. However, the main differential features between ASD and mental retardation are that mentally retarded children usually relate to adults and other children in accordance with their mental age; and use the language they do have to communicate and indicate a relatively even profile of impairments without fragmented functions (Sadock & Sadock, 2007).

As much as there may be relative advances in understanding the nature and possible causes of ASD-related disorders over the years, early diagnosis remains a rare process, and parents remain unsatisfied with this process (Howlin & Asgharian, 1999). Siklos and Kerns (2007) stipulate that what frustrates parents is that they generally begin to note problems between the child's first and second birthday, however a formal diagnosis is only obtained when the child is between five and six years of age. It is suggested that a child with obvious delays in language and cognition stands a better chance of being diagnosed at an early stage, whereas diagnosis may be rather delayed for those children whose disorder is more subtle and not identified easily (Howlin & Asgharian, 1999). Generally children with ASD are typically diagnosed in late toddlerhood or pre-school age, despite parents having reported delays earlier (Moh & Magiati, 2012). Hence, a child's diagnosis is still only made on average at the age of six (Moh & Magiati, 2012). In many instances however, it has been found that prior to diagnosis, as much as some parents may suspect something is not right with their child, they do not anticipate a diagnosis of ASD, due to the fact that it is such an unusual/atypical disorder (Nissenbaum, Tollefson & Reese, 2002). Research has found that "one in five parents report that their child developed normally as an infant and then lost their skills and developed autistic symptoms at age of 18 months" (Osterling & Dawson, 1994, p.249).

This delay tends to cause severe distress for the parents and intense emotional strain when the diagnosis is received. Studies indicate that reactions to the diagnosis of ASD are often characterized as being negative; for example denial, emotionality, misinterpretation of the diagnosis, anger and disinterest, dislike, and uncooperativeness towards the professional (Schall, 2000). In most cases, when diagnosis is first made, families report a negative perception of their child's prognosis (Nissenbaum *et al.*, 2002). The study conducted by Nissenbaum *et al.* (2002) states that parents described their children as "salvageable", and felt that if interventions were provided their child would "recover" from ASD. Nissenbaum *et al.* (2002) also suggest that parental reaction to a diagnosis of ASD varies, and is dependent on the extent to which ASD is previously anticipated. By way of elaboration, Nissenbaum *et al.* (2002) formed three groups based on prior knowledge of the diagnosis:

- Parents who suspect ASD
- Parents who suspect developmental delays but not ASD
- Parents who do not recognise any problem

Parents who suspect ASD typically have positive reactions on hearing the diagnosis and are receptive to additional information; those who suspect delays, but not ASD, exhibit a mixture of both positive and negative reactions including relief, receptiveness, denial, anger, devastation and feelings of being overwhelmed; while those who do not recognise a problem tend to have the most negative reactions (Nissenbaum *et al.*, 2002).

When taking a positive outlook, parents state that 'relief' is a great benefit of a diagnosis, and as a result, they discontinue with feelings of guilt and self-blame; having an explanation for themselves and others as to why their child exhibits unusual behaviours (Nissenbaum *et al.*, 2002). Parents state that they often get a sense of empowerment because now they have something to work on, research to do, experts to find, and an explanation, albeit incomplete, for their child's difference (Schall, 2000). In other words, the diagnosis of ASD psychologically supports and motivates parents to obtain more information about the disorder, and to find and utilize networks and services of support. This is more effective when the diagnosis is early, since early diagnoses increase the likelihood of progress (Rodriguez, Morgan & Geffken, 1990). In addition, due to the lack of evidence for most therapies and treatments that may be of assistance, parents often turn to each other for support, and to gain insight into how best to deal with certain challenges (Johnson, 2009).

2.4.2. Experiences with the process of diagnosis

There is no doubt that parents' understandings and reactions to a diagnosis of ASD varies, and is inevitably a process through which they are called upon to endure. The process of diagnosis of ASD is experienced as both overwhelming and empowering; with feelings of despair felt most in the face of the pervasive nature of the disorder (Schall, 2000). Common reactions experienced by parents during the diagnosis process are reported to be: crying; devastation; relief; surprise; helplessness; seeking additional information; not believing the diagnosis; anger; questioning of the professionals' ability; and great concerns about reactions from family and friends (Nissenbaum *et al.*, 2002).

Often parents and their families will go through a grieving process after hearing the diagnosis. Rodriguez *et al.* (1990) further add that common feelings reported by parents who have children with ASD are anxiety, frustration and tension, as they face this often overwhelming situation.

Nevertheless, parents report that an ASD diagnosis can come as a relief in the tumult of emotions. Parents state that through the diagnosis, they are able to get a 'label' for their child's behaviour, and an opportunity to know what it is and what to do next (O'Neill & Midence, 1999). Whether diagnosis is experienced as a breakthrough is dependent on many factors, as stated by Rose (2011, p.2): "the age at which the child is diagnosed, the length of the diagnosis process, and the definitiveness with which the diagnosis was given" are all factors that determine parental reception of the diagnosis. Parents will then endure significant stress and anxiety, particularly when the diagnosis process takes excessively long, and is not dealt with accordingly through the appropriate tools and healthcare providers (Schall, 2000). According to O'Neill and Midence (1999), parents reported that they would actually prefer that their child be diagnosed with a visible disorder or disability; as ASD is more of an 'invisible condition' which makes the experiences of, and understanding from others more difficult.

However, once the correct diagnosis of ASD has been issued, parents and family of the child then move towards understanding the diagnosis, and the child's behaviour, and eventually reach a point of acceptance. Most parents feel that after diagnosis and appropriate help being offered, acceptance of their child's condition is of paramount importance (O'Neill & Midence, 1999).

2.5 Care-giving and Culture

Culture is a dynamic and creative process, shared by groups of individuals coming from specific life circumstances and histories (Lopez & Guarnaccia, 2000). Culture can be viewed as acknowledging the agency of individuals in establishing their social worlds, and it also can be viewed as both a product of group values, norms, experiences as well as individual innovations and life histories (Lopez & Guarnaccia, 2000). Marsella (2008) states that cultures are represented both internally (i.e. beliefs, attitudes, values) and externally (i.e. social structures, roles).

Culture shapes and constructs the group's reality (i.e. it contributes to their worldview perceptions), with ideas, attitudes, and morals (Marsella, 2008). As such, culture is perceived to be a dynamic process that grows, develops and changes over time. This then, is why culture is so crucial in understanding how a person may perceive certain aspects of health and health-related issues. African black people tend to be invested in their ethnic, traditional culture; this study refers to singular culture.

A central factor influenced by culture is the process of socialization and child rearing, where each culture contains an adaptive formula for parenthood, and a set of customs that evolved historically in response to the most prominent hazards in the locally experienced environment of parents (Schall, 2000). The term 'African-centered worldview' is used to describe cultural values of people from the African origin and African descent throughout the world (Graham, 1999). This African-centered worldview stipulates that childrearing is a collective responsibility, instead of that of the nuclear family alone (Graham, 1999). The formulas and child-rearing practices have developed to maximize adaptive cultural practices and beliefs in subsequent generations (Mandell & Novak, 2005). Across cultures and races, the lived experience of parents is that child-rearing is a challenging and demanding time; even more so when the child has a developmental disorder such as ASD (Troy, Connolly & Novak, 2007).

In addition, this experience can be yet more demanding for single parents who have little or no support. The dynamics involved in caring for a child with developmental difficulties can be exacerbated when the disorder is pervasive or is difficult to define and understand. For African parents and cultures this experience can be seen as even worse, because of the lack of understanding ASD in the community.

Undoubtedly the culture to which a primary caregiver belongs often determines the meaning they attach to their children's ASD symptoms, causes, prognosis, and most appropriate course of care and intervention (Mandell & Novak, 2005).

When the caregiver notices that a child is not developing according to preconceived ideas of what is "normal", they may seek an understanding, and then on the basis of this understanding, they might seek an intervention. Moreover, despite there being consistency in children's achievements of culturally independent developmental signs, the parental knowledge of when children gain developmental skills, seem to differ between cultures (Ertem *et al.*, 2007). Assuming that ASD is more a 'western disorder' based on western developmental milestones. This makes recognising "delayed" milestones difficult for African parents. Parents from different cultures have been found to explain their child's condition as a varying mixture of biomedical and socio-cultural or folk beliefs (Valdivia, 1999). In addition, they tend to consider the symptoms or condition as being temporary and curable, leading to them seeking a combination of both cultural and professional practices to help their child (Valdivia, 1999).

2.6. African Parents

Traditional African epistemologies and cosmologies may contribute to an attempt to understand the extent to which African parents comprehend and come to experience a child who has ASD. This is done through African cosmology, which is, much like other cosmologies, a worldview; a quest to understand the true nature of the universe; and finding a place in that universe (Harvey & Rauch, 1997). The African cosmology brings a sense of togetherness considered to eliminate the differences in urbanization, class, tribal affiliation, religion and geographical location across Africa and its people (Eagle, 2005).

African families and parents ascribe their child's problem as being linked to potential messages from their ancestors or as a sign of lack of goodwill from neighbours (Ramosé, 2005). This shows that those who are traditional in their beliefs and practices are more likely to perceive symptoms to define their life circumstances, and interpret health conditions from the perspective of holistic African perspectives, seeking traditional healing systems (Mandell & Novak, 2005). In cultures where conformity to western norms and value of social relatedness are emphasised, parents might be able to recognise symptoms earlier (Malhotra & Vikas, n.d.).

Ramose (2005) explains that the family is the first communal unit to discover that one of its members is afflicted by a certain illness. In most African families, this is when that individual will be reported to the ancestors; and the burden of the illness is shared among the afflicted individual and family members until they are cured, or die at the behest of the ancestors (Ramose, 2005).

2.6.1. Parents of atypically developing children

Parents of atypically developing children report having noted certain behaviours that were either absent or present in their children from a very young age, despite not knowing what could be wrong. Schall (2000) conducted an interesting study looking at families and their perceptions of raising children with ASD. Two of the families shared that they had noted a difference in their child's development around eighteen months, and that the children appeared very skilled in specific tasks. Although the families had sensed that there was something different about their child, they were often confused by the behaviours and mixed signals that they observed from their children (Schall, 2000). Osterling and Dawson (1994) add that parents report having observed delays in motor, speech, communication and social abilities in their infants during their early developmental stages. Further, O'Neil and Midence (1999) add that delay in language; pointing and awareness; rituals and behavioural problems such as eye contact and sleep were noted. However, failing to understand why their child behaved in a certain way is experienced by parents as confusion that is frustrating and a cause of great despair (O'Neill & Midence, 1999). In fact, during the pre-diagnosis process, not knowing has been described as the most difficult situation (Charman, 2002). In this confusion phase, parents find that they blame themselves and feel extremely guilty for what is happening to their child, which often leads to difficulties within the family (Schall, 2000).

2.6.2. Parents of children with ASD

Chronic illness inevitably presents major challenges, not only to the individual afflicted, but also to the family (Gray, 1993). In the case of children, their parents take more strain as the children are dependent on them. The literature emphasizes that parents of children with ASD experience several kinds of stress.

Gray (1993) states that some of the challenges that contribute to parents' stress levels are:

- the fact that ASD comes with extremely disruptive asocial behaviour
- the frustration and long duration of getting an accurate diagnosis and appropriate treatment
- that even when the diagnosis has been identified, services available are limited and are mainly in large cities, which leaves families in rural areas at a disadvantage
- although there is some improvement in educating the public, there is no doubt that some of the public are still unfamiliar with ASD and have little, if any, knowledge about it
- the prognosis for ASD is poor, as there is no cure, and in most cases autistic individuals remain dependant all their lives.

Studies have consistently shown that parents of children who have ASD experience severe challenges and problems in coping with their child. From the moment symptoms manifest, right to the time of diagnosis and thereafter, parents tend to be drained and desperate alongside trying to cope (Schall, 2000). Kediye, Valeo and Berman (2009) add that parents of children with ASD have a greater risk of suffering psychological distress than parents of children without ASD. A study conducted in China states that families are challenged by the social and cultural beliefs around disability and that it is these beliefs and understandings that determine the way they perceive their child's disability or ASD (McCabe, 2007).

Parents of children with ASD are found to use various methods as a means of coping with raising a child with ASD. Rodriguez *et al.* (1990) states that parents tend to use information seeking, wish-fulfilling fantasy and self blame as coping strategies. A practical implication of these findings is that, when parents avidly pursue information, this can be seen as an adaptive response as it may push parents to learn ways of effectively helping their child. However, it may also suggest that parents are relying on themselves, and not using professional health services or other networks (Rodriguez *et al.*, 1990). The hesitation by parents may be influenced by the assumption that front-line healthcare services make professional information seeking difficult. Other research have found that coping strategies that assist parents to maintain family stability, self-esteem and an optimistic definition of their child's condition, are related to positive family adaptation (Rodriguez *et al.*, 1990).

A study conducted by Wong *et al.* (2004, in McCabe, 2007) stated that parents of children with ASD are in great need of more support, professional help, and information about how to raise their child with this developmental disability.

A study conducted by Rodriguez *et al.* (1990) states those parents of children with ASD report having less knowledge about parenting than those of other developmental disorders. In relation to this, it appeared that parents of children with ASD reported to lower perceived parenting competence, which suggests feelings of uncertainty about their ability and skills necessary for good parenting in comparison to parents of other developmental disorders such as Down syndrome and developmentally normal children (Charman, 2002).

Research states that ASD may affect parents in various ways throughout their journey with their child. It is found that mothers of children with ASD may be at higher risk for psychosocial challenges because of scarcity of professional resources, unrelieved parental responsibilities, parental loneliness or isolation, and their child's minimal or slow progress (Nissenbaum *et al.*, 2002). Some of the difficulties that parents report are increased stress; poor physical health; depression; parental burnout; concerns about their child's dependency; effect on family life; and future psychosocial problems (Rodriguez *et al.*, 1990). Studies indicate that families find knowledgeable family members to be their greatest support and, when more was provided, it was more useful when the individual was specifically knowledgeable (Johnson, 2009).

The significant role played by families is highlighted. Although the parent's experience of raising a child with ASD may affect them directly, the larger family system also is affected. The manner in which the family then understands ASD will influence the relations among them, the parents and the child.

2.7. Families of children with ASD

In families of children with ASD, adaptability is an essential variable for the ability of the family to cope with the changes and stressors that arise in living with a child with ASD (Shakhmalian, 2005). Research suggests that cohesion, open communication, and the pursuit of recreation activities are variables that serve as safeguards for stress in families living with and raising children with ASD (Shakhmalian, 2005).

For health professionals, it is essential to bear in mind that their clinical encounter will be informed by each family's individualized experience, which is grounded in the family's local social world (Lakes, Lopez & Garro, 2006). This can inform the level of knowledge the parent has and their ability to understand the outcome of intervention or diagnosis.

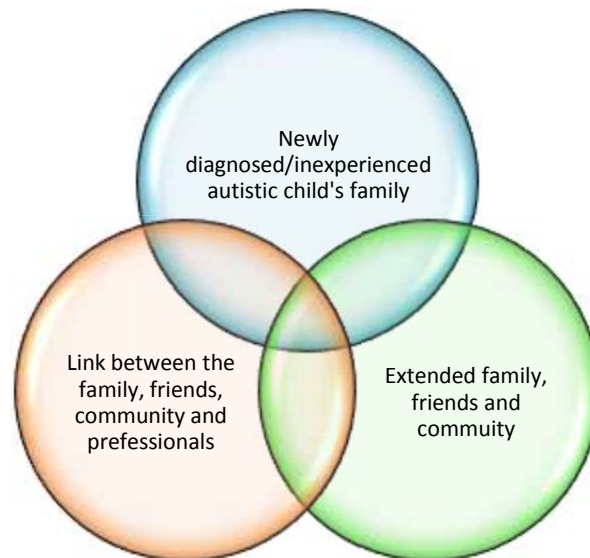


Figure 1: Understanding families of children with ASD

The experience and reality of parents and families with children with ASD can be understood on three levels. Glass (2001) explains these as:

Level 1: Firstly, the ASD must be understood by the newly diagnosed child's family. The nuclear family about to embark on a life-long journey, as the parents may be overwhelmed with disbelief; needing to come to terms with the fact that transformation must take place to ensure adaptation to the new 'stressful' lifestyle of living with a child who has ASD;

Level 2: Secondly, this new experience must be understood by extended family, friends and the community, to encourage empathy not sympathy, support, and acceptance. Furthermore, the professional and para-professionals involved should ensure that they avoid unintentionally adding to the stress the parents are already under;

Level 3: Thirdly, is the importance of establishing a healthy and effective link between the family and extended family, friends, community and professionals; where the support and resources provided by the above mentioned enable the family and parents to adapt and develop a positive manner for living with a child who has ASD (Glass, 2001).

2.8 Modern interventions

Parents often will seek several interventions in attempt to aid and cope with raising a child with ASD. The fact that this unique disorder has no cure, suggests that parents have to find strategies that are ideal for enhancing living conditions for the child.

2.8.1. Culturally based interventions

Health-seeking behaviour is largely influenced by culture and the availability of resources (Mpono, 2007). Culture shapes people's thoughts, beliefs and behaviours as well as their understanding and treatment of illness (Mandell & Novak, 2005). This therefore impacts on the parent's process in seeking cultural explanations for their children with ASD. Prioritising cultural explanations is very common among African communities, and tends to affect the acceptability of medical assistance (Mpono, 2007). It is estimated that up to 80% of the South African population make use of traditional medicine; and consult with traditional healers as means of acquiring specifically cultural explanations for the experienced illness (Mpono, 2007). For the traditional healers the aim is not necessarily to rule out medical possibilities, but to rather explore culturally what the implications of the experienced illness may suggest, and if so, obtain access to the ancestral message being communicated (Mpono, 2007).

Mandell and Novak (2005) state that because traditional African healthcare givers often have limited understanding of the symptoms, prognosis, and treatment of ASD, parents are left with conflicting information about treatment from various sources. Given this inconsistency, the parents' own interpretation and recognition of symptoms of ASD; their beliefs about the etiology and course; and their experience with the health system where their child may receive care plays a crucial role in treatment decisions (Mandell & Novak, 2005).

2.8.2. Religious

Often when parents are faced with the challenge of raising a child with ASD, they turn to various forms of resources, intervention and support as means of coping with the given challenge. In fact, the way in which the parents and family will accept the child's condition is largely determined by the way in which they cope with the stress of raising such a child (Glass, 2001). Pargament and Tarakeshwar (2001) suggest that religion has been a great influence and resource in parental coping strategies.

Parents, who lean on religious practices, rely on their church and spiritual leaders to guide and enlighten them during challenging times. Some families of children with ASD may grow to hold religious beliefs that inform their understanding and acceptance of children, child-rearing and the challenges that may arise while raising a child with ASD (Jegatheesan, Miller & Fowler, 2010). Jegatheesan *et al.*, 2010 state the emergent acknowledgment is growing that religious beliefs may influence how parents of children with disorders or disability interpret and experience ASD.

Religion as a resource means different things for different families, and may be used differently according to the families' experiences and cultural background. Research suggests that some people look to religion for various means of support, such as that meaning or comfort which is to be found from a nonjudgmental divine other (Pargament & Tarakeswar, 2001). Three different approaches to responsibility and coping in the stressful situation of raising a child with ASD are shown as: (1) a self-directing approach, where the individual relies on the self rather than on God; (2) a deferring approach, where individual places the responsibility for coping on God; (3) a collaborative approach, where individuals and God both become active partners in coping (Pargament & Tarakeswar, 2001).

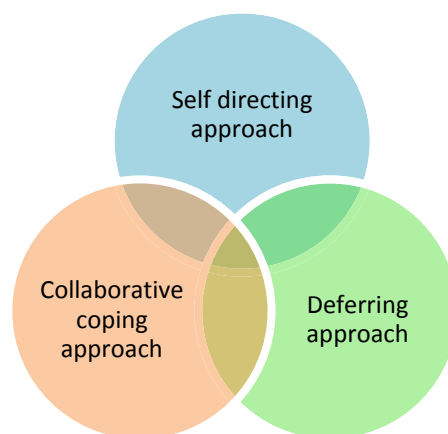


Figure 2. Approaches for coping with raising a child with ASD: religious perspective.

2.8.3. Other Interventions

Recent research has highlighted what is termed CAM (Complementary and Alternative Medicine). This is defined as a broad sphere of healing resources that includes all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically-dominant health system of the specific culture or society in a given historical period (Wong, 2009). In addition, Wong (2009) states that the National Centre for Complementary and Alternative Medicine (NCCAM) defines CAM as embracing practices and ideas which are outside the area of conventional medicine in numerous countries; and defined by its users as preventing or treating illness, or promoting health and well-being.

Depending on the given culture and ethnicity, there is a wide range of usage of CAM among pediatricians, which varies from 1.8 to 83.5% worldwide; this shows how significantly CAM is becoming increasingly popular worldwide (Wong, 2009). This is due to the fact that parents of children with chronic illness, such as ASD do in fact seek alternative treatments. Wong (2009) states that more parents of children with ASD are asking their pediatricians about the role of CAM during initial consultation visits. This interest in CAM is seen to be due to the fact that there is no cure for ASD. Inevitably, this is one of the biggest challenges for families raising children with ASD. As much as CAM may be in the picture of alternative measures, parents tend to use it concurrently with other conventional medicine, and therefore it is crucial that healthcare providers increase their awareness of CAM usage and discuss these with their clients (Wong, 2009).

2.9. Summary

In summary, the literature indicates that parents raising children with ASD have abnormally frustrating and demanding roles. Parents specifically in African cultures have experiences that have not been researched enough; an indication of this was noted by the limited literature available showing the experiences of African parents raising children with ASD. It is concluded that more research is an urgent necessity in South Africa that may lead to creating better health services that accommodate Africans in their frame of reference and understanding of ASD.

Chapter Three: Methodology

The following chapter will summarize the aims and design of the study, sampling techniques and data collection methods. In addition, the ethical issues that were involved both in the data collection and analysis phases of the study will be discussed.

A qualitative methodological approach was utilized in this study, as this research was primarily interested in the meaning that people attach to experiences, to help them in making sense of their lived experiences and the structures of the world around them (Creswell, 1994). This study aimed at understanding the cultural factors that may have influenced black African parents when raising children whose development did not follow expected patterns or norms, and who have subsequently been diagnosed with ASD. The focus of the study was to investigate a parent's cultural understanding and experiences of ASD before and after diagnosis of their child. The data required to build this understanding was obtained through individual interviews and a focus group discussion.

3.1. Aims of study

The study aimed at gaining a culturally-sensitive and in-depth understanding of how African parents who are raising children diagnosed with ASD, have understood and experienced their child. In particular, the focus was to ask them to retrospectively describe their experiences and understandings of early childhood developmental, variation, dysfunction and impairment before the time that their child was diagnosed with ASD; and to note the changes that then followed diagnosis. It was important to observe how these parents have experienced raising a child with ASD from the time that they realised that their child was not following a typical or normative pattern of development.

The study assumed that there were differences in understandings of childhood development, developmental variance, and disorder between that of western-oriented cultures and that of cultural understandings endemic to the African continent and South Africa in particular; and thus to perceives understandings of ASD, across cultures, communities and parents.

The significance of this study is exploring the parents' perceptions, attitudes and lived experiences of raising a child with ASD, so that health practitioners and researchers gain understanding from the concerned people.

3.2. Research Question

The aim of this research was to explore African parents lived experiences and understanding of raising a child with ASD. The research questions of the study were as follows:

- What experiences do African parents have before and after their child is diagnosed with ASD?
- How (if) do African parents relate their understanding and experience to their culture? Is there a cultural link?
- What (if any) cultural interventions have been used.

3.3. Research Design

The study utilized a qualitative design to gain an in-depth understanding of the experiences of African parents who were raising children with ASD, and how their cultural perceptions and understandings affected this process. Qualitative research lends itself to more descriptive data and interpretive analysis according to (Sandelowski, 2000). This research design fitted well with the research aim of understanding the process, meaning and practices associated with having an atypically developing child, who is subsequently diagnosed with ASD. This design also relies on the participants' subjective accounts to understand social life (Babbie & Mouton, 2005). The techniques in the qualitative design allowed for "thick descriptions" of the African parents experiences in raising a child with ASD, from the participant's perspective (Babbie & Mouton, 2005, p. 272). Alternatively if quantitative methods were used for the study only descriptive statistics, such as the frequency of various aspects would be possible (Sandelowski, 2000). Such a design would therefore not allow for an understanding of African parents experience of raising a child with ASD. A qualitative design was thus optimal for this study.

It was accepted that as the parents went through the various processes associated with atypical development in their children, that their understanding may have changed or been modified over time. Thus, the data collected was based on the participants' recall of past and potentially difficult events. Furthermore, it was considered to be useful for them to be able to recount the whole story from the beginning of the process of identifying an atypical path of development in their child, through the diagnostic process, to current conceptualizations.

Sandelowski (2000) further suggests that for researchers to understand any phenomenon or experience, they should know the “facts” about that phenomenon. This serves the purpose of providing the platform into gaining insight and acknowledging the lived experiences. In this research, the parents were the source of facts concerning their perceptions and lived experiences.

3.4. Sampling

Non-random, purposive sampling was used. This sampling technique was most suitable because the study required specific participants who had the experience of raising a child, before and after ASD diagnosis. The criteria for inclusion were that the participant be a parent of a child with ASD and that they be black African. The sample size comprised of eight African parents who had children with ASD. Participants comprised of both mothers and fathers of children with ASD, and their children’s ages ranged from four to sixteen years (see Table 2).

Various steps were taken to obtain the sample. Firstly, informed consent was obtained from all relevant gatekeepers at a Pietermaritzburg-based school, which caters for the needs of children with ASD (see Appendix A.3). Once these initial gatekeepers had provided consent for the study, the African parents of children with ASD were contacted through school channels. An initial letter was sent which invited parents to attend a meeting. However not many parents arrived for this initial meeting and further attempts were also unsuccessful. The next step in dealing with the difficulty in finding participants was to allow for individual interviews. This approach worked well, and although it was with minimal participants, those interested were interviewed. These participants were given information sheets and consent forms before the start of the interview (see Appendix A.3). In a further attempt to solve this recruitment problem, Durban-based special needs schools were also contacted and permission was granted to attend a meeting that had already been planned with parents of ASD children. The researcher attended the meeting and requested that parents directly participate in a focus group discussion. Once the parents agreed, information sheets and consent forms were provided for these parents and the discussion then began.

Although the initial aim was to conduct a focus group discussion with between eight and twelve participants, recruitment of participants proved to be extremely challenging. In addition, it was challenging to coordinate the interested participants to attend at the same time, date and venue. It therefore became necessary to have a combination of individual interviews and one intensive focus group discussion. In retrospect, this seemed to provide an interesting spread of experiences that could then be analysed, bearing in mind the source of the data. This combination of interviews and focus group elicited rich sources of data, as these were parents with the lived experience of raising a child with ASD, who were sincere in their participation.

Table 2. *Research participant characteristics*

Participant number	Data collection method	Participant's characteristics					Autistic child's characteristics		Number of other children in family
		Location	Parent role	Marital status	Occupation	Religion	Sex & age (in years)	Age when diagnosed	
1	Interview	PMB	Mother	Married	Student	Christian	Boy (9 yrs)	3 yrs	2
2	Interview	PMB	Mother	Married	NGO self-employed	Christian	Boy (10 yrs)	3 yrs	4
3	Interview	PMB	Mother	Single	Administration /secretary	Rastafarian & Christian	Boy (4 yrs)	3 yrs	0
4	Interview	PMB	Mother	Married	Housewife	Christian	Boy (16 yrs)	3 yrs	3
5	Focus group	DBN	Mother	Single	Secretary	-	Boy (10 yrs)	4 yrs	1
6	Focus group	DBN	Father	Married	Employed	Christian (Methodist)	Boy (15 yrs)	4 yrs	2
7	Focus group	DBN	Father	Married	Employed	-	Boy (11 yrs)	3-4 yrs	2
8	Focus group	DBN	Father	Married	Employed	Christian	Boy (11 yrs)	3 yrs	3

Note. PMB = Pietermaritzburg, DBN = Durban

3.5. Data Collection

In collecting data, the techniques used were focus group and individual interviews. By using two methods of data collection, the study strengthened triangulation, and therefore the validity of the research (Babbie & Mouton, 2005). As mentioned, the initial plan was to conduct focus group discussion with African parents of children with ASD.

However, the uptake for participation precluded this; as there were difficulties obtaining consensus about time, date and venue. Thus, the researcher initially reverted to conduct individual interviews with the parents from the Pietermaritzburg School. Again, participation remained minimal. A Durban school was then approached and the principal invited the researcher to come and present the research aims and request to the parents during a meeting.

3.5.1. Individual interview data collection

The individual interviews were conducted with four parents in Pietermaritzburg. These parents were all black mothers of children with ASD. The interview lasted between 30 and 40 minutes each. The participants were provided with letters that elaborated on the nature of the research; once read and understood they were asked to sign a consent form (see Appendix A.3). The participants were informed that the interview would be audio-recorded. For each participant, confidentiality and anonymity was emphasised.

The interviews were semi-structured (see Appendix B). The use of a semi-structured interview served the purpose of guiding the discussions to ensure that the topic remained focused on the study objective, while gaining useful rich data (Sekaran, 2003). Also, the objective of having the interviews semi-structured was to bring some preliminary issues to the surface, so that the researcher could determine which aspects required further in-depth investigation (Sekaran, 2003). At the commencement of the individual interview, the researcher took a few minutes to establish rapport, as there had been no prior relationship between the researcher and participants. This proved to be effective and beneficial for both researcher and participant, who were then able to generate a more relaxed atmosphere while talking about a rather sensitive issue. Participants were encouraged to speak openly and the semi-structured nature allowed for this opportunity.

3.5.2. Focus group data collection

Typically a focus group involves a group discussion on a specific topic that is the ‘focus’ of the conversation, with the advantage that the researcher is able to get a deeper meaning from the rich data provided by the participants (Stewart & Shamdasani, 1998). The purpose of conducting the focus group was to obtain the participants’ impressions, interpretations, and opinions, as participants described their lived experiences (Sekaran, 2003).

Hence, in this study the objective of utilizing the focus group technique was to obtain the African parents' cultural understandings and lived experiences of raising children who have been diagnosed with ASD.

Focus groups are particularly well suited for exploring and stimulating discussion concerning the issue of interest for this study. The two main reasons why focus group discussions are conducted are to collect opinions, beliefs and attitudes about the issue of interest and to check the assumptions made by the researcher (Simon, 1999). Simon (1999) further elaborates that through this qualitative method, the uniqueness of each participant's experience and understanding is recognised as a source of data, and through this method, the specific cultural understanding and background may be revealed during the discussion and across the group.

The focus group discussion was held at a Durban school, after the individual interviews in Pietermaritzburg had been conducted. The focus group consisted of four African parents of children with ASD, one mother and three fathers. These parents had volunteered to participate in the discussion, after being introduced to the research during a meeting held at the school. The duration of the focus group discussion was approximately an hour and half. A semi-structured interview format was used to guide the discussion on the outlined topic of developmental variance, ASD, and the understanding and experiences of raising a child with ASD (see Appendix C).

3.6. Data collection settings

The data collection setting utilized for the individual interviews was a therapy room at the School of Psychology at the University of KwaZulu-Natal Pietermaritzburg Campus. The venue room used for the individual interviews was conducive to providing a private setting which ensured confidentiality and freedom for the participants to express themselves as they shared their experiences. The data collection setting for the focus group discussion was held in the school hall. At the commencement of the discussion, consent forms (see Appendix A.3) were provided to the participants.

An emphasis on maintaining confidentiality and respect for each other during the discussion was highlighted. Rapport was established using an ice-breaker technique. The participants were also informed that two recorders were to be used for audio recording of the discussion.

Unfortunately, the setting of the hall resulted in poor recording quality. However it was a private setting with minimal interruptions which ensured confidentiality.

3.7. Recording the interviews and focus group

Audio recording was considered an appropriate method of data collection. It ensured the accurate recording of the interviews and discussions without impinging or causing discomfort for the participants. This was supplemented with note taking. It seemed that participants were comfortable and not distracted by the fact that they were being audio-recorded. In order to ensure accurate recording, two different recorders were used. Also the two recorders ensured that no data was lost.

Participants could choose to respond in either isiZulu or English as the researcher is fluent in both languages. The supervisor was only fluent in English and so all data was translated into English before analysis. It was important also to ensure that the meaning is not lost in translation. However, when a direct translation seemed impossible, the isiZulu terms were kept and explained.

3.8. Translating and transcribing the interviews

Once data was audio recorded, it was transcribed as accurately as possible. The transcribing was converted into an English-only record. Through the process of transcribing, a written record of the discussion and interviews is established, and then the raw data is converted into text that requires further in-depth analysis. Once the transcriptions were completed, transcriptions were saved electronically in one database ready to be utilised in the next step of coding and analysis. One limitation of transcribing audio recordings is that only verbal responses are reflected and documented; whereas non-verbal responses are only observed, but not recorded.

It was considered crucial that all data was managed accordingly at all times. This entailed keeping the recordings safe and private before transcribing. Once transcribed the texts were kept privately and shredded when no longer needed.

Some of the individual interviews were conducted in isiZulu - the home language of the participant; this served the purpose of best allowing the participants to express themselves comfortably. However, the transcription was in English only, with isiZulu words translated. This served the purpose of allowing the university supervisor access to the content of the interviews.

3.9. Data Analysis

Audio recordings were translated and then transcribed, before being analysed using thematic analysis; an interpretive analysis method. Thematic analysis is a way of seeing, as well as a process of coding qualitative information, and ultimately allows for interpretations to be made (Bryne, 2001). It is a technique that allows for flexibility when working with a variety of information in a systematic manner that increases the accuracy and sensitivity in understanding and interpretation of observations (Boyatzis, 1998). Thematic analysis method allows for the reports of experiences, meanings and the reality of the African parents (Braun & Clarke, 2006). This technique was best suited to draw out the crucial aspects required by the research question.

In order to achieve a good interpretive analysis, the following five steps suggested by Terre Blanche, Durrheim & Kelly (2006) were used: (1) familiarisation and immersion; (2) inducing themes; (3) coding; (4) elaboration and interpretation; and (5) checking. These will be further discussed below.

3.9.1. Familiarisation and Immersion

The first stage involved familiarisation with the data. In achieving this, reflection on the discussion and interviews was immediately revised after each of the sessions. After transcriptions were completed, the researcher repeatedly read the text, with the aim of becoming fully immersing and familiar with the data; and enabled a deeper understanding of the language usage, along with the experiences of what was shared. During this stage of familiarization, reflections were recorded, key ideas highlighted, and emerging codes noted.

3.9.2. Inducing Themes and Coding

Through productive immersion in the data, the coding process gradually materialised. Identification and recording of emerging themes and codes was done. Through working closely with the text, themes and key ideas were obtained and then checked and cross-checked to ensure accuracy and consistency.

3.9.3. Elaboration

At this stage the identified codes were then organised into emerging themes, which summarised the codes. These themes were elaborated upon through re-reading the data for other ways in which a theme may have been raised.

3.9.4. Interpretation and Checking

This stage involved the checking of themes in existing literature, with newly arising themes from the present study being identified.

3.10. Validity and Reliability

The study aimed at ensuring that poor reliability and validity be avoided. Reliability and validity are salient because constructs in social theory may be ambiguous and not directly observable. Furthermore, both are important in establishing the truthfulness, credibility or believability of findings (Neuman, 2003). In qualitative research, four criteria of design should be considered in order to ensure validity and reliability. These are: Credibility; transferability; dependability and conformability (Trochim, 2006).

3.10.1. Credibility

The credibility criterion involves finding whether or not the results of qualitative research are believable. Since this study aimed at understanding the African parents' lived experiences of raising children living with ASD, credibility was achieved, as the parents gave their understanding and experiences.

3.10.2. Transferability

Transferability looks at the extent to which the research results are able to be transferred to other situations. In this study, the design used could be transferred to other contexts and yield similar results. Because the results are specific to the standards and requirements in this study (African parents raising children with ASD in which the child has been accommodated in a government special needs school) the transferability of the study to other populations is limited.

3.10.3. Dependability

Dependability relies on the researcher documenting closely every change that unfolds in the research setting; and how these may have affected the research material. The research difficulties and changes during the process were considered in the analysis stage. Some of the challenges surrounded the fact that the researcher is a young, African, isiZulu speaking woman, who was possibly viewed as not being able to empathise with the participants' lived experience of their children.

Overall the impact of this research was mainly positive, with acceptance and understanding of the ethos that "abnormalities" need not be obstacles, but can be seen as an opportunity for gaining knowledge and insight.

3.10.4. Conformability

Conformability is the extent to which other researchers would be able to apply the same methods and confirm the research results. In this study, ensuring credibility and trustworthiness was crucial. This was made possible by the participation of African parents raising children with ASD, who were assumed to have disclosed true recounts of their experiences. Further, the factor that could have influenced the nature of the reports given by the participants was the data collection method utilized. To a certain extent triangulation dealt with this issue as it allowed the researcher to draw information from two contexts, namely the focus group and individual interviews (Silverman, 2010).

3.10.5. Reflexivity

It was crucial that the researcher be reflexive in the way in which she conducted the interviews. This was done during interviews, where the researcher had to allow either isiZulu or English to be used by the participants in expressing themselves. Again, the fact that the researcher is an African isiZulu individual ensured this flexibility throughout the study.

3.11. Ethical Considerations

A research proposal was submitted to the Ethics Committee in the Faculty of Humanities Development and Social Sciences (HDSS) and approval for this study was granted (see Appendix D). The ethical considerations in this research served the purpose of protecting the interests of the participants and addressing issues of scientific misconduct and plagiarism (Wassenaar, 2006). The basic philosophical principles considered in this research are:

3.11.1 Informed consent

The aims and purposes of the study were explained fully to all participants before commencement of interview or discussion. Agreement to participate was voluntary and thereafter informed consents had to be signed by each participant (see Appendix A.3).

3.11.2. Autonomy and respect for the dignity of persons

This requires that the individual is protected and there is institutional confidentiality (Wassenaar, 2006). This was assured by informing the participants that all information they disclosed would be protected. Participants were also informed that all data collected during the interviews and focus group would be kept confidential and would be used for research purposes only. Pseudonyms were used. Participants were informed of their option to opt out at any point.

3.11.3. Non-maleficence

The researcher is required to ensure that there is no harm caused to the participant due to direct or indirect consequence, be it physical or psychological (Wassenaar, 2006). Although the nature of this study was unlikely to harm participants, it might have caused emotional distress. The facilitator is a psychology student under supervision. If problems had arisen, referral to a qualified psychologist would have been arranged.

3.11.4. Beneficence

This compels the researcher to maximize the benefits for the participants (Schenk & Williamson, 2005). In this study, the participant's benefits will be maximized in terms of enabling them to discuss developmental variance, delay, and disorders which will enhance their understanding. The researcher will also present in writing the brief summary of results and study to the participants as token of gratitude towards their sharing of personal experiences, which may play a huge role in others lives and field of research.

3.11.5. Justice

It is stated that the participants in the study must be treated equally (Wassenaar, 2006). It can be said to be beyond doubt that all participants who took part in this study were treated fairly; before they agreed and signed anything, they were informed that their participation was voluntary and highly appreciated.

3.12. Summary

This chapter outlined the methodology used in the study. Due to the initial difficulties in identifying suitable participants, the researcher needed to adapt the study by conducting both individual interviews (with four African mothers of children with ASD) and a focus group discussion (with three African fathers and one mother). This mixed method of data analysis both created challenges and deepened the data collected. The study involved a sensitive topic with potentially vulnerable subjects; therefore careful considerations of ethics were applied. All participants reported how much they enjoyed and benefited from sharing their experiences. Issues of reliability and validity had to be constantly considered by the researcher. Also, the way in which issues related to the participants and the research design had to be effectively analysed.

Chapter Four: Results

The following chapter aims to present the results of the focus group and individual interviews. This study explored the experiences and understandings of developmental disorders from the perspective of African parents involved in raising children who have been diagnosed with ASD. Themes and sub-themes that emerged during the course of data collection and the analysis are discussed with illustrative examples of the transcripts. Direct quotes will be illustrated using italics. The following notation will be used to give clarity about the sources of this data:

- FG will be used to indicate that the participant is from the focus group, and the number five to eight have been used to designate specific individuals who participated in the focus group.
- INT 1/2/3/4 will be used to indicate that the participant is from an individual interview, with the number indicated which participant is being quoted
- M and F are used to indicate if the participant was a mother or father. Three of the focus group participants were fathers.
- ... (an ellipse) is used to show that part of the extract has been removed to shorten it and to highlight the relevant parts of the extract only
- IsiZulu words will be underlined and found in the glossary

The data will be presented in terms of the chronological sequence experienced and described by the participants i.e. pre-diagnosis; the process of diagnosis itself; and then their adaptations and concerns after diagnosis of their children as having ASD (see Table 3). Overall, the main objective was to demonstrate the parents' lived experiences and understandings, taken specifically from their African cultural perspectives.

Table 3: Themes that emerged during interviews and the focus group

<p>Pre diagnosis “Frustration and worry”</p>	<ol style="list-style-type: none"> 1: Early signs 2: Age of concern 3: Challenges with professionals 4: Misdiagnosis 5: Lack of knowledge 6: Impact on family 7: Cultural perceptions
<p>Diagnosis “Revelation and relief”</p>	<ol style="list-style-type: none"> 1: Average age of diagnosis 2: Professional consulted 3: Reaction to the label 4: Cultural gap 5: Self advocacy
<p>Post diagnosis “And then what?”</p>	<ol style="list-style-type: none"> 1: Emotional impact 2: Family and community responses 3: Empowerment 4: Coping post-diagnosis 5: Future concerns 6: Awareness 7: Cultural factors

4.1. Pre-diagnosis experiences

During the pre-diagnosis stage, parents in the study reported experiencing frustration, worry, and confusion during the pre-diagnosis stages. This was largely due to not knowing or understanding what may be happening to their child. This section will explore the parent's reported experiences of the time before their child was diagnosed. All participants reported that this was a very difficult time for them, and although their reports were based on memories of their earlier experiences, it seemed to reflect a period of intense turmoil, guilt and concern. Below are the themes that unfolded during interviews with the parents regarding their experiences before the diagnosis.

4.1.1. Initial reactions to atypical development

In engaging with the parents, most reported that their understanding of child development was that certain time frames of their development see particular changes taking place; and, that when there is a delay in that developmental task, it raises concern. Generally the parents reported that they had not known anything about ASD until they were actually going through the experience with their child, as presented in the excerpts below:

"I suppose if a child is born there are certain stages he will go through ...so if those do not happen at expected times, then it obviously raises questions..." (FG: P7: F).

"When you give birth you know maybe by eight months your child will start maybe sitting, then crawl, and then walking; maybe by one starting to say words like 'mama' ...if they cannot you see [this developing in your child, then you begin to think] maybe there is something wrong" (INT: P1:M).

"I did not know anything about autism, until my child was diagnosed" (INT: P3: M).

Several of the participants described their children as developing normally followed by a sudden change. It was this change that alerted them to the difficulties in their child's developmental path. At this point they seemed to have been perplexed, with no idea of what could be going wrong. They shared experiences thus:

"...from day one up to ten months, he was normal then he had a stomach bug...after hospital he was never the same, the development, then there was a huge setback" (FG:P8:F).

“I was confused by the sudden change, he was not talking...couldn’t say ma to me...physically there was nothing wrong with him” (FG: P5: M).

It is interesting to note that several of the participants emphasised that their child had been developing normally, before the sudden change in behaviour and development. It was perhaps only at the time identified as a time of sudden change that the parents were able to identify that their child’s development was not following an expected or normative pattern.

4.1.2. Parents early signs and experiences

The very early experiences that the parents reported highlighted the challenges in which they encountered. The parents’ initial experience and the signs that gave way to aggravating their confusion and frustration as the parents had no idea of what was happening to the child. The experiences were shared as being:

“He slept a lot and did not cry...we thought oh what a good boy” (INT: P4: M).

“I could see he does not give or keep eye contact, and does not like playing with other kids but likes playing alone” (INT: P3:M).

Furthermore, parents shared that they experienced the appearance of maladaptive symptoms and negative features in their child’s behaviour as worrying and difficult to cope with:

“It was difficult for me, the frustration; he was throwing tantrums was just uncontrollable and he could not say anything...I really thought something had happened to his head” (FG: P5: M).

“...he became very hyperactive, he couldn’t stay in one place...and then he started banging his head” (INT: P2: M).

In their turmoil, the parents sought an understanding of what was happening. These parents reported experiencing a need to try to find someone, or something, to blame for what was happening to their child, and in desperation and confusion would often blame those around the child.

“...he had a nanny and so I thought she had dropped him...” (FG: P5: M).

“For a long time I blamed my child minder, [I believed that] there is something she did to my child...” (FG:P8:F).

Parents however reflected that this was influenced by the fact that they had perceived a time when they had noticed a sudden change in the child's development.

4.1.3. Age of concern

For all the parents involved in this research, the common age of concern with their child was during the early childhood stage, between ages one and four, as presented in the excerpts below:

"After his first birthday his speech started to deteriorate...by 18 months, his speech faded day by day."(INT: P2: M)

"[he] started saying single words very early, around 11 months he was imitating TV, then all of a sudden he could not say a word"(INT: P5:M)

"...he was a normal child, but after two years something was not right..."
(INT: P4:M).

These reported memories are consistent with the participants' reports that the child had been developing normally and then seemed to undergo a time of sudden change.

4.1.4. Experienced lack of knowledge among medical and allied professionals

Parents reported that at times, the doctors would misdiagnose the child, because they simply did not have the experience and knowledge of ASD, and this prolonged the diagnosis process. The mere fact that parents' experiences with the medical professionals is such, indicates that there still remains a lack of knowledge, especially when it comes to early diagnosis and intervention. Some of the experiences were:

"... [the] doctor said he suspected a problem with hearing, which could explain why he is unable to talk, because he does not hear other people talk" (FG:P6: F).

"...the doctor told me he was a normal child...but after two years something was not right" (INT: P4: M).

"...all tests were done...and nothing, they could not find anything wrong physically, even his hearing was fine. They said he might be fine after sometime, two years still no speech..." (FG: P5: M).

Generally the parents were disappointed by their experiences in the process of getting a diagnosis and intervention. This is largely influenced by the fact the ASD diagnosis requires caution, which may focus on elimination of medical; neurological; and/or psychological aspects. This process of elimination can be pro-longed and tends to create a sense of professional incompetence amongst patients. While there may be instances where the doctors misrepresent the patient, sometimes the patient's disappointment is ignorance to the process. The following extract captures the general experience among parents:

"...GP's they let us down because they do not know." (FG: P8: F).

4.1.5. Cultural insight

For these African parents, often their culture would offer insight into what was unfolding. In particular, the elders of the family would suggest cultural understandings that they believed explained what was happening. For the parents though, it was a matter of doing what they could to find understanding and solutions. The participants described many different feelings related to the input they were given on cultural factors. Some reported an initial sense of comfort accompanied by clear ideas about what they needed to do to perform the required rituals. Others reported being annoyed, pressured and blamed to conduct ceremonies in which they had no faith. As much as the need to find a solution provided a sense of purpose and guidance on what to do, several of the participants described feeling frustrated and pressurized into conducting rituals that were costly. Some reported not fully believing in these traditional practices, but feeling pressure to perform the required rituals in case they would suffer the consequences and blame for not protecting their child and disrespecting their ancestors. Some of the experiences of how culture guided the process to gain insight were shared as follows:

"When you have a problem, as an African, there are aunts, uncles, grannies who say if we take this child to someone who can pray for this child, things will be ok...[they also tell you] there is the inyanga..." (FG: P6:F).

"...one of the things about Africans is that you get elderly person... saying be aware, maybe there is an ancestor who is crying and wants a ritual..." (FG: P7: F)

"...people would tell you that the child is in desperate need of a ritual, a slaughtering or I must burn impepho..." (INT: P3: M)

Fathers in this study shared some of their emotional responses of their experiences having sons with ASD. For the fathers, it seemed significantly distressing that they had a child, especially a son, whom they could not proudly show off to relatives, friends and community members.

“...people do not know the pain and frustrations you are carrying, seeing your child behaving this way...” (FG: P6: F).

What stood out from the father’s emotional experience is that they kept their emotions hidden and felt largely responsible for their child’s disorder. As a result, they were also determined to explore every possible solution. The men in the study reflected that there was a need to make sure that they were not seen as failures, unwilling to provide and protect for their child.

“...when you are desperate you will agree upon anything because you just need one thing, to see your child being normal, your son being the same as others...” (FG: P6:F).

One of the fathers spoke primarily of his feeling of desperation when trying to intervene and find ways that would help him cure his son. For the other fathers, it was evident that their experiences had been similar, as they related strongly with feelings of desperation and the ultimate need of finding something that would cure their sons. Significantly through their experience, the fathers reported that they had come to the realization and acknowledgment that cultural practices were not enough to cure ASD.

“...my son is 15 years old and no inyanga is going to help me, except for intervention in terms of teaching him skills to survive.” (FG: P6:F).

In contrast to the fathers’ experiences, a mother reported her cultural experience as insightful, viewing it in a positive perspective. She had been told that her son possibly had what is known as inyoni, and would require treatment through an enema. Following this procedure she did not see results, and the African doctor suggested it was possibly an advance state of illness, known as ‘ithuko’.

Based on this failed attempt, the mother then saw a different African doctor, and to her astonishment the doctor said, “I have seen people - but this condition, I have not seen before; in my prophecy there is no spell cast on you, no witchcraft, nothing from culture that you did not perform, it is just a gift that you have to accept and try to get some experts who can try and help you live with it.” The mother shared that this was eye-opening, and that although confused at first, she took it as valuable advice and an experience on her cultural path with ASD.

For most of the parents in the study, it was evident that out of helplessness they abided with instructions to seek cultural interventions. However, with experience and failed trials, they then let go and acknowledge that although ASD and the nature of this disorder cannot be cured or treated culturally, their culture does play a role in guiding their process of acceptance and coping.

4.1.6. Summary

The parent’s initial experiences of the pre-diagnosis stages highlight the intensity of the challenges that parents often must face when a child has been observed as atypical. These experiences are often just the beginning of more challenges and frustration to come as they head towards the diagnostic phase.

4.2. Diagnostic experiences

Following unsuccessful cultural interventions, the parents in the study sought western intervention. This process will be referred to as the diagnostic experiences. This section will explore some of the experiences that parents went through during the process of getting an official diagnosis.

Most of the parents in the study reported this process and experience, of the diagnosis process, as extremely challenging, as described one of the mothers:

“...it was tough...really tough...” (INT: P3: M).

4.2.1. Average age of diagnosis

The average age of the official diagnosis for the children was soon after the age of two years if parents were fortunate; or often as old as four or five years of age. This was despite the fact that the parents had actually sought help as early as a few months into their child's life. Extracts below show what parents' experiences were:

"He was two years eight months by then..." (INT: P2: M).

"...he said 'from all the reports that I have read, obviously you do not know what autism is'; and then he started to explain, and this was after age three maybe close to four" (FG: P6: F).

The delay in diagnosing the child after symptoms were first noticed was extremely stressful for the participants.

4.2.2. Self advocacy and search

The participants reported that they often had to consult with various professionals before they actually found one who could diagnose ASD. Also, it appeared that the parents would want a second opinion because of dissatisfaction when told to wait. While in other instances, the doctor would refer to a specialist, who would also then further refer the parents on to another with more experience.

On the journey of obtaining the diagnosis, parents reported how media, particularly magazines and television, had played a role in educating them and often their families too. For the parents it was an alarming relief to know that there were other parents who were experiencing the same issues with their children.

"...I was reading a reader's digest which had an article in front written: "Boy who climbed windows"; and was really interested because my boy likes to climb windows. ...everything they had written, these parents were explaining is things that my boy was doing and towards the end of the article was written 'autism'" (INT: P2: M).

"...it happened one day I was listening to Oprah and they were talking about autism. All the conditions those parents were talking about of their children was what my son had; all they explained was exactly what I experienced with my son." (FG: P5: M).

“...so I have read about it from magazines and watched the 3 Talk Noleen show which was on autism...I knew before we went to the doctor, after watching the show...” (INT: P1: M).

Often from that moment, the parents would feel empowered and would research more in an attempt to understand their child and this disorder.

When the parents consulted, it would often be merely to obtain the formal diagnosis from the doctor or to just confirm their experience of what the media had already exposed them to regarding the disorder and the child’s behaviour.

“When we went to see the doctor, I went with that article in the back of my mind...” (INT: P2: M).

“I knew he would diagnose autism...from the moment I heard about it I read, and told his father before we went to the doctor... it was just a formality” (INT: P1: M).

These results were significant, as they gave an impression of how effective media can be when it comes to educating viewers faced with the unknown. It is encouraging that South Africa is making the effort to educate society about ASD, through accessible avenues, such as media.

Therefore, although parents may have been frustrated by the process, the influence of the media gave them a sense of control; and they could conduct further research for a better understanding - having the comfort that they were not alone in experiencing ASD.

4.2.3. Various professionals consulted

Following experiences of self-advocacy and enlightenment about what may be going on with the child, parents soon made a shift in their understanding and way forward, moving towards the realization that traditional African interventions alone could not assist. Parents then leant on the Western and medical side for assistance and intervention. The lengthy and frustration of not knowing remained consistent through this experience and change of consultants. Media proves to have played a role in motivating parents to seek western methods of assessment and intervention for their child. However, this change of consultants proved to be more long-winded and tedious than they anticipated:

“We saw specialists...were referred to a doctor, an educational psychologist, an assessment centre...eventually a specialist in Chief Albert Luthuli Hospital” (P8: FG: F).

“... [we] took him to see doctor...he gave me letter to see another who was paediatrician...” (INT: P4: M).

“...took him to a paediatrician, he was delayed...went for second opinion in private sector, they did not help...took him to Edendale hospital, and referred for physiotherapy and occupational therapy and another referral to Grey’s Hospital...for hearing...” (INT: P2: M).

These experiences are reflections of the tiresome battle of obtaining a diagnosis, and finding someone who could effectively assesses for PDD (pervasive developmental disorder). For the parents this was disappointing as they had expected that the Western medical professionals would be better equipped and able to assess and provide diagnosis sooner. This highlights the parents (innocent) unfamiliarity of the diagnostic process which allowed for these unrealistic expectations of the western system.

4.2.4. Challenges with medical professionals

The overall experiences were frustrating and disappointing as there were no quick answers. The common frustration and challenge experienced was that parents were often sent home and told that things would get better in time. Some of the parents reported that they were told that ‘boy’ children are generally slower and would pick up, or not to worry until the child reached a certain age. This is presented in the excerpts below:

“...he told us not to be concerned until the age of three years...after age three if he continues he will refer us to other specialists...” (FG: P6: F).

“...because he is a boy they will say, oh boys they always lazy, their development is slower than girls...more lacking than girls” (FG:P7: F).

Parents had to wait with the symptoms of the child, knowing there was something not right. A father shares how torturous this was;

“They always tell us do not worry but you go home and you feel there is something wrong but they tell you do not worry, let’s wait a year, it eats you up like poison.” (FG: P8: F).

Several of the parents reported that it was not until they received specialized assistance, either from special schools or mental health specialists (occupational therapy; speech therapy and psychology) that things began to make sense.

“autism especially in South Africa is diagnosed more in psychological point more than medically...medical link everything with heredity and that throws us out as parents...” (FG: P8:F).

“...there was no doctor that could diagnose him until he started attending the special school...” (FG:P8:F).

4.2.5. Impact on the parents

The duration and the process of moving from doctor, to specialists; in and out of hospitals and assessment centers was not just tiring and frustrating, but it was causing intense strain on the parents' wellbeing. Parents reported that soon their marriage was characterized by tension, financial problems, feelings of failure, and ultimately a sense of desperation for a solution and diagnosis.

“...it almost destroyed my marriage because I protected my boy and I ignored other kids in my house...I wanted to be there for him all my life, and forgot that outside there is also life” (FG: P8: F).

“We had to sacrifice a lot of things for us to afford private assessments and consultations...at times we would not know where money would come from...” (INT: P2: M).

The parents reported that their own pain and confusion of the experience of having a child with ASD impacted deeply on their marriages and their family system as a whole. In most instances these families reacted with much distress and helplessness, given the circumstance that ASD is a complex and unique disorder. The theme of blame was strongly evident in the parents' experience, as illustrated in the following excerpt:

“...I blamed the mother, saying if she took him [to the hospital] in time he may have been ok...” (FG: P8: F).

“...it has potential of destroying...blaming your other half...later realizing it was not this person's fault...” (FG: P7: F).

For some of the parents the helplessness and pain was mutual and actually brought them closer together:

“We were confused...he would only bite and scratch myself and his father, no one else...we would cry together sometimes and could not understand why there was no solution...” (INT: P2: M).

“...his father wakes up earlier to bath and assist him...he goes the extra mile for his son, which helps me get a break...” (INT: P1: M).

For these fathers, the ordeal of having a son with ASD was beyond their capacity and caused huge emotional distress, which they often did not share with their spouse. This was possibly motivated by the fact that these fathers were black African men, who tend to take great pride in being the head of the family and having a son who will carry the family name. The idea of this tradition can be seen threatening by this unpredictable disorder.

“...it is mostly boys who have autism and it hard because they carry the family name and if I take my child to the doctor and they tell me they do not see anything, I must try something else, and if it does not help then you accept...” (FG:P7:F).

“Of course we have all been to them, inyanga; isangoma...my son is 15 years now, no inyanga is going to help me, except for intervention in terms of teaching him skills to survive. As an African I have been to the sangoma” (FG: P6:F).

4.2.6. Summary

The diagnosis stages prove to be draining and tiresome for the parents, as they slowly strive towards obtaining the diagnosis. The challenges of not knowing what is happening or what to do overwhelm the parents and in desperations several interventions are sought. These interventions often impact on the parent’s family and well-being. Once diagnosis has been obtained, stressful consequences follow.

4.3. African parents' post diagnosis experiences and understanding

The diagnosis of ASD has lifelong impact, not just on those in the child's life, but also those around the child. This includes their extended family members and community members. When the child receives the diagnosis, all these systems react and are impacted in various ways. The parents in the study reported how this impact had been experienced by themselves and the child, in relation to the reactions of extended family and community and their adjustment to the diagnosis. For the parents, the post diagnosis stages were experienced in a more positive light when compared to the pre- and diagnostic stages; which were characterized by not knowing, and negative feelings because of the long, tiring journey to getting to the knowing and understanding. However it does not make the process of raising a child with ASD any easier, as others may never truly understand this unique disorder. It was common among the parents that the pain never goes away, but may get easier with time and knowledge.

“I think the effect of autism on parents has got no age limit or time limit even at whatever age your child is there are days when this sinks on you and you start to imagine things and the pain is destroying, but knowledge is strength...it is only when you accept” (FG:P6:F).

The above comment is a reflection of the parents' overall experience, that at the end of it all the significant lesson is that knowledge is power and the key to coping with ASD.

4.3.1. Impact on extended family and community

The formal diagnosis had an impact on the rest of the family and community members too. The first of these was the impact on the parents who had gone through frustration and difficulty to finally receive the diagnosis for their child. As a result of this protracted journey, all parents reported that in one way or the other, the biggest challenge was to begin to cope with extended family members and the community.

“Sadly, sometimes families do not want their children to associate with yours...” (FG: P7: F).

Another source of difficulty for the parents in the study was the effect that the formal diagnosis had on their relationships with extended family and the community. Parents reported this as their biggest challenge in developing and implementing coping mechanisms. Below are extracts that illustrate some of these experiences:

“...people do not understand; they think your child is rude, that he is spoilt...”
(FG: P8: F).

Parents reported several failed attempts of sharing information and educating their families about this condition:

“This is an unknown condition within the black community...just know child is disabled not the specific disability...” (INT: P3: M).

“...with family it is difficult for them to understand what autism is...to them it is just a term...” (INT: P3: M).

Another perspective was that if you are living in a community where you grew up or where your child was born, coping is easier as the members show empathy towards your child:

“...the adults will tell me they just saw my son and wandered where I was...you can tell they love him and look out for him” (INT: P4: M).

The biggest disadvantage in some black communities is that they do not have the facilities and structures that cater for people with disabilities, especially those as unique as ASD:

“Daycare centers do not cater for children with autism...the ones in town are too expensive...so we end up keeping our children at home, which is not good because they do not get special assistance.” (INT: P3: M).

“...issue of African community is majority does not understand and I know that also among white community they pretend to understand but they actually do not understand...” (FG: P6: F).

As result, parents will slowly start to avoid contexts which trigger unnecessary tension between them and the next person, and as a defense mechanism will isolate themselves;

“...then you isolate yourself...family gatherings and public places...you need to protect your child...you ask family to watch programs on autism...” (FG: P7: F).

“...often with family gatherings, one of us will have to stay at home with him, while the other goes with the other children...” (FG: P6: F).

“When you go out, you cannot control their [people’s] comments and reactions and it is not always easy because you do not know the challenge you will find...even if it is family, if he does not like the environment, I have to leave” (FG: P8: F).

“...it challenging because you are not comfortable in public places, he might throw tantrum and people will look at you as [an] unfit mother...” (INT: P4: M).

4.3.2. Religious contributions and experiences

From the discussions with the parents, religion appeared to play a role in the psychological processing of having a child with ASD. The parents reported how in the initial stages, they often questioned God, blamed Him and felt he had turned away from them. However after being through the process of getting the diagnosis most parents returned to seek comfort and guidance from Him as they tried to accept and cope with the diagnosis. An arising coping mechanisms utilized by the parents, was to see their child as a gift from God.

“Sometimes you question, ‘Why did God give it to me and not other people?’...” (FG: P6:F).

“...we have taken him to a pastor for prayer...healing comes from God and it may not be immediate.” (INT: P3: M).

The parents reported that for them it was the beginning of acceptance of the child as gift from God, and motivated them to lean on their faith for strength and divine intervention:

“I was in the process of saying ‘I am going to accept this because I just found it by coincidence; I would say it was divine intervention... (INT: P2: M).

“...I believe it is God who solves everything; I put my trust in him... (INT: P1: M).

Having a relationship with God also helped parents to make sense of their own shortcomings when adjusting to raising a child with ASD:

“I must thank God...when I was neglecting my other kids I repented and went to church, and started taking him with...” (FG:P8:F).

“...because we believe in God we believe that God will heal and the child will develop, even though he may not develop fully into being like other children but with Gods power we have hope...” (INT: P3: M).

In nurturing the relationship with God, parents would attend church services and take their child with ASD along with everyone else in the family, though they would have to keep close supervision over the child with ASD. The experience of this was challenging in many ways, as illustrated by the comments made below:

“...going to church is still a challenge; in Sunday school you get teachers and other kids who do not understand autism; it hurts because they ridicule him...” (FG:P6:F).

Although parents may have felt rejected by their fellow church members, they did not lose their faith in and relationship with God:

“...if your faith is in God it is difficult to divert from that...” (INT: P3: M).

“I always pray and speak to God about my issues...and believe he has said anything I ask in name of Jesus...” (INT: P1: M).

Some of these experiences in church became rather overwhelming for the parents and as resolution decided to discontinue attending:

“...as result for long time I did not go to church with him...I was protecting him...but now he is teenager and he tells me he wants to go...but sits next to me...” (FG: P6: F).

“...not much support from church because I had to stop going...he would be annoying people...during quite times he would roll on floor and cry”. (INT: P2: M).

4.3.3. Summary

For most parents, having a relationship with God gave them a sense of support in the experience of raising a child with ASD. Initially, the process was characterized by anger towards the feelings of helplessness; then a plea for understanding and light into finding a diagnosis and finally. The strength to accept and cope with a child with a diagnosis of ASD was for a majority of parents attributable to their faith.

Chapter Five: Discussion

The following chapter is the discussion of the findings based on the experiences and understanding of developmental disorders from the participants raising children diagnosed with ASD. The qualitative methodology of using focus groups and individual interviews, allowed for in-depth insight into these parents' lived experiences.

Some of the parents indicated that their experiences were, to a large extent, influenced by their frames of reference; which had developed and changed over time, and were an amalgamation of cultural and religious beliefs. Most acknowledged starting from a position of uncertainty about child development; and so their first source of reference was from their own families and cultures. The first source of seeking understanding was usually from elders of the family. They first aired their concerns about their child's development to their own parents and other members of their extended family; who in turn usually either reassured them, or suggested that various rituals needed to be conducted to appease ancestors, or to right previous potential wrong-doings. Gradually in the agony of not gaining the understanding or desired solutions, the participants then moved to seeking a religious explanation. This was done in the form of having community church leaders pray for the child and for the parents; this provided emotional support and strength to face the challenge.

The African cultural frame of reference undoubtedly impacted on the initial experience of raising a child with ASD. Following unsatisfactory explanations from traditional experts, members, and practices, the parents' sense of disillusionment and a feeling of not being able to help their child effectively motivated them to broaden their frame of reference to draw upon other Western and religious beliefs and sources for explanations and intervention. The literature shows that parents are likely to be the first to realize that their child is experiencing some developmental variance (Midence & O'Neil, 1999). These participants, as most parents globally would, first sought guidance and assistance from their own parents and family elders (Mpono, 2007). Even though many families globally now live in nuclear family units that are at a distance from the extended family, grandparents tend to be the major source of information if they feel that they are not coping as well as they should be (Mpono, 2007).

The findings strongly highlighted that the process from initially noticing a difference in the child's development, to getting a diagnosis, is significantly long and strenuous. The experience was that for these parents more than one professional was consulted in the process of getting not just the understanding, but also to getting the diagnosis of ASD. The common trend is that African parents will initially seek understanding from their elders and cultural and religious leaders; then, when all seems to fail, western and medical professionals were consulted. This trend implies that there still remains a lack of knowledge surrounding ASD in South Africa, specifically African communities (Kauchali, 2008). This was apparent not just among the parents, but also among health professionals. The following chapter elaborates further on these aspects.

5.1. Parents' experiences before the diagnosis of ASD

It was evident that the parents' experiences before the child's diagnosis of ASD were largely shaped by the cultural group to which they belonged. All cultural groups have certain beliefs and frames of references that shape their understandings of particular circumstances (Mandell & Novak, 2005). This is the case among both the African and western cultures. Therefore, developmental disorders such as ASD would be understood differently by African communities, and the core of their understanding would be influenced by the frame of reference and the exposure that they have acquired. Research suggests that children with ASD and their parents from non-dominant cultures are faced with triple-layered problems (Trembath, Balandin & Rossi, 2005). They are culturally different, they may be linguistically different, and they have exceptionality that is filled with behavioural repertoires (Trembath, Balandin & Rossi, 2005). The findings of this research suggest this by the mere fact that the parents and their child with ASD have a frame of reference that is characterized by culture specific beliefs and practices. This is to say, any given parent certainly experiences childhood development, ASD characteristics, and specifically their child with ASD, differently from another parent.

However, across all cultures, the initial stages of ASD are characterized by the parent's struggle to gain understanding, and then the long path to obtaining the official diagnosis. Swanepoel (2003) emphasises that the pre-diagnostic phase is where the parents are often anxious, and confused as their child's problems manifest, while the struggle to obtain an accurate diagnosis and treatment for their child remains.

Some of the significant findings that the current study found indicate that the parent's experience before a diagnosis is generally negative. The parents found themselves in a state of confusion and helplessness, as their observations of behaviour in their child made no sense to them as parents, due to the fact that it contradicted the expected norm. In their perplexity, parents had to further seek ways of gaining control and finding explanations for this confusion. This experience could be understood as the parents' need to find missing pieces to a puzzle that may be misunderstood. At this stage, they experienced various interpretations and insights from trusted sources, such as family elders, community members, religious leaders, culture, medical models and westernized professionals. The greatest frustration experienced was that there was no fixed explanation of the behaviour which was being experienced by the parents from their child. Only when medical attention was sought did they gain effective insight.

5.1.1. Early signs and age of concern

Early signs and concerns seem to have been prominent for all the parents. Research confirms that parents of children with ASD are the first to notice the symptoms (Midence & O'Neil, 1999). The study found that parents often had the suspicion that 'something was not right' early in their child's life, and would notice certain signs that become cause for concern. According to Siklos and Kerns (2007), parents are typically aware of some of the problems somewhere between the child's first and second birthday, however a formal diagnosis is often only obtained when the child is between five and six years of age. Cassel *et al.* (2007) further adds that children with ASD are typically diagnosed in late toddlerhood or pre-school age, despite parents having reported the symptom recognition somewhere between sixteen and twenty months. This suggests that despite the parents' circumspection in relation to their child's development, a diagnosis is still gained at average towards the age of six years (Moh & Magiati, 2012). In this study, the parents' experience was noted and confirmed between the age of one and four years, although their suspicions were reported much earlier. According to Greenspan and Wieder (1997), parents in fact report reliable early signs of communication and relationship dysfunctions long before their doctor makes the diagnosis. In this study, the parents reported that in their quest to find answers and gain understanding, they had, coincidentally, been informed by means of television talk shows, magazine articles etc., that their child displayed signs of ASD.

The experiences of being exposed to such media allowed parents to be empowered, and to have others they could identify with. It also encouraged parents to seek greater understanding, with a slight idea of what was unfolding before them.

The parents' concern about their child was often exacerbated when they experienced seeing the child having delays in development. Moh & Magiati (2012) state that often parents report noticing delays in speech and social development; followed by an awareness of the child's failure to develop age-appropriate symbolic play together with the presence of ritualistic behaviours. For most of the parents in this study, speech was experienced as the greatest concern. Osterling & Dawson (1994) suggest that retrospective studies state that parents often report having noted delays in speech, motor, social abilities and communication, when their child was an infant. For African parents the delay in age-appropriate play and ritualistic behaviour, was exceptionally concerning, as this is how development for these parents is measured (Mpono, 2007).

Unfortunately, some of the parents experienced their child as developing normally, and then suddenly the development changed. This change was obscure and functioned as an agent for frustration. Research has found that "one in five parents do report that their child developed normally as an infant and then lost their skills and developed ASD symptoms at the age of 18 months" (Osterling & Dawson, 1994, p. 249). For the participants, this triggered deeper frustration and self or spouse blame, as it simply did not make sense how a 'normal' functioning child could suddenly deteriorate to the extent of being mute; or having inexplicable behaviours.

5.1.2. Various 'consultants'

Undoubtedly, any parent would require insight and guidance through this extremity of confusion and frustration. For the participants, this meant seeking every source possible to assist and enlighten them. Therefore, various sources were approached within the desperation of making sense of this turmoil. From the findings of the current study the sources approached by the parents have been grouped into two categories, namely traditional medicine and western medicine.

5.1.2.1. Traditional

For African parents, it is not by chance that their first reactions and insight into ASD symptoms, was fostered by their given cultural beliefs and practices. Such resources ranged from ancestors, family elders, community members, and church leaders (Ramose, 2005). The literature estimates that up to 80% of the South African population make use of traditional medicine, and consult with traditional healers as means of acquiring cultural explanations for the illness that they experience (Mpono, 2007). Evidently in this study, a majority of the parents made use of cultural beliefs and practices for their child as prophesied mainly by the elders in the family. These elders would direct the parents to culturally seek help from traditional healers where they could enquire whether the ancestors were communicating a need for a ritual and, if so, once the required ritual was performed, the child would heal. Ramose (2005) states that for African parents, unexplained problems may be perceived as being linked to traditional beliefs and possibly messages from their ancestors.

Health-seeking behaviour is largely influenced by culture and the availability of resources (Mpono, 2007). Culture shapes people's thoughts, beliefs and behaviours as well as their understanding and preferred method of curing illness (Mandell & Novak, 2005). This therefore impacts on the parent's process in seeking cultural explanations when faced with the unknown. Seeking cultural explanations is common among African communities, and tends to affect the acceptability of western medical treatment (Mpono, 2007).

However, for some of the participants the results indicated, their perspective shifts, as they lean more on religious practices to shape their understanding and experience of the unknown. This implies that these parents relied on their church brethren and spiritual leaders to guide and enlighten them during the experience and process of encountering ASD. Jegatheesan, *et al.* (2010) state there is emergent acknowledgment that religious beliefs can influence how disorders or disability is interpreted and explained by parents. In some cases, families of children with ASD who have chosen not to engage with ancestors, hold religious beliefs that inform their understanding of children, childrearing and the disorder itself (Jegatheesan *et al.*, 2010).

5.1.2.2. Western

For African communities, the western/medical field tends to be a secondary option when it comes to explaining and understanding the unknown (Mpono, 2007). Parents of children with ASD in this study sought advice and intervention from western/medical professionals when traditional interventions were unsuccessful. By this time, parents felt that western health practitioners would explain and intervene with their child. The expectation was that the answers would come quickly and easily. However, this turned out not to be the case, as parents faced the tiresome path of being referred from one doctor to the next with no quick solution. This indicates how the parent's experience of getting a diagnosis is prolonged by the fact that not all health providers may have sufficient knowledge and expertise to assess and give a reliable diagnosis (Mubaiwa, 2008). Hence, parents were forced to see a number of different doctors and specialists before getting an official diagnosis.

Moh and Magiati (2012) state that the process of obtaining a diagnosis of ASD could add up to a period of three years, with an average of 4.5 professionals who may have been consulted. For parents this does not reflect satisfactory engagement from the professionals. Often parents were less satisfied in the cases where they had consulted a number of professionals (Moh & Magiati, 2012). It appeared though, that the frustrations lay with not just the parent, but the health practitioners themselves. Since there are poor resources available in South Africa, numerous challenges in the managing of ASD by medical health practitioners are evident (Mubaiwa, 2008). Gray (1993) states that some of the reasons why there may be complications with getting a diagnosis is because of the absence of a biological marker, the normal variation in human child development, and the infrequency with which medical practitioners come across the problem. Despite these difficulties, it is suggested that health practitioners should be sensitive in managing ASD and the parents of children with the disorder, particularly in South Africa where there is the possibility that the traditional healer plays a role among the parent's consultations (Mubaiwa, 2008). Mubaiwa (2008) further suggests that the practitioners should be prepared to provide rational, supportive counseling to the parents. This would serve the role of providing parents with effective interventions that focus specifically on ASD.

5.1.3. Need for knowledge

According to the findings of this study, there still remains a gap in knowledge among the lay population about ASD. As mentioned before, this is not merely among parents, but communities at large. The common experience for parents is that it was not until they had a child with ASD that they became aware of disorders such as ASD. Ironically, it appeared that popular media is playing a significant role in educating society (as opposed to professional services). Most of the parents in this study testified to the fact that knowledge was gained through media modes such as television shows and magazines.

Despite this, there still is a call of urgency in better awareness and understanding; early diagnosis; effective intervention and management by the health professionals in South Africa. This is suggested by the findings in this study; which reflect the parents' large degree of frustration toward the lack of knowledge among health professionals in South Africa.

This was exacerbated by their devastation of sensing something wrong with their child but not being able to receive an answer or diagnosis that informed them of what was wrong. A study by Kauchali (2008) found that as in many other countries, South African health professionals still require ways of providing early diagnosis for ASD. This suggests a continuous need for knowledge enrichment; both for parents and more especially for professionals who receive and are expected to handle ASD effectively. Hence, the findings of this study can contribute towards measuring how parents are experiencing ASD, and possibly the extent and urgency of the knowledge required by society.

5.1.4. Summary

The parents experiences before the diagnosis of their child is obtained is undoubtedly the most difficult, where the parent is clouded with confusion and greatly frustrated by not knowing the cause towards her child being atypical. The findings when integrated with literature support the fact that the parents given cultural frame of reference will largely influence the experiences encountered before diagnosis.

5.2. Parents experiences after an ASD diagnosis

The repercussion of the diagnosis was not easy for parents and was a process with various unpredictable experiences and uncertainties. This process also followed significant experiences that lead from obtaining the diagnosis of ASD to living with and raising a child with ASD. It is evident that by the time the parents have obtained diagnosis for the child, that they have also gained some degree of understanding about ASD. One of the parents gave her understanding of her child having ASD as a neurodevelopment disorder;

“A neurological disorder...there are affected nerves that cause delay in the child’s development in many areas of his/her life” (P3: M).

According to research the process of getting a diagnosis is often complex, time consuming and challenging for parents, be it emotionally, physically or financially (Gray, 1993). Research emphasises how the process of getting a diagnosis of ASD has been described by parents as stressful and unsatisfactory (Siklos & Kerns, 2007). One of the consistent negative experiences that was often reported by parents is the long delay between the first time they raise their concerns with a doctor to the time they actually receive the formal diagnosis (Moh & Magiati, 2012). Hence, this is experienced as a hurdle that hinders efforts of early intervention and again leads to increased parental dissatisfaction and stress (Moh & Magiati, 2012). This study also found that parents’ overall experience of the diagnosis process is somewhat tiring, frustrating and it is seen as largely unsatisfactory.

The current study’s findings in the post-diagnosis phase matched Mugno, Ruta, D’Arrigo and Mazzone (2007) study, in that once the diagnosis was received, the parents’ situations did not ease, as the parents raising children with ASD experienced increased stress levels, a sense of devaluation and self-blame; alongside impaired physical and mental health, due to exhaustion. Thus, when the parents finally got the official diagnosis, a stream of emotions was experienced. These ranged from relief, to the question of ‘what now’. The parents interviewed experienced relief that they could now name the unknown, yet asked themselves how they ought to proceed with that knowledge. Midence and O’Neil (1999) state that the diagnosis may be experienced as relief, in that someone has corroborated what the parents suspected from the beginning, as much as it may also be confirming feelings of fear.

The implication of this is that although parents may have their suspicions, they still require a formal diagnosis from professional health providers.

5.2.1. Reaction to the diagnosis

Consequently, after the official diagnosis has been provided, the impact of it was either negatively or positively experienced by the parents. Each parent and family will have a different reaction to the diagnosis (Siklos & Kerns, 2007). It may possibly take the parents months and sometimes years to actually accept the diagnosis (Mugno et.al, 2007). Research suggests that some parents may even deny the presence of ASD, hoping and praying their child will heal one day (Jegatheesan *et.al*, 2010).

Siklos and Kerns (2007) state that parent's reaction to the diagnosis of ASD or any other chronic disability is resonant with the feelings in the stages of grief (e.g. shock, grief, anger, helplessness and guilt). This was confirmed by the parents in this study, who had experienced these stages of grief in their experience of the aftermath of obtaining the diagnosis. Despite the grief the diagnosis brought upon the parent and families, soon this was viewed as a platform for understanding. Kessler (1974, in Swanepoel, 2003) suggests that the diagnostic labeling is essential, as it allows the parents and professionals to customize individual centered intervention for the child with ASD. Negatively, the parent's reaction to the label causes shock, pain and blame, towards self or/and others around them (Jegatheesan et.al, 2010). This was evident in the findings of this study. Further, parents may experience emotional stress, anxiety, fear and guilt, as reaction to the label of ASD (Grindle, Kovshoff, Hastings & Remington, 2009).

For the parents in this study, it appeared that most of these feelings remained for a very long time after the diagnosis has been obtained. They experienced them as feelings that never disappeared entirely, but just take away the guilt and blame that they may feel towards themselves or a partner. This then made living easier, as they knew the diagnosis and could obtain a better understanding of it; hence they are able to control their emotions more effectively. Midence and O'Neil (1999) state that the emotional pain of raising a child with ASD does not entirely diminish, even though the diagnosis may be accepted.

The negative reactions to the diagnosis were also triggered and maintained by the experience with professional health care providers when there was no congruency. Siklos and Kerns (2007) suggest that when parents receive a vague diagnosis, their experience becomes largely dissatisfying. As result the receptiveness of treatment, intervention is jeopardized. The implications thereof are that professionals at all times should be precise and clear when giving a diagnosis to parents.

Some of the positive reactions to the label of diagnosis were that, parents experienced the diagnosis as a step towards an optimal knowledge of understanding their child and putting meaning to the experience by researching using the correct term and diagnosis. This may have added value to the experience, as the parents felt that they had an opportunity to gain knowledge to understanding their child's behaviour and to accept it (Midence & O'Neil, 1999).

For this reason, the diagnosis can be viewed as an “agent of change”, which enabled the parents to shift away from confusion to a more stable point of reference for their upcoming experiences after the diagnosis. For the parents in this study, what was significant was their attitude towards the diagnosis, which was challenged and improved, coming from the unknown to empowerment of knowing. They reported experiencing it as an empowerment, as it gave them the platform to take control, by educating themselves. One father stated that “knowledge is power”, and once they had the diagnosis, they could explore finding information. Parents stated that the sense of empowerment gave them something to work on, research to do, experts to find and an explanation for their child's difference (Schall, 2000).

5.2.2. Family and community responses

Families, who are traditional in their beliefs and practices, are more likely to respond to their life circumstances and health conditions from the perspective of holistic African understanding, especially if they seek traditional healing systems (Mandell & Novak, 2005). The parents in this study started with seeking traditional healing systems, either from their elders, traditional doctors or their local church leaders. Parents received guidance from prospective supports and because ASD is so unique and foreign, the parents were left with no cure and had to explore further. Also, the lack of success in traditional and cultural interventions meant that parents soon explored medical and western systems.

Obtaining of a diagnosis consequently had an impact not just upon the parents, but on the family and community at large. It has been suggested that having a child with ASD diagnosis can harshly disrupt family life (Midence & O'Neil, 1999). The rationale of this is that those family members will have to be willing to make certain adaptations in their family lifestyle and patterns of practice to effectively accommodate and understand the characteristics of a child with ASD. Gray (1993) argues that the pattern of family adaptation to ASD is a challenging process; though it entails the surmounting of the initial crises, it also reflects the stubbornness of the disorder and its long-term effects on the family. This was strongly evident in the current study, as parents experienced the effects of raising a child with ASD in every aspect of their lives. Effects on the family ranged from tension among the parents themselves and confusion for other siblings because of the characteristics of their brother or sister with ASD.

Gupta and Singhal (2005) state that since ASD is a complex and intractable disorder those families have to cope with; research has indicated that the experience can create greater tension and anxiety for the parents and families of a child with ASD. The implication of this for African parents is to be aware of the effects that ASD can have on their family system. Gupta and Singhal (2005) suggest that siblings of children with ASD are at risk of various emotional and psychological impacts, where one of the challenges is that they often feel secondary to their parents' worry, as more attention is placed on the child with ASD. Relevant to the current study, this was reflected as the parents reported tendencies to worry and to give more attention to the child with ASD; especially in the initial stages of this experience.

Reactions from extended family members also took a negative and positive position. The initial reaction of the extended family was to distance themselves from the nuclear family dealing directly with ASD. Clearly the rationale behind this behaviour was that those individuals were not exposed to developmental disorder such as ASD. So, when they actually allowed themselves to interact with the family and child with ASD, they gradually adapted to their character and behaviour. Consequently, this made relations much easier for the parents of the child. Most importantly, this change was brought upon by the fact that the parents had equipped themselves with knowledge and shared this with their extended family members to allow them also better understand. South African research does not clearly indicate such findings, but it was evident in the current study.

A study by Mubaiwa (2008) highlighted the fact that mothers of children with ASD experience “constant struggle of navigating public spaces”, which become problematic when the child appears to be “normal” but behaves in an eccentric manner (Kediye, Valero & Berman, 2009). As a result, the mothers then isolate themselves and the child from all social interactions. Alternatively, as found in this study, one parent will remain at home with the child whom has ASD, while the other goes out with the other children. Silverman (2008) reports that parents of children with ASD, often experience social isolation and stigma. He further elaborates that parents may experience feelings of incompetence; because of the abnormal characteristics of ASD for which other people have no understanding or compassion for (Silverman, 2008).

Midence and O’Niel (1999) concur that for parents, the behavioural difficulties and absence of language is the most challenging when it comes to dealing with ASD in their children. For this reason, parents often feel that if the child’s disorder were more physical, then possibly the community would understand and overlook the disruptive behaviour. However, this is not the case for parents with children who have ASD. Therefore, the implication of this is that South African communities still require exposure - specifically to the characteristics of a child with ASD.

5.2.3. Religious contribution and experiences

For the participants in this study it seemed that religion has become a major influence in their lives both in terms of belief systems as well as through the support they could access from within church and other religious structures. Although each family may have their own understanding and belief of religion, more and more African families are adopting religion as a resource for coping with the challenge of raising a child with ASD (Pargament & Tarakeshwar, 2001). Under the umbrella of religion, Pargament and Tarakeshwar (2001) state that the three approaches to responsibility and coping are: (1) self-directing approach, where the individual relies on self rather than God; (2) deferring approach, individual places the responsibility for coping on God; (3) collaborative approach, individual and God both are active partners in coping. In the current study, this was illustrated by parents’ experience, where they in the first stage took their own initiative to finding what was wrong with the child; the second, they put all they hope on God and that he would provide reason and solution; lastly, parents get involved and think of God as giving them the strength to cope and accept ASD.

Other religious themes are: kindly religious appraisal; seeking support from church members; discontent with congregation and God; perceiving illness as the will of God or opportunity for spiritual growth (Jegatheesan *et al.*, 2010). All of these impact on the families and parents experiences of raising a child with ASD, as they adapt to accepting and coping. Most participants reported on the critical role of religion as a consistent variable through which they were able lean on God for strength, get wisdom to get a diagnosis, find acceptance of the diagnosis, and finally to live with and be reconciled to the diagnosis of ASD.

Evidently, religion can serve as a source of support for families. Religion reportedly helped families accept their challenge as a gift from God, as part of God's plan; it also seemed to offer meaning to the misfortune and suffering of the parents, as it gave them hope, patience and strength (Pargament & Tarakeshwar, 2001). Jegatheesan, *et al.* (2010) reported a study with Muslim parents which indicated that they found God in their lives, which helped them gain a deeper understanding into having a child with a disability. This was similar to the findings of the current study, which illustrated how having a relationship with God gave much more comfort and strength to the experience of raising a child with ASD.

The implications of these findings for African parents suggest that African culture no longer just entails ancestral beliefs, but a lot is embedded in the belief and practice of religion. Shiraev and Levy (2010) stipulate how belief in supernatural forces, spiritual healing is becoming more common in and around the world. Gray (2002) also suggests that parents use a variety of coping strategies in dealing with the strain of raising a child with ASD. In a study that Gray (2002) conducted, he found that parents commonly cope from the use of treatment services and support from members of their family, religion, social withdrawal and various individual attainment and activity, in order to better cope with the impact of raising a child with ASD (Gary, 2002).

Furthermore, the parent's experiences of religion and church varied from being supportive to causing distress, as parent's reported that often they felt abandoned by their church members, who discriminated against their child because of the behaviour they showed during services. Many parents withdrew from attending church against their own preferences. Pargament and Tarakeshwar (2001) state that parents report gaining more support from their personal beliefs, than organized religion. The implications of this finding on the parents was that despite them withdrawing from church, they did not lose their relationship with God and this then has kept them going.

5.2.4. Summary

The discussion of the findings has illustrated some of the links between the findings and the literature available. The discussion was presented with the parents initial experiences of the symptoms and early signs of ASD, then the process into obtaining a diagnosis, finally how the diagnosis was accepted and how it impacted on those around the child and the parents. Also, there was indication that some of the parents lived experiences were corroborated in available literature.

However there still remains much more to be researched, so that the influence of background cultures of parents and caregivers are better understood. The majority of Africans have been known to use traditional beliefs and practices when it comes to their wellbeing. This study highlighted how, with ASD, this may not always be applicable. The discussion and literature suggested that there has been a shift in the way that African parents deal with issues. This is the shift from seeking interventions from cultural or ancestral perspectives; religious perspectives; to seeking a western/medical intervention.

Although, more research is required, implementation of changes in the health professional services requires improvement with regards to ASD awareness and intervention in African culture. Also, the major finding in the study was the experiences of the slow diagnostic process. The shifts in interventions sought can be accounted by the slow diagnostic process which extremely frustrates parents. Therefore, considerations should be made to ensure that the diagnostic process is efficient and effective avoiding unnecessary delays. In return, parents raising children with ASD and the professionals will work collaboratively towards treating and providing for the child with ASD.

Chapter Six: Conclusion

6.1. Conclusion

In this chapter the implications of this study; the limitations encountered; and considerations and recommendations for future research will be discussed and suggested.

The aim of the study was to explore the African parent's lived experiences of raising children with ASD. The study indicated that although the experiences of raising a child with ASD may be common across cultures, all cultures have their own beliefs and practices that shape the experience of child-rearing. Results suggested that African parent's cultural frames of reference indeed shape their understanding and experiences. The study suggests that these frames of reference include ancestral and religious beliefs.

6.2. Implications of study

Given the results from the discussions held with the parents, it was highlighted that there is a great need for awareness and understanding of ASD amongst parents, African communities and the health professionals. Parents strongly felt that if there was a better awareness, then so much of the unnecessary strain could have been eliminated when experiencing raising a child with ASD. If not eliminating fear entirely, then parents need to be prepared for what is to unfold, especially after the diagnosis. Midence and O'Neil (1999) argue that parents often wish for a way of obtaining early diagnosis, which in their view can be possible if there was better awareness of developmental problems in children, especially amongst general practitioners.

Findings of this study suggests that therapies learnt at speech therapy, occupational therapy and school, impact positively on the child's development and makes coping easier for the parents. The implication of these findings not only impacts on parents, but on the families, professionals, and South Africa as a society at large. It is clearly evident that there still remains a need for awareness and knowledge among African communities and health care professionals.

This emphasises the need for improved expertise in the field among the health professionals; and for effectual competence in assessment and service delivery to parents and their children with ASD. This may ultimately result in sooner diagnoses, early intervention and less dissatisfaction from parents. Specifically for psychology, it indicates the need for the field to be known and for practitioners to reach out to African communities.

The fact that research indicates a rapid increase of ASD among African communities, does not suggest that it has never been there, but that possibly parents are now seeing the need and importance to come out and seek intervention and assistance. Hence, the implications of this for South Africa now is to ensure that better facilities are built to cater for and assist parents with the resources and information required for effective coping and experience while raising a child with ASD.

6.3. Limitations encountered

Some of the challenges experienced during this study manifested in the early stages of the research. These were finding the sample, as the initial intention was to use Pietermaritzburg groups; however with little turn-up there had to be an extension to Durban. In Durban one school that was approached had parents who were reportedly reluctant to participate. In this school, this may be the result of researchers who came to them, elicited the information they sought, and never shared the findings with the participants. Hence they felt exploited by researchers, who come to them for interviews and benefit from their difficulties and yet in return do not communicate the findings of the research. The current researcher then reassured the parents of the value of their participation and agreed she would contact them for feedback once the research was complete. Thereafter, the parents participated in a deep fruitful discussion about their experiences.

The venue used for data collection was challenging in terms of recording the focus group. This is because it was a big hall and it echoed making the transcribing process rather difficult.

Transcribing seemingly took longer as the researcher had allowed participants to respond in their home language if preferred, and translation was done for certain words so the text of the transcription could be in English.

Time was a major influence to the limitations in this thesis. Certain aspects were then negatively influenced by the limitation:

- It would have been useful to have a more detailed and in-depth understanding of the literature, culture and discourses.

Literature was mainly limited as not much research has been conducted in South African that addresses the experiences of African parents raising children with ASD. Therefore, majority of the citations are from foreign countries.

6.4. Future considerations and recommendations

Future research is vital concerning the issue of how African parents experience raising a child with ASD, as this will allow for richer literature and understanding among health professional working with these parents. Future studies could be more representative, by having larger sample and parents of diverse backgrounds. They could also explore how parents perceive the various intervention options which have been largely influenced by their cultural beliefs. This could allow both qualitative and quantitative methods to be implemented. As pointed out by the parents in this study, researchers should ensure that they provide the parents with feedback regarding the findings of the research.

In dealing with and assisting African parents to cope effectively with their child who was diagnosed with ASD, it is crucial that the fundamental intervention be holistic. This implies that parents be made aware that their cooperation will be essential when therapists and educators suggest that they implement learnt strategies from therapy even at home to enhance communication (Trembath *et al.*, 2005). The challenge though, may be that culturally parents may have to modify their way of interaction, which is largely influenced by their differing, culturally bound child-rearing practices (Trembath *et al.*, 2005).

Areas identified by the study as being in need of further research regarding African parents experiences with ASD are: knowledge and awareness of variance of developmental disorders; access to information and resources; the way in which media impacts on the experiences of received information; and professionals' awareness and acceptance of the various cultural groups beliefs and understandings towards health and disorders. For South Africa, there needs to be an effective way of ensuring better understanding of developmental variance among parents, so as to ensure early intervention.

6.5. Final comments

The study has provided some insight into African parent's experiences of raising children with ASD in South Africa. It is hoped that this research will contribute to the knowledge and understanding of what parents raising children with ASD face, as they struggle with understanding the disorder; obtaining the official diagnosis; finding an intervention that is effective; and finally obtaining sufficient support from health and educational facilities, as well as other resources.

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Appendices

Appendix A.1



March 2011

Dear Parent/Caregiver

Focus group discussion on African parents experience raising a child with ASD

My name is Pinkie Madlala. I am a Clinical Masters Psychology student at University of KwaZulu Natal. As part of my Masters course, I am doing a study investigating how African parents understand and experience raising a child with ASD, before and after diagnosis. I would like to request that you participate in this study, which is hoped to benefit the health and professional workers in understanding how ones given culture influences understanding.

If you choose to participate, you will be asked to take part in two small discussion groups of about 6-8 other participants, for roughly an hour, at a mutually agreed venue and time. In the first group discussion, you will be asked to discuss how according to your culture you understand a typical development of a child; when is it that you may notice an 'abnormality'; and how if so, you may see this as being linked to your culture. In the second group, you then will be asked to share your personal experience of living with an autistic child, and again how your culture has influenced your understanding and experience. If you decide to participate, your participation will be greatly appreciated, and unfortunately I cannot offer any direct benefits for your participation. However, the experience may be rewarding as your contribution is of great value.

With your permission, the discussions will recorded (audiotape), and later transcribed. Note that no personal details or names will be exposed in the reports; all will be kept confidential between you, the researcher and supervisor. Confidentiality will be maintained by ensuring that the consent forms are stored privately and not accessible to anyone besides the researcher and her supervisor. All signed consent forms will be kept by researcher for period of five years and destroyed by shredder. The results of the discussions will be written up in form of dissertation as part of the Masters Course requirement, and may be presented at conferences.

If you have questions about the study or would like some insight on the findings, you may contact me via email at 206521899@ukzn.ac.za or my supervisor Dr Beverley Killian at Killian@ukzn.ac.za (tel. 033 260 5371).

Yours Sincerely

Pinkie Madlala

Clinical Psychology student

Dr. B. Killian

Head: Child and Family Centre

Appendix A.2



March 2011

Mzali

Inxoxo mayelana nokuthi nabazali abamnyama bazini futhi bayikhulisa kanjani ingane ene-ASD

Igama lami nguPinkie Madlala. Ngingumfundi weClinical Masters Psychology eNyuvesi yaKwaZulu Natali. Njenge nxgenye yezifundo zami ngizobe ngicwaninga ukuthi abantu abamnyama abangabazali bazini futhi bayikhulisa kanjani ingane ene-ASD, phambi nasemuvakokuba baziswe ukuthi ingane inalesisifo. Ngizothanda ukukukhuthaza ukuthi ube yingxenywe yalesisifundo, esithembayo ukuthi izoba usizo kwabezempilo nabemfundo ephakeme, ukuthi bazikabanzi ukuthi usiko ludlala yiphi ingxenyeeukuqondeni nezempilo.

Uma ukhetha ukuba inxgenye yalesisifundo, uzocelwa ukuthi ubekhona kabili ekuxoxeni nabanye abazali abawu 6-8, isikhathi esingangehoranendawo ekuzovumelwanwa ngayo. Engxoxweni yokuqala, uzocelwa ukuthi uxoxe ukuthi ngokwe siko lwakho wazi kanjani uma ingane ikhula ngokujwayekile, inini futhi kanjani la ongabona khona ukuthi ingane yakho inenkinga? Ugabona kanjani ukuthi loku kuxhumene nosiko lwakho. Engxoxweni yesibili, uzocelwa ukuthi uxoxe ukuthi wena njegomzali uphila kanjani nengane yakho ene-autism, nokuthi usiko lwakho ludlalelyiphi indima ekwazeni lesisifo. Uma ukhetha ukuba inxgenye yalesisifundo, singayibonga kakhulu imibono yakho, kodwa angikwazi ukuthi ngibonge ngento ephathekayo, kodwa ngiyakuthembisa ukuba khona kwakho kuzodlala enkulu indima, nawe uzozizwa unomthelela ebalulekile.

Ngemvume yakho, lezinxoxo zizorekhodwa (ngekhasethi), besezibuye zibhalwe. Yazi ukuthi ayikho imininingwane yakho noma igama lakho elizofakwa emibhalweni, konke sizokuhlonipha sikugcine phakathi kwakho, umhloli, nomphathi. Inhlonipho izogcinwa ngokuthi iziqephu zokuvuma zigcinwe ngasese, zingatholwa umuntu ngaphandle komhloli nomphathi. Zonke izivumelwano zizogcinwa iminyaka engu5 beseziya lahlwa. Imiphumela yezinxoxo izobhalwa kube iphepha elide njengenxgenye yeMasters Course efunekayo, kungenzeka ipresentwe kuma-conference.

Uma unemibuzo noma ofisa ukukwazi mayelana nalesisifundo, noma ufisa ukwazi ngemiphumelo, ungangithinta kwi email 206521899@ukzn.ac.za noma umphathi wami u Dokotela uBeverley Killian kwi email yakhe killian@ukzn.ac.za (ucingo 033 260 5371).

Ozithobayo

Pinkie Madlala

Clinical Psychology student

Dr. B. Killian

Head: Child and Family Centre

Appendix A.3

Consent forms



INFORMED CONSENT FOR PARTICIPATION IN A REASEARCH PROJECT

I _____, voluntarily give my consent to serve as a participant in a discussion focus group conducted by Pinkie Madlala. I have received a clear and complete explanation of the general nature and purpose(s) of the discussion and the specific reason(s) for the discussion. I have also been informed of how the results of the research will be used. The issue of confidentiality regarding the information I reveal has been explained to me. I understand that I may withdraw my participation in the process at any time.

Signature

Full Name

Date

Researcher signature

ISIVUMELWANA SOKUBA INGXENYE YALESI SIFUNDO

Mina _____, ngiyavuma ukuzinikela ukuba yingxenyeyeqoqo lezingxoxo eziholwa ngu-Pinkie Madlala. Ngiyitholile imininigwane nencazelo efanele mayelana nenhloso yalezi zingxoxo, nezizathu ezinzulu ngayo. Ngiphinde ngatshelwa ukuthi lemiphumela izosetshenziswa kanjani. Indaba yemfihlosifuba yemininigwane engiyilethile ichaziwe kabanzi kumina. Ngियाqonda ukuthi ngingakwazi ukuyeka ukuqhubeka nezingxoxo noma ingasiphi isikhathi.

Isigenesha Yakho

Igama Lakho

Usuku

Isigenesha Yomholi

Appendix B

Semi-structured individual interview questions

1. What was your experience before your child was diagnosed?
 - a. Can you relate to specific examples from your experience that you can remember during that time?
 - b. What if anything was different in your child's development compared to other children of his/her age?
2. Please describe your experience and understanding of your child being diagnosed as having ASD.
 - a. Can you describe what was unusual about his/her behaviour?
 - b. When did you first notice this?
 - c. Did you relate this to your culture?
3. Can you explain how you understood what was happening to your child?
4. Could you relate this to your culture?
5. What was your reasoning for this diagnosis that your child was given?
6. How do you as a parent with a child with ASD perceive:
 - a. Typical development in children?
 - b. Atypical development, i.e. variations from expected patterns of development?
 - c. Specific disorders such as ASD?
7. Has your understanding or perception changed over the time you have been raising your child?
8. What would you say has been the most challenging? Most helpful?
9. How did family or community members relate to you/your child?
10. What interventions have you sought and what have been the results or experience?

Appendix C

Focus Group Outline

Topic: Experiences of raising a child with ASD.

Aim: To gain insight to how African parents have experienced raising a child with ASD, how this impacts on family and social life.

Ice-Breaker: Game

Questions:

- What are the characteristics of a typical developing child?
- When do you/did you notice that your child was not developing typically? What were the behaviours?
- What did this mean for you according to your culture? Is there a cultural link in your understanding?
- How does your culture understand your child's behaviour/ disorder?

- Did you know / do you know what autism is? Is it known in your culture?
- Has your understanding changed? (i.e. African to Western understanding?)
- What has it been like raising a child with autism?
- What makes it most difficult?
- What has made it easier?
- How have you experienced extended family and your community towards you or your child with autism?
- What interventions have you utilized? How have they been effective or have you experienced them?

Appendix D



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4 July 2011

Ms PN Madlala (206521899)
School of Psychology
Faculty of Humanities, Development &
Social Sciences
Pietermaritzburg Campus

Dear Ms Madlala

PROTOCOL REFERENCE NUMBER: HSS/0435/011M

PROJECT TITLE: African primary caregivers understanding and experience of having a child with autism

In response to your application dated 29 June 2011, 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 school/department for a period of 5 years.

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

Yours faithfully

.....
Professor Steven Collings (Chair)
HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

cc. Supervisor: Dr B Killian
cc. Mrs B Jacobsen, Higher Degrees Office, Pietermaritzburg Campus



Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

Glossary

- Inyanga: African healer/herbalist that uses natural herbal medicine to heal
- Inyoni: African condition that is culturally treated when child is baby.
- Ithuko: Illness found among children and requires traditional treatment
- Isangoma: African traditional doctor with ability to serve as interpreter/link between individual and their ancestor.
- Ukuchatha: African use of an enema for treatment
- Impepho: African incense