KNOWLEDGE, BELIEFS AND PRACTICES OF MOTHERS RAISING A CHILD WITH AUTISM IN THE CITY OF TSHWANE:
AN AFRICAN PERSPECTIVE

by

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Declaration

I declare that the mini-dissertation- **Knowledge, Beliefs and Practices of Mothers Raising a Child with Autism in The City of Tshwane: An African Perspective**- hereby submitted to Sefako Makgatho Health Sciences University, for the degree Master of Science in Clinical Psychology, has not previously been submitted by me for a degree at this or any other university; that it is my own work in design and execution, and that all material contained herein has been acknowledged.

B. M. Menoe (Mrs). 10 October 2017

Student Number: 200906019
Acknowledgements

This mini-dissertation is dedicated to all the courageous mothers raising a child with autism and also to my brother, Kevin, whose two-year-old son was diagnosed with autism in September 2017.
Abstract

Autism or autistic disorder is one of three neurodevelopmental disorders on the Autistic Spectrum Disorder. It is a worldwide phenomenon with no known cause or cure. Neurobiological and genetic theories have received increased empirical support, whereas alternative and so called non-scientific explanatory models of autism have been marginalised. Six black South African mothers’ conceptualisation, aetiological beliefs and practices adopted in the treatment of autism were explored. The study was approached from an African epistemological paradigm. Purposive sampling was used to select the six mothers and the conversational method was used to collect data. The conversations were analysed using thematic analysis. The mothers were between the ages of 30-45 years and the children were between the ages of 6 and 13 years. Language delay was the most common and initial sign that alerted mothers to a possibility that something may be wrong. The induced themes were: cultural interpretation of language delay, journey to diagnosis, communicating the diagnosis to parents, mothers’ reactions to autism diagnosis, additional sources of information, beliefs surrounding the cause of autism, management of autism, challenges faced by mothers and lastly coping strategies to deal with these challenges. The recommendations arising from this study include the integrative view that autism be considered as a disability and public schools be built that can cater for children with severe autism where inclusive education is not a possibility.

Keywords: autism, worldview, culture, knowledge, beliefs, practices
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CHAPTER ONE

Introduction

This chapter will discuss the historical background of autism. This historical background brings to the fore the complexity of the condition. Second, the problem statement is outlined. Here the researcher stresses the importance of including alternative explanatory models of autism into the literature. Following from the problem statement, the aims of the study are discussed. The rationale of the study is provided; which is followed by the definition of the key concepts. Last, this chapter concludes with an overview of all the chapters.

Historical Background of Autism

Autism was first known as “childhood schizophrenia” in the early 1930s, and only in 1943 was the disorder termed “early infantile autism” by an Austrian psychiatrist named Leo Kanner, after he noticed distinct differences between childhood schizophrenia and early infantile autism. The key disturbance in early infant autism as noticed by Kanner was the child’s lack of ability to relate to people and social situations (Farrugia, 2009; Foster, 2007). This led Kanner to apply the term “autism” which means “an absorption in the self”. Foster (2007) documents how other researchers started to observe what Kanner had observed, which led to autism being recognised by the major classification systems; that is, the Diagnostic and Statistical Manual of Mental Disorders (DCM) and the International Classification of Diseases (ICD): Mental Disorders. Kanner also noted a higher prevalence of autism in children of very intelligent parents. Furthermore, Kanner observed that the parents were not particularly warm-hearted towards their autistic child (Ravindran & Myers, 2012).
Like Kanner, and around the same time, Bettelheim observed that parents of children with autism were cold and rejecting. From this observation came the phrase “refrigerator mother” (Daley, 2002; Ravindran & Myers, 2012). Therefore, the recommended treatment during this time was psychoanalytic therapy (Ravindran & Myers, 2012). However, Bettelheim’s theory was disproved because a biological link was found in 1964 (Foster, 2007). Then in the 1980s, Sanua proposed that autism is an illness of Western civilization (Daley, 2002; Ravindran & Myers, 2012; Russell, Kelly & Golding, 2009; Sanua, 1984). According to Grinker (2007) a common belief held by Europeans who colonised Africa was that Africans were too primitive to suffer from mental illnesses because of their lack of exposure to stresses associated with life in industrialised societies. This belief was disproven by Lotter, who found cases of autism in Ghana, Nigeria, Kenya, Zimbabwe, Zambia and South Africa (Bakare & Munir, 2011a). Moreover, cases of autism have been reported in other non-industrialised countries apart from African countries.

**Statement of the Problem**

Despite the research highlighted above, a definitive cause of autism has not yet been found, and misdiagnoses are still made today (Brookman-Frazee, Baker-Ericzén, Stadnick & Taylor, 2012). Over the years neurobiological and genetic theories have received increased empirical support (Ametepee & Chitiyo, 2009; Barlow & Durand, 2005; Nyarambi, Enwefa & Enwefa, 2011). The focus on neurobiological and genetic causes places autism firmly in the field of psychiatry where a medical and linear model of disease aetiology is deemed plausible. Alternative explanations that cannot be proven by Western scientific methods have been and are negated. Negating the so-called “non-scientific” methods is problematic as it disregards non-Western epistemes to knowledge. It is crucial to recognise that multiple epistemes exist, just as there are many cultures. Moreover, all knowledge comes from our
cultural experiences (Okere, 2005). Therefore, knowledge systems that differ from Western knowledge systems should not be abandoned, as every episteme is valid and relevant within its own context.

Aside from the marginalisation of non-Western knowledge systems, problems relating to stigma and the impact that socio-political and economic factors have on families raising a child with autism in the South African context will also be considered in chapter two and five.

**Aim of this Study**

This research addressed alternative understandings of autism, as neurobiological and genetic causes are not the only way of understanding and explaining autism, nor are they universally applicable. The role that context and culture play in the conceptualisation of autism needed further investigation. The aim of the study was to deconstruct the meaning that autism holds for black mothers in South Africa, which would place autism appropriately in the field of psychology. The deconstruction was achieved by adopting a narrative inquiry approach into the knowledge, beliefs and practices of black mothers raising a child with autism in urban South Africa. The City of Tshwane was the chosen setting for the study.

**Objectives of the Study**

The objectives of the study were to:

1. Explore how African mothers conceptualise autism;
2. Explore African mothers’ beliefs about the aetiology of autism; and
3. Explore treatment modalities used by African mothers for their children.
Rationale for the Study

A paucity of research exists on the knowledge, beliefs and practices of parents raising a child with autism. The focus in the literature has been more on the knowledge and beliefs of mental health professionals. The focus of this research was parents’ perspectives of autism. It must be borne in mind that parents are important stakeholders in the management of autism.

Since there is no cure for autism some parents may be disillusioned about the possibility of any meaningful future for their child (or children) with autism. The frustration associated with a “no-cure situation” may result in parents seeking complementary and alternative medicine. The treatment that parents seek for their autistic children is also largely influenced by their belief systems. Most research that exposes alternative parental beliefs systems does not investigate the South African context. The majority of this research has been conducted in West Africa and Asia. Experiences, beliefs and practices are not transferable from one context and culture to another. Experiences and beliefs cannot be universalised. Black South African mothers’ beliefs and practices may be unique so we cannot generalise to Africa as a whole. The researcher is aware that there are elders and sangomas that describe autistic children as “ba hlanyaa” meaning “they are mad”. Some Basotho carry out veneration to the “badimo” (ancestors) like “ke ho phasetswa” (ritual) where the parents resort to changing children’s names (phetoho). Therefore, the need exists to investigate what these traditions and ceremonies are, and how they assist both the family and the child with autism.

The researcher proposes the necessity to explore the alternative explanatory models that exist in South Africa. Consideration of parental explanatory models may enhance epidemiological studies on autism and provide mental health practitioners with valuable information to consider when dealing with families who have alternative explanatory models.
Definition of Key Concepts

**Autism.** Autism or autistic disorder is one of three neurodevelopmental disorders on the Autistic Spectrum Disorder (DSM-V, 2013). Autistic disorder, Asperger's disorder, and pervasive developmental disorder have been consolidated into the autism spectrum disorder in the DSM-V.

**Worldview.** A set of basic assumptions that a group of people develops in order to explain reality and their place and purpose in the world (Mkhize, 2004, p.35).

**Culture.** “Culture” refers to the ways in which a community of people think and behave that have been created, fostered and maintained by a group of people over a long period. Culture serves as a guide for future generations on what is acceptable (Gyekye, 1997).

**Knowledge.** Knowledge is the representation of a proposition preceding any judgment of a concept’s truth or falsehood (Griffin & Ohlsson, 2001).

**Beliefs.** Beliefs are the representation of a truth-value associated with a proposition (Griffin & Ohlsson, 2001; Kaphagawani & Malherbe, 2002). Beliefs may either come about from a collection of facts or are accepted through tradition and culture (Sogolo, 2002).

Overview of Chapters

This dissertation comprises six chapters.

**Chapter 1-** In this chapter a synopsis of the research orientation and context was provided.

**Chapter 2-** This chapter explores the literature relevant to the knowledge, beliefs and practices of African mothers’ raising a child with autism.

**Chapter 3-** The theoretical framework that will underpin this research is explained.
Chapter 4- This chapter explores the Afrocentric research paradigm, qualitative narrative inquiry and the conversational data collection method that will be applied to capture the knowledge, beliefs and practices of African mothers raising a child with autism in the City of Tshwane.

Chapter 5- This chapter presents the results and discussion of the knowledge, beliefs and practices of mothers raising a child with autism in the City of Tshwane.

Chapter 6- This chapter provides a reflective summary of the results and concludes with recommendations.
CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter explores the literature relevant to the knowledge, beliefs and practices of African mothers’ raising a child with autism. Hofstee (2006) defines a literature review as a critical and factual survey of published works pertaining to the area that will be investigated. Although there has been much research done on autism, the area of interest that has not received sufficient attention is the understanding of autism from an African perspective. This study is therefore likely to provide useful information that will enhance the body of knowledge in autism from an African epistemological paradigm.

According to Baloyi (2008), any human knowledge landscape comes from a particular epistemological paradigm, and this epistemological paradigm has its own ways of theorising and philosophising. These ways of theorising and philosophising are embedded in a particular culture. In the context of this study, the focus on and conceptualisation from African indigenous knowledge systems (IKSs) provide the opportunity to deconstruct autism and understand its meaning in its cultural context.

Autism has been, and is still, firmly rooted in the medical model, more specifically the field of psychiatry, where a medical and linear model of disease is deemed plausible. The classification of autism as a neurodevelopmental disorder of biogenetic aetiology implies that the criteria for diagnosis, course and treatment should be the same for everyone across the globe. This universal approach to autism has limitations in indigenous contexts. The understanding of any disorder or illness, as well as its interpretation and treatment, cannot be divorced from the culture within which it is conceived. Against this background, the literature starts off by exploring culture in general.
Culture

Ferraro (2004) states that culture encompasses knowledge, values, beliefs, art, morals and social practices. Nobles (2006) defines “culture” as a scientific construct representing the vast structure of language, behaviour, customs, knowledge, symbols, ideas, and values that provide a people with a general design for living and with patterns for interpreting reality. Therefore, all peoples of the world have a culture. All epistemological paradigms are premised on historical reality and cultural contexts. In the section that follows, the Western and African cultures’ patterns of interpreting reality will be outlined.

**Western and African culture.** The West has many nationalities and ethnic groups. However, a common culture prevails within this diversity (Asante, 1987; Durie, 2004; Holdstock, 2000; Kwate, 2005; Mbiti, 1990). The same applies to Africa. The Western and African patterns for interpreting reality will be expounded using the constructs listed by Ferraro (2004) and Nobles (2006) above; namely, knowledge, beliefs, practices and values.

**Knowledge.** Knowledge is the representation of a proposition preceding any judgment of a concept’s truth or falsehood (Griffin & Ohllson, 2001). According to Ndubisi (2014) knowledge is regarded as true only if evidence is presented to support its claim. A high regard in the West exists for knowledge that has been acquired using scientific methods (Ani, 2013; Marczyk, DeMatteo, & Festinger, 2005). The assumption is that the use of scientific methods would produce knowledge that is objective, is supported by empirical evidence, is rational, and therefore is universal. Universal knowledge is knowledge that is applicable to all people irrespective of their cultural context. This knowledge is also claimed to be value free, thus its application to multiple and different contexts is deemed objective. Scientific and documented findings give a researcher more credibility; therefore, Westerners tend to place greater value on this form of knowledge. Psychology is an example of this form of knowledge, as it grew out of scientific traditions (Holdstock, 2002).
The written tradition of producing, disseminating and preserving knowledge takes precedence in Western culture. Knowledge that has not been rigorously and scientifically tested is not regarded as valid and reliable (Ani, 2013; Pastorino & Doyle-Portillo, 2014).

Inasmuch as the scientific method of acquiring knowledge is valuable in the “hard” sciences or natural sciences, loopholes exist within the “soft” sciences or human sciences. Mkhize (2004) points out the negative repercussions of trying to model the human sciences to the natural sciences. Attempts to emulate the natural sciences devalue the human experience as it presupposes a universal experience, a single reality. Baloyi (2008) cautions that the view of knowledge as a single reality is problematic and should be questioned. This is because there are multiple epistemes to knowledge as there are different cultures in the world. It is of critical importance to note that Africans are not a homogeneous group. There is heterogeneity among Africans, as not all African believe in knowledge as presented here.

**Oral discourse and knowledge.** The transmitter of knowledge in African cultures is mainly oral tradition (Ani, 2013; Eyong, Mufuaya & Foy, 2005; Mbiti; 1990). These oral traditions include storytelling, folklore, folktales, fairy tales, myths, proverbs, songs, pithy sayings, rituals and spiritual and religious activities. Such traditions make up an integral element of Africa’s past, present and future story (Ekeke, 2011; Watson, McMahon, Mkhize, Schweitzer & Mpofu, 2011). Maree and du Toit (2011) state that thousands of years before the arrival of writing systems, indigenous knowledge and tribal customs were kept alive through an oral tradition that was passed on from generation to generation. Baloyi (2008, p.41) asserts that “oral traditions should not be considered ‘illiterate’ and ‘non-text’ but authentic, viable and scientific method”. Neither the written- or oral tradition is superior. They are both forms of expression or communication and are equally important and scientifically legitimate when it comes to producing, disseminating and preserving knowledge (Baloyi, 2008).
Okere (2005) states that all humans have some form of knowledge that is coloured by their culture. Knowledge therefore comes from our cultural experiences. As there are many cultures so are there many knowledge systems. Other knowledge systems, like IKSs, need to be treated with respect and given equal recognition. According to Nobles (2015), Africans have their own forms of knowledge and practices that help them to deal with life’s challenges. African knowledge and methods have successfully guided Africans in all areas of functioning, including the spiritual, social, educational, agricultural, political and economic (Akbar, 1984; Owusu-Ansah & Mji, 2013). However, African knowledge and methods have been overlooked, as they have been considered primitive and inferior to the dominant Western ways of knowing and doing.

Durie (2004) explains that Western knowledge systems and IKSs are built on distinctive philosophies, methodologies and criteria. IKSs cannot be verified by scientific criteria, nor can science be adequately assessed according to the tenets of indigenous knowledge.

Knowledge and beliefs can be distinguished from each other as each refers to qualitatively different aspects of mental representation. Griffin and Ohllson (2001) state that people can have knowledge of an idea or proposition, but either not believe it to be true or hold a belief that the concept is false. Most people’s reality is reinforced and shaped by the belief in their cultural knowledge system.

**Beliefs.** Beliefs are the representation of a truth-value associated with a proposition (Griffin & Ohllson, 2001; Kaphagawani & Malherbe, 2002). Beliefs may either come about from a collection of facts or are accepted through tradition and culture (Sogolo, 2002). Beliefs cannot always be explained by the use of logic and many times beliefs are unquestionably adopted through custom and tradition. Holdstock (2000) maintains that beliefs should be regarded as more authentic by psychologists, more so than anything in the
physical world. Beliefs aid in the understanding of the psychology of people. Beliefs are context and culture based and is therefore premised on a particular epistemological paradigm. This means that the truth of a belief can only be established within the context of a specific culture as the conception of truth is also dependent on one’s epistemological paradigm and culture (L. J. Baloyi, personal communication, 2015). In the context of this study, beliefs will assist in the cultural understanding of autism.

Westerners have a dualistic conception of the world and believe that the world comprises two distinct and separate realms – the secular realm and the sacred realm (Jenkins, 2007). The secular realm is the physical component that includes the normal activities of basic everyday living (Jenkins, 2007). The sacred realm is the spiritual component. This realm is beyond the physical, it is the unseen component where God is deemed to exist.

In contrast, the sacred and the secular are not separate in African culture (Jegede, 2002; Jenkins, 2007). Mbìti (1969) states that the universe and everything in it was created by an eternal Supreme Being. Therefore, the universe is automatically regarded in a spiritual manner. Unlike Western psychology that was imported to Africa; African religion did not arrive with missionaries (Ekeke & Ekeopara, 2010). Rather, African religion came into existence as a result of personal African experiences over a long period of time (Awolalu, 1976). African religion is a traditional or indigenous religion that has been passed down from generation to generation (Awolalu, 1976; Emeke, 2011). The medium of transmission of African traditional religion has been the oral tradition (Awolalu, 1976). As already indicated under the sub-heading “oral discourse and knowledge”, oral tradition of religion includes myths, folktales, songs, dances, liturgies, shrines, proverbs and pithy sayings.

Africans believe that everything is spiritual and part of a unified whole from the low level of plants and objects right up to the Supreme Being (Jenkins, 2007; Grills & Ajei, 2002; Mkhize, 2004). The Supreme Being is the living eternal Being who is the source of all living,
the one whose power sustains the universe and is known by different names across Africa (Ekeke & Ekeopara, 2010). Here are a few examples of the names of the Supreme Being across Africa. The Akan use the name *Onyame* (Grills & Ajei, 2002), the Ibibio or Efik, the name *Abasilbom*, the Yoruba use the name *Odudumare*, the Igbo use the name *Chineke* or *Chukwu* (Etim, 2013) and the Batswana the name *Modimo*.

African culture is intertwined with religion as religion gains meaning through culture (Awolalu, 1976; Holdstock, 2000; Mbiti, 1969). Religion is the strongest element in African cultures; it filters into every part of an African’s life and influences the way an African thinks and lives (Emeke, 2011).

For African people being religious is not necessarily in the sense of church participation, but rather being aware of a power or source that transcends the human condition (Ayuyu, Ireri, Kimani, Mathenge, Muriithi & Otieno, 2015; Holdstock, 2000). Mkhize (2004) and Holdstock (2000) refer to this power or source as a life force and vital force respectively. Gyekye (1995) refers to this life force as *sunsum*.

**Vital life force.** Life force, known as *seriti* in Setswana and *isithunzi* in Isizulu, is the energy or creative force that is inherent in all phenomena both material and immaterial (Mkhize, 2004). Objects and beings are endowed with this life force; from the inanimate at the lowest tier of the hierarchy to the Supreme Being at the highest level (Mkhize, 2004). Human beings are partakers of this life force as they use it to maintain vital connections and interdependence between family, the community, nature and the ancestors.

**Ancestors.** In addition to the Supreme Being, Africans also believe in ancestors (Awolalu, 1976; Etim, 2013). Africans use various names to refer to their ancestors. In the South African context the ancestors are called by names such as *amadlozi* and *izinyanya* in the Nguni languages and *badimo* in the Sotho languages. The ancestors are also referred to as
the “living dead” (Ekeke, 2011; Etim, 2013; Edwards, Makunga, Thwala & Mbele, 2009). The term “living dead” illustrates a belief in the continuity of life in African culture. The ancestors continue to connect to and influence the actions and life of those still living in the physical world. This relationship is dynamic and interdependent. Holdstock (2000) describes the relationship between the ancestors and the living as a symbiotic relationship where there is a mutual aspiration to keep each other happy, content and healthy. Furthermore, the ancestors also provide a link between the living and the Supreme Being, who is the highest source of life.

However, during times when the living do not act in accordance with high moral standards, the ancestors may sanction bad conduct by withdrawing their interests in family matters (Mkhize, 2004). Such withdrawal has calamitous repercussions, as the family is cut off from the highest source of life which is the Supreme Being. Should a person have high moral standards, however, the ancestors can be a source of strength and wellbeing (Feigin, 2013).

It has been observed that in the African context the living members of the family can communicate with the ancestors. According to Holdstock (2000), this communication is maintained through dreams, visions and voices, or through the medium of a diviner. A diviner is a human being who possesses spiritual powers and may be consulted for advice and direction (Etim, 2013).

In addition to their belief in the Supreme Being, ancestors and diviners, Africans also believe in the practice of magic and medicine.

**Practices.** The practice of magic and medicine can either be used for good or bad. Ekeke (2011) explains that in terms of bad purposes or evil deeds, sorcery and witchcraft are practised with the aim of bringing about harm and preventing a person’s progress in life.
According to Cimpric (2010), witchcraft is an inherited practice. Individual operators of witchcraft unconsciously devour the life essence of their victims at night. A sorcerer is a socially recognised person who uses plant substances or rituals to harm people during the day. Africans do not believe in chance or accidental events (Etim, 2013; Feigin, 2013; Glocke, 2011). Instead they believe that a witch or a sorcerer can manipulate the life force to bring about an unfortunate event to someone (Feigin, 2013). Traditional healers can then be consulted to counteract these harmful forces through treatment or through exorcism of the harmful source that is grappling with the life force of the possessed (Ekeke, 2011; Feigin, 2013). Traditional healers may also instruct the person to perform rituals as directed by the ancestors to counteract these harmful forces (Etim, 2013).

In South Africa traditional healers are called by different names. In isiZulu a traditional healer that uses herbs to heal is called an *Inyanga* (Madlala, 2012). *Isangoma* in the Nguni languages or *dingaka* in the Sotho languages are traditional healers that act as a link between the individual and his or her ancestor. *Isangoma* are able to interpret messages sent by ancestors. Feigin (2013) states that another difference between an *Inyanga* and *Sangoma* is that an *Inyanga* learns from the living, while the *Sangoma* learns from the dead.

Last, the values espoused by Western and African cultures will be now be explained.

**Values.** There are also differences between the values of African and Western culture. “Values” refers to the fundamental operating principles by which people conduct their lives and organise the lives of their families (King, et al., 2006). Western cultures value individualism and autonomy whereas Africans value connectedness, collectivism and relationships. The self, according to the Western thought is individualistic, while Africans view the self collectively (Mkhize, 2004). According to Jenkins (2007), Western culture views everything in the world as independent from each other, whereas African culture views
all things as connected and united in existence. This unity is evident in the philosophy of *Ubuntu*.

*Ubuntu*. *Ubuntu* has sustained African culture for centuries. The word *Ubuntu* exists in many other African cultures but goes by different names because of the differences in languages. Letseka (2012) explains the elements of *Ubuntu* as *motho ke motho ka batho* (in Sotho languages) and *umuntu ngumuntu ngabantu* (in Nguni languages). The English translation of these expressions is “a human being is a human being because of other human beings”. Properly understood, *Ubuntu* articulates social interdependence which is captured by Mbiti’s maxim, “I am, because we are; and since we are, therefore I am” (Mbiti, 1969, p.8). Maree and du Toit (2011, p.23) define *Ubuntu* as a “common humanity, an interconnectedness that is used to provide relief and a meaningful engagement in communal life and supported the ethical-moral self.” According to Smith (2012), *Ubuntu* is maintained by respecting, listening to and affirming “others” in order to create trust, fairness, shared understanding and dignity and harmony in relationships. A similar definition is posed by Ramose (2005) who states that *Ubuntu* is a humane, polite and respectful attitude towards others. African culture espouses respectful, caring and just behaviour to both the animate and inanimate, the material and immaterial (Ayuyu, et al., 2015; Mkhize, 2004). Indigenous peoples have a tradition of unity and connectedness with the environment and the tradition is reflected in song, custom, subsistence, approaches to healing, birthing, and the rituals associated with death (Durie, 2004; Eyong, Mufuaya & Foy, 2005). In times of bad luck, pathological behaviour and all related miseries are displayed; and in moments of celebration, Africans display support and connectedness through their collective participation.

This brief differentiation between Western and African cultures does not imply that one culture is superior to the other. Each culture is valid in its own right in specific contexts.

Culture also provides a framework for the conceptualisation of health and illness (Ayuyu, et
al., 2015; Emeke, 2011; Juma, 2011; Kwate, 2005). On this basis, illness, pathology or health should be understood within its cultural context. The next session will discuss how culture influences the way in which health and disease are conceptualised.

Cultural Conceptualisation of Illness

Health and illness or disability is culturally conceived. The manner in which they are experienced, understood and managed is dependent on the cultural background of the people concerned (Kleinman, 1988). To provide the reader with an indication of how culture informs the conceptualisation of illness (or disability) and/or health, a few examples are provided by Ravindran and Myers (2012) below:

In Indian culture, Ayurveda is a widely practised system of medicine that views illness as a disharmony between the body, sense organs, mind and soul. Traditional Chinese medicine views health as a balance between yin and yang, the two complementary forces of the universe. Yin and yang are loosely translated into the ‘‘hot’’ and ‘‘cold’’ qualities of an individual. There should be a balance between these two forces to achieve health. For the Native American Navajo (also spelled Navaho) tribe, health has to do with achieving a balance between human beings and the spiritual world. The Navajo tribe views a person with a disability as a teacher for the clan, one who brings special lessons to the tribe and who offers a sixth sense or a unique gift. This view causes the tribe to be reluctant to accept treatment as it might interfere with the delivery of the disabled child’s message to the tribe.

Contrary to the aforementioned examples, the conceptualisation of illness in the West is traditionally based on the biomedical model. The biomedical model of disease is a scientific model that seeks to isolate causes of specific diseases. The biological component focuses on pathogens such as toxins, bacteria, and viruses as the cause of illness; and the medical
component focuses on cure and the prevention of disease (Fincham, Roomaney & Kagee, 2015). The biomedical model of disease adopts a linear explanation of disease. This means that there is a linear, one-directional and sequential relationship between cause and effect. The causes and management of illness are based on scientific evidence that is in line with Western culture as discussed above. Knowledge in Western culture is regarded as true knowledge if it is rational and universal, empirical support is provided, and the scientific evidence has been documented.

According to Radomsky, Hassane, Hoy-Watkins and Bandawe (2011), the African understanding of psychological problems is based on the spiritual model that considers the continuity and interrelatedness among mind, body and spirit. For this reason, illness is conceptualised as a discontinuity or disintegration between mind, body and spirit.

Notions of health and well-being are also inextricably linked to a person’s relationships with others, whether the divine or members of the family or clan (Kamwaria & Katola, 2012; Watson, et al., 2011). Owusu-Ansah and Mji (2013) assert that health or wholeness is about harmony in relationships. Conversely, illness is an outcome of disharmony in relationships (Ayuyu, et al., Kwate, 2005; 2015; Mpofu, 2006; Obasi, 2002). This notion is supported by Mpofu (2006), who states that illness is a result of the absence of a harmonious relationship with the members of the family, community and supernatural world. It is therefore important to maintain harmonious relationships with nature, the living and the ancestors to create a healthy relationship space.

The strong influence that culture plays in the conceptualisation of illness is highlighted in a South African study that investigated how social work students perceived illness and health behaviour (Feigin, 2013). These students experienced conflict between the African and Western models of illness. In this study, many students held onto their traditional African beliefs regarding illness despite receiving an education that is rooted in a Western
epistemological framework. Illness was conceptualised as a result of something bad or wrong that the sick person or their ancestors had done. Scriptures from the Bible were used to support this view, which highlights that culture and religion are intertwined in Africa. Feigin (2013) also provided evidence for the relationship between illness and harmony in relationships, as quoted by one student, “If only my auntie apologised to her mother-in-law about the incident, her son would not have the sickness he has today”. Furthermore, these social work students expressed that witchcraft was a probable cause of illness. In addition, these social work students stated that jealousy and grudges between families can propel a person to bewitch another, in this way inflicting illness or disability.

Inasmuch as the Western and African systems of medicine have different premises, they can be viewed as complementary to each other. Each system of medicine makes a useful contribution to the manner in which illness is understood. These two systems, if viewed in relation, may focus on different explanations of aetiology, but together provide a more integrated, wholistic and comprehensive view of illness. This integrated view includes physical, mental, social and spiritual aspects. Therefore, each culture plays an important role in the conceptualisation of illness (Jegede, 2002; Mpofu, 2006). The illness of interest in this study is autism. The Western conceptualisation of autism that is based on the biomedical model of illness will be explained.

**Biomedical model of autism.** Autism is firmly rooted in psychiatry, which adopts the biomedical explanation of illness. The definition, symptoms, diagnostic tools, aetiology and treatment of autism will be discussed from the viewpoint of the biomedical model.

**Defining autism.** Autism or autistic disorder is one of three neurodevelopmental disorders on the Autistic Spectrum Disorder (DSM-V, 2013). Autistic disorder, Asperger’s disorder, and pervasive developmental disorder have been consolidated into the Autism Spectrum Disorder (ASD) in the DSM-V. ASD is a new DSM-V disorder encompassing the
previous DSM-IV autistic disorder (autism), Asperger's disorder, childhood disintegrative disorder, Rett's disorder, and pervasive developmental disorder not otherwise specified (Sadock, Sadock & Ruiz, 2015).

Autism is characterised by symptoms that cause significant impairment in behaviour. These symptoms are discussed in the next section.

**Symptoms.** Many aspects of the child’s difficulties or impairments gradually come to the notice of parents during the first two years of the child’s life (McConachie & Diggle, 2006). In severe cases, a lack of developmentally appropriate interest in social interactions may be noted as early as the first year (Sadock, Sadock & Ruiz, 2015).

Autism is characterised by deficits in two core domains that exist along a continuum from mild to severe impairment. The first constitutes deficits in social communication and social interaction. Deficits in social communication and social interaction negatively impact on the understanding, development and maintenance of relationships as children with autism typically possess a limited capacity for social reciprocity (DSM-V, 2013). Non-verbal communicative behaviours like smiling socially, maintaining eye contact, orientating to their name and sustaining attention are either absent or limited in children with autism (Coonrod & Stone, 2004; Mendez, et al., 2015).

The second domain is characterised by excessive repetitive behaviours, restricted interests, and insistence on sameness (DSM-V, 2013; Sadock, Sadock & Ruiz, 2015). Repetitive behaviours and mannerisms may include hand-flapping and rocking (Barlow & Durand, 2005; Mendez, et al., 2015). Autistic children may also display a preoccupation with parts of objects or the alignment of objects (Barlow & Durand, 2005; Mendez, et al., 2015).

These symptoms are key criteria used in the diagnosis of autism.
**Diagnostic tool.** There are various diagnostic tools that were developed in the West to assess autism. Lord, et al. (1989) developed the Autism Diagnostic Observation Schedule (ADOS) and Le Conteur, et al., (1989) developed the Autism Diagnostic Interview (ADI). According to Bernier, Mao and Yen (2010) the ADOS and ADI are regarded as the gold standard assessment tools for diagnosing autism and have significantly improved the standardisation of assessment and characterisation of ASD in children of Western descent. The ADOS, which is based on the child’s behaviour, has also been translated into 12 languages. However, the effect of potential cultural confounders on the validity and reliability of the instrument has not been thoroughly assessed (Bernier, et al., 2010). Caution should thus be exercised when using these diagnostic tools on people with cultures that are different from those of the West. Nyarambi, Enwefa and Enwefa (2011) stress the importance of exercising caution even within the West due to the heterogeneity of cultures that exist. The causes of autism using the biomedical model are discussed next.

**Aetiology.** The medical community maintains that autism is caused by a combination of genetic- and environmental factors, which conclusion is supported by empirical evidence (Adams, 2013; Ametepee & Chitiyo, 2009; Baltus-Herbert & Koulouglioti, 2010; Nyarambi, Enwefa & Enwefa, 2011; Rahbar, Ibrahim & Assassi, 2011; Russell, Kelly & Golding, 2009). Genetic factors predispose a child to autism and environmental factors act as triggers to the onset. Modern technologies and modern living were found to be the most common environmental factors (Blaxill, 2008; Russell, Kelly & Golding, 2009). By extension, the more industrialised the world becomes, the greater the risk of children having autism. Potential environmental factors may include immunisations, heavy metals, infectious agents, or pharmacological agents. However, the specific biogenetic cause has not yet been found (Farrugia, 2009; Lee, 2011).
Baltus-Herbert and Koulouglioti (2010) found that parental beliefs of autism aetiology were consistent with those proposed by the biomedical model. The findings of the review indicate genetic or hereditary factors as the causes, especially when the child was diagnosed soon after birth. Vaccinations or environmental toxins were also identified as causes when regression of developmental skills was evident after a period of normal development. The Measles-Mumps Rubella (MMR) vaccine was particularly implicated. Unfortunately parents continue to be concerned about vaccinations, despite scientific evidence that disproves a possible association (Freed, Clark, Butchart, Singer & Davis 2010). The prenatal maternal-risk factors like advanced maternal age, smoking, influenza, medications, maternal vaccination, uterine bleeding, toxaemia, use of street drugs and maternal illnesses were also identified as causes. Other causes included premature birth and perinatal events (such as trauma during birth, foetal distress, low birth weight, induced labour, emergency caesarean section, anaemia and infection after birth). Furthermore, childhood illness or injury and the child’s diet were also believed to be the causes (Baltus-Herbert & Koulouglioti, 2010). The above review mentioned above clearly indicates that parental beliefs on the causes of autism are largely of a neurobiological, genetic and environmental nature.

The lack of a definitive cause of autism means that the treatment of autism is primarily based on the presenting symptoms.

_Treatment_. The biomedical model consists of two treatment modalities: the conventional (allopathic) medicine as well as complementary and alternative medicine (CAM). The majority of Western families use both these approaches (Bowker, D’Angelo, Hicks & Wells, 2011; Huang, Seshadri, Matthews & Ostfeld, 2013). It is also important to note that because autism is a spectrum disorder that ranges from mild to severe, the treatments that may work for one child might not necessarily work for another child, as no child with autism is the same (Adams, 2013). Therefore, the treatment plan for each child
should be individualised. However, there are no guarantees that these treatments will be effective.

Conventional medicine. Conventional medicine is a Western intervention conceived from the medical model. The medical model focuses on prevention, treatment and/or cure of disease (Fincham, Roomaney & Kagee, 2015). Since there are no preventative and curative measures for autism, the medical model for autism is primarily therapeutic. Conventional treatments for children with autism are categorised into educational, psychiatric, psychological and social interventions (O’Reilly, Cook & Karim, 2012). Weitlauf et al. (2014) describes these interventions as follows:

Educational interventions include learning programmes that use visual tools and are based on the Treatment and Education of Autistic- and Communication-related Handicapped Children (TEACCH) approach. The use of these visual tools requires trained educators.

Psychological treatment is divided into two types. These are intensive behavioural intervention and cognitive behavioural therapy (CBT). Intensive behavioural intervention targets the child’s overall development through the use of the following programmes: Lovaas Model, Early Start, Denver Model, Pivotal Response Training, Hanen More Than Words and Applied Behavioural Analysis (ABA). CBT is done to manage the child’s anxiety through the following programmes: Coping Cat and Facing Your Fears.

Social interventions address impairments in social skills, attention and play through the use of the following programmes: skillstreaming and the Joint Attention Symbolic Play Engagement and Regulation (JASPER).

Psychiatric interventions include the administration of drugs to manage a wide range of symptoms that a child with autism may display.
According to Bowker, et al. (2011), other conventional interventions might include speech therapy, physical therapy or occupational therapy. Apart from the aforementioned conventional medicine, the use of CAM is gaining popularity (O’Reilly, Cook & Karim, 2012).

**Complementary and alternative medicine.** CAM is a diverse array of practices that are either used in conjunction with or as a replacement for conventional medicine (O’Reilly, Cook, Karim, 2012). Dietary supplements have been found to be the most common CAM, whereas sensory integration was perceived by parents to be the most effective CAM (Bowker et al., 2011). Other CAM treatments include chiropractic therapy, Bowen Therapy, cranial osteopathy, homeopathy, chelation therapy and music therapy (Lee, 2012). According to Lee (2012) the most significant gains with the use of CAM were shown in improved danger awareness, less demanding behaviour, better sleep, better concentration and improved eye-contact. The areas that did not show improvement were head banging, rigid routines, destructive behaviour, impaired play and disliking physical contact.

O’Reilly, Cook and Karim (2012) warn that some CAMs have not been tested and might therefore pose some health risks to the child with autism. For this reason parents should exercise caution when using CAM that has insufficient scientific data to support the efficacy of the treatment.

Although the biomedical model is the most widely accepted and applied model in the understanding of autism, the DSM-V cautions clinicians to consider cultural issues when diagnosing autism. The reason that clinicians are cautioned to considered culture is that “culture provides an important lens through which an understanding of human psychological and social functioning can be attained.” (Grills & Ajei, 2002, p. 6)
**Culture and autism.** Autism carries different meanings in different societies, and results in a variety of different experiences of autism as an illness across cultures (Daley, 2002; Ecker, 2010; Ravindran & Myers, 2012). Culture provides an interpretive framework for the experience and expression of the symptoms, signs, and behaviours that are criteria for diagnosis (DSM-V, 2013). Daley (2002) states that social and cultural influences clearly shape the experience and expression of autism. Therefore, autism should be defined and diagnosed in relation to cultural, social, and familial norms and values.

**Different cultural values and diagnosis.** Values contribute to a family’s attitudes about child rearing, disability and assessment (Ennis-Cole, Durodoye & Harris, 2013; Mendez, et al., 2015). Different cultures may have different expectations on which child behaviour is valued and acceptable. The values espoused by a culture have a direct effect on the timing of the diagnosis of autism; that is, the time at which children’s difficulties are noticed by their parents is dependent on culture (Rahbar, Ibrahim & Assassi, 2011). Nsamenang (2005, p.3) states that “every culture recognizes and assigns different developmental tasks to their perceived phases of human ontogenesis”. Similarly, Kwate (2005) states that “normal” behaviour can only be defined by the culture that gives behaviour meaning. It becomes apparent that culture can either be advantageous or disadvantageous to early diagnosis as it depends on what is understood and valued by that culture. For example, some cultures may value open communication and social interaction with their children, and some may not. Others may value direct eye-contact and other cultures may see it as a sign of disrespect from the child. Difficulties in social interaction and social communication – for example, the absence of eye contact – are key criteria in the diagnosis of autism (Bernier, et al. 2010). The relationship between cultural values and the diagnosis of autism is demonstrated in examples 1 to 5.
1. In the USA parents tend to first notice the delay in language development. These concerns were noted before a child reached two years of age (Coonrod & Stone, 2004). Expressive language is valued among Americans.

2. African American children are more likely to receive the incorrect diagnosis of conduct or adjustment disorder in comparison to White children (Bernier, et al., 2010).

3. In Saudi Arabia girls are expected to interact less and being shy and reserved is the social norm. As a result of this norm girls are usually diagnosed later than boys (Al-Salehi, Al-Hifthy & Ghaziuddin, 2009). The value placed on reserved behaviour can also pose challenges to intervention as one of the goals of therapy would be recognition and expression of emotion.

4. In India social participation is the basis of personhood, therefore the first concern of Indian parents would be the lack of social relatedness of the child (Daley, 2002).

5. Reduced eye contact is considered to be a part of the impaired nonverbal behaviour criteria for the diagnosis of autism (Bernier, et al. 2010; Nyarambi, Enwefa & Enwefa; 2011). Direct eye contact with elders is considered to be a sign of disrespect in some African cultures, including certain cultures in South Africa. In rural South Africa, young children do not necessarily make direct eye contact because it is considered disrespectful (DeWeerdt, 2012). In these cultures the absence of eye contact is a socio-culturally acceptable behaviour that could lead to a late diagnosis if parents are not vigilant about other symptoms. However, a lack of eye contact is a hallmark of social deficits in people with autism and it is what clinicians from the West look for. In Western
culture the absence of eye contact in non-sufferers from autism is considered disrespectful.

From the examples set out above it can be concluded that the assessment of autism should not be universal. The heterogeneity of behavioural expectations across different cultures poses a challenge for clinicians in the screening and diagnosis of autism. Stepke (2009) stresses the importance in considering cultural value systems early in the assessment, as cultural values influence the treatment plan and ultimately the prognosis. It is not only important to consider how behavioural norms and values are influenced by culture, but also how culture influences how the causes of autism are conceptualised.

**Cultural conceptualisation of the causes of autism.** Culture influences how causation of autism is interpreted. Various cultural conceptualisations of the causes of autism exist.

**Supernatural causes.** Supernatural causal beliefs are beliefs that cannot be investigated with the use of scientific methods, as these beliefs operate outside natural laws (Clarke, 2009; Eastwell, 2011). In Taiwanese culture it was found that autism was not perceived as a developmental disorder by parents (Shyu, Tsai & Tsai, 2010). In this study the beliefs about the causes varied; however, the dominant view (85%) was that autism was caused by some supernatural power. Similarly, in Saudi Arabia most of the parents had non-medical explanations for the causes of autism like the “evil eye” and black magic and, therefore, sought alternative interventions like consulting religious leaders and reciting the Al-Quran (Alqahtani, 2012). The Arabic word *al-ʿayn* means evil eye and refers to the act of intentionally or unintentionally harming another with one’s eye as a result of jealousy (Stobart, 2006). Black magic on the other hand is a branch of paranormal power “dealing in death, destruction, manipulation and spells” (Stobart, 2006, p.31).
Attribution to supernatural causes was also found in the African context. Nigerian healthcare workers were of the opinion that autism could be attributed to lineage curses, enemies, and actions of the devil (Bakare, 2009a). By the same token, Nyarambi, Enwefa and Enwefa (2011) found that Africans were inclined to attribute the cause of autism to witchcraft. Attribution of autism aetiology to witchcraft is a cultural belief that results in tremendous amounts of suffering for both the child with autism and the family (Cimpric, 2010; Mgbako & Glenn, 2011; Nyarambi, Enwefa & Enwefa, 2011). Violence, mistreatment, stigmatisation, physical and sexual abuse, murder, imprisonment, abandonment and a lifetime of discrimination are some of the atrocities inflicted on children with autism in Africa (Cimpric, 2010; Stobart, 2006). Paradoxically, it is families who turn against their children and become perpetrators of this violence.

In addition to attribution to supernatural causes, parents may also believe that having a child with autism is either a blessing or a form of punishment.

**Blessing versus punishment.** Muslim parents in South Asian cultures felt that a child with autism was a blessing from Allah (Jegatheesan, Miller & Fowler, 2010). These families believed that Allah had chosen them to raise His special child based on their moral character, loving nature, resilience, ability to protect the child and their fate or Karmic connection to the child. The Muslim beliefs are in total contrast to those that exist in African cultures, where autism is attributed to punishment from God or the ancestors. This perspective can be illustrated by a study conducted in Kwazulu-Natal, South Africa. In this study, parents reported that they were advised by elders that autism indicated an unhappy ancestor and that a ritual should be carried out to conciliate the ancestor (Madlala, 2012). An ancestor could be unhappy in cases where prescriptions and directives had not been subscribed or adhered to. Such disobedience could result in autism, which is regarded as a form of punishment.
From this discussion it can be concluded that parental beliefs about the cause of autism largely influence how parents manage their child’s autism and the treatments parents seek (Bernier, et al. 2011; Ravindran & Myers, 2012).

**Cultural treatment of autism.** Although a discussion on treatment has already been provided from a biomedical perspective, various cultures may also have different approaches to the treatment and management of autism. According to the World Health Organization (2001) the majority of the world’s population uses indigenous or traditional systems for their healthcare. Healing from an African worldview comprises knowledge and practices used in the diagnosis, prevention, cure and treatment of physical, mental, spiritual and social imbalance (Mpofu, 2006). Therefore, healing is a wholistic process of integrating the individual back to society (Cimpric, 2010). The healing practices that will be discussed are traditional healing, the oral tradition and religious healing.

**Traditional healing.** In West Africa healing is most commonly sought from a traditional healer (Edoo, 2013; Jegede, 2002). Similarly, Mpono (2007) states that up to 80% of the South African population make use of traditional medicine and consult with traditional healers as a means of acquiring specific cultural explanations for the experienced illness. Traditional healers act as a mediator to interpret messages sent by the ancestors, especially the reasons for the illness (Feigin, 2013). Traditional healers use a mixture of practices comprising prayers, sacrifices, exorcism, herbs, plants and the drinking of holy water (Edoo, 2013). According to Ayuya, et al. (2015), traditional healers might use a combination of externally oriented methods like ritual cleaning, enactment, sacrifices or internally oriented healing methods such as bodily incisions, vomiting and purging. The last of the three is perceived to keep evil spirits, witches and bad luck far away from the daily lives of the individuals and the community (Ayuya, et al., 2015). Madlala (2012) reports that traditional
treatment for autism in Kwazulu-Natal might be *ukuca*tha* (*African enema*), a ritual, slaughtering of an animal or burning *impepho* (*African incense*).

**Oral tradition.** Aside from traditional healers, the oral tradition plays a role in the healing process of people of African ancestry (Ayuya, et al., 2015; Watson, et al., 2011). Oral traditions take many forms. Among the documented oral traditions that can be used in the treatment of illness are singing, music, dance and drumming. Music, dance and drumming are innovative and beneficial practices in West Africa and regarded as important ingredients for healing, as they restore peace and harmony in the individual and the group (Edoo, 2013).

Music may benefit children with autism through improving communication skills and social interaction. Western culture separates music and medicine, whereas in African culture music is medicine (Drake, 2010; Mbatha, 2015). Music, singing and movement were found to aid children with autism to develop the intent and pre-language to communicate (Madaule, 2003). Madaule (2003) also found that healing was achieved by the coupling of singing and music with the autistic child’s strong craving for movement. The strong craving for movement is observed in the rocking and hand-flapping behaviours that are common in children with autism. Madaule (2003) postulates that this coupling of movement with singing and music triggers vocalisation and provides an opportunity to connect with the child. Neuberger (2012) found that dance/movement therapy (DMT) resulted in improvement in the social and behavioural domains of children with autism. Linked to song, music and dancing is drumming.

The idea of drumming in Western culture is mainly associated with entertainment or as a means of enhancing the musical quality of a song (Mbatha, 2015). However, drumming – particularly Djembe drumming – is an integrative healing modality that facilitates deep human connections, interactions and psychological relief (Mbatha, 2015). Drumming for a sustained period of time is a healing agent for the whole body (Drake, 2010; Edoo, 2013;
Mbatha, 2015). Edoo (2013) states that sound is the force of change and that the drum rhythm captures the movements of the human body, its sensations and nature itself. The use of drumming for autistic children is particularly beneficial as it permeates all parts of the brain (Drake, 2010). In his study Drake (2010) states that drumming has a calming, focusing and healing effect on autistic children. The sound of drumming generates dynamic neuronal connections in all parts of the brain, even where there is significant damage or impairment. The rhythm of the sound can be a soothing way for autistic children to connect with others, either in a one-on-one therapeutic session or within a group (Drake, 2010; Boso, Emanuele, Minazzi, Abbamonte & Politi, 2007). Therapists regard drumming as a source of communication for autistic children as it has shown to serve as a way to model more difficult verbal interactions and responses and to improve cooperation within a group environment (Boso, et al., 2007). In addition to being a source of communication and cooperation skills, drumming can help reach the creative, right side of the brain that also helps stimulate socialisation (Boso, et al., 2007; Drake, 2010). Drumming helps both adults and children with autism express emotion. The premise is that the speed and volume of the rhythm emulate or translate into many emotions like sadness, anger, frustration and happiness among other emotions (Boso, et al., 2007; Khetrapal, 2009).

Therapeutic rhythm techniques is not a new modality, but have been used for thousands of years to create and maintain physical, mental and spiritual health (Drake, 2010). Neuberger (2012) stresses the importance of integrating these therapeutic rhythm techniques with the modalities of the biomedical model in order to have a broader, integrative and holistic approach to the treatment of autism.

Another therapeutic source that is common in Africa is religious leaders.

Religious leaders. In addition to using oral tradition, parents might also seek religious guidance from religious leaders (Ravindran & Myers, 2012; Yeh, et al., 2005). Bakare and
Munir (2011b) found that in cases where autistic symptoms are less severe, African parents are more likely to consult in prayer houses. These prayer houses are believed to provide encouragement, comfort, support and healing through fellowship, which is facilitated by a religious leader (Louw, 1998). Louw (1998) adds that prayer is an important religious practice that can be used for healing. Through prayer the child as well as his or her parents may ask from the Supreme Being the power and strength to deal with the challenges that the family is facing as a result of the illness.

This section has covered the cultural practices used in the treatment of autism. An important construct that should not be overlooked during the assessment and treatment of autism is language. Language, like values and experiences, affects the way people feel and see things and also what matters to them (Grills, 2006). According to Baloyi (2008), people express their culture, experiences and ways of being through language.

**Autism and language.** Language is not the actual content of academic knowledge, but a symbolic representation and mechanism for communicating this content (Cummins, 1980). Therefore, not knowing the word “autism” is not indicative of no knowledge of autism. Autism may be known by a different name or known by the descriptions of behaviour according to the culture of the parent.

Daley (2002) reports how children displaying autistic characteristics are known as “Nit-ku-bon” or “marvellous children” in Senegal. These children display lack of speech and social unresponsiveness. In another early study, Westermeyer (1979) reported that rural Laotians use a category known as “Samqng Uan” to describe children who have developmental difficulties such as delayed learning, difficulty getting along with others, lack of flexibility and adaptability. The latter two characteristics may be regarded as restricted interests and insistence on sameness which are DSM-V criteria. One mother in India reported
going to the police station when her autistic son was lost (Daley, 2002). The best word that she felt described her son was “pahgal”, which means crazy.

There are 11 official languages in South Africa so there is the possibility that autism is understood differently within the various cultures. Therefore, caution should be exercised before concluding that people do not know what autism is. According to Madlala (2012) autism may be called “inyoni” (an African condition that is culturally treated when a child is a baby) or “ithuko” (an illness found among children that requires traditional treatment) in the Zulu culture in South Africa.

Aside from having a different term for the term “autism”, the acceptable age at which children acquire language varies from culture to culture. It is believed that Indian boys typically acquire language later than girls; for this reason boys tend to be diagnosed much later (Daley & Sigman, 2002). Second-language development studies have revealed that a child that is exposed to a second language may go through a normal developmental "silent period" in language development that may be viewed as autistic behaviour (Mendez, et al., 2015) and culminate in a false positive diagnosis. This research is especially relevant in South Africa where there are 11 official languages.

In diverse cultural contexts clinicians should also pay attention to the phrases that parents use to describe the child’s behaviour. Parents may use the same language but the manner in which the behaviour is described may differ according to race. DeWeerdt (2012) explains that white parents in the USA often emphasise a child’s lack of communication by saying, “my child doesn’t respond when I call his name”, while black parents in the USA tend to use phrases like, “my child won’t mind me”. The language used to describe the child’s behaviour may be misinterpreted if the clinician and parent are not of the same race. Clinicians may be less inclined to consider a diagnosis of autism when they think a parent is
describing a disobedient child rather than a socially impaired one. This could be a possible reason why autism is diagnosed less frequently among black children in the USA.

Paying attention to language, in terms of both terminology and the description of behaviour used by parents, is an element that a clinician needs to be aware of. Parents may opt to replace the word “autism” with a more euphemistic word to avoid stigma. Researchers found that autism is underdiagnosed in South Korea due to the stigma attached to receiving this diagnosis (DeWeerdt, 2012). The genetic link that has been found with respect to autism has cascading and negative consequences for South Korean families. One mother feared that the confirmation of a genetic link would limit marital prospects for all her children on the basis that one of her children was diagnosed with autism (Daley, 2002; DeWeerdt, 2012). Owing to the stigma and negative connotations that an “autism” label carries in Korea, parents often prefer that their child be labelled as having “reactive attachment disorder”, or “lack of love”. The latter explanation, “lack of love” affects the mother’s reputation only and not the whole family. “Border child” is a new term that is also used in Korea. This is an autistic child who does not have intellectual impairment but significant social impairment.

There are advantages and disadvantages in opting for alternative, euphemistic labels. In the Korean study, two thirds of the children attended mainstream schools (DeWeerdt, 2012). This widespread mainstreaming raises the question of whether a Western-defined autism diagnosis is meaningful if children are able to function reasonably well in their cultural context. Opting for a euphemistic label has proven advantageous in Korea. However, it also raises the question: What happens to the remaining one third of autistic children in Korea who do not attend mainstream school? Owing to stigmatisation these children may be kept at home and not receive any autism-help-related services. Therefore, the severity of the disorder as well as the community’s perception of the disorder is shown to influence the level of autism-help-related services that a family seeks to access.
Knowledge, language and culture are intertwined constructs. The relationship between language and knowledge is reflexive. Language is used to express knowledge and knowledge is obtained through language. All knowledge comes from our cultural experiences (Okere, 2005).

**Autism and Sources of Knowledge.** There are various sources that provide parents with knowledge of autism. These sources may include healthcare workers, traditional and religious leaders and the media.

*Healthcare workers.* With regard to health care workers, it has been documented across the globe that staff at many community health clinics lack specialised training and have inaccurate knowledge and beliefs regarding ASD (Bakare, et al., 2009a; Bakare & Munir, 2011a; Brookman-Frazee, et al., 2012; Daley & Sigman, 2002; Heidegerken, Geffken, Modi & Frakey, 2005; Igwe, Ahanotu, Bakare, Achor & Igwe, 2011; Rahbar, Ibrahim & Assassi, 2011). Limitations in knowledge about autism were evidenced by healthcare workers misdiagnosing autism as an early onset of schizophrenia or behaviour resulting from parental psychopathology or cold and rejecting parents (Farrugia, 2009; Foster, 2007; Brookman-Frazee, et al., 2012; Rahbar, Ibrahim & Assassi, 2011). Evidence suggests that parents were told that the child would eventually outgrow the observed and obvious developmental delay (Heidegerken, et al., 2005). Because of this inaccurate knowledge of autism, healthcare personnel did not advocate for special education of a child with autism (Heidegerken et al., 2005).

Another study conducted in Pakistan revealed that general practitioners (n=332) had never heard of autism (Rahbar, Ibrahim & Assassi, 2011). This could suggest that autism may be known by a different name in Pakistan. A study conducted by Madlala (2012) in Kwazulu-Natal, South Africa, supports healthcare workers’ limitations in knowledge of autism. In this study, South African parents recounted their frustration with health professionals because
they were told that the condition was either temporary or the child had hearing loss and would be normal again within two years.

It is therefore imperative that the diagnosis of autism be culture sensitive. The cultural issues should always be taken into consideration before a diagnosis of autism is made or ruled out. Healthcare workers need to expand their repertoire by increased exposure and appreciation of the values espoused in various cultures. A deep appreciation of both the richness and limitations of the client’s socio-cultural contexts, as well as that of healthworkers’, would be beneficial. Such an achievement would be reached only by being open to new experiences and seizing opportunities to learn more about cultural differences. Cultural confounders should not be ignored during the assessment of children who may be suspected of having autism.

**Divination.** Various sources of knowledge are culture specific. According to (Croucamp, 2013), divination is a method used by most cultures as a source of knowledge. Stein-Frankle and Stein (2005) define divination as a method of acquiring knowledge about unknown phenomena. In China, I-Ching is a divination text that uses numbers as a method for knowledge inquiry. Interpretation of these numbers is based on the sequence of order and interpreted according to the I-Ching book (Legge, 1899). Unlike the Chinese culture that uses numbers, in the African culture the throwing of bones by the diviner is the method for knowledge inquiry. Once thrown, the way these bones fall is understood and interpreted as a message from the ancestors. The ancestors communicate through the diviner the causes and the management of the illness (Mankga, 2013). However, it has been reported that a wealth of these knowledge resources from Africa has been overlooked (Croucamp, 2013). A source of knowledge that is not overlooked and which parents rely heavily on is the media.

**Media.** According to Young (2012) the media reaches a mass audience, and in this way has a much greater impact than research with respect to access to information on disabilities.
Knowledge of autism can be gathered from the television, radio, Internet, magazines, books and newspapers to name but a few media sources. Media sources of knowledge should be approached with caution as the accuracy of the information may be questionable. For example, some movies tend to glamorise the difficulties faced by people living with autism and portray characters with autism as geniuses that are able to surmount impossible odds (Belcher & Maich, 2014; Dillenburger, Jordan, McKerr, Devine & Keenan, 2013). It must, however, be noted that the primary intention of movies is not dissemination of knowledge, but to entertain and make profit (Belcher & Maich, 2014). Therefore, movies may misrepresent the realities of many families affected by autism.

In complete contrast, books and articles that are peer-reviewed have been found to provide information that is more accurate, as they are mostly written by authors based on their real-life experiences and on scientific methods (Belcher & Maich, 2010). Since the authors of books and articles may have a personal connection with autism, the writing of a book or article may be part of the author’s healing process.

From the discussion set out above it can be concluded that media can be informative or misleading sources of knowledge. Limitations in knowledge of autism may pose various challenges to the parents raising a child with autism.

**Challenges Faced by Mothers raising Children with Autism**

**Stigma.** An important social element to consider is stigma. Parents experience humiliation and shame in social settings due to the behaviours that many children with autism display. This culminates in high levels of stress, isolation and stigmatisation. Balfour (2007) reports that the normal physical appearance of those diagnosed with autism makes these
unpredictable, inappropriate, disruptive and sometimes self-injurious behaviours even more stigmatising for parents.

**Socio-political and economic factors.** Socio-political and economic factors influence the availability and accessibility of specialised care for children with autism (Ennis-Cole, Durodoye & Harris, 2013). A large cross-sectional study conducted in the USA found that autistic children of high socioeconomic status (SES) were more likely to be diagnosed earlier and have access to specialised treatment in comparison to autistic children of low SES (Durkin, et al., 2010).

Raising a child with autism is costly, and the majority of South Africans can ill-afford the much needed services (Balfour, 2007). The disparities in wealth and health in South Africa are among the widest in the world (Benatar, 2010). The more financially viable the family is, the more chances of accessing the best services for their child with autism, culminating in a better prognosis for that child. Conversely, the chances of poor South Africans accessing appropriate and specialised services are remote, resulting in a poorer prognosis for that child.

**Lack of inclusive education.** In addition, parents of children with autism may struggle to educate their children. Attempts are made to implement inclusive education but these are not effective because of a lack of expertise and funding for proper training of teachers. In the South African context the mainstream schools are not equipped to deal with the special needs of children with autism. For this reason attempts at incorporation have failed dismally (Balfour, 2007; Hoffman, 2012).
Conclusion

This chapter reviewed the literature on parental knowledge, beliefs and practices of raising a child with autism. Culture is the quintessential aspect of this research. The relevance of culture in this study can be summed up as follows: knowledge comes from our cultural experiences; culture informs and shapes our beliefs; and beliefs largely influence our practices. Therefore, it can be proposed that culture is the foundation that informs how parents conceptualise autism, their beliefs regarding the causes and, lastly, the interventions sought. While there should be recognition and respect for cultural belief systems, it is imperative to adopt an integrated approach to the understanding of autism. An integrated approach is an inclusive approach that acknowledges the biomedical-spiritual-cultural perspectives of autism, as each has its place in psychology. The next chapter discusses the theoretical framework underlying this study.
CHAPTER THREE: THEORETICAL FRAMEWORK

Introduction

This chapter provides a discussion of the theoretical framework adopted in this study. A theoretical framework provides a likely interpretation or explanation of a phenomenon and helps us to make sense of the world around us (Hofstee, 2006). All people have their own theoretical framework, which is consistent with their worldview and culture. Historically, Africans have attempted to make sense of their world using theoretical frameworks that are foreign and imposed, and were developed in Western Europe and North America. The marginalisation of IKSs and the adoption of a foreign, Western epistemological paradigm was an outcome of colonialism (Carroll, 2010; Holdstock, 2000). Psychology arrived in Africa with colonialism, making Africa a net importer, rather than a generator of psychological knowledge (Ayuya, Ireri, Kimani, Mathenge, Muriithi & Otieno, 2015).

Nobles (2015) equates the importation of Western knowledge systems to mental brainwashing, psychic terrorism and the uncritical consumption of poison as if it were medicine to heal Africans. For Nobles (2015) it appears unfathomable to adopt the tools and theories that have been used to demean, dehumanise, defame, debilitate and damage Africans. However, Western tools continue to be used on people of African descent.

In its current form psychology is construed as a universal science. This universalisation disregards indigenous people’s values and culture (Mkhize, 2004). The push to adopt a Western epistemological framework in mainstream psychology marginalised IKSs (Ani, 2013; Kwate, 2005; Nsamenang, 2005). African experiences and phenomena that are at variance with Western conceptions and scientific explanations have in this way been either discarded or misinterpreted. The importation and application of a foreign knowledge system
to interpret and explain African phenomena is detrimental as it often results in misunderstandings, misinterpretations, misdiagnoses and subsequent interventions that may do more harm than good to Africans.

Nwoye (2015) and Owusu-Ansah and Miji (2013) stress the importance of a corrective, counter-discourse; a protest, emancipatory psychology that will highlight the psychological significance of African cultural traditions. Similarly, Holdstock (2000) argues for a generative psychology, a psychology that will imbue the people of Africa with a trust in the uniqueness of their African heritage. This trust can be achieved only if psychology fully recognises and incorporates the worldview of Africans. Triandis (1996) asserts that psychology will be a universal psychology when the indigenous psychologies are incorporated into the current “universal” framework. Ayuyu, et al. (2015) propose that psychology be used as a platform to integrate the African worldview and scientific inquiry in the research and practice of psychology in Africa.

Worldview and Psychology

Sue, Ivey and Pedersen (1996) state that worldviews are highly correlated with cultural upbringing and life experiences. In support of this view, Baloyi and Makobe-Rabothata (2014, p.234) state that “a worldview is the embodiment of people’s cultural beingness and identity”. A worldview is embedded within a particular culture. Therefore, it can be said that culture informs the worldview that people adopt. Culture provides the framework for the manner in which a group of people perceive and interpret the world. Glocke (2011) states that culture provides the details for a worldview. Similarly, Kamwaria and Katola (2012) state that culture is an inclusive term comprising both implicit and explicit guidelines that tell a group of people how to view the world. This statement implies a synergetic association between culture and worldview. Smith (2003) posits that worldview and culture shape each
other with equal measure, with worldview finding expression in culture. Johnson (2003) maintains that culture is the operationalising of a group of people’s worldview. People from the same culture share a similar worldview; they perceive and interpret occurrences in the world in a similar fashion. It is this shared worldview that unites people of the same culture.

Mkhize (2004, p.35) defines a worldview as “a set of basic assumptions that a group of people develops in order to explain reality and their place and purpose in the world”. These basic assumptions aid people to address psychological problems and shape attitudes and values. In Africa, historically psychological problems have been primarily addressed using a Western worldview. Holdstock (2000, p.7) states that “psychology is a product of the culture which gave it birth and provided the framework for its development”. Psychology is a product of Western culture. Therefore, the often held view that psychology is value free is misleading because psychology subscribes to the values of Western culture, which is itself premised on a Western value system, thought and worldview.

The individualism, competitiveness and materialism of Western cultures are in contrast to African cultures whose worldview is characterised by communalism, coexistence and interdependence. The application of Western paradigms of thought to African people and the practice of Western medicine on African people limit African possibilities, as application and practice disconnect the person from his or her authenticity (Karenga, 1997; Lyons, Bike, Johnson & Bethea, 2012). The application of Western paradigms poses challenges in psychological research, diagnosis, assessments and treatment of people of African ancestry. These challenges have been discussed with respect to autism in Chapter Two under the rubric “Culture and Autism”.

Ayuya et al. (2015) propose an integration of the African worldview in the context of psychological scientific research, diagnosis, assessments and treatment of clients. The integration of the African worldview in psychology could most likely provide a better
understanding of African experiences and the manner in which Africans interpret and make
sense of the world. The principles of an African worldview may differ from those of a
Western one; yet neither is superior, but each is equally valid and relevant to the respective
contexts. Psychology can only be relevant to Africans if it explains using the African
worldview and lived experiences.

**African Worldview**

Carroll (2010) argues that the African worldview is the essential foundation of African-
centred psychology. The African worldview describes the cultural values of people of
African origin and African descent throughout the world (Graham, 1999; Grills, 2002;
Nobles, 2006). Any theory on counselling or study that explores the traditions of African
people must consider the African worldview, which is the lens through which phenomena are
examined (Glocke, 2011; Louw, 2011). The African worldview can be dissected into the
following philosophical assumptions: cosmology, ontology, axiology and epistemology
(Ayuya, et al., 2015; Grills, 2002). These assumptions permit an understanding of the mental,
behavioural and spiritual trends of African people (Carroll, 2010). Each philosophical
assumption will first be defined and then explained from an African perspective.

**Cosmology.** Cosmology is the structure of reality (Grills, 2002). Okon (2006) describes
cosmology as the sum total of people’s opinion concerning life, happiness, fears, purpose of
life, death and after-life. African cosmology is grounded in interdependence, collectivism,
harmony with nature, and is a definition of the relationship with the divine (Carroll, 2008;
Glocke, 2011; Grills, 2002). Ekeke (2011) defines African cosmology as a religious
cosmology that has evolved from the experiences of Africans.
The cosmology of an autistic child may be described as fragmented. Madaule (2003) states that the world of the autistic child does not make sense to the child, as the world is perceived through separate fragments of information and sensory experiences that do not form a complete whole. Madaule (2003) further contends that even though an autistic child is able to see, hear, and feel, what they see is not related to what they hear, and what they hear is not related to what they feel. The nature of reality of an autistic child should therefore be understood against this background.

**Ontology.** Ontology is a branch of philosophy concerned with fundamental questions of being and existence (Imafidon, 2012; van Vlaenderen & Neves, 2013). Graham (1999) defines ontology as the essence of all things. Ontology is “the nature of reality to be studied and what can be known about it” (Mkhize, 2004, p.36). Similarly Udefi (2012) states that ontology is the study of meaning and the nature of being.

The African worldview espouses the physical and metaphysical ontologies. Reality is not just physical, sensible and material, but spiritual (Carroll, 2008; Etim, 2013; Kamwaria & Katola, 2012). These ontologies cannot be separated as matter and spirit (or life force) are one (Nobles, 2015, Parham & Parham, 2002). They are one, as life force permeates everything (Etim, 2013; Nobles, 2015, Parham & Parham, 2002). The metaphysical ontology is central to African cultures understanding of the world and they serve as a foundation for an African-based psychology (Akbar, 1974; Nobles, 2015). The metaphysical context of being is a context that is irrefutable by science as it does not conform to the notion of logic. It is a context where cosmic connectedness, spirituality and cultural practices represent authentic lived experiences (Baloyi, personal communication 2015). Nobles (2015) posits that the African reality is based on spiritness; all that exists in the material and metaphysical are spirit expressions, and all being is spirit. On this basis spirit can be equated with the life force (Mkhize, 2004) or vital force (Holdstock, 2000).
In the context of this study, Africans may for example believe that this life force has been used for sinister purposes and caused a child to have autism. The sinister purpose could be witchcraft or punishment for not heeding directives from the ancestors (Mgbako & Glenn, 2011; Stobart, 2006). Should these sinister purposes be regarded as the cause of autism, African parents may consult with *iSangoma* or *nyanga* to assist in interpreting the reasons for the illness and counteracting these negative forces respectively (Madlala, 2012).

Stillman (2006) provides a different take on the spiritual way of being in children with autism. He posits that the senses of children with autism have a higher vibrational capacity, which allows them to perceive all things, both seen and unseen. Stillman (2006) further states that the souls of autistic children are spiritually elevated and allow them to communicate with the spirits of the deceased. However, this communication with the living is limited, misinterpreted and misunderstood.

Both cosmology and ontology capture the study of reality. Once the structure and nature of reality is known and understood, the values espoused within this reality can be addressed.

**Axiology.** Axiology is the theory of values that includes morality, ethics and aesthetics (Vidal, 2008). Stepke (2009, p.149) defines axiology as “the philosophical discourse concerned with values and human behaviour as reflected in habit and custom.” The preferred value system in African culture is *Ubuntu* (Graham, 1999; Grills, 2002; Ramose, 2005). There are different definitions of *Ubuntu*, depending on one’s context. Mkhize (2004) states that *Ubuntu* is to know and practice one’s duties and responsibilities within a community of others. A community of other being anything connected with human relationships, be it with non-living objects, plants, the living and the living dead. Owusu-Bempah and Howitt (2000) state that *Ubuntu* is an African cultural value system that emphasises human relatedness and a shared identity. Holdstock (2000) states that *Ubuntu* is an ultra-humanity where an individual
takes responsibility for the wellbeing of others and where the individual respects the self and other animate and inanimate objects.

This human-to-human interaction and ability to connect with others is assumed to be diminished or absent in children with autism. Social communication and social interaction are core deficits that are present in children with autism (Sadock, Sadock & Ruiz, 2015). In addition, it may be taken for granted that the *Ubuntu* philosophy inherent in African cultures would provide the child with autism a safe environment where the child’s wellbeing and rights are protected, and where the child will have a sense of belonging. However, there have been reports of children with autism being killed, abused and ostracised across Africa (Cimpric, 2010; Mgbako & Glenn, 2011; Stobart, 2006). In these cases the assumption that these children are witches or possessed by evil spirits have fuelled these atrocities. It is the ethical obligation of people in the helping professions to protect vulnerable children. Protective strategies should include educating communities on autism. In addition, cultural beliefs and practices that are in violation of Human Rights and disregard the Constitution should be punishable by law.

**Epistemology.** Kaphagawani and Malherbe (2002, p.220) define epistemology as “the study of theories about the nature and scope of knowledge, the evaluation of the presuppositions and basis of knowledge, and the scrutiny of knowledge claims.” Grills (2002, p.15) defines epistemology as “a system of truths and a method for revealing or understanding truth or generating knowledge”. In support of these views Ndubisi (2014, p.32) states that epistemology enquires into the “nature, possibility and veracity of human knowledge”.

African epistemology can be regarded as an inclusive epistemology, as it extends beyond logic, linear reasoning and tangible verification as a method of knowledge generation and acquisition (Grills, 2002). Science is not considered the only valid and genuine means of
knowledge acquisition in Africa. Old-age knowledge, mystical knowledge and the oral tradition are also considered important authentic forms of knowledge (Ndubisi, 2014). Firstly, old-age knowledge is knowledge imparted by the elders. The elders are considered more knowledgeable because of their life experiences (Glocke, 2011). The older people become, the less fleshy they are, and the closer they are to the gods. Their closeness to the gods is interpreted as the possession of more divine wisdom (Ndubisi, 2014). Secondly, mystical knowledge is considered privileged knowledge possessed by a few that may include but are not limited to diviners, priests and traditional healers (Croucamp, 2013; Etim, 2013; Stein-Frankle & Stein, 2005; Kamwaria & Katola, 2012). Old-age knowledge and mystical knowledge may provide parents with information regarding the cause of autism as well as the healing practices that should be performed. The third form of knowledge in African cultures is the oral tradition.

The oral tradition is a major form of knowledge acquisition and transmission of knowledge down through the generations, according to the African epistemological paradigm. Examples of this form of knowledge include proverbs, myths, storytelling, folklore, folktales, fairy tales, songs, pithy sayings, rituals and spiritual and religious activities (Ekeke, 2011; Watson, McMahon, Mkhize, Schweitzer & Mpofu, 2011). Song, music, drumming and dance have been found to be beneficial in the treatment of autism (Boso, et al., 2007; Drake, 2010; Edoo, 2013; Madaule, 2003; Neuberger, 2012). The manner in which these treatment modalities are applicable has been explained in Chapter Two under the rubric “Cultural Treatment of Autism”. The five principles that underpin these philosophical assumptions will now be explained.

**Principles of the African worldview.** The principles that underpin the philosophical assumptions have been listed by Akbar, Asante, Myers and Schiele (as cited in Graham, 1999) and can be summed up as follows: (i). the spiritual nature of human beings; (ii).
collective/individual identity and the collective/inclusive nature of family structure; (iii). the value of interpersonal relationships; (iv). the interconnectedness of all things; (v). oneness of mind, body and spirit. These principles are therefore seen as being relational and each principle incorporates part of another principle. These principles encapsulate the relational, spiritual and connected nature of African beings. The spiritual nature of human beings will first be explained because, according to Glocke (2011, p.201):

One’s spirit becomes the guiding factor in the way in which African people gain knowledge (epistemology); choose what to place value on (axiology); decide what is real (ontology) and structure and interpret the universe (cosmology). The African worldview will live on forever through the spirit that never dies.

**The spiritual nature of human beings.** Africans embrace both the physical and spiritual ontologies, and it is the spiritual ontology that makes human beings unique (Glocke, 2011). Spirituality is the essence of all human beings and forms the foundation of the African-centred worldview (Graham, 1999). Nobles (2015) distinguishes “spirituality” as having the quality of “being spiritual” from “spiritness”, which pertains to the condition of being spirit, which is an intrinsic essence. The spiritness of an African is his psychology; it is the core essence of his being that guides him when dealing with life circumstances and existential struggles (Parham & Parham, 2002). It is within this spiritual ontology that the life force is engaged, where the individualised self/ego/mind is lost and where harmony of the collective identity of being one with the source of all good is experienced (Kwate, 2005).

**Collective/individual identity and the collective/inclusive nature of family structure.** The African self cannot be understood separately from other people. Mkhize (2004) explains the rootedness of the self-in-community as evident by the sayings such as “Umuntu ngumuntu ngabantu” (Nguni languages) or “Motho ke motho ka batho babang” (Sotho languages) or “Muthu u bebelwa munwe” (Xhivenda language). These sayings translate to “one becomes a
human being through other human beings.” The self is not a bounded entity defined in terms of a self-contained, independent individual, but rather the self is defined in terms of one’s relationship with others (Kwate, 2005; Mkhize, 2004; Obasi, 2002; Parham & Parham, 2002). According to Owusu-Bempah and Howitt (2000), the African self is not an independent self that becomes known through introspection or that develops against the backdrop of a community. Rather, the African self becomes known in relation to others; the African self finds its expression and identity from the family and the community. According to Glocke (2011), knowledge of the self in relation to one’s community and nation is the most important type of knowledge one gains in one’s lifetime.

Unfortunately, that sense of self-becoming known through relations with others is diminished or absent in the life of an autistic child. Both the world external to the child and the world within the child are discontinuous as the child is unable to integrate information from different sources to form a whole (Madaule, 2003). Therefore, Madaule (2003, p.2) poses the questions, “if we cannot perceive ourselves as a whole, as an entity that makes sense to ourselves, how can we perceive or relate to others as people as our ability to perceive and communicate with ourselves is the starting point for communication with others?” This ability to be self-aware and to communicate and connect with others is important for health and development. The African self comes into being through interpersonal relationships. According to Owusu-Bempah and Howitt (2000), the African concept of self is the place of the individual in a web of interpersonal relationships.

The value of interpersonal relationships. The value of interpersonal relationships is reflected in what Nsamenang (2005, p.3) terms the social or experiential selfhood that starts from the naming ceremony after the child’s birth where the child is incorporated into the human community, and ends with biological death. The child is viewed as part of the community. Being part of a community provides the individual with a sense of social
significance, meaning and belonging, which in turn contributes to the physical, emotional and spiritual wellbeing of the self (Ayuyu, et al., 2015; Juma, 2011; Mpofu, 2006; Obasi, 2002).

Owusu-Bempah and Howitt (2000) are of the view that dissociation of the self from the community culminates in loneliness and isolation for an African, which would be a personal and cultural sense of hell. This explanation could possibly capture the experiences of autistic children as they display an impaired sense of self and are disconnected from others. Isolation and loneliness reinforce the impairments of social communication and social interaction that are typical in children with autism. Owing to these impairments the autistic child’s ability to express his or her needs, wants, thoughts and desires are impeded and, therefore, limit the possibility of initiating and sustaining interpersonal relationships (Stillman, 2006).

Aside from the great value that Africans place on interpersonal relationships, Africans also believe that all things are interconnected.

**The interconnectedness of all things.** Africans believe that all things in the universe are connected ontologically to each other (Ayuya, et al, 2015; Etim, 2013; Grills, 2006; Imafidon, 2012; Mkhize, 2004; Parham & Parham, 2002). Such a belief affirms that there is interdependence, a cosmic unity between all things, from the inanimate to the Supreme Being (Ayuya, et al, 2015; Mkhize, 2004). Akbar (1976) uses the analogy of a spider’s web to explain this unity, interconnectedness and interdependence of the African cosmos. Akbar (1976) explains that touching the smallest element of a spider’s web results in vibrations throughout the web. The smallest element is represented by inanimate objects in the universe and the highest element by the Supreme Being (Grills & Ajei, 2002; Etim, 2013; Jegede, 2002; Imafidon, 2012; Obasi, 2002). Therefore, these connections extend beyond physical beings to include spiritual beings. Mkhize (2004) states that within this dynamic and unified system things are continuously influencing each other. This connection means that when
something goes wrong in one element, it reverberates throughout the cosmos. This interconnectedness of all ontologies means there is oneness in the African cosmos.

The concept of oneness is an all-inclusive unity that also incorporates those not yet born and those who have died, which indicates that all beings are linked spiritually across time and space (Graham, 1999; Grills, 2002; Grills & Ajei, 2002; Holdstock, 2000; Kwate, 2005; Nobles, 2015; Obasi, 2002). It is apparent that the concept of oneness is made possible through a spiritual unity of beings. Oneness also includes the African concept of time, which is regarded as relational, cyclical and continuous (Kwate, 2005; Mkhize, 2004). According to Etim (2013), Western societies emphasise the future and the mathematical division of time, whereas African societies concentrate on the past, present and future. The past refers to the relationship one has with the ancestors (the living dead) and the present refers to the relationships with fellow human beings and nature (Mkhize, 2004). The future refers to those not yet born. The cyclical nature of time is also illustrated with procreation, as children continue the ancestral lineage. Ani (1980) states that having children is very a significant part of African life because it completes the circle of past, present and future. The past is representative of the ancestors, the present represents the parents, and the future is represented by the children.

With respect to autism, the interconnectedness of all things means that nothing happens by chance, and when something does happen it reverberates throughout the cosmos causing the vibrations to be felt at every level of the hierarchy. Autism not only affects the life of the child, but that of the family and the family’s relationship with the ancestors (living dead). Holdstock (2000) describes this relationship as an interdependent and symbiotic relationship where both the living and the living dead aspire to keep each other happy and content. Therefore, in the case of a child with autism from an African background the family may
offer animal sacrifices, perform rituals and burn *impepho* to keep the ancestors happy and content (Madlala, 2012). In so doing, harmony within the cosmos may be restored.

The relational, cyclical and continuous nature of time is illustrated in the belief that autism may be caused by lineage curses (Bakare, et al., 2009b). Such a conceptualisation of autism may repeatedly occur within the same family. Lineage curses could possibly be equated with the genetic link that was mentioned in chapter one.

Lastly, some children with autism have been found to not only have a deeper connection with spirits, but also with animals. Siewertsen, French and Teramoto (2015) report that children are more receptive to stimuli from animals than from humans. Viau, Arsenault-Lapierre, Fecteau, Champagne, Walker and Lupien (2010) found that animals, especially dogs, reduce the stress hormone cortisol in the blood, which in turn reduces the child’s problematic behaviours. Furthermore, it has been shown that children with autism find it easier to develop social bonds with dogs and with time may extend this connection to humans (Davis, et al., 2015). These studies report the benefits of animals in improving symptoms in children with autism. The exact mechanism of action or reasons for these benefits have not been explained scientifically by the Western paradigm. However, from an African epistemological paradigm the mechanism of action can be explained spiritually. The deeper connection that some autistic children have with spirits and animals demonstrates the connectedness and oneness of living systems.

In line with the concepts of oneness, interconnectedness and unity as discussed above is the notion that the mind, body and spirit are one.

**Oneness of mind, body and spirit.** Traditional Western psychology views the mind and body as separate entities. The spiritual part of an individual has not been an area of interest in traditional psychology as attention is mainly given to cognition, emotion and behaviour. The
mind can be studied through thoughts and the body through behaviour. In African psychology, the spirit is the essence of everything in the cosmos, permeating, connecting and uniting entities. The spirit is a stimulating power that moves the mind (Grills, 2006; Obasi, 2002). The spirit cannot be regarded as a scientific construct that can be dissected and researched like behaviour. Therefore, the notion of an invisible spirit does not fit with the notion of psychology as a science. Contrary to the dominant Western worldview, the African worldview does not place division between mind, body and spirit (Graham, 1999). The mind, body and spirit are interrelated and can be regarded as equally valuable and important to the psychological wellbeing of people (Mbiti, 1969; Obasi, 2002). According to Radomsky, Hassane, Hoy-Watkins and Bandawe (2011), wellbeing or wholeness is a reflection of the continuity and harmonious interrelatedness of mind, body and spirit. Being whole means to possess optimal emotional health, physical health, intellectual health, and spiritual health (Mbiti, 1969). Should one of the four areas of health be disturbed, inner peace is compromised and the psychological, social, and physical wellbeing of a person is threatened (Graham, 1999).

Autism is a reflection of the discontinuity and disharmony of mind, body and spirit as it is regarded as an illness. The concept of health or wholeness from an African perspective includes emotional, physical, intellectual and spiritual health. Although children with autism may appear physically normal, their diminished capacity to integrate the external world with their internal world results in inappropriate, repetitive behaviours and poor emotional control. In addition, some autistic children may have intellectual disability (Davis, et al. 2015).

Conclusion

This chapter provided an explanation of the African epistemological framework that informs this research. Any research that claims to be approached from an African perspective
needs to seriously consider the African worldview and African culture (Glocke, 2011). The most appropriate way to understand African culture and Africans’ lived experiences is through the African worldview or African philosophical tradition (Baldwin, 2002). The philosophical assumptions of the African worldview, as well as the principles that underpin these philosophical assumptions have been explained. The principles that recur across the philosophical assumptions are spiritness, unity, interconnectedness, oneness, harmony in relationships, collectivism and an interdependent self that is becoming through relationships with family and the community. The most significant of all, and what makes all the other principles real, possible and true for an African, is the spiritness. The spiritual part has been incorporated into the African understanding of autism, as the cognitive, emotional and behavioural components do not provide a wholistic conceptualisation of autism. For Africans, it is the spiritual that guides one’s thoughts, emotions and behaviour.

The philosophical assumptions of a worldview impact on research methodology within the social sciences (Dixon, 1976; Carroll, 2008). The research approach needs to be consistent with the worldview. Having provided the theoretical exposition on the African worldview and related it to autism, in the next chapter the researcher looks into the methodology used in conducting this research.
CHAPTER FOUR: RESEARCH METHODOLOGY

Introduction

This chapter discusses the research methodology that was used to explore the knowledge, beliefs and practices of African mothers raising a child with autism in the City of Tshwane. The chapter begins with explaining methodology in research. This explanation is followed by the research paradigm, research design, sampling method and data-collection method. The study also addresses the trustworthiness of the study findings. Lastly, ethical issues related to the study are addressed.

Methodology

Terre Blanche, Durrheim and Painter (2006) define research methodology as a practical way for the researcher to investigate a topic of interest. Methodology includes the study methods that can be used to gather knowledge (Rajasekar, Philominathan, & Chinnathambi, 2008). The research method is construed within a particular context and culture. According to Okere (2005), the methods for gathering knowledge arise from a particular experience, culture and epistemology. Therefore, when knowledge and experiences of Africans are being gathered, Western methodology cannot account for and be consistent with this population (Ibhakewanlan & McGrath, 2015). It is on this basis that Baloyi (2008) argues that the research methodology should be consistent with the epistemological paradigm of the people involved. The methodology should be a reflection of the culture and context of the people concerned. According to Milam (1992), research methodologies have inherent paradigmatic assumptions. It is on this basis that in this research the African epistemological paradigm is adopted to be consistent with the cultural experiences of black mothers raising a child with autism.
**Research paradigm.** Harman (1970, p.5) defines a paradigm as “the basic way of perceiving, thinking, valuing and doing associated with a particular vision of reality.” A paradigm defines and establishes boundaries and instructs the type of behaviours permitted within those boundaries (Baker, 1992). According to Capra (1996, p. 6) a paradigm is a group of “concepts, values, perceptions and practices shared by a community and it defines how that community organises itself” Based on this definition, it can be concluded that each and every community and society have a particular paradigm that assists in viewing reality and the world. In the context of inquiry, a paradigm defines the researcher’s nature of enquiry along three dimensions: ontology, epistemology and methodology (Terre-Blanche & Durrheim, 2002).

This study was approached from an African epistemological paradigm. Kuhn (1962) recognised that paradigms are based upon a particular epistemology and research methodology that is reflective of a particular scientific community at a particular time in history. This relationship with time implies that paradigms are dynamic and evolve with time. At the core of African paradigms is ‘Afrocentricity’ (Milam, 1992; Mkabela, 2005). Afrocentricity is a paradigm that is aimed at understanding African identity as rooted, centred and located in the African culture in all aspects – spiritual, social, political and economic (Owusu-Ansah & Mji, 2013). In the context of this study, Afrocentricity centres mothers’ experiences of raising a child with autism within the African cultural context.

This paradigm emphasises that African IKSs should be a central consideration and valued in research carried out in Africa (Asante, 1987; Muwanga-Zake, 2010). Research involving Africans should be grounded in African value systems, methodologies and environments that are characteristic of African culture. The location of research in African culture and methodologies enables the involvement of Africans in all aspects and stages of the research process, from the beginning to the end (Muwanga-Zake, 2010). This
involvement means that there is no distinction or distance between the ‘knower’ and the ‘known’, the researcher and the researched (Carroll, 2008; Dunbar, 2008; Du Plessis & Raza 2004; Milam, 1992). Following this lack of distinction, research becomes a collective practice between the researcher and the participants (Emeagwali, 2003). From the African paradigm participants are not labelled as objects or informants but they are viewed as humans and subjects of their experiences (Mkabela, 2005). Alternatively, these subjects can be regarded as non-academic researchers (Ibhakewanlan & McGrath, 2015).

The location of research in African culture and methodology permits indigenous research to break free from Western epistemology that is foreign to indigenous ways of thinking (Smith, 2012). It is only then that research can be useful, ethical, respectful and beneficial to colonised people (Smith, 2012; Wiredu, 1998). Dunbar (2008) argues that when researchers use Western research methods with indigenous people, they slowly erase the knowledge, experiences, culture and language of those being researched. Therefore, the research paradigm that is used should be consistent with the worldview of the population that is being researched. Within a research paradigm there are various research designs that can be used in a study.

**Research design.** Creswell (2009) defines a research design as the plan and procedures for research. It is based on the nature of the research problem, the researcher’s personal experiences and the audiences for the study (Creswell, 2009). A research design plans and structures the data collection and data analysis. The research design also includes the exact techniques that will be used, such as the type of sampling, sampling techniques, method of inquiry and method of analysing the material (Appel, 2010). The researcher adhered to a qualitative, narrative approach as the interest was in exploring parental conceptualisations, beliefs and practices regarding autism. According to Lyons, Bike, Johnson and Bethea (2012) the use of qualitative inquiry is symbiotic with the African worldview, offers the opportunity
to honour African culture, and the values espoused by African culture guides each aspect of the research process.

**Qualitative research approach.** According to Creswell (2009), qualitative research is an inquiry process of understanding a social or human problem based on building a complex, holistic picture formed with words. The research is conducted in a natural setting with the aim of helping people to understand the world they live in and why things are the way they are. In qualitative research, the researcher is an integral part of the investigation (Golafshani, 2003; Lyons, Bike, Johnson & Bethea, 2012). The researcher and the participant mutually influence each other during the research process, as both are knowledge bearers. The researcher makes use of open-ended questions in order to explore and understand social problems holistically. In this study, the role of the researcher was to understand and take note of how mothers subjectively experience raising a child with autism, as well as what the mothers’ explanation for those experiences is.

According to Muwanga-Zake (2010), qualitative research is both observational and narrative in nature and relies less on experimental elements such as reliability, validity and generalisability, which are normally associated with scientific research. Dunbar (2008) asserts that the use of narratives challenges the traditional meritocratic paradigm that is rooted in science, objectivity and neutrality.

**Narrative inquiry.** Narratives are considered to be the spoken or written account of connected experiences (Moen, 2006). The researched is given a voice such that her position changes from the object of research to contributor to research (Dunbar, 2008; Ibhakewanlan & McGrath, 2015). A narrative describes a people’s identity, context and knowledge systems. Elbaz-Luwisch (2005) views narratives as collective stories that are shaped by the cultural, historical and institutional settings in which they occur. According to Thomas (2005) a story
is holistic in nature; it provides the means for sharing remembrances that evoke spiritual, emotional, physical, and mental processes.

A narrative inquiry is situated within the qualitative research approach (Gudmundsdottir, 2001). Therefore, narrative research is a form of inquiry in which the researcher studies the lives of individuals and asks one or more individuals to provide stories about their lives. This information is then retold by the researcher in a narrative chronology (Clandinin & Connelly, 2000). Moen (2006) maintains that narrative inquiry focuses on how individuals assign meaning to their experiences through the stories they tell. According to Moen (2006), meaning and understanding cannot be transferred from one person to the next; rather, they are created when voices engage in dialogue with each other. Therefore, during narrative inquiry the researcher and the research subjects work together in a collaborative dialogic relationship to create meaning. In support of this view, Bishop (1999) maintains that the researcher during story telling is positioned as a participant. This is because both the storyteller and the researcher engage in a collaborative relationship to create meaning as the stories are shared.

Narrative inquiry allows authentic communication of IKSs in the research process and outcomes (Muwanga-Zake, 2010). Through the use of narratives, this research explored how African mothers make sense of their reality and experiences. Their reality and experiences include raising a child with autism. Narrative inquiry is an appropriate design as it is a model of contextualism, meaning making, providing access to truths and realities, and enabling human experiences to be seen as socially positioned and culturally grounded (Hiles & Čermák, 2008). These factors are in line with the Afrocentricity paradigm.

An explanation on the research paradigm and design having been provided, the manner in which the study was conducted will now be explained.
Study setting. This study was conducted in the City of Tshwane, located in the Gauteng Province, South Africa. There are various areas within the City of Tshwane. These areas include Pretoria Central, Pretoria North, Pretoria East, Pretoria West and the suburbs that constitute Centurion. Tshwane is a heterogeneous city as it accommodates people from different backgrounds, cultures, ethnicities and demographics. However, this study targeted a specific population within Tshwane.

Target population and sample. A population can be defined as a “totality of all the objects, subjects or members that conform to a set of specifications” (Polit & Hungler, 1999, p. 37). The participants were selected from the population of South African Black mothers who are raising a child with autism and residing in any area of the City of Tshwane. Only mothers whose children had a definitive diagnosis of autism and aged six years and older were included in the study. The reason for this age group is because these children were more likely to be attending school. In addition, the literature indicates that there is a possibility of autistic children receiving a late diagnosis in Africa (Bakare and Munir, 2011b; Nyarambi, Enwefa & Enwefa, 2011). Therefore, it might have proved difficult to access mothers of autistic children younger than age six.

The study excluded mothers belonging to the White, Coloured and Indian racial groups. Mothers whose children did not reside with them were also excluded from the study. Mothers whose children were suspected of having autism but had not yet been diagnosed were also excluded from the study. Furthermore, mothers of children younger than six years of age were excluded from the study. The inclusion and exclusion criteria informed the sampling technique.

Sampling. A purposive sampling technique was used to select the participants. Purposive sampling is almost always the means of sampling where qualitative methods are used (Babbie, Mouton, Vorster, Prezesky, 2001; de Vos, Strydom, Fouché & Delport, 2005).
Purposive sampling is when the researcher intentionally selects who to include in the study (Bless & Higson-Smith, 2000). The study included six Black South African mothers raising children with autism. The mothers’ ages ranged from 31 to 44 years. The ages of their children ranged from 7 to 12 years. Most of the children were boys, with the exception of one child. Owing to the qualitative nature of this study, a sample of six was deemed adequate. An abundance of research participants is not necessarily required to make a qualitative study authentic (Joubish, Khurram, Ahmed, Fatima & Haider, 2011).

Table 1 illustrates the biographical data of the mothers involved in the conversations, as well as information about their children. Owing to the sensitive nature of the study and the ethical responsibility to protect participants, the exact places of residence were omitted. In addition, each mother was assigned a number. For example, M 1 refers to the first mother that participated in this study.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Biographical Information of Mother and Child</th>
</tr>
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<tbody>
<tr>
<td>Participant</td>
<td>Age</td>
</tr>
<tr>
<td>M 1</td>
<td>36</td>
</tr>
<tr>
<td>M 2</td>
<td>44</td>
</tr>
<tr>
<td>M 3</td>
<td>31</td>
</tr>
<tr>
<td>M 4</td>
<td>38</td>
</tr>
<tr>
<td>M 5</td>
<td>37</td>
</tr>
<tr>
<td>M 6</td>
<td>31</td>
</tr>
</tbody>
</table>
Sampling procedure. After approval of the research proposal by the Sefako Makgatho University Research Ethics Committee (SMUREC) the researcher obtained telephonic consent from the two gatekeepers. The gatekeepers were two African mothers who are both raising children with autism, and both are known to the researcher. These gatekeepers also participated in the study. It is at this time that written consent was obtained for being a gatekeeper (Appendix A) and a participant (Appendix B). Following these telephonic conversations, there were challenges in obtaining additional mothers from the gatekeepers. Therefore, other means of obtaining participants were sought.

The researcher approached one fellow researcher at Sefako Makgatho Health Sciences University and shared with her the challenges encountered with the gatekeepers. During this conversation, one researcher shared some information about a mother she knew personally who was raising a child with autism. The researcher then informed the potential participant about the study intentions and asked if she would be interested in participating in the study. The mother agreed, and her contact details were then provided to the researcher. The mother was contacted telephonically and the study aims were explained. The mother agreed to participate and she informed the researcher of the date and time that she would be available for the conversation.

Following this conversation, the researcher asked the mother whether she knew of any other mother/s raising a child with autism. This is how all the other remaining mothers were contacted. When these mothers were contacted the aims and objectives of the study were explained prior to the meeting. The mothers also informed the researcher about the venue, date and time of availability for the conversation.

Data collection method. For most indigenous Africans, narratives are expressed in an oral form. It is on this basis that conversation was used as the method of data collection. The conversational method is of significance to indigenous methodologies as it is a method of
gathering knowledge based on the oral (storytelling) tradition and it is congruent with an indigenous paradigm (Dyer, Jones, Rowland & Zweifel, 2016; Kovach, 2010).

The conversation method focuses on the verbal and nonverbal communicative practices which people recurrently use in interacting with one another (Drew, Chatwin & Collins, 2001). The verbal and the nonverbal behaviour influence the dynamic process through which connected sequences of actions are built up. What a participant says and does is generated by, and is dependent upon, what the researcher has said and done, and vice versa. Through conversation the participant and the researcher are able to produce meaning. Lave and Wegner (1991) maintain that conversation is a meaning-making process. Conversations assist with exchanging knowledge and generating understanding (Feldman, 1999). A conversation allows the researcher and the participant to both engage in a collaborative and creative process where they talk, listen, reflect upon and respond to each other. During this process new understanding emerges. Both the researcher and the participant enter into a conversation to seek connection as human beings. In addition, during the conversation learning takes place (Dyer, Jones, Rowland & Zweifel, 2016; Feldman, 1999). The conversation method necessitated the use of certain data-collection tools.

**Additional tools.** A voice recorder was used to record the conversations. In addition, a narrative guide was used as a guideline for the conversation (Appendix C). The narrative guide included biographical information of the mothers and children; such as age of the child, culture and religion. Additional biographical information included place of residence, age of the mother, marital status and employment status. Nonverbal behaviour was also observed and recorded in a notebook.

**The process for collecting data.** Data was collected from January to June 2016. All conversations took place at the mother’s home. This environment was selected by the mothers because it was convenient, comfortable and private for them. Hoyt and Bhati (2007)
state that collecting data where the behaviours of interest are likely to occur provides the researcher with a sense of the lived experiences of the participants.

On meeting the mothers in their respective homes, the researcher re-introduced herself and repeated the aim and objectives of the study that were previously explained telephonically. The consent form was also discussed and the participants were invited to ask questions before beginning the conversation. Thereafter, the conversation started by the researcher inviting the mother to discuss her background, which included the biographical information mentioned above. This invitation was given to put the mother at ease and to obtain background and contextual information pertaining to her child’s difficulties. Before ending the conversation the participant was invited to add any information that she felt may have been left out. The mother was also afforded the opportunity to again questions ask. The conversation was then ready to be analysed.

**Data analysis.** Prior to analysing the data, the researcher transcribed the audio material into text. After transcription, thematic analysis was used to analyse the conversation, induce themes and extract meaning. According to Braun and Clarke (2006), thematic analysis is a flexible and versatile method of analysing qualitative data. It is important to note that thematic analysis is not a linear process, but a recursive one (Braun & Clarke, 2006). To analyse participants’ narratives several steps were followed. These steps are as follows:

**Step 1: Familiarisation and immersion.** The raw transcript was read several times in order to obtain a clear picture of the context and the mothers’ stories as a whole (Braun & Clarke, 2006; Hiles & Čermák, 2008). The raw transcript was cross-checked with the audio recording to ensure that the content corresponded.

**Step 2: Coding.** During this phase, a list of initial ideas of interest were coded. These codes are the basic segments of the raw data that can be assessed in a meaningful way with
respect to the phenomenon under investigation (Braun & Clarke, 2006). The researcher marked the various sections of the data from phrases, lines, ideas and events considered as being interesting or relevant to the objectives of the study.

**Step 3: Inducing themes.** The third phase entailed collating and sorting all the codes into potential themes (Braun & Clarke, 2006; Hiles & Čermák, 2008). A theme captures something important about the data in relation to the research question (Braun & Clarke, 2006; Frost, 2011). Identification of a theme is not dependent on the frequency of specific items but rather the relevance and importance of the items, which are determined by the researcher. The researcher has to bear in mind the theoretical framework and objectives of the research (Braun & Clarke, 2006; Frost, 2011). The different codes were organised and sorted into main themes and sub-themes (Braun & Clarke, 2006).

**Step 4: Reviewing themes.** The fourth phase entailed organising, reviewing and refining all the themes so that each theme was coherent and had sufficient data to support it (Braun & Clarke, 2006). The themes should be distinct. The themes that emerged frequently were collapsed into one theme. The raw data was read again in order to see if there were any additional data that needed to be coded within the existing themes or any data that may have been initially overlooked. Data extracts that did not fit into an existing theme, which did not combine to form a new theme or did not relate to the overall meanings within the data set were discarded. During this stage the researcher kept “coding, elaborating and recoding until no further new insights appeared to emerge” (Terre Blanche & Durrheim, 2002. p. 91).

**Step 5: Defining and naming the themes.** Once all the themes were refined a thematic map was generated. All the themes in this map were defined and named (Braun & Clarke, 2006). All the themes and sub-themes that were generated are identified and discussed in the next chapter. All these themes have an accompanying narrative without resorting to paraphrasing the content of the transcript.
**Step 6: Writing a report.** The sixth and final phase necessitated a write-up of the story of the transcript in a manner that exhibits the merit of the information and the analysis of that information (Braun & Clarke, 2006). The merit of the information is termed “trustworthiness”.

**Trustworthiness.** There are four criteria that were considered in pursuit of a trustworthy and academically sound qualitative study (Morrow, 2005; Shenton, 2004). These four criteria are transferability, credibility, confirmability and dependability.

**Transferability.** According to Merriam (1998, p.39), transferability is “concerned with the extent to which the findings of one study can be applied to other situations.” The results of this study are not generalisable to other contexts, or even to people that may have similar socio-demographics or similar experiences. This was a qualitative study using a very small sample where participants spoke about their personal experiences. Although this study involved a small number of mothers, the narratives produced rich data.

**Credibility.** Credibility refers to the manner in which rigour is ensured during the research process and then the manner in communicating how it was achieved (Morrow, 2005). Shenton (2004) succinctly states that credibility is congruence of the findings with reality. The researcher ensured credibility of the research process through documentation, reflexivity, the use of well-established research methods, triangulation, debriefing with the researcher’s supervisor and member checks.

The researcher provided an inclusive and comprehensive account of the research process. Linked to documentation of actions is reflexivity. Personal reflexive considerations that were documented were: how the researcher’s experiences of and beliefs about autism shaped the research; how the research process affected the researcher; and whether or not changes were evident. The researcher will reflect on the impact of each interview on the
researcher, as well as the researcher’s impressions of the patterns that began to emerge from these interactions. Epistemological reflexive considerations are also documented.

Epistemological reflections require that the researcher reflect on her assumptions about knowledge in order to ascertain whether the research question limited what could be found from mothers’ interpretations and experiences. The researcher also reflects on whether or not the phenomena could have been explored differently and, if so, what implications would that have for the findings. For example, a change in the research design and method of data analysis would mean that the results would be constructed differently. The method of analysis is a contentious issue for the researcher as it is rooted in the empirical mind-set. All these reflections are discussed in more detail in Chapter Six, which addresses reflexivity.

In terms of the research methods, conversations and the use of thematic analysis are well-established data-gathering- and data-analysis methods in qualitative research respectively (Braun & Clarke, 2006). In addition, the line of questioning adequately addresses the aims and objectives of the study.

Triangulation at the level of data collection enhanced the understanding of the data. The researcher recorded all the interviews, observed nonverbal behaviour and, in one case, a mother permitted the researcher to review a medical report.

Debriefing in the form of research supervision is important as the research supervisor can draw attention to any flaws in the proposed course of action. Debriefing assisted me to become aware of misinterpretations or any biases I had. In essence, the supervisor acted as a sounding board for the researcher to bounce ideas off and then incorporated that feedback to ensure authenticity of the research process.

Member checks also aided in enhancing the credibility of the research. Participants were allowed to read the transcripts and/or listen to the tape recordings to ensure accuracy of
the information. Participants checked if their words matched what they actually intended to mean, and the mothers were permitted to delete, change and/or add anything that they had forgotten or felt was relevant. In research that adopts an Afrocentric paradigm the participants are regarded as the final empirical authority (Asante, 1990). Therefore, member checks are a crucial step in the research process.

Lastly, participants were genuinely willing to participate in the study. A genuine willingness would imply that the participant would be more likely to engage honestly.

**Confirmability.** Confirmability refers to the accuracy of the results in relation to the actual phenomena under investigation (Morrow, 2005). The findings should be a representation of participants’ realities and not the researcher’s biases (Shenton, 2004). Confirmability was addressed through participant validation and co-analysis of the data. Reflexivity as discussed under credibility is also important in enhancing confirmability.

The researcher made an appointment with the mothers after data analysis in order for the mothers to “validate” the findings. This meeting demonstrates ethical responsibility and sensitivity to the different realities that people possess. Differences in the participants’ interpretations and those of the researcher highlight our multiple realities and should not be disregarded. Morrow (2005) states that there are no “true” knowers and that differences are an elaboration of the emerging findings and should be treated as additional data. Willig (2008) maintains that participant validation is not a requirement. However, if participant validation is carried out it constitutes good qualitative research.

Lastly, the researcher requested another researcher who is familiar with thematic data analysis to analyse the data to rule out any errors.

**Dependability.** According to Morrow (2005), the manner in which a study is conducted should be consistent across time, researchers and analysis techniques. Researchers should
strive to enable a future investigator to repeat the study (Shenton, 2004). This is not a simple task in qualitative research. Shenton (2004) argues that if credibility is demonstrated it ensures some degree of dependability as the two criteria go hand in hand.

Dependability was enhanced by the researcher being explicit and detailed about the process in which the findings were derived. Each step was clearly stated to enable another researcher to repeat the research process is the same manner.

Closely linked to the trustworthiness of the information are the researcher’s ethical considerations.

Ethical considerations. Before carrying out the study, approval of the research proposal was sought from the Sefako Makgatho University Research Ethics and Committee (SMUREC). Approval was granted by the issuing of a clearance certificate. (See Appendix D)

Informed consent was also obtained from the mothers before the conversation began (Appendix B). The participants were informed about the nature of the study and given a clear explanation of what was expected of them in the research. Participants were also informed that participation was voluntary and they had the right to withdraw from the study at any time without having to give a reason. Participants were also informed of the sound recordings, and agreed for the conversation to be recorded for the purpose of transcription, followed by analysis.

In addition to obtaining consent from the participants, the researcher ensured confidentiality and anonymity. The researcher protected the participants’ identity by using pseudonyms. All the information that was obtained from the participants was stored in a secure place and is accessible and available to the mothers and research supervisor on request.
A crucial ethical principle that should be adhered to is that of non-maleficence (Terre Blanche & Durrheim, 2002). According to this principle the researcher should ensure that no participant is exposed to harm. The researcher was aware that mothers might become emotional when talking about their children’s impairments. Therefore, the skills learned as a student clinical psychologist in training were required to contain the mothers. This need arose with one mother and the audio recorder was switched off. After containing the mother, she agreed for the conversation to be continued. The researcher also utilised her clinical judgment with respect to referral for psychotherapy following the conversation. None of the mothers expressed this need. In addition, all participants were treated with courtesy, respect and professionalism (Terre Blanche & Durrheim, 2002). This conduct is echoed by Ramose (2005) who stresses the importance of treating others with a humane, polite and respectful attitude. This is consistent with the philosophy of Ubuntu. Similarly, Smith (2012) states that research ethics extends far beyond the issues of consent and confidentiality discussed above, but requires a researcher to be humble, respectful and be willing to listen and learn.

The ethical ideal of beneficence was partially achieved. Dunbar (2008) states that indigenous people have been researched extensively, the results obtained incorrectly interpreted, and the benefits being for the researcher and not those being researched. In this study, the use of Afrocentricity places African ideals at the centre, in this way ensuring that the participants were the beneficiaries of the study. This study was conducted with the hope of providing useful information that would enhance the body of knowledge in autism from an African epistemological paradigm. Throughout the research process the researcher maintained communication with the participants, feedback was always provided in terms of progress, and interpretations checked by the participants to ensure accuracy of the information. The collaboration, cooperation and collective responsibility between the researcher and the mothers captured the African axiology. There is no denying that the
process was meticulous and drawn out. However, this attention to detail and the continuous collaboration with the mothers enhanced the trustworthiness of the findings. The researcher also felt that it was an ethical obligation that needed to be adhered to. The researcher’s openness and fairness with regard to her conduct, the design chosen, the collective nature of both data collection and data clarification are all in line with the Afrocentric paradigm that stresses that research should be undertaken not for the benefit of the researcher but for the participants (Asante, 1990).

Research is beneficial to participants when it values their knowledge, experiences and culture. The researcher earlier mentioned that this principle was not completely achieved. The use of the English language during the conversations attenuated the degree of beneficence. English is the dominant language used to impart knowledge, and yet it is not the mother tongue of the majority of the South African population. Therefore English was not the mother tongue of the mothers in the research. This limitation will be discussed in Chapter Six as part of the researcher’s reflections on the importance of language in research.

**Conclusion**

This chapter explored the Afrocentric research paradigm, qualitative narrative inquiry and the conversational data-collection method as applied to capture the knowledge, beliefs and practices of African mothers raising a child with autism in the City of Tshwane. The process of thematic analysis was explained sequentially. The actions that were taken to ensure trustworthiness were also discussed. Lastly, the ethical considerations and the manner in which the researcher adhered to these were explained. The next chapter presents and discusses the findings that were generated from the conversations.
CHAPTER FIVE: RESULTS

Introduction

This chapter will present the results and discussion of the knowledge, beliefs and practices of mothers raising a child with autism in the City of Tshwane. Literature will be used to either support or contradict these results. Six black mothers participated in this study. For simplicity and to avoid any breach in confidentiality, the mothers will be represented by a number. For example, the first mother is referred to as M1, and this format is followed through until the last and sixth mother, who is referred to as M6. In the event where a mother mentioned her child’s name, a pseudonym will be used to replace the child’s real name. An asterisk is placed in front of the child’s name to indicate that a pseudonym is used.

Prior to introducing the themes that were induced in this study, a brief history of the mother and child is provided. The background will be presented under the following subheadings: birth order, mode of delivery, maternal age at delivery, and autism and siblings. These factors are then compared with literature to ascertain whether they present risk factors for autism.

Brief History of the Mother and Child

Birth order. Most of the children in this study are firstborns. This observation is consistent with Glasson et al. (2004) who reported an increased risk of autism among firstborn children. However, the relationship between birth order and autism risk is not conclusive. Turner, Pihur and Chakravarti (2011) found linear effects, where risk increased with each additional birth. However, Gustafson (2010) found extremely low and non-significant correlations between birth order and the risk of autism.
**Mode of delivery.** Most of the mothers reported that they gave birth by caesarean section. This is evident in the following excerpts:

*M3:* “I had a c-section because he couldn’t be delivered normally as he was breeched”.

*M4:* “I chose the day (laughing). I was lucky enough, they said I could choose any day this week because it was it was a c-section”.

A caesarean section is abdominal surgery performed to deliver the infant. According to Verdult (2009), a caesarean birth has long term negative consequences for the infant. Following caesarean delivery the infant may show lower glucose levels, lower body temperature, respiratory problems, lower calcium and protein, and less stimulation of the nervous system. These post-delivery signs have shown to increase the risk of food allergies and autism (Verdult, 2009). The literature maintains that a caesarean section may be a risk factor for autism (Baltus-Herbert & Koulouglioti, 2010; Glasson et al., 2004).

**Maternal age at delivery.** The mothers in this study had their children at ages ranging from 23 to 32 years (see Table 1, Biographical Information of Mother and Child). There is a relationship between maternal age during pregnancy and the risk of autism. According to Croen, Grether and Selvin (2002), increasing maternal age is a risk factor for autism. Similarly, Sandin et al. (2012) found that there is a higher risk for autism in the offspring of mothers aged 35 or older. Furthermore, Durkin et al. (2008) found that offspring of older mothers (over 40) are more likely to develop autism than offspring of younger mothers (between 20-34 ages). The observation noted in this study is contrary to that of the literature.

**Autism and siblings.** All the mothers indicated that there were no developmental concerns with their other children. None of the siblings of the autistic child displayed autistic symptoms. However, various literature indicates that there is a genetic link to autism (Adams,
Lauritsen, Pedersen, and Mortensen (2005) found that siblings of children with autism were 22 percent more likely to be diagnosed with autism.

**Developmental milestones.** There are various developmental milestones that a child is expected to achieve by a certain age. These may include holding the head up, sitting independently, crawling, walking, potty training and talking. It is important to consider the culture of both the person who is interpreting developmental milestones, and the culture of the child who is being assessed. Nsamenang (2005, p.3) maintains that “every culture recognizes and assigns different developmental tasks to their perceived phases of human ontogenesis”. Therefore Western theories of childhood development may not be applicable to all people of all cultures.

The developmental milestone that alerted the mothers that something may be wrong, was language delay. According to Heidgerken et al. (2005), language delay is the common descriptor for the diagnosis of autism. This is evidenced in the following excerpts:

*M2:* “What surprises me is that the other milestones he achieved on time. Like sitting, crawling and even walking. But it was the speech that was a problem, so when he was 3 and a half years and he wasn’t verbal, now I began to worry”.

*M5:* “His speech was delayed. This we noticed just after his second birthday”.

Language is the primary mode of communication in most cultures. Language provides a communicative interaction between the child and their environment. According to Tamis-LeMonda and Rodriguez (2014), language enables children to share meanings with others and to learn their cultural ways. Therefore, language delay may impair all levels of the child’s social interaction (van Kleeck & Richardson, 1988). Social interaction is impaired as
the child may have difficulty expressing their needs and others may not be able to initiate appropriate responses due to a lack of understanding.

Having provided a background history of the mother and child, the themes that were induced are now presented. The themes represent the experiences of mothers and their children.

**Theme 1: Cultural interpretation of language delay**

As noted, the developmental milestone that was delayed was speech. In this study, the cultural interpretation of language delay related to gender differences and environmental factors.

**Subtheme 1: Gender differences.** The expectations that mothers have for their children are dependent on the knowledge gained through the mothers’ experiences. This knowledge is then passed down from generation to generation. The effect of knowledge gained through cultural experiences is demonstrated when M2 said:

“*My mother said boys are slow. Because I remember my daughter was already speaking when she was two. Girls are quicker*”.

This response indicates that girls are expected to reach their developmental milestones earlier than boys. Similarly, Daley and Sigman (2002) found that Indian boys acquire language later than girls. In contrast, a study by Carter et al. (2007) conducted in the USA found that language delay is more evident in girls than in boys.

**Subtheme 2: Environmental factors and language delay.** The environment plays a crucial role in a child’s development. There are environmental factors that can either hinder or stimulate optimal development in a child. For example, a context that does not encourage social interaction, expression of emotion and knowledge acquisition is disadvantageous for
the child (Tamis-LeMonda & Rodriguez, 2014). Social interaction, verbalisation of emotion and knowledge acquisition all require language. According to M4:

“I decided eish, maybe she’s not getting a lot of stimulation here at home because there are no kids that she’s playing with. So let her go and play at the crèche maybe the speech will pick up from then”.

This response indicates that peer interaction in a mainstream educational setting may promote development in general and language development in particular. This is supported by van Kleeck and Richardson (1988) who found that children with language delay who are placed in a special educational setting may have little opportunity to develop their language skills as their peers are also mute. It is acknowledged that mainstream schooling is not always possible for children who are severely autistic. Therefore, it is suggested that parents arrange small playgroups to increase opportunities to learn social behaviour from ‘normally’ developing peers. M6 added that:

“My brother-in-law’s wife suggested we take my son home, to Venda, so that he can play with kids who are only speaking one language. She thought maybe that was (laughing) the reason. Yeah so we took him home for three months”

The Child Assessment Service, Department of Health [HKSAR] in Hong Kong (2008) encourages parents to refrain from speaking multiple languages during the early stages of child development as this may confuse the child. It is believed that a young child exposed to multiple languages may need more time to comprehend a language that is not their first or home language. In contrast, Cummins (1980) reports that bilingualism does not cause language delay.
Although mothers took initiatives to stimulate language development in their children, there was still no change. Instead, additional symptoms started to manifest. This is supported by M2 when she said:

“He was approaching his 4\textsuperscript{th} birthday and started having erratic mood swings. He started being disruptive, aggressive and violent. There was a time when he would be agitated at the malls by many people and then he would want us to come home. If we didn’t come back home he would even take off his clothes and roll on the floor and hit other people”.

M1 added that:

“He cries as if he is scared of something. He runs looking back as if somebody is chasing him. He has nightmares and is forever scared. He runs to hide under the table, he doesn’t want to play with other kids, and he’s weird. So I didn’t understand what was wrong with him”.

The language delay coupled with these additional symptoms prompted mothers to consult a health professional with the hope that they will gain insight into the child’s behaviour.

**Theme 2: Journey to diagnosis**

The journey to diagnosis started with mothers consulting paediatricians. Paediatricians are specialist doctors dealing with infant and child health issues. Consultation with a paediatrician was noted when M6 said:

“We took him to a paediatrician. The paediatrician asked me about his developmental milestones and observed his behaviour during the consultation. He
suspected autism. *The paediatrician then suggested that we take our son to see a professor in Johannesburg who is an expert in autism*.

According to Aluri and Karanth (2002), once the paediatrician has been consulted other professionals such as psychologists, occupational therapists, speech and language pathologists, and special educators may also be consulted. This is evidenced in the following excerpts:

*M1*: “*So we took Jabulani to a specialist. The first test that was done was a hearing test. They said his ears are fine, 100%*”.

*M5*: “*We took him to a place called the Baby Therapy Centre in Lynnwood where he had an assessment by an occupational therapist and physiotherapist. Then later he was seen by a paediatric neurologist. And then she confirmed that it is autism*”.

The journey to diagnosis may be a lengthy process. Not only is there the necessity to rule out other disorders, but the availability of super-specialists, like paediatric neurologists or child psychiatrists, are limited. This was expressed by M6 when she said:

*“We had to wait six months for an appointment. On the day of the appointment the professor observed Rophiwa and she told us on that same day that it was autism”.*

There is a plethora of research highlighting that few healthcare workers possess specialized training and knowledge of autism (Bakare, et al., 2009a; Bakare & Munir, 2011a; Brookman-Frazee, et al., 2012; Daley & Sigman, 2002; Heidegerken, Geffken, 2005; Igwe, Ahanotu, Bakare, Achor & Igwe, 2011; Rahbar, Ibrahim & Assassi, 2011). These deficits in healthcare increase the likelihood of autism being misdiagnosed (Farrugia, 2009; Foster,
The experience of misdiagnosis was experienced by M2:

“He was five and a half years old when he was correctly diagnosed. All along they said it was ADHD. And then he was put on Ritalin. I don’t think doctors themselves understand it very well”.

According to Jepson (2007) and Mori, Ujiie, Smith and Howlin (2009), autistic children may have comorbid health and behavioural issues such attention deficit-hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), sleep disturbance, seizure disorder, gastrointestinal problems, food allergies and hypersensitivity. Mandell, et al. (2009) propose that professionals should continuously educate themselves with regards to the heterogeneity of the presentation of autism. In addition, a thorough history of the child’s development and behaviour should be taken in order to reach an accurate diagnosis (Dzubays, 2011).

M2 stated that because of the misdiagnosis she does not have confidence in the diagnostic process as indicated by the following comment:

“Most of the times they misdiagnose it, and I think it is because of the diagnostic tools which I think may be inadequate. As Africans we don’t have confidence in the diagnostic tools used for testing for autism”.

This response indicates that caution should be exercised when using diagnostic tools on populations in which these diagnostic tools were not standardised (Nyarambi, Enwefa & Enwefa, 2011). Diagnostic tools cannot be applicable to all people of all cultures. Culture provides an interpretive framework for the experience and expression of the symptoms, signs, and behaviours that are criteria for diagnosis (DSM-V, 2013). Therefore, autism should be defined and diagnosed in relation to cultural, social, and familial norms and values.
It can be concluded from this theme that the journey to diagnosis of autism is not a clear-cut and straightforward process, but may be a long and tedious one.

**Theme 3: Communicating the diagnosis to parents**

According to Hughes (2003) sometimes professionals may be insensitive to parents’ feelings when communicating information which concerns their child’s health. This was expressed by M1 and M3 when they said:

*M1*: “She was just so formal with it. She said, ‘There is nothing you can do about this disease. It’s like this, you are going to give medication. It’s gonna be like this. That’s the way it is’. That’s what she said. She was not sympathetic like she was feeling for our fears or what. Just like that. There’s the medication; go and try it with him. No further explanation was provided”.

*M3*: “The doctor didn’t go much into autism. All I remember being told is Risperdal”.

These responses suggest that there was no emotional sensitivity and empathy displayed by the health professional. According to Rogers (1961), a health professional should display empathy when interacting with a client. When empathy is expressed it promotes communication, the formation of an alliance and agreement of therapeutic goals (Maroda, 2010). Once all of these have been achieved, the patient is more likely to buy into the proposed interventions. Should empathy not be shown, negative reactions may be exhibited.

**Theme 4: Mothers’ reactions to autism diagnosis**

After receiving the diagnosis, mothers may have different reactions to the news. According to Bashir, Bashir, Lone and Ahmad (2014), mothers appear to be more affected as
compared to fathers. These reactions differ from person to person (Gibson, 2004). The following were the identified emotional reactions of the mothers: confusion and frustration, sadness, blame and hopelessness.

**Subtheme 1: Confusion and frustration.** Matenge (2014) conducted a study to explore the lived experiences of mothers raising a child with autism in Cape Town, South Africa. It was found that mothers experienced on-going confusion regarding the diagnosis of autism. Similarly, M1 reported the following upon hearing the diagnosis,

“It was confusing because I didn’t know if one day he'd be fine. Will this child scream everyday? I didn’t know what will happen to him”.

This confusion is exacerbated by the absence of a definitive cause (Mansell & Morris, 2004).

**Subtheme 2: Sadness.** Another reaction which was reported is sadness. According to Gupta and Singhal (2005) and Meadan, Halle and Ebata (2010), sadness is a common feeling expressed by parents upon hearing the child’s diagnosis. This is supported by M6 who stated:

“I was so emotional and heartbroken when I heard the news”

According to Olson (2010), what saddens the mothers is the possibility of their child not being able to live a normal life. Mansell and Morris (2004) maintain that most parents find the news about the diagnosis upsetting as they begin to anticipate the consequences for their lives.

**Subtheme 3: Blame.** Olson (2010) states that guilt is one of the common emotions that parents experience after hearing their child has been diagnosed with autism. Mothers may blame themselves for their child’s diagnosis (Olson, 2010). Willis (2006) maintains that self-blame is a common reaction experienced by mothers after receiving the diagnosis of
autism. Mothers may feel that they have done something wrong during pregnancy that caused the child to have autism. Self-blame was observed when M4 said:

“\textit{You know I tried to look for reasons. I couldn’t…it’s like… I thought there’s something wrong that I have done. Like you know there’s all these things you are not supposed to do when you are pregnant. But there’s nothing I can say. Everything I went by the book. It was my first child. I didn’t drink coke, I didn’t drink sprite. I gave up everything but I was eating grapes, a lot. I love grapes”}.

Mothers may also blame others for their child’s diagnosis. This is evidenced from M3 when she said:

“\textit{If he was put in an incubator it could have been prevented. Because from the time he was born to the time he was diagnosed… it would have been worse if I hadn’t spoken to that woman (the nurse). I mean he was getting blue. I mean immediately after birth if they had put him in an incubator or if they had given him oxygen, I would like to think that he would have been better. I think it could have been prevented”}.

Similarly, M3 reported:

“\textit{And then you go to your gynae and they give you the vitamins. Maybe the vitamins could be the cause”}.

\textbf{Subtheme 4: Hopelessness.} According to Hughes (2003), the news of a child’s sickness may make mothers feel hopeless. A sense of hopelessness was observed when M1 said:

“\textit{I didn’t see a way forward to having other kids as I was stressed already with this screamer in my house all the time. Oh my God, it was like my life was finished}”.
**Subtheme 5: Acceptance.** According to Olson (2010), when mothers realise their child has autism they may accept it and put all other emotions behind and focus on ways to better their life and the lives of their children. This is supported by M2 when she said:

“I decided that I am not going to bother, the fact that whether God will miraculously take away the condition from him. He can. I believe He is God and he is the one who created him. He can easily take it. But my concern, or what I am interested in, is to find coping mechanisms to raise him. Because I can never predict God. No one can.”

After receiving the diagnosis and experiencing a plethora of emotions, mothers decided to seek additional sources of information.

**Theme 5: Additional sources of information**

Mothers reported that the information provided by health professionals was limited. It is on this basis that mothers consulted other sources to enhance their knowledge of autism. Mansell and Morris (2004) maintain that parents obtain useful information from a range of other sources including a parents’ support group, school teachers, the internet, books and academic journals. This was evidenced by the following excerpts:

*M6:* “No one explained autism to me, I just had to google myself”.

*M3:* “Google provided us with more information. My husband read extensively on autism”.

During the process of acquiring knowledge, mothers discovered that the prevalence of autism is explained by both gender and ethnicity. With respect to gender, Giarelli et al. (2010) and Holtmann, Bolte and Poustka (2007) found that autism is 4-5 times higher in boys than in girls. This is supported by M1 when she said:
“I have realised that it attacks mostly boys. Girls are few. Like in my son’s class there is only one girl and in the previous four classes there weren’t any girls. So majority attacks boys”.

According to Giarelli et al. (2010), there is limited information supporting the higher prevalence in boys. However, Werling and Geschwind (2013) argue that the high prevalence of autism in boys is due to their sex-hormone and difference in their genetic make-up. Werling and Geschwind (2013) further explain that testosterone in boys modulates the effects of genetic variation on the presentation of an autistic phenotype.

In this study, mothers did not report any ethnic bias with respect to autism risk. This is evidenced when M3 said:

“Because that school is reasonable, obvious you can find more black people. But if you are watching TV it’s everywhere. And it is on the rise, whether Black, White or Indian”.

In contrast, Mandell et al. (2009) found that autism is higher in White children as compared to Black, Hispanic and other ethnic groups in the USA. Ethnic differences were found to be a result of bias and discrimination of the clinicians towards specific racial groups (Balsa, McGuire & Meredith, 2005). For example, most Blacks are more likely to get the diagnosis of conduct disorder rather than autism (DeWeerdt, 2012). Societies may assign certain stereotypical behaviours to ethnic groups, thereby exaggerating any behaviour that mildly resembles the stereotype.

Additional resources not only provided mothers with information on the condition, but inspired them to find better ways to meet the needs of their children. This was indicated by M2 when she said:
“I never knew about autism until *Matome was diagnosed. I started making it my responsibility to learn or teach myself about the condition so that I can be able to raise my son properly”.

The responsibility to learn more about autism began with mothers’ seeking a cause for the diagnosis.

Theme 6: Beliefs surrounding the cause of autism

As previously indicated, the specific cause of autism is unknown. There is no single factor that causes autism but rather a combination of factors are thought to possibly cause autism (Adams, 2013; Ametepee & Chitiyo, 2009; Baltus-Herbert & Koulouglioti, 2010; Nyarambi, Enwefa & Enwefa, 2011; Rahbar, Ibrahim & Assassi, 2011; Russell, Kelly & Golding, 2009) In this study the following factors are discussed: diet and medical conditions during pregnancy, oxygen deprivation after birth, biblical explanations and metaphysical powers as possible causes according to the mothers.

Subtheme 1: Diet during pregnancy. Pitten (2008) found that diet, food processing and toxins in food may increase the risk of autism. When it comes to the beliefs surrounding what causes autism most mothers questioned whether there was something they had done wrong or had eaten during pregnancy that later resulted in their child having autism. This is evidenced from M4 when she said:

“When I was pregnant I would buy a big box of grapes which was R54.00. And I was eating all the time. I used to get nauseous if I am not eating. So every second of every minute I was having something in my mouth, for the first three months. So I ate lots of grapes. So when they started talking about pesticides and everything my thinking went there because I didn’t always wash my grapes”
Shelton, Hertz-Picciotto and Pessah (2012) maintain that the mothers’ consumption of food with residues of pesticides during pregnancy increases the risk of autism in the baby.

**Subtheme 2: Vitamins during pregnancy.** Although prenatal vitamins are perceived to be beneficial in the development of the foetus, DeSoto and Hitlan (2012) found that folic acid supplements taken during pregnancy may increase the susceptibility of the child to autism. This was supported by M3 when she said:

> “And then you go to your gynae and they give you the vitamins. Maybe the vitamins could be the cause. But we will never know”.

This response re-emphasises that in the absence of a definitive cause answers are sought in all spheres.

**Subtheme 3: Diet of the child.** Baltus-Herbert and Koulouglioti (2010) argue that the child’s diet can be a possible cause of autism. A child that continuously consumes food containing gluten and casein may develop autism, on condition that they are allergic to these proteins (Zammit, 2013). This is supported by M5 when she said:

> “Autism is caused by allergies you know so they allergic to casein in the milk and allergic to gluten you know”.

**Subtheme 4: Oxygen deprivation after birth.** In a meta-analysis of the various prenatal and neonatal causes of autism, Gardener, Spiegelman and Buka (2011) identified the lack of oxygen shortly after birth as one of the risk factors of autism. This was confirmed by M3 when she was asked of the possible cause of her child’s autism. Her response was:

> “Lack of oxygen. If he was put in an incubator it could have been prevented. Because from the time he was born to the time he was diagnosed (pause…) it would have been worse if I hadn’t spoken to that woman. I mean he was getting blue. I mean immediately after birth if they had put him in an incubator or if they
had given him oxygen, I would like to think that he would have been better. I think it could have been prevented”.

M3 implies possible negligence on the side of the medical staff. Her immediate response to the question may also demonstrate her firm belief in the cause of her son’s autism.

**Subtheme 5: Spiritual forces.** Some mothers had non-medical explanations regarding the causes of autism. According to M2:

“So at one stage my parents felt that maybe this is witchcraft or ancestral, you know possessed by ancestral spirits. And then you get Christians that they it is an attack, it’s a demonic attack”

This response is consistent with the literature (Nyarambi, Enwefa and Enwefa, 2011; Bakare, 2009a; Alqahtani, 2012; Stobart, 2006; Shyu, Tsai & Tsai, 2010) which states that autism may be perceived to be caused by supernatural forces such as witchcraft, sorcery, “evil eye” and black magic.

**Subtheme 6: Biblical explanation.** According to Emeke (2011) religion is the strongest element in African cultures; it filters into every part of an African’s life and influences the way an African thinks and lives. Africans believe in the Supreme Being who created everything. There is an acknowledgement of this Supreme Being in every religion. It should be noted that in the African context there are various religions. Christianity is one of these religions that influences people’s understanding of their experiences. This was observed when M1 said:

“Autism doesn’t have any cause. Autism is just one of those diseases when you read your Bible that says later on the earth will collapse, there will be diseases
that cannot be cured. There will be this and this. I think it is one of those things. That’s what I believe”.

This response indicates that autism may be viewed as a disease that was not a chance occurrence in their families. In support of this response, South Asian Muslim mothers believe that autism should be accepted, as the child with this condition is a gift from Allah (Jegatheesan, Miller & Fowler, 2010).

It can thus be concluded that, in understanding mothers’ interpretations of the cause of autism, culture should be taken into consideration. This is because culture is a lens through which people view a phenomenon. The above findings provide evidence that there are multiple cultural conceptualisations of the causes of autism. The beliefs regarding the causes of autism largely influence how parents manage it (Bernier, et al. 2011; Ravindran & Myers, 2012).

**Theme 7: Management of autism**

Most mothers are of the opinion that autism is not curable. This was observed from the narrations of M3 when she said:

“*Usually the doctors would put it this way. You cure what you know, and you manage what you don’t know. So now it’s just the treatment.*”

A similar response was provided by M1 when she was asked if autism is curable. She responded:

“No, I don’t think so. It’s a matter of taking medication. It’s easier to manage, but as for a cure, I don’t see it”
These responses are consistent with current literature that indicates that autism cannot be cured, only the symptoms managed (DSM-V, 2013; Ennis-Cole, Durodoye & Harris, 2013). The management of autism is dependent on the symptoms presented. On this basis, the treatment plan for each child is individualised. The treatment plan may include a combination of medication, various types of therapy, CAMS, traditional healing and faith healing.

**Subtheme 1: Medication.** The use of medication was observed to be the most common treatment of autism as reported by the mothers. This was demonstrated by the following excerpts:

**M3:** “He was put on Ritalin and another drug for depression, but I cannot remember its name”.

**M4:** “She’s on Risperdal and Strattera as she is hyperactive and has problems falling asleep”.

**M6:** “The doctor prescribed the Risperdal, Ritalin and Lorien; and it’s really helping him a lot. He was very anxious, I think that’s why the doctor prescribed Lorien”.

According to O’Reilly, Cook and Karim (2012) there are various drugs which are used to reduce a wide range of symptoms that a child with autism may display. Kumar, Prakash, Sewal, Medhi and Modi (2012) identified neurotransmitter reuptake inhibitors (fluoxetine), tricyclic antidepressants (imipramine), anticonvulsants (lamotrigine), atypical antipsychotics (clozapine) and acetylcholinesterase inhibitors (rivastigmine) as the drugs used in the treatment of autism.

In contrast to the majority, M5 reported:
“He doesn’t take any drugs. Like I mean, he doesn’t have aggression enough to be on Risperdal or to be needing a mood stabiliser”.

This response suggests that the use of medication is dependent on the severity of disruptive behaviour exhibited by the child. Medication is indicated in cases where behaviour is causing impairment in the child’s daily functioning and distress for the family (Volkmar, Cook, Pomeroy, Realmuto & Tanguay, 1999).

Drug therapy may not necessarily be effective as the child may react negatively to the medication (either by observed side-effects or exacerbation of the behavioural symptoms). This was demonstrated in the following excerpts.

M1: “It was drama with the medication. The doctor gave him Risperdal but it didn’t work with him. It made him like a zombie”.

M2: “Even with Risperdal he was still agitated and aggressive at times”.

M6: “He was initially on Cipramil. But that made him worse”.

In support of these responses, Handen, Johnson and Lubetsky (2000) found that some of the medications used in the management of autism produce side effects such as loss of appetite, aggression and insomnia.

Subtheme 2: Therapies. The therapeutic services that were being accessed by these mothers included speech therapy, occupational therapy, music therapy, applied behavioural analysis therapy (ABA), neurofeedback and kinderkinetics.

Occupational therapy. Occupational therapy is an intervention aimed at improving the individual’s ability to participate optimally in activities of daily living (Law, 2006). Human beings are social beings. Therefore their ability to engage in the environment is crucial for health and well-being and helps give meaning to life (Law, Steinwender & Leclair, 1998). Occupational therapy is a holistic approach which is adaptable in various contexts such as the
home environment, school and the community. According to Bowker, et al. (2011), occupational therapy is one of the therapeutic interventions used to assist children with autism and their families. The use of occupational therapy was expressed by M1 when she said:

“He has occupational therapy at school. They have everything there. However, before he got into the school we had to find everything for ourselves as the doctor said that the only thing was medication”.

**Speech therapy.** Language delay was considered one of the primary descriptors of autism. Therefore most parents seek interventions aimed at improving the child’s speech. Bowker, et al. (2011) maintain that speech therapy is one of the therapeutic interventions of autism. Speech therapy may include language aspects such speech articulation, vocabulary, grammatical complexity or reading comprehension skills (Fernandes, Molini-Avejonas & Amato, 2003). The benefit of speech therapy was expressed by M4 when she said:

“I saw improvement in speech because now she was doing speech therapy at school”.

When doing speech therapy, the primary language of the child should be taken into consideration as language is a mode of expression and communication, and it is embedded in peoples’ culture (Cummins, 1980).

**Music therapy.** According to Lee (2012), music therapy is another therapeutic intervention that can be used for children with autism. Music, dance and drumming are innovative and beneficial practices in Africa and regarded as important ingredients for healing as they restore peace and harmony in the individual and the group (Edoo, 2013). Similarly, Marokane (2014) states that music is more than entertainment, it promotes healing
and preserves the culture and identity of African people. The importance of music in healing was demonstrated by M4 when she said:

“I saw a bit of improvement in speech because now she was doing music therapy at school”.

Music is able to trigger vocalisation and provides the opportunity to connect with others (Madaule, 2003). Therefore the benefits of music for a child with autism are twofold.

**Applied behavioural analysis therapy.** ABA is a scientific, American approach to the evaluation and selection of behaviour based on the principle of operant conditioning (Ringdahl, Kopelman & Falcomata, 2009). Operant conditioning was pioneered by Skinner in the 1950s. It is based on the premise that behaviour is shaped by a person’s interaction with their environment. In autistic children ABA addresses the difficulties in social interaction, communication and stereotypical behaviours through reinforcement. This form of therapy was described by M5 as follows:

“He has been receiving ABA therapy from the age of two years and nine months. And he is still receiving it. ABA basically stands for Applied Behavioural Analysis Therapy. In order to simplify ABA, it is based on positive and negative reinforcement. ABA has helped in improving his eye contact and emotional outbursts”.

According to Ringdahl, Kopelman and Falcomata (2009), ABA is an intensive and costly therapy. Therefore ABA may not be available and accessible in all contexts and populations.

**Neurofeedback.** Neurofeedback is a new form of treatment for autism that is based on the principle of positive reinforcement (Kouijzer, van Sheie, de Moor, Gerrits & Buitelaar, 2009). This treatment primarily targets the oscillatory activity or rocking that is present in
children with autism. The child is first made aware of the rocking motion. Then if he/she is able to inhibit this action then he/she is rewarded (Kouijzer et al., 2009). Neurofeedback was mentioned by M5 when she said

“Neurofeedback is also one of the therapies that he is receiving at the Young Health Centre”.

Kinderkinetics. Kinderkinetics is a programme that is used to enhance motor and cognitive skills (Pienaar, van Rensburg & Smit, 2011). This therapy entails being aware of one’s body and executing physical activities like jumping, skipping and running which are considered important prerequisites for the development of basic learning skills. This therapeutic intervention is conducted by trained professionals in the field of motor development. This programme was mentioned by M5 when she said:

“Yes, their therapy also includes kinderkinetics”.

Subtheme 3: Supplements. Supplements have been found to be the most common CAM which is used in the management of autism (Bowker et al., 2011). CAM is a diverse array of practices that are either used in conjunction with or as a replacement to medicine and therapies (O’Reilly, Cook, Karim, 2012). A group of CAM supplements include vitamin C, pyridoxine, magnesium, melatonin, probiotics and vitamin B12 (Kumar, 2012). These supplements have been found to be helpful in the management of sleep disturbances, reduction of stereotypic behaviours and improvement in body functioning (Nickel, 1996; Dolske, Spollen, McKay, Lancashire & Tolbert, 1993). The use of supplements was evident when M5 said:

“He’s on omega 3 and supplements like zinc and magnesium for brain functioning”.

Subtheme 4: Diet. A gluten-free, casein-free (GFCF) diet has been regarded as a possible treatment of autism. This diet is based on the elimination of any food containing
wheat, flour and milk (Zammit, 2013). These proteins are believed to affect brain functioning by eliciting behaviours associated with autism. However the efficacy of this treatment is not conclusive (Zammit, 2013). This is supported by M5 when she said:

“I spoke with *Dr P. There’s this thing called the GFCF diet. And *Dr P. said that it is not proven to work”.

Inasmuch as M5 expressed that GFCF diet may not be a beneficial intervention, she indicated that a diet can be used to modulate the symptoms of autism. This was observed when she said:

“I believe that sugar, or rather too much sugar, can sort of alter your mood and brain functioning. So we avoid sugary drinks and refined foods like white bread and those kinds of things. We don’t have a specific diet, but I encourage the children to eat fruits, brown bread and less cool drinks you know”

Subtheme 5: Essential oils. According to M5:

“I also use essentials oils like lavender, vetiver and frankincense to calm him down and give him mental clarity”.

Similarly Godfrey (2009) reported that parents in England use essential oils like lavender, eucalyptus, geranium and peppermint to help reduce hyperactivity and increase attention span in children with autism.

Subtheme 6: Traditional healing. According to Baloyi (2008), healing is not an isolated activity but involves inclusiveness and togetherness. Africans believe in the performance of rituals in order to bring about healing and balance in all areas of a person’s life which includes the spiritual, physical, emotional and mental. Participation in rituals is a communal experience within the African context. This is based on the premise that no man
exists in isolation, no man is an island. All things are connected. The performance of a ritual
was demonstrated by M1 when she said:

“The old people they would say he’s not talking because you didn’t follow one,
two, three. They said we didn’t name him after our ancestors. So they gave him
the grandfather’s name. Immediately when we called him by that new name, he
responded. Whereas before he didn’t respond to his name”.

This response underscores the importance and meaning that ancestors have in the lives
of Africans. The ancestors continue to influence the life and actions of those still living in the
physical world. There exists an interconnectedness between the ancestors and the living
(Holdstock, 2000). For harmony, balance and peace to be achieved this relationship should be
maintained. The above response also signifies the meaning that a name carries in African
culture. The concepts of person and self are historical social products. Therefore a name is
not a word that only connotes identification and individuation, but rather a name embodies
life experiences, values and is believed to influence the character of the bearer (Guma, 2001).

In contrast to M1, most of the mothers opted not to conduct any traditional African
ceremonies for their children. This was demonstrated in the following excerpts.

M4: “there were those things we must do, like, imbeleko for yena which was
never done so still it has not yet been done. So it’s not done because of family
politics. It’s something that is still not done but yeah most people were saying
even...people joke when they see her. My husband’s friend this other day he was
saying no no no ni fanele muyise e Natal lomtwana bamu hlabele I umbuzi. And
it’s not like we are thinking if we do it then it’s gonna change things. So we are
just sitting and waiting (M4 chuckles)”.
Due to the researcher’s lack of familiarity with the ceremony, M4 explained *imbeleko* as follows:

“*Imbeleko is the welcoming of a newborn baby. It’s done differently depending on the family. In my family we don’t slaughter a goat, we slaughter a sheep. But most families it’s lesiko, like it’s something that must be done. So they slaughter a goat for it*”.

This ceremony also featured in the narrative of M3 even though she did not name it. Like M4, M3 also did not carry out *imbeleko*.

M3: “*My mum once said that with this child maybe you should touch the child, bless by slaughtering a sheep or something. Maybe, just maybe we will never know. And my father hasn’t done it until now. And I was okay, if God can’t heal him, why would the sheep heal him. But I was more than willing. If my father was going to say, “I am going to slaughter, come with the boy, then I would do the ritual. I was gonna go. Even today if now he said “come”. I was going to go. Because you never know. Maybe he just needs my father to touch him. We’ll never know. But if he says “come”, I will do it. I’ll go. But he doesn’t. I don’t think he is keen*”.

The narratives of M3 and M4 demonstrate that mothers possessed knowledge of traditional African practices even though they did not believe in the effectiveness thereof. Other mothers did not entertain traditional African ways of knowing and doing as shown by M2, M5 and M6 below.

M2: “*My mum kept on saying, “I know that you are born again but please the child cannot suffer. You must allow us to take this child to get some help. And*”
then afterwards you can go back to church”. I said, “no”. So I decided that I am not going to bother”.

M2’s response demonstrates both a disconnection between the two generations and the impact that religion (in this case Christianity) has had on later generations. There is variance in the belief systems, with later generations tending towards separating religion from traditional African values and practices, and older generations still espousing to traditional beliefs and practices.

M5: “I didn’t grow up in the most traditional kinda belief system and neither did my husband so we not very traditional or spiritual people. Therefore, I’ve never entertained alternative treatment or healing or you know or sort of answers in terms of spiritual, traditional healers or medicine men or anything like that. We don’t slaughter, we don’t talk to ancestors, we don’t do rituals...no we don’t do that”.

M6: “We did not do any ceremonies or rituals as my family and my in-laws don’t believe in that”.

The comments made by both M5 and M6 shows how the meaning of ceremonies and rituals have been misconstrued by Western thinking. Parham (2002) asserts that our own biases and assumptions regarding rituals may cause us to be reluctant in employing this technique. Parham (2002) further states that a ritual is simply a means of connecting with others and not a means of evoking some sort of mystical hocus-pocus. Therefore is it important to understand that ceremonies and rituals can be simple acts of attending church and a handshake respectively.

In addition to rituals, herbs were mentioned by M1 as a possible treatment. This is what she said:
“I got this muti (traditional medicine) from the herbalist. He usually treats people who are regarded as crazy. He said I must give my child 3 tablespoons of this muti. I do not know the name of this muti. He got it from the mountains.”

M 1 further stated that, because of this traditional medicine:

“He no longer runs away, goes to the neighbours and embarrasses us and peeing everywhere. He stopped the cat stuff like putting saliva on his face and shrieking like a cat when a cat is angry. His appetite is also much better.

Africans believe in the consultation of traditional healers and the use of traditional medicine (Madlala, 2012). However, this was evidenced only by M1. For M1 there was some therapeutic gain although the primary symptoms of autism have persisted to the present.

*Jabulani continues to display deficits in social communication and social interaction across multiple contexts and displays restricted and repetitive patterns of behaviour, interests and activities. The family continues to believe in a spiritual model of autism. This belief has been reinforced by *Jabulani’s recent seizures and hospitalisation. M1 recently informed the researcher of *Jabulani’s present condition.

“*Jabulani was having something we and the doctors do not understand. He was turning his neck to the back, his arms were twisted also and he was sticking his tongue out. The CT scan and EEG were clear. The doctors ended up discharging him because they said it was the first time they see something like this and they cannot help us. He is still so weak”.

Traditional healers are believed to be knowledgeable in various illnesses and their treatment. However, there are also reports where the prescribed treatment did not result in any therapeutic gain. M4 expressed her disappointment after a traditional healer was able to accurately describe her daughter’s symptoms but failed to treat these symptoms. M4 narrated
her family’s consultation with a man she describes as in-between a traditional healer and sangoma:

“Some point I think it’s 3 years back our uncle from my husband’s side called us and said you know you need to see Baba mang mang and we went there. Mina I am not a believer….So we went and saw this guy and there was no money involved. We just bought candles and you know just by looking at her he said all those things that she doesn’t play with other kids…. the problems were this and this, which was exactly what *uZenande has. He told us to light this candle at night, don’t switch it off and you gonna have a dream. You gonna dream of *uZenande when she was born, and what what it’s a whole lot of things that he said….he said she’s gonna be fine….First day, nothing happened I never dream. I didn’t dream. Second weekend my husband said let’s try again. So we lit the candles and we slept. He had the dream….so we went back to Natal and there was a sort of a ceremony that was done. We had to buy clothes for the old *uZenande when she was a baby, and the new *uZenande, like after the ceremony. We bought a blanket for the small baby and then a dress for *uZenande, a new dress that she had to wear on the day, after the ceremony. Everything was done, and he said in two-three weeks she’ll be talking. And nothing happened….We don’t even talk about it.

M4’s comments demonstrate that African mothers have not totally abandoned traditional practices and are willing to follow the directives of the elders. This may be more out of respect than belief as M4 was not optimistic. The family has opted to put this event behind them and continue to adopt Western interventions.

**Subtheme 7: Faith healing.** In addition to traditional healing, some mothers reported praying as a healing technique. According to Louw (1998), prayer is an important religious
practice that can be used for healing. Prayer provides encouragement, comfort, support and healing (Louw, 1998). Through prayer the child as well as his/her parent may ask the Supreme Being for healing or the power and strength to deal with the challenges that the family is facing as a result of the illness. The importance of prayer in healing was expressed by M2 when she said:

“You know I am a Christian. I believe in miracles. I believe that God can heal any condition. We just pray and hope that God will miraculously take away the condition from him”.

The above discussion on the management of autism suggests that no treatment is more effective than the other. Contextual and cultural factors should be taken into consideration in understanding and treating autism. According to Fernandes, Molini-Ave Jonas and Amato (2003), social and familial contexts play an important role in choosing different therapeutic approaches and in deciding the duration of the treatment. Decision-making becomes a communal process rather than an individual one in many African families.

Even though there is treatment for autism, it does not take away the fact that raising a child with autism comes with its challenges.

**Theme 8: Challenges faced by mothers raising children with autism**

According to Dzubays (2011), parents of children with autism face many challenges. During the conversations, most mothers indicated that raising a child with autism is not an easy task. The challenges faced by mothers raising a child with autism are discussed under the following subthemes; emotional distress, family discord, financial strain and finding a school, accessing healthcare, stigmatisation and self-injurious behaviour.
Subtheme 1: Emotional distress. According to Gupta and Singhal (2005), mothers raising children with a disability or impairment are more vulnerable to stress than fathers. Mothers bear most of the emotional burden as the responsibility of caring for the child falls predominately upon them (Sander & Morgan, 1997). The stressful nature of raising a child with a disability was observed by M1 when she said:

“To be honest, it’s so stressful. You must have a heart and believe in God. And know that you are not responsible for everything that is happening. The minute you blame yourself the whole thing is going to breakdown. You just have to focus on the brighter side”.

According to Gupta and Singhal (2005), what contributes to the distress is the absence of spousal support. This was supported by M2 when she said:

“I think that still depresses me because of the fact that his father is not even helping at all. I haven’t seen him for five years. So he is not even helping. He has not seen the child since we parted ways”.

Subtheme 2: Family discord. In addition to emotional distress, autism may place strain on family relations. Due to the difficulty of finding someone who can take care of the child during the day when parents are at work, parents may decide for one of them to stop working and stay home full-time with the child (Olson, 2010). This is supported by M4 when she said:

“Yoh!! It’s difficult. My husband is not talking to me right now because he wants me to resign. He feels we will be financially fine. However, it’s my career and I don’t want to be dependent on him, because I know money brings another dimension in a relationship”.
This response indicates that mothers may have to re-evaluate career goals due to their child having autism (Dzubays, 2011). Gray (2003) found that most mothers raising children with autism experience challenges with their careers. They miss work, may perform poorly, resort to part time jobs or quit work as they have a gender role to attend to their child needs.

Fathers on the other hand may be less engaging with the child and other family members as they may feel that their role is to work hard and financially support the extra demands on the family as a result of the child’s disability (Gray, 2003). Fathers may feel stressed by the financial toll that autism puts on their income (Koegel & LaZebnik, 2004).

Subtheme 3: Financial strain and finding a school. In the South African context, the mainstream schools are not equipped to deal with the special needs of children with autism; and attempts at incorporation have failed dismally (Balfour, 2007; Hoffman, 2012). Therefore very few schools cater for the needs of autistic children. This is supported by M2 when she said:

“So far there aren’t many government schools that cater for autism. Except in some mainstream schools you have one class, just one class that caters for autism”.

M1 added that most of the schools that cater for children with autism are very expensive. This is what she said:

“Most schools that we were finding were very expensive at that moment. The money was a problem. They were like R5000. And then you wonder R5000. I do not have that amount of money for school every month”.

M5 shared similar sentiments when she said:

“There’s something called the School of Johannesburg in Pretoria and then there’s the American International School or International School of America.”
The fees there are like R300 000- R400 000 a year. And that school was actually recommended by the therapist. They said that would be the ideal place; but we don’t have that kind of money (chuckling) yeah. It’s ridiculously expensive”.

These costs are not limited to the South African context. Peters-Scheffer, Didden, Korzilius and Matson (2012) found that education of children with autism in Netherlands is also costly. This may make the financial situation of the family worse, particularly for families with low income as they cannot afford these schools (Barrett et al., 2012).

As fees increases annually, some parents reported that they are unable to afford the school which forces them to take their children out of the school. This was observed when M2 said:

“They wanted money. So at the time when I took *Matome out, I think tuition, boarding and toiletries would cost R15000 a month. So it was too much for me.

He is now at home with the nanny”.

M6 added that, besides the schools being expensive, there is no guarantee that the child will be taken even if one can afford the fees. She stated that:

“To get your child into a school you can wait and wait. I heard about this other school from this other lady whose son was at Little Leaps with my son. She told me that she’s filling the application forms for her son. Then I said, ok let me just do it also. Then the following year after submitting the forms we still had not received their call. So after calling them they said we can bring our son for an assessment the following month”.

This response indicates that the process of applying at a school for the child to be placed is a long process that requires patience, frequent checking and follow ups because of
the limited spaces available. According to Dzubays (2011), before placing the child most schools request to meet the child and observe him/her in the school setting.

Although schools that cater for children with autism are expensive, some mothers reported that they find these schools beneficial in improving some of their child’s symptoms. This is supported by M6 when she said:

“At Flutterby’s he wasn’t benefiting and at Little Leaps I didn’t see any change. But since he started at UNICA I see a lot of difference. They are really helping him a lot”

M3 also shared the same sentiments. She elaborated on the changes that occurred with her son while attending UNICA.

“At UNICA now, you can see the difference. He’s speaking, He can make his own food. He can make bread, and put cheese on. He can bathe himself. He has improved from where he was”.

According to Sharpe and Baker (2007) special schools offer various therapies and activities which are designed to effectively assist the child in different domains of life and aid in optimal development.

**Subtheme 4: Accessibility of healthcare services.** Socio-political and economic factors influence the availability and accessibility of specialised care for children with autism (Ennis-Cole, Durodoye & Harris, 2013; Nyarambi, Enwefa & Enwefa, 2011). Autistic children from low income households are placed at a disadvantage. This is supported by M3 when she said:

“So if you are not working you are not going to know that your child is autistic, because to see those people, they would charge you...first consultation, crazy money. Risperdal I think it was around R600 at that time. So for people who don’t
have money they will not be able to access those services. I would like to think that we actually paid to know what is going on”.

Working comes with other benefits such as getting a medical aid and this can help with accessing treatment for the child. This was reported by M1 when she said:

“With the medication there was no obstacle because we have medical aid”.

Although a medical aid may assist in accessing treatment, M3 reported that:

“We had a medical aid, but you know some of the things, like *Dr X, she doesn’t use medical aid. Then we would pay cash. And then the OT’s, we would usually pay cash because we think, ag what’s the point of claiming R180? Then others would be over medical aid rates, then we would pay them. So most of them were cash and sometimes you don’t have it.

The above response indicates that health insurance may not cover all the expenses and treatment required to assist the child (Sharpe & Baker, 2007). In South Africa, healthcare professionals are allowed to charge fees that are above medical aid rates and may also request that the patient pays a co-payment over and above the consultation fee. In this study the majority of the mothers were able to access private medical care for their children.

**Subtheme 5: Stigmatisation.** According to Gupta and Singhal (2005), families of children with autism are more likely to feel socially isolated and stigmatised by families of children with no disability at all. Gray (1993) reported that parents of children with autism may feel stigmatised in public places. The fear of stigmatisation was observed when M5 said:

“I don’t like play groups because you must tell the parents that your child has autism and all that comes with it. And you don’t know how they will receive that and how they will react to that, so I actually don’t bother taking my child to a play group”.
This response indicates that mothers choose to socially isolate themselves and their children rather than always having to explain or defend their child’s behaviour (Mancil, Boyd & Bedesem, 2009). According to Gupta and Singhal (2005), social isolation may thwart parents’ chances of developing any support systems. This is supported by M1 when she said:

“Yoh, I do not have friends, I am by myself with them (the kids). My friends are my kids. I see people on whatsapp, that’s my social life. Then and there, maybe we are forced to go out with my husband. I call it force because we are not happy to go out. We are like eish, what will *Jabulani do when we are not here? So we are forcing ourselves to go out, no matter what. And even when we are sitting there, you can’t exactly relax, like 100%.”

For many parents having an autistic child is a constant worry, thereby increasing the intensity of stress in mothers (Mancil, Boyd & Bedesem, 2009). Clearly, some parents with an autistic child are also socially isolated and lonely.

**Subtheme 6: Self-injurious behaviour.** Apart from the impairments noted by mothers, there were behaviours that mothers found extremely alarming. These behaviours resulted in self harm and are described by M4 and M6:

* M4: “She bites herself until she bleeds. She also uses a blade and nail cutter and tries to remove her fingernails and toenails. She ends up cutting herself”.

* M6: “I almost forgot to mention that my son was very anxious. I think that’s why the doctor prescribed Lorien. He was anxious in such a way that he would pull out his eyebrows, his hair and even bite his nails”.

Self-injurious behaviours may include nail picking, thigh slapping, orifice poking, eye poking, hair pulling and violent head banging to name a few (Weiss, 2002). Furthermore, Weiss (2002) explains that children with autism do not wilfully harm themselves. It is
hypothesized that self-injury may be maintained by positive reinforcement or motivated by negative reinforcement, or alternately be reinforced by sensory stimulation (Weiss, 2002).

**Theme 9: Coping strategies**

According to Vidyasagar and Koshy (2010) mothers of children with autism are at a higher risk of succumbing to the effects of long term stress than fathers. Therefore they need ways to cope (Olson, 2010). The following are the ways mothers handle stress: music, religious activities and social support network.

**Subtheme 1: Music.** Music forms an integral part of African cultures. Through music Africans are able to express their feelings and thoughts (Biko, 2004). According to Parham (2002, p. 109), “music is comprised of vocal and instrumental sounds with rhythms, melody and harmony”. Music stimulates feelings and sustains a person’s movement and momentum in the face of emotional, psychological, spiritual and behavioural pain (Parham, 2002). Furthermore, music instils hope. The use of music as a way of dealing with distress was supported by M2 when she said:

“One way of coping is to play my favourite gospel music or worship songs. I couldn’t sleep despite the fact that I was on heavy antidepressants and anti-anxiety medication. There was a time when I couldn’t sleep even with sleeping pills. So I started playing music throughout the night, and then I would fall asleep”.

**Subtheme 2: Religion.** Twoy, Connolly, and Novak (2007) found that parents utilise religious organizations as resources to assist in dealing with their challenges. Similarly, Gray (2006) found that most parents of autistic children living in Brisbane, Australia, coped through their religious faith. This is supported by M6 when she said:
“We go to church and pray, I believe that God can hear us also”.

M1 added that:

“You know I am a spiritual person. I used to have terrible headaches and high blood pressure. Ever since I started praying, I’m fine. I don’t even take medication for high blood anymore. Now I just tell God, you are the one who knows what is happening. Just take control. I am putting you in control of everything. I am not scared anymore”.

**Subtheme 3: Support systems.** According to Altierre and Von Kluge (2009), parents who seek support during times of high stress are more likely to experience fewer psychological and physical problems. Two support systems were reported by the mothers. These include social support groups and family systems.

**Social support groups.** According to Olson (2010), support groups may have a positive impact on parents of autistic children. A group consisting of mothers raising autistic children may enhance mothers’ knowledge of autism. This is supported by M4 when she said:

“We have a group where we talk. Most of the time you will find that what you are experiencing is different from what other mothers are experiencing. Our kids’ behaviours are so different. For example, one of the mothers in the group told us that her son is turning 10 and is still doing number 2 in the nappy. Yoh we get to know other behaviours of autism.

Olson (2010) further asserts that a group context allows mothers to vent their feelings. This results in improved mood and lower levels of stress and anxiety. Kerr and McIntosh (2000) maintain that participating in support groups decreases stress and negative mood.

**Family system.** Support from family members is considered to be an effective coping mechanism for dealing with the daily stress of rearing a child with autism (Mancil, Boyd &
Bedesem, 2009). Gupta and Singhal (2005) maintain that a family is the most important system which provides support for mothers raising children with autism. Mothers reported that talking with other family members assisted with dealing with their emotions. Family as a support system was indicated by M2 when she said:

“*My whole family is supportive. My mum, dad and siblings are very supportive, even though I differ with them in terms of our religious beliefs*”.

The support from social groups and family members emphasises the importance of oral discourse, connectedness, interdependence and collectiveness in African cultures in promoting wellbeing and optimal health.

**Conclusion**

This chapter presented and discussed the results. Nine themes were induced. The themes were presented as a narrative from the time mothers suspected that something may be wrong with their child to the current circumstances. A common thread ran through the journeys of the six mothers. These included never knowing the cause, worry about the future and the daily challenges of raising the child. The next chapter will conclude with a reflective summary of the findings and reflections on the process of conducting this study.
CHAPTER 6: SUMMARY, REFLEXIVITY AND CONCLUSION

Introduction

The aim of this study was to explore the knowledge, beliefs and practices of black South African mothers raising a child with autism in the City of Tshwane. These topics were approached and explored using an African epistemological paradigm. In order to achieve the objectives of the study a qualitative narrative inquiry was employed. The conversational method of data collection was chosen to align with the oral tradition that is inherent in African culture. The conversations were analysed using thematic analysis. With respect to ethical issues, ethical clearance and informed consent were obtained and pseudonyms were used to conceal the identity of participants. Ubuntu philosophy – which is premised on a humble, polite and respectful attitude towards other human beings – is inherent in the researcher and therefore was displayed throughout the research process.

Summary of findings

This study aimed to highlight the influence that culture has on African mothers’ knowledge acquisition, belief systems and practices with respect to autism. Culture is the overarching construct that provides mothers with a lens to view their world.

The study found that African mothers’ views of autism aetiology, symptomatology and management are largely influenced by scientific rather than the so-called ‘non-scientific’ explanations. The non-scientific explanation arose with M1 who believed that her child with autism is possessed and controlled by ancestral spirits. Belief in ancestral spirits implies that all things in the universe are believed to be spiritually interconnected, from the Supreme Being to inanimate objects. This spiritual interconnectedness implies that the ancestors are
able to influence the lives of human beings in the natural world. Illness is regarded as a sign in the natural world of a break in unity in the spiritual world. Therefore, in African culture, autism as an illness may be regarded as communication within the spiritual realm that disconnection and disharmony are present in the cosmos.

In order to restore harmony, M1 engaged in traditional healing practices like a naming ceremony and the use of traditional medicine which benefitted *Jabulani somewhat. The findings show that traditional medicine may be effective in calming the child to the extent that idiosyncratic and self-injurious behaviour is decreased. M4 also conducted a traditional African ceremony, but no improvement was noticed. The other four mothers did not conduct any traditional African healing practices, although some considered them. Traditional healing practices are communal activities. Communal activities highlight the interdependence of African people. These results also show that traditional African ways of knowing and doing have not been completely abandoned. The traditional African ways of knowing and doing are intertwined with religion.

The importance of religion in this study is evident on at least three levels. Firstly, M1 used Bible scriptures to explain the cause of autism. This mother believes that autism is a sign of the end times documented in the Bible. Secondly, M2 viewed prayer as a powerful healing technique. Thirdly, prayer and gospel music provided comfort and strength to cope with the challenges associated with raising a child with autism. The mothers in this study reported that the challenges occur through the whole process of diagnosis and beyond. Apart from prayer and music, mothers also rely on family members and friends. The reliance on family and friends signifies the value that Africans place on interpersonal relationships and social interdependence.

The challenges faced by the mothers in this study made me reflect on my own experiences of raising a child with a disability.
Reflexivity

The mothers’ narratives have impacted on me, not only as a researcher, but as a mother and a future clinical psychologist. I would like to begin my process of reflection by explaining the reasons for the chosen topic. According to Lyons, Bike, Johnson and Bethea (2012), researchers who conduct qualitative research with people of African descent may be stakeholders in the communities they choose to study. Furthermore, it is in this space that they may generate topics by drawing on personal experience, relationships and observation. My reasons for conducting this study are consistent with these ideas. On a more personal note, my son was initially diagnosed with autism. Later on, the diagnosis was changed to another diagnosis. Just like with the mothers in this study, the journey to diagnosis was tedious, expensive and emotionally taxing. Raising a child with a developmental disorder, be it autism or any other, is very stressful and challenging. As a mother who is also a student, this requires the ability to persevere in the face of adversity. Thus, based on these personal experiences, this research study was not free of bias. It was partly based on my subjective experiences.

Subjectivity can also be observed in the selection of the study paradigm. As a coloured South African woman who has spent most her life in South Africa, with the exception of four years in Europe, I realised that I am unfamiliar with the African worldview and ways of knowing and doing. Therefore, adopting an African epistemological paradigm was more like a starting point in my journey towards understanding the episteme and research methodologies that are consistent with African people. This study was based on experiences of black South Africans raising a child with autism. To fully capture and understand their experiences, adopting a paradigm consistent with their worldview was of critical importance. According to Mkhize (2004), the experiences of Africans are embedded in their cultural
worldview. Therefore, the use of methodologies that are foreign to Africans may not capture the authenticity of their experiences.

Conducting a study in African communities made me realise the importance of language during conversations. Language is a tool to connect with one another. According to Anderson (2012), language is a way of expressing feelings, thoughts and experiences. The late South African first democratic president, President Nelson Mandela once said: "If you talk to a man in a language he understands, that goes to his head; but if you talk to him in his language; that goes to his heart". I believe that the narratives may have been richer if the conversations had been conducted exclusively in the preferred language of the mothers. However, language has been a key obstacle for me, as I can only speak English fluently. Although I may have a little understanding of some indigenous languages such as Setswana and isiZulu, I was unable to converse with mothers in their vernaculars as this would have hindered the authentic meanings to emerge from conversation and possibly resulted in misunderstandings and misinterpretations. Reflecting on this experience, it made me realise the limitations of my inability to speak my mother’s mother tongue, isiZulu. My mother prohibited us from speaking her language as it was considered inferior. Colonisation and then the apartheid regime influenced the perception of indigenous people’s view of their own languages. This fact highlights the extent of oppression that black South Africans have experienced and are still experiencing, especially as the oppression relates to indigenous languages and practices. This has profound negative impact on areas like research as I experienced it in this study. Although there are some universities in South Africa that have started to de-construct this reality, African languages still remain marginalised (Mkhize, Dumisa & Chitindingu, 2014).

Closely related to the language discourse, is the race discourse. Race also needs acknowledgment in this research. Race relations have always been a contentious issue in
South Africa, given our history. Black and white race relations have dominated South African politics. Black and coloured race relations have also recently come to the fore, which shows the divide present in our country and the work that still needs to be done to address racial issues. For example, recently a school in Johannesburg was shut down by coloured parents and teachers who were protesting the appointment of a black principal; preferring a coloured principal (Maketha & Mkwananzi, 2017). The premise is that coloured people in South Africa are not afforded equal opportunities and are resisting policies that are focused on the redistribution of resources. Brown (2017) explains that the two groups possess a heightened awareness of their differences with blacks viewing coloureds as “mixed-breeds” with no nationhood, identity, land or culture. Being a coloured women who is essentially an outsider to the African culture may have caused some discomfort and suspicion for the mothers. The mothers may have not felt comfortable in disclosing knowledge, beliefs or practices they thought I may not understand or be familiar with. The adoption of a humble, polite and respectful attitude towards the mothers, and my non-judgmental nature, may not have been sufficient to ensure rich, honest and detailed narratives, especially as it relates to cultural belief disclosure. Race is a socially constructed reality that is used to categorise, judge, measure competence and segregate. My position as the “other” placed me in a vulnerable and disadvantaged position as it may have limited the quantity and quality of the data obtained. The mothers may have perceived me as ignorant and different based on stereotypes. Although I did not experience any reluctance from the mothers to engage, these variables need to be considered as a possible bias. Taking into consideration both my race and lack of fluency in vernacular, the notion that a black female researcher may have obtained richer narratives is also a possibility.

It is also important to reflect on the reasons for most mothers not adopting traditional African beliefs and practices with respect to autism. The mothers’ adoption of mostly
scientific explanations may be attributed to the process of urbanisation as the study was conducted in the City of Tshwane, which is an urban area. Urbanisation affords both accessibility to clinics and hospitals, and an education system that is rooted in the Western paradigm. The Western paradigm provides African mothers with a Western lens through which their experiences are interpreted. The mothers in this study were highly educated. These high levels of Western education resulted in a disconnection inter-generationally with respect to how the mothers viewed African beliefs and practices.

I initially discarded the narratives of those mothers that did not adopt traditional African beliefs and practices. However, after perusing this data and dissecting the reasons behind these mothers not espousing indigenous African knowledge systems, I found some valuable and insightful information. As it is impossible not to communicate, even the data that appeared irrelevant and unusable provided significant information. It became apparent that the mothers understanding of African cultural values and practices have been contaminated by Western education and values. Traditional African practices were seen as foreign and mothers were sceptical about the effectiveness of carrying out rituals and ceremonies. In fact, their very understanding of rituals and ceremonies was not accurate. This underscores the impact that a Western value system has had on Africans. African knowledge and cultural values are being eroded and are losing significance as the lens through which the majority of mothers viewed their reality was through a Western lens. The Western value system has alienated African people from their indigenous knowledge systems.

In conclusion, approaching this study from an African epistemological paradigm was a novel experience. It has been educational, stimulating and enlightening.

On the basis of the summary of the study findings and my reflections above, the following recommendations are made:
Recommendations

- Healthcare professionals should be culture sensitive when diagnosing autism as cultural norms prescribe certain behaviours.

- Health professionals should take time explaining the exact meaning and implications of autism to mothers.

- Empathy and respect should be displayed at all times when delivering the diagnosis of autism to the mother. This is consistent with the philosophy of Ubuntu.

- Consideration should be given to the possibility of recognising autism as a permanent disability by policymakers.

- More public schools should be built that cater for children with autism. Such schools would be more relevant for children at the severe end of the spectrum, where inclusive education is not deemed plausible. These schools should be fully equipped to meet the needs of children with autism.

- Indigenous languages should no longer be marginalised and should be compulsory from primary school to develop the vernacular terminology that will enable professionals and parents to understand concepts such as autism from a cultural linguistic point of view.

- A study of this nature should be conducted in rural South Africa to determine whether espousal of indigenous African knowledge systems is more prevalent in that context as opposed to the urban context.
Conclusion

It is important to take note that one’s knowledge, beliefs and practices are embedded in one’s culture. Therefore, as there are many cultures, there are many knowledge systems and belief systems. The practices that mothers engage in (whether as part of the diagnostic process, healing process or as a means of coping) should be respected and valued. There is no method of knowing or practice of doing that is superior to the other in conceiving and understanding autism. Whether a condition is approached from a Western epistemology or an African epistemology, each is equally valid and relevant to the context. The mothers in this study adopted both Western and African practices in the management of autism, with Western practices being the most likely choice. The adoption of both clearly demonstrates the significance of considering both worldviews and cultural experiences in conceiving and understanding autism. The use of both worldviews will promote an integrative and holistic approach to the treatment of autism.
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APPENDIX A: GATEKEEPER CONSENT FORM

SEFAKO MAKGATHO HEALTH SCIENCES UNIVERSITY
GATEKEEPER CONSENT FORM

Dear Gatekeeper

My name is Bronwyn Menoe, I am a Clinical Psychology Masters student at the Sefako Makgatho Health Sciences University. I am conducting a research study titled: Knowledge, beliefs and practices of mothers raising a child with autism in the City of Tshwane: An African perspective. The study aims to explore the knowledge, beliefs and practices of mothers raising a child with autism in the City of Tshwane. The objectives are therefore as follows:

1. To explore how African mothers conceptualise autism.
2. To explore African mothers’ beliefs of autism aetiology.
3. To explore treatment modalities used by the African mothers for their children.

I am hopeful that the findings of this study will be useful in expanding the indigenous African epistemology and also to sensitize mental health professionals to alternative perspectives on autism.

I therefore request your permission to assist me with the recruitment of participants. Your assistance with recruitment will involve obtaining contact details of potential participants. By signing this consent form you agree to be contacted and to participate as a gatekeeper in this study.

.................................. .................................. ……………….
Name of Gatekeeper               Signature                  Date                      Place
.................................. .................................. ……………….
Name of Researcher                Signature                  Date                      Place
Statement concerning participation in a Research Project

Name of Study: Knowledge, beliefs and practices of mothers raising a child with autism in the City of Tshwane: An African perspective.

I have heard the aims and objectives of the above study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name is not revealed.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my child’s condition neither will it influence the care that s/he receives from my regular doctor.

I know that this study has been approved by the Sefako Makgatho Health Sciences University’s Research Ethics Committee (SMUREC). I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this study.

............................................................  ...................................................
Name of parent                                      Signature of parent or guardian.

....................................  ..................................  ............................................
Place                                    Date                                    Witness
APPENDIX C: NARRATIVE GUIDE

Age of child/ren: Age of mother:
Marital status: Employment status.
Culture:
Religion:
Place of Residence:
Narrative guide (adapted from Alqahtani, 2012; Lotus Shyu, Tsai & Tsai, 2010).
Please tell me about yourself/family/cultural background.
Please tell me about your child’s difficulties/ What raised your concerns? Symptoms? And how old was he?

Knowledge
Had you heard of autism prior to your child’s diagnosis? What had you heard/known?
Another name in your home language.
What is your understanding of autism/What type of illness is autism?
Do you think it affects a particular group of people more than others?
Do you know if autism is preventable/curable?
What is your view on the traditional African ways of knowing?

Experiences with healthcare/education
How did you come to find out that your child had autism?
Please tell me how the diagnosis of your child was explained to you.
Did you find that the healthcare provider was knowledgeable on autism?
Is your child in a special/mainstream school? And how is it going?

Beliefs

Self-efficacy
How did you feel as this explanation was being given to you?
How did you feel after you found out the diagnosis?
How has the disorder influenced your life and your family? (decreased parental efficacy and parenting stress).

Aetiology
What do you think about this disorder (the nature, causes and prognosis)?
What do you believe likely caused your child’s autism?
Practices

Tell me about the treatment your child has been receiving. Since his diagnosis or just when you noticed that something may be wrong, were there any other practices or treatments that you adopted?

What made you accept these treatments?

Was there any treatment that was stopped?

Did you seek alternative or traditional treatments?

What is your view on the traditional African ways of knowing?

What is your view on the traditional African ways of doing?

Were there any obstacles in accessing care/treatment/admission to a school that could cater for your child’s needs?

Is there anything else you would like to talk about with respect to having a child with autism?
APPENDIX D: CLEARANCE CERTIFICATE
28 February 2017

TO WHOM IT CONCERNS

I, Barbara English, of WORDSMITHS ENGLISH CONSULTANCY, declare that I carried out the language editing of Bronwyn Menoe's MSc dissertation.

I take responsibility for the language-related changes that I made on this dissertation. Any changes made without my seeing them I cannot take responsibility for.

Regards

Barbara English

wordsms, ths
english consultancy
APPENDIX F: TURN IT IN REPORT

MSc Dissertation
by Bronwyn Menoe
# MSc Dissertation

## Originality Report

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