

**EXPLORING THE JOURNEY OF SOUTH AFRICAN
CAREGIVERS WHO HAVE A CHILD WITH AUTISM
SPECTRUM DISORDER (ASD) SYMPTOMS**

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ABSTRACT

The principal aim of the present study was to explore the experiences of Black South African caregivers with children that present with Autism Spectrum Disorder (ASD) symptoms. The specific objectives were, inter alia, to discover how these caregivers interpret and understand their children's symptoms, the kind of help providers (African and/or Western) they approached in search of diagnosis and healing for their children's illness, and the specific ways their efforts impacted on their lives.

The findings showed that the participating caregivers were severely and negatively affected in four main ways in their journey towards obtaining an understanding and a cure for their children's ASD symptoms. These negative effects included firstly, the stress and demoralizing experience when discovering that they had children with ASD symptoms. Secondly, there was emotional restlessness and lack of closure that came with knowing that there would be no predictable way of finding a lasting solution to their children's illness. Thirdly, there was the pain of conflicted epistemology of healing that came with discovering that neither of the two worldviews for explaining people's illness, indigenous or Western, was able to give decisive and conclusive guidance in the interventions being sought. This forced most of the caregivers (five of the seven) to engage in multiple and emotionally draining back-and-forth approaches consulting with help providers drawing from conflicting and alternative epistemologies of healing. Finally, there was the damaging impact of excessive financial erosion and burden that go with the challenge of having to engage in multiple and alternative journeys in search of solutions to the problem of their children's ASD symptoms.

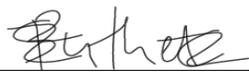
DEDICATION

For Enamile Libo Buthelezi

DECLARATION

I, **Zinhle Cynthia Mthombeni**, declare that:

1. The research reported in this thesis, except where otherwise indicated, and is my original research.
2. This thesis has not been submitted for any degree or examination at any other university.
3. This thesis does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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CHAPTER ONE: INTRODUCTION

1.1. Background of the Study

Autism Spectrum Disorders (ASD) have been cited as a rapidly growing public health concern (Newshaffer & Curran, 2003). Not only are ASDs difficult to treat, but they are also not entirely understood (Newshaffer & Curran, 2003). As a result, only a small portion of people are able to receive suitable treatment (Kazdin & Blase, 2011). This problem is exacerbated when people of an African background are offered treatment solely packaged from a Eurocentric perspective that fails to take into account the African theory of illness causation.

Thus in South Africa, the understanding and treatment of mental health disorders is complicated by two differing approaches (Stricklin, 1990). These approaches have their foundations in the European and African worldviews. While both the European and African systems of healing are used extensively, the African system is seldom understood by mental health practitioners who have been trained in European based theory (Nwoye, 2006; Vilakazi, 1997).

1.2. Statement of the Problem

The differing approaches of understanding mental health in South Africa poses a challenge to African communities regarding which worldview to resort to when a mental health problem that is difficult to explain is confronted and needs to be understood, particularly in the context of determining the type of treatment to be followed to achieve a lasting cure. This challenge is a problem not only to mental health users from African communities but also to mental health practitioners trained mainly in the bio-medical and the Eurocentric perspective of illness causation. In this case, without understanding the presenting mental disorder from the client's cultural background, finding an intervention with suitable treatment for the disorder may be problematic for the health practitioner. This problem is much more palpable when children with autism spectrum disorder symptoms need to be treated. In this case, the paradox to be faced becomes that of deciding which worldview, African or Western, to draw from in responding to the illness. The present study has been designed to explore the journeys and experiences of

parents/caregivers of children with autism spectrum disorder symptoms who are in need of finding an appropriate understanding of and a lasting treatment regimen for their children's illness. Finding an answer to this question is the major task of the study

1.3. Purpose of the Study

The major purpose of the study was to explore the journeys of African caregivers who have children with ASD symptoms. The aim was to determine how they interpret and understand ASD symptoms from an African perspective. An access to their understanding in this regard, could be achieved at least in part by getting to know the kind of experts they consult for help with the ASD symptoms, the types of treatments that they received for their child's symptoms as well as how the caregivers felt about the overall journey of attaining help for their child's symptoms. By exploring this theme, the aim is to acquire a better understanding of the intricacies involved when caregivers of an African cultural background are faced with certain symptoms of illness, particularly those that do not respond well to Western-centred bio-medical or bio-psycho-social treatment.

1.4. Objectives of the study

The specific objectives of the study were:

1. To explore how ASD symptoms are interpreted and understood by African caregivers/parents and the kind of diagnosis they obtain for their children's illness.
2. To establish the journeys undertaken by African caregivers/parents during the process of help seeking and search for solution to their children's ASD symptoms.
3. To investigate how African caregivers are specifically affected by their journey of attaining help for their children's symptoms

1.5. Research Questions

There were three dominant questions asked by this research:

1. How do African caregivers interpret and understand the origin and meaning of their ASD symptoms?
2. What journeys or experiences do African caregivers undergo to obtain help and treatment for their children with ASD symptoms?
3. In what specific ways are African caregivers affected by the journey of attaining help for their children's ASD symptoms?

1.6. Significance of the Study

Despite ASD symptoms being on the rise presently in South Africa, very little has been written about them in the context of Africans and their cultural beliefs. Yet, given the multicultural nature of South Africa, it is crucial that theories of illness causation that purport to guide professional actions and attitudes of mental health practitioners in the country be sourced not only from the perspective of one of the two dominant cultural groups, African and Western, but must include attention to the tested wisdom of the different people of the two cultures. Unfortunately, the current approach for responding to problems of children with ASD symptoms in South Africa and other parts of the world is completely Western or Eurocentric in orientation, with an African perspective of the same problem largely ignored. The present study is significant as it planned to help to bring African alternative explanations for the problems of children with ASD symptoms to the fore. The result is meant to create a platform for the emergence of mutual respect and understanding between the European and African worldviews when attending to the mental health challenges of people in South Africa.

1.7. Assumptions of the Study

This study is grounded on a number of assumptions. The first is that the South African mental health system is currently predominantly embedded in European culture. The second assumption is that many people of African culture continue to hold onto traditional African belief systems when confronted by certain illnesses that are not easily explainable through the idioms and theories of the Western bio-medical model. The third assumption of the study is that Africans who are rooted in their indigenous belief system may find themselves in a conflicted

position when faced with mental health problems because of the significantly different ways of viewing mental illness within European and African cultural systems. The fourth assumption of the study is that this conflict would result in cognitive dissonance for the caregivers resulting in the caregivers' experience of psychological distress. It is finally assumed that the dissonance that caregivers would experience in this process would result in an inadequate implementation, on their part, of the treatments recommended by Western-oriented health practitioners for their children's symptoms. Here the critical assumption is that this conflict will not be experienced by Europeans living in African countries because the worldview and belief system of European caregivers still resonate within the Eurocentric climate of the African country.

1.8. Scope and Delimitation of the Study

The scope of this study in terms of sample population coverage was limited to Black South African caregivers who have children that present with ASD symptoms. Other African caregivers from other parts of the continent whose children have ASD symptoms are therefore outside the scope of the present study. By limiting the study to Black Africans who reside inside South African, the study aimed to avoid presenting findings which would result in unwarranted and misleading broad generalizations to the experiences of peoples from other African cultures which are not South African.

1.9. Operational Definition of Terms

The terms used in this thesis have been defined according to their applicability in this research. These terms have been defined as follows:

1.9.1. Mental Health

A state of well-being in which the individual has the ability to realize his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.

1.9.2. Autism Spectrum Disorders Symptoms

A term that is used to describe presenting symptoms of a group of pervasive neurodevelopmental disorders which include autistic disorder, Asperger syndrome, childhood disintegrative disorder, Retts syndrome, atypical autism and pervasive developmental disorder not otherwise specified (PDD-NOS).

1.9.3. Culture

Culture refers to shared learned beliefs, assumptions and ways of life that are passed on from one generation to another for purposes of individual and societal growth, adjustment, and adaptation. It is also a resource which people use to define, process, interpret, understand and navigate their lives.

1.9.5. Worldview

A worldview is the perspective from which people understand and interpret their world, and includes a person's beliefs, values and culture.

1.9.6. Mental Health Practitioner

This is a person working in one of the helping professions who provides mental health services, such as a psychologist, psychiatrist, doctor, nurse or social worker.

1.9.7. Traditional Healer

This person practices traditional African healing based on African cosmology.

1.9.8. Help Provider

This is a person who provides treatment for a mental illness who is either a mental health practitioner or a traditional healer.

1.9.9. Caregiver

The term caregiver refers to any person providing direct care to the child with ASD symptoms. In the study, caregivers consisted of biological parents, aunts and grandparents.

1.10. Summary and Overview of the Study

This thesis is comprised of five chapters. The material covered in each of the chapters is summarized below.

Chapter One presents the study's background, the research problem, study objectives, key research questions and the key assumptions of the study. In addition to this, the significance of the research, the scope and delimitations of the research, the operational definition of terms, and overall summary of the study is provided.

Chapter Two provides a literature review of theoretical and empirical studies related to the topic of the present investigation, and ends with a conceptual framework for the research.

Chapter Three outlines the research design, location and the study population. It also highlights the sampling technique, sample size and the research instruments. In addition to this, issues pertaining to the reliability and validity of the study are considered. This is followed by a description of the method used to analyze the data as well as the ethical issues that were considered when conducting the research.

Chapter Four presents the findings of the study. Extracts from interviews with caregivers are provided to illustrate the themes that emerged from the research.

Chapter Five concludes with a discussion of the findings and the study's recommendations for policy action and further research.

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

This chapter consists of four sections. The first section reviews literature in the area of mental health and culture. The second section provides a comprehensive literature review of ASD symptoms. The third section presents an account of the differences between the European and African worldviews and their applicability to ASD symptoms. The fourth section draws on Festinger's theory of Cognitive Dissonance and the Health Belief Model to operationalize the key assumptions of the study. The chapter concludes with the conceptual framework which illustrates how the concepts of the research have been organized.

2.2. Mental Health and Culture

This theoretical review section is concerned with highlighting the existing literature in the field of mental health and culture in relation to the topic of the present investigation. It defines what is meant by the term mental health and considers the approaches used to understand mental illness, namely, universalism and relativism. From there, the role of culture in mental health is discussed by drawing on previous studies of the influence of culture in mental health practice. This review of mental health and culture also looks into the evolution or history of the dominant approaches to mental health and highlights why this approach can be problematic.

2.2.1. A Definition of Mental Health

One of the earliest definitions of mental health which was founded in the 1950s still holds true today. It was proposed by Jahoda (1958), a social psychologist who reasoned that mental health was not a mere absence of mental illness, but also required that an individual was able to engage with their environment in a positive, realistic and productive way. Fifty two years later the World Health Organization (2010) defined mental health in a similar way. According to the World Health Organization (WHO) mental health is defines as a state of well-being in which the individual has the ability to realize his or her own abilities, is able to cope with the stresses of

daily life, has the ability to work productively and purposefully, and possess the means to contribute positively to his or her community. Both these definitions indicate that in a state of sound mental health, individuals are self-aware and self-accepting, feel they have mastery over the actualization of their potential, have a sound perception of reality, and are able to cope in their environment competently. Based on these understandings, there is little doubt that achieving a state of mental health is a necessary resource for both personal gain and in making a meaningful contribution to society.

However, not all people enjoy sound mental health. Some are challenged by a number of mental disorders. In this regard, the American Psychological Association (2012) defines a mental disorder as behavioral or psychological pattern or syndrome which reflects an underlying dysfunction. For the behaviour or psychological pattern or syndrome to be classified as a mental disorder, the consequences must result in significant clinical distress or disability for the individual (American Psychological Association, 2012). The effects of living with a mental disorder often have profound effects on an individual's quality of life (Mitchell & Holdt, 2014). However, as documented in the literature, numerous populations face challenges in accessing adequate mental health care when experiencing mental disorders (Eisenberg, Golberstein & Gollust, 2007). Some of the major challenges in this regard stem from differences in approaches that have been used when attending to mental health issues.

2.2.2. Approaches to Mental Disorders

There are two approaches to understanding and treating mental disorders. These are the Universalist and relativist approaches (Visser et. al., 2006).

2.2.2.1 Universalist approaches

According Lonner (2011) Universalist approaches to mental health are founded on the assumption that people are alike in terms of the human psyche and therefore uniform treatment can be applied across all populations irrespective of their culture. The universalism perspective therefore uses the etic concept which refers to findings that appear to be consistent across different cultures as a basis of universal truth (Lonner, 2011). In response to the Universalist

perspective, some critics argue that certain phenomena are culture specific, such that what is true of one culture may not necessarily be true in a different culture.

As a way of illustrating what is meant here, a study by Napo, Heinz and Auckenthaler (2012) examined how West African patients understood and explained schizophrenia. The results of the study indicated that although African patients displayed key symptoms of schizophrenia such as delusions, hallucinations, beliefs of inserted thoughts and alien control, from the perspective of West Africans, these symptoms were explained as possession by witches, and not as psychopathology, as postulated by European theory. The findings of this study demonstrate that differences in meaning and understanding can be assigned to the symptoms of an illness based on the particular context in which the illness is experienced.

In a similar study, Matson, Worley, Fodstad, Chung, Suh, Jihn, Ben-Itzchack, Zakor and Funis (2011) investigated whether symptoms of the same disorder would manifest themselves differently across dissimilar cultures. These scholars studied symptoms of ASD which were reported in Israel, South Korea, the United Kingdom, and the United States of America. Their findings indicated that the manner in which these symptoms expressed themselves were not consistent across these countries. For instance, children from the United Kingdom expressed significant impairments in all the core symptoms of ASD when compared to children from Israel. These findings indicated that it is possible for symptoms of the same mental health issue to manifest differently in different cultures.

Seen from the above perspective, it becomes difficult to see the basis for the current tendency by mental health practitioners in South Africa to continue to depend solely on the Western model of explanation for understanding and treating the problem of African children with ASD symptoms.

2.2.2.2. Moving Away from Universalist approaches in Mental Health

Marsella and Yamada (2007) argue that European mental health perspectives are cultural constructions themselves and are therefore not universal. These researchers argue that these must be seen as representations of cultural knowledge rather than considered to be objective

constructs, as they are influenced by European cultural traditions. This therefore means that assumptions based on European mental health approaches may be relevant in a European cultural context, but this does not mean that they are relevant in all other cultural contexts (Marsella & Yamada, 2007). Moreover, a close examination of the aetiology of Universalism reveals the foundations of this perspective which are deeply rooted in unequal relationships between cultures.

According to Hall and Livingstone (2003) the universalization of European value systems originated with the creation of relationships of domination and subjugation of colonial administration. Ndlovu-Gatsheni (2013) in support of Hall and Livingstone's observation, notes that colonisation was mostly concerned with the exercise of control over colonised subjects. According to Quijano (2007) one of the ways in which this control was manifested was through the naturalisation of European knowledge and the creation of cultural systems which revolve around Eurocentric hierarchies.

The significance of hierarchies in this context lies in the fact that they are representations of power. According to Weiler (2011) hierarchies determine who is higher and lower in rank, who is dominant and subordinate, and who is of greater and lesser value, thus reflecting structures of authority and power. The creation of hierarchies was seen equally as a deliberate act by colonists (Quijano, 2007). According to Martinot (2012) Europe did not simply gain supremacy, its claimed supremacy was largely invented as a system wherein they would be deemed supreme while other cultures were accorded lower positions. Ndlovu-Gatsheni (2013, p. 129) writes that the construction of these hierarchies served to "form the foundation of the codification and institutionalization of differences between conquerors which were the Europeans and the conquered, which were colonised populations". Through this codification, colonists were enabled to assume superiority over the colonized peoples. Ndlovu-Gatsheni (2013) noted on the theme of how Europe became a universal culture:

The repression fell, above all, over the modes of knowing, of producing knowledge, of producing perspectives, images and systems of images, symbols, modes of signification, over the resources, patterns, and instruments of formalised and objectivised expression,

intellectual or visual... The colonisers also imposed a mystified image of their own patterns of producing knowledge and meaning... European culture became a universal cultural model (p. 169).

For Europe to become a universal cultural model necessitated the empowerment of the values of a single dominant culture which, in the process, submerged and excluded the cultural perspectives of other populations. The results of this are what scholars Mignolo (2012) and Suárez Krabbe (2009) refer to as coloniality of knowledge. The process of coloniality of knowledge resulted in the translation and reorganization of other cultures, knowledge systems and ways of being through European rationality (Mignolo, 2012). Saraceno (2012) argues that the postcolonial legacy is a contradictory juxtaposition of “enlightenment ideals of respect, freedom, and equality [against] European domination in the form of colonialism” but that that very same social contract is, in fact, predicated on the subordination of [the] other (Jakobsen, 1998, p. 4). As noted by Grosfoguel (2007) acknowledging the realities of power enables one to gain a deeper understanding of the hierarchies of power that are present in modern medicine. These observations together demonstrate that the current dominance of the hegemonic biomedical model in the South African health system is a product of colonial experience, and in this postcolonial stage of history, a sign of continuation of the same colonialism. It would therefore be interesting to explore how caregivers from an African cultural background are responding to the challenge of having to reconcile the conflicting perspectives of the Western and African healing systems about what is involved and must be done when working with children that present with ASD symptoms.

2.2.2.3. Relativist approaches

The central argument of the relativist approach to mental health is the view that mental health problems can only be understood and identified if the cultural context in which the problems are encountered is taken into account (Gould, 2006). Thus, in contrast to the Universalist perspective which focuses on the etic approach, the relativist perspective uses the concept of an emic, which refers to findings that appear to be different across cultures (Lonner,

2011). Following the relativist approach, therefore, what is to be considered as normal or abnormal in mental health should be culturally determined, that is, they should be so defined relative to what is regarded as normal or abnormal in specific cultural contexts. Following the relativist perspective would mean that what is to be defined as normal or abnormal should be determined from the perspective of the culture in which the problem manifests.

2.2.2.3.1. Culture as a concept

According to Hellman (2014) culture plays a major role in influencing the belief systems of people, which in turn informs their perceptions, thoughts and behaviour. Marsella and Yamada (2007) defines culture as shared learned behaviour which is passed on from one generation to another for purposes of individual and societal growth, adjustment, and adaptation. Somma and Bodiang (2004) concur that culture is deeply rooted in all aspects of society, including perceptions of illness and health-seeking behaviors. These definitions of culture indicate that culture has an influence on how people understand themselves and how they interact or connect with their social environment.

Contributing to this debate, Matsumoto and Juang (2012) propose that culture extends beyond providing a model for people to understand themselves and their world, to being a framework through which people construct themselves. This means that culture does not only define what the self is, but it also determines how people manage themselves and their circumstances in daily life (Draguns & Tanaka-Matsumi, 2003). However, the way people manage themselves across cultures varies. For instance, in European society the self is conceptualized as self-contained and autonomous whereas in non-European societies, the self is understood as extended, as implicating the well-being of others and therefore there is an avoidance of overemphasis on self-centredness or individualism and the notion of self-containment or self-sufficiency (English & Chen, 2007).

Given this disparity in self conceptualization based on cultural background, people from different cultural backgrounds will have differing values, beliefs and attitudes (English & Chen, 2007). To illustrate, Draguns and Tanaka-Matsumi (2003) noted that persons from collectivistic

cultures responded more sensitively to group opinions, and harmony was placed as a more important factor when they were compared to persons from individualistic cultures. Cohen and Gunz (2002) similarly found that East Asians were more likely than European North Americans to take the perspective of their partner into consideration when it came to interpersonal communication. Additionally, East Asians were more sensitive to the establishing of a common ground in social interaction, when compared to European North Americans (Haberstroh, Oyserman, Schwarz, Kühnen & Ji, 2002).

The above observations illustrate how culture as a concept serves as a lens through which people construct, define and interpret reality. Hence, as argued by Marsella and Yamada (2007) the understanding of mental disorders will vary across cultures because they cannot be differentiated from cultural experience.

2.2.2.3.2. The Role of Culture in Mental Health

The importance of culture in mental health was first recognized by Kraepelin (1926, cited in Jilek, 1995) when he recognized that his classification system for mental disorders seemed to have little applicability to groups in South East Asia and the Lakotah Indian tribes. According to Jilek (1995) Kraepelin, who is known as the father of psychiatry, recognized that to arrive at a valid diagnosis, the cultural background of the patient needed to be taken into consideration (Masella & Yamada, 2007). This discovery made in 1904 remains valid today and is supported by a growing body of research which advocates for cultural considerations to be made when attending to mental health issues (Bass, Bolton & Murray 2007; Fernando, 2010).

The notion of culture-bound syndromes illustrates the critical role that culture plays. According to Visser et al. (2006) culture-bound syndromes are forms of abnormal behaviour which are uncommon and occur only in specific communities. Mzimkulu and Simbayi (2006) indicate that these syndromes are a collection of signs, symbols and symptoms which are limited to specific cultures only. Thus, among the people of the Nguni culture there is a phenomenon known as *ukuthwasa*. Commenting on this peculiar syndrome noticeable among the Nguni people of South Africa, Niehaus, Oosthuizen, Lochner, Emsley, Jordaan, Mbanga and Stein (2004) observed that a *thwasa* presents with clinical symptoms resembling emotional disturbance which is also

combined with physical symptoms. Offering further clarification on this, Niehaus et al. (2004) indicated that the afflicted person becomes withdrawn and irritable when spoken to and sometimes becomes restless, violent, abusive and aggressive. There is also a tendency for a *thwasa* to aimlessly wander, and they may disappear for extended periods (Mzimkulu & Simbayi, 2006). Mzimkulu and Simbayi (2006) also stated that the afflicted person would appear to be in a pseudo psychotic state as he or she would present with symptoms such as hallucinations, delusions, reclusiveness and wild running. Niehaus et al. (2004) indicated that the resulting symptoms of *ukuthwasa* can be confused with schizophrenia. However, if close examination is made, the universalistic understanding of these symptoms is disputed by traditional African understandings of these symptoms. That is to say, rather than perceiving these symptoms in a negative way, as they are regarded in the Western medical model, according to the Nguni culture symptoms of *ukuthwasa* are a positive occurrence where the person is interpreted as being called on by the ancestors to become a traditional healer. Diagnosis of *ukuthwasa* is therefore made by a diviner rather than a psychiatrist, and the afflicted person is usually made to enter into a period of treatment under the supervision of an experienced traditional healer. The *thwasa* then remains in training until the symptoms have cleared.

Marsella and Yamada (2007) argue that those in support of universal approaches to understanding of mental disorders may claim that these disorders are simply variants of European disorders that have been contextualised in non-European cultures. On the contrary, Matsumoto and Juang (2012) opine that although there may be similarities in symptom presentation between culture-specific disorders and those recognised across cultures, the patterning of culture-specific syndromes does not, however, fit the diagnostic criteria of European classification systems. The phenomenon of culture-specific syndromes demonstrates that some forms of behaviour are not universal but are unique to certain cultural contexts. This explains why numerous studies based on observations of mental health disorders within their cultural context aim to move away from imposing ‘imported external frameworks’ when trying to give meaning to mental health issues (Bass, Bolton & Murray 2007; Draguns & Tanaka-Matsumi, 2003).

The present study sees this as a positive development which would be useful in determining the extent to which cultural context is being implemented in practice in South Africa in the area of offering care to children who present with ASD symptoms.

2.3. Autism Spectrum Disorders

The prevalence of children reported to have ASD symptoms globally has risen dramatically in recent years. The extant literature, for instance, shows that in 2007, ASD was estimated to occur once in every 110 children. However, recent estimates now place ASD to occur once in every 88 children (Centre for Disease Control, 2012; Kogan, Blumberg, Schieve, Boyle, Perrin, Ghandour & Van Dyck, 2009). Furthermore, researchers indicate that the increase in ASD estimates is not a phenomenon occurring in the United States of America alone, but the dramatic increase that has been reported around the world (Manning-Courtney, Murray, Currans Johnson, Bing, Kroeger-Geoppinger, Sorensen, Bass, Reinhold, Johnson, & Messerschmidt, 2013).

In this context, ASD is a term that is used to describe a group of pervasive neurodevelopmental disorders. The umbrella of neurodevelopmental disorders includes abnormalities such as autistic disorder, Asperger syndrome, childhood disintegrative disorder, Retts syndrome, atypical autism and pervasive developmental disorder not otherwise specified (PDD-NOS) (APA, 2000; World Health Organization, 2010). More specifically, ASD symptoms are described as impairments which present in early childhood that affect social interaction, social communication, and language development, and which result in restricted, repetitive and stereotyped patterns of behaviour (Lauritsen, 2013). The complex nature of these disorders presents significant challenges in the effort to understand and treat them (Centre for Disease Control, 2012). Worse still, although ASD symptoms are extensively described and well documented in academic writing (Newshaffer & Curran, 2003; Whitehouse, Durkin, Jaquet & Ziatas, 2009) these are often approached from a Eurocentric perspective which does not account how for non-European cultures understand the causes of presenting symptoms as well as how these symptoms can be treated. For instance, in the African cultural context, ASD as a mental

health disorder does not exist. However, ASD symptoms are commonly identified, acknowledged and understood in a way which differs considerably from descriptions provided by mental health classification tools, the DSM-V, used in Europe and North America, and by extension, by mental health practitioners in South Africa who rely solely on the Western approach to medical diagnosis and intervention in the context of their work.

The increasing number of children being diagnosed with ASD each year, particularly in South Africa, indicates that there is an undeniable need for practical intervention programs that go beyond the currently recognized dominant Western approach for addressing this problem. Hence, since ASD is on the increase across cultures, it becomes reasonable to suggest that interventions should extend beyond explanations provided by a single dominant culture in order to enable people from other backgrounds other than the West to access treatment that is appropriate for their specific settings. The present research is intended to identify which alternative options are resorted to by African caregivers faced with the task of managing the problem of a child who presents with a developmental problem that is associated with ASD symptoms.

2.3.1. A Description of ASD Symptoms

The extant literature currently suggests that the three areas of functioning that ASD symptoms are known to affect, include social interaction and social communication, language development, and restricted, repetitive and stereotyped patterns of behavior (APA, 2013; Dawson, Toth Abbott, Osterling Munson, Estes, Liaw, 2004). Reviewed below are the reports of researchers concerning the developmental complications and arrests which are faced by an affected child along each of these areas.

2.3.1.1. The Problem of Social Interaction and Communication in Children with ASD

According to Lopes, Salovey, Côté, Beers and Petty (2005) in ordinary life social interaction is defined as a process which involves reciprocal stimulation and responding between two or more people. In that way, social interaction plays an important role in the lives of humans as social beings, as it serves to enable people engaging in the interaction an opportunity to

develop social relationships. Thus, from social interaction, a person develops the ability to converse effectively with other individuals, has the possibility to find a mate, is able to understand his or her place in society, and can recognize and attend appropriately to other people's emotional states. Unfortunately, children with ASD symptoms are extremely handicapped in the context of social interaction.

Attwood (2006) notes that a child with ASD symptoms usually experiences limitations in social interaction and reciprocal communication. This limitation is often exhibited by a lack of understanding of the unwritten rules of social communication and behaviour which results in socially intrusive or awkward behavior (Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005).

In addition, a child with ASD symptoms may fail to display nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction adequately. They may also be unable to develop peer relationships which are appropriate to their developmental level. Similarly, studies indicate that a child with an ASD may fail to share enjoyment, interests or achievements with other people spontaneously by a lack of showing, bringing, or pointing out objects of interest (Newshaffer & Curran, 2003). Many children of Black African parents in South Africa who present with ASD symptoms have limitations along these lines.

2.3.1.2 .The Problem of Language Development in Children with ASD Symptoms

The extant literature indicates that problems in the area of communication form part of ASD symptoms, and that these difficulties encompass problems with words, sentence meaning, intonation, and rhythm (Landa, Holman & Garrett-Mayer, 2007). According to Burnette, Mundy, Meyer, Sutton, Vaughan & Charak (2005) having problems with these aspects of language in the affected child obstructs the process of producing and understanding language and speech. In this way, a large number of children who experience profound deficits in language development become non-verbal or go through a period of using echolalia (Mitchell & Holdt, 2014).

According to Mitchell and Holdt (2014) echolalia is the immediate repetition of speech by the child that they have just heard. Most echolalia is not functional language. For instance,

Chakrabarti (2009) notes that a child may repeat a phrase over and over again as a means of alleviating stress rather than to communicate. However with children whose speech improves, the child might learn to use echolalia purposefully to communicate. This usually begins with a child using a single word. Over time the child may learn to break down larger expressions used in language into smaller more meaningful units (Jónsdóttir, Saemundsen, Antonsdóttir, Sigurdardóttir, Ólason, 2011). Echolalia is one of the problems which most African caregivers may find in their children that present with ASD symptoms.

2.3.1.3. Restricted and Repetitive Behaviours among Children with ASD Symptoms

Leekam, Prior and Uljarevic (2011) define restricted and repetitive behaviours (RRBs) as a core feature of ASD. According to these authors, RRBs are characterized by a child's desire to maintain sameness in the environment (Kanner, 1943). A child displays restricted behaviour by having a narrow focus, being inflexible in their interests and activities, and also insisting that their environment remains unchanged (Leekam et. al., 2011). In contrast, repetition is displayed when a child has rhythmic motor stereotypies, and repetitive speech and rituals (Leekam et al., 2011). A child's preoccupation with restricted interests and non-functional routines or rituals can be seen from an insistence on specific foods, wearing only certain items of clothing, and resisting any changes in the environment (Szatmari, Georgiades, Bryson, Zwaigenbaum, Roberts, Mahoney, Goldberg & Tuff, 2006). Non-functional routines or rituals may involve intense interests or preoccupation with certain objects, activities, or information (Leekam et. al., 2011). Contributing to this debate, Attwood (2004) describes these behaviours as special interests that are pursued obsessively and sometimes to the exclusion of all other activities.

The extant literature also suggests that most children with ASD do display repetitive and stereotyped motor behaviours at some point (Boyd, McBee, Holtzclaw, Baranek, & Bodfish, 2009; Chen, Rodgers, & McConachie, 2009; Leekam et. al., 2011). These can be manifested by a child engaging in hand and finger flicking, rocking, or tapping or repetitive pouring of sand (Mitchell & Holdt, 2014).

2.3.2. Implications for Children living with ASD Symptoms

According to Toth and King (2008), living with ASD symptoms can cause significant problems in important areas of life for the affected person. For instance, for interpersonal relationships to be successful, a person needs to have good social understanding (Liu, King, Bearman, 2010). Social understanding means that a person understands the social codes of communication and behaviour. Unfortunately, because most social laws are unwritten, persons with ASD symptoms are often unaware of these expected behaviours and the implications of failing to adhere to them (Mitchell & Holdt, 2014). These social laws of interaction are founded on presenting adequate social communication and reciprocity which are core deficiencies of persons with ASD symptoms.

Studies that have sought to explore how people with ASD symptoms feel about interpersonal relationships indicate that persons with ASD symptoms find it challenging to establish and maintain interpersonal relationships (Carrington, Papinczak, Templeton, 2003; Whitehouse, Durkin, Jaquet & Ziatas, 2009). For instance, research by Whitehouse, et al. (2009) indicates that adolescents with ASD had less self-determined motivation to develop friendships in comparison to their typically developing peers. Although previous understandings assumed that individuals with ASD had a “powerful desire” for social isolation (Kanner, 1943), what this signifies is that even though motivation to establish social relationships is lower in people with ASD, the desire is not completely absent. Therefore individuals with ASD may have a need for social interaction. However, the implication of failing to engage in desired social relationships is that individuals with ASD may experience a certain degree of loneliness.

2.4. European and African Worldviews of ASD Symptoms

The way a person’s behaviour is interpreted may be based on one’s own beliefs which are informed by one’s worldview (Koltko-Rivera, 2004). However, this interpretation may be inaccurate if the behaviour being interpreted is from a different worldview. In this regard, the term ‘worldview’ can be understood as suggested by Swidler (2013) who proposes that a worldview can be defined as the way in which a person perceives and understands his or her world. According to Marsella and Yamada, (2007) such ways of perceiving and understanding

the world can influence the way in which one interprets and makes sense of reality. Thus, as Matsumoto and Juang (2012) points out, separating oneself from one's own cultural backgrounds and biases to understand the behaviours of others may be challenging. Overcoming such a challenge is crucial in order to challenge oneself to step aside from one's personal frameworks, especially when trying to understand an aspect of mental health, since European and African worldviews, or ways of knowing, differ significantly. Literature indicates that there are comparative differences between values emphasized in the European worldview and those emphasized in the African worldview. Using this as a backdrop, how ASD symptoms are understood and treated from a European perspective and from an African perspective will now be described.

2.4.1. The Eurocentric Worldview

2.4.1.1. Classification of mental illness

In European culture, there are two systems that are used to classify mental illness. These systems are the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Disorders (ICD) (Katerndahl, Larme, Palmer, & Amodei, 2005; World Health Organization, 1992). Both of these systems offer criteria for classifying mental health conditions and are considered to be official diagnostic tools throughout the world (Sartorius, Kaelber, Cooper, Roper, Rae, Gulbinat, & Regier, 1993). In South Africa, the DSM is the most commonly used classification system compared to the ICD. For that reason the review focuses on how South African patients with ASD symptoms are diagnosed according to the DSM.

2.4.1.2. Diagnosis of ASD symptoms based on the DSM-IV and DSM-V

At the time that this research was conducted, ASD were diagnosed according to the DSM-IV (APA, 2000) however, subsequent to this the American Psychological Association (APA) released the DSM-V (2013). For the purposes of this section, the DSM-IV is used to describe ASD as this was the understanding at the time of conceptualizing this research.

According to the DSM-IV (APA, 2002) a diagnosis of ASD was given if a total of six or more items from the list given in (1), (2), and (3) below is present, with at least two from (1), and one each from (2) and (3) being present:

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

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

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

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

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

- (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (b) Apparently inflexible adherence to specific, non-functional routines or rituals
- (c) Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements)
- (d) Persistent preoccupation with parts of objects

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

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder. These diagnostic criteria are influenced by the Eurocentric assumption that all medical problems can only be explained through a biomedical model or at most, the biopsychosocial approach.

In the current DSM-V, ASD are identified as a pervasive developmental disorder with deficits in communication and social interaction, and restricted, repetitive patterns of behavior, interests or activities (APA, 2013). Similarly to the DSM-IV, in the DSM-V, in order for a child to qualify for a diagnosis their symptoms should cause significant impairments in important areas of functioning which cannot be accounted for by intellectual disability or global delay. However, the major difference between the two schedule lies in that the different categories of ASD such as autistic disorder, Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorder (not otherwise specified) now fall under the term ASD which implies that children who have previously received a diagnosed for any of the disorders mentioned above are now given one diagnosis which is an Autism Spectrum Disorder diagnosis (APA, 2013).

2.4.1.3. Treatment of ASD Symptoms

Following the Eurocentric perspective, ASD symptoms are commonly treated through behaviour based intervention programs. According to Hayward, Eikeseth, Gale and Morgan (2009), intensive behavioural interventions (IBI) are aimed at targeting the presenting symptoms by improving the core problem areas such as communication and social skills. In addition to this, by improving problematic symptoms, IBIs aim to reduce behaviours which are regarded as inappropriate (Miagiati, Charman & Howlin, 2007). The term 'intensive behavioural intervention' is often used interchangeably in literature with that of 'applied behavioural analysis (ABA)'. This is owing to the premise of IBI being founded on the principles of ABA which

require that these programmes are implemented within structured learning environments (Eikeseth, Smith, Jahr & Eldevik, 2007; Peter-Scheffer, Didden, Korzilius & Sturmey, 2011).

According to Eldevik et al. (2007) IBI is a structured learning intervention for ASD symptoms which typically begins when the child is between the ages of 3 to 4 years. Green, Brennan and Fein (2002) note that this treatment requires approximately 20-30 hours a week for two years and consists of one-on-one interaction. In addition to this, caregivers and parents are required to participate in the programme by implementing activities which are referred to as reinforcers to enable the child to cope with the demands of the program (Weiss & Harris, 2001)

At the initial stage of the intervention, the treatment is provided by a therapist who uses a system known as Discrete Trial Instruction (DTI) as a teaching method (Smith, 2001). According to Scott and Baldwin (2005), this method systematically simplifies instructions into small components as a way to teach the required skills to the child. Following the DTI stage, the child then progresses to a stage where she or he can be taught in a more natural environment, possibly with other children (Weiss & Harris, 2001). There are a number of IBI programs which have been developed over the years, however the literature indicates that they all share the same components (Larson, Fair, Good, & Baldwin, 2010).

Below is a table of three different types of IBI programs adapted from the Autism Society of America (2004). These are the Lovaas, PECS and Inclusion. Summarised in the table is information pertaining to the interventions background of the treatment, its aim and the manner in which it is implemented.

TABLE 1

SUMMARY OF THREE IBI TREATMENT PROGRAMMES

	LOVAAS	PECS	INCLUSION
Background	<p>Also known as Discrete Trial Intervention (DTI), Intensive Behaviour Intervention (IBI), Applied Behaviour Analysis (ABA)</p> <p>One of the earliest forms of behaviour modification</p>	<p>Derived from need to differentiate between talking and communicating</p> <p>Combines in-depth knowledge of speech therapy with understanding of communication</p>	<p>Initially intended for children with mental retardation and disabilities other than autism</p> <p>Developed from sociological, educational, and political mandates</p>
Aim	<p>Teach child how to learn by focusing on developing skills in attending, imitation, receptive/expressive language, pre academics, and self-help</p>	<p>To help child spontaneously initiate communicative interaction</p> <p>To help child understand the function of communication</p> <p>To develop communicative competency</p>	<p>To educate children with disabilities together with neurotypical children</p> <p>To educate children with disabilities in the chronological setting they would be in if they had no disability and they lived at home</p>
Implementation	<p>Uses ABC model; every trial or task given to the child consists of: antecedent — a directive or request for child to perform an action, behaviour — a response from the child that may include successful performance, non-compliance, no response, consequence — a reaction from the therapist, including a range of responses from strong positive reinforcement to faint praise to a negative “No!”, pause — to separate trials from one another</p> <p>Utilizes repetitions of learned responses until firmly imbedded</p> <p>1:1 instruction</p>	<p>Recognizes that young children with autism are not strongly influenced by social rewards therefore training begins with functional acts that bring child into contact with rewards</p> <p>Begins with physically assisted exchanges and proceeds through an hierarchy of eight phases</p> <p>Requires initial ratio of 2:1 instruction</p>	<p>Children with autism typically placed in inclusive education settings with 1:1 aide</p> <p>The curriculum is modified to accommodate to specific learning strengths and deficits;</p> <p>Requires team approach to planning; approach may be selective inclusion (by subject matter or class),</p> <p>Partial inclusion (1/2 day included, 1/2 day separate instruction), or full, radical inclusion with no exceptions</p>

2.4.2. Diagnosing Illness within the African Healing Paradigm

2.4.2.1. Classification of mental illness

According to Van Dyk (2001) at the cornerstone of understanding illness, Africans are concerned with the questions of who is at the cause of the illness and why the illness has occurred. The answer to this question is what determines how the mental illness is classified. Classification of illness causation in the African traditional system consists of two categories. These categories are the natural causes of illness and the supernatural causes of illness.

2.4.2.1.1. Natural causes of illness

Pretorius (1999) indicated that natural causes of illness in African context are known as *Umkhuhlane*. Illnesses that are in this category are those where their impairments are accounted for by physiological symptoms. For instance, pathologies such as diabetes, stress, epilepsy and asthma are regarded as natural causes of illness (Murdock, 1980).

2.4.2.1.2. Supernatural causes of illness

Supernatural causes of illness on the other hand are known as *ukufa kwabantu* (Pretorius, 1999). Lewando Hundt, Stuttaford and Ngoma (2004) affirm that this term is a literal translation of the words a disorder of the African people. According to Ngubane (1977) this literal meaning refers to the disease and symptoms as not only associated with African people, but also that the interpretation of symptoms is in unison with African ways of understanding illness. *Ukufa kwabantu* ascribes the illness causation to external supernatural forces, and is used more specifically in explaining illnesses that are uncommon or rare. According to Lewando Hundt, et al., (2004) it is when ordinary treatments used for natural causes of illness have failed that illness are classified in this category or in the category of illnesses assumed to be caused by supernatural forces.

In this regard, three theories are used to explain supernatural causes of illness. According to Pretorius (1999) these theories are the animistic, magical, and mystic theories. The animistic

theory attributes the cause of illness as a response to the withdrawal of protection by a supernatural spirit, god or ancestor. The magical theory, on the other hand, explains the cause of illness as arising from the intention of a malicious person who uses magical means to harm the victim. The mystic theory sees the illness as a consequence of being in contact with places or people who are closely associated with major life events such as birth, death, or menstruation, or environmental hazards such as lightning.

As documented in numerous studies, ASD symptoms are often complex and difficult to understand (APA, 2013; Dawson, Toth, Abbott, Osterling, Munson, Estes & Liaw, 2004; Mitchell & Holdt, 2014). Not only do they present challenges in understanding, but also similarly the treatment these symptoms does not coincide with an illness with a physiological basis. Therefore, of the two categories which classify mental illness in African culture, ASD does not fall under natural causes of illness, but fits the criterion of supernatural causes of illness.

2.4.2.2. Diagnosis of ASD symptoms according African culture

In traditional African culture, no distinction is made between the diagnoses of illness resulting from natural or supernatural causes. Diagnoses of illness are made by traditional healers (Edwards, 2011). These traditional healers broadly include a herbalist (*inyanga*), a diviner (*isangoma*) and a faith healer (*umthandazi*). While different traditional healers employ different methods of diagnosis, the common elements of these methods is that they draw on analysing causality of the illness and they use aspects of divination to identify who is the root cause of the illness and why the illness has occurred (Abrahams, Jewkes & Mvo, 2002; Edwards, 2011). Within such a system there are no specific criteria for diagnosing ASD symptoms.

2.4.2.3. Treatment of illness in African culture

Treatment of illness in African culture is to a large extent determined by the causality of the illness. According to Edwards (2011) the treatment administered by the traditional healer is dependent on the theory of causality of the illness. The following summary of treatment based on the theory behind the causation of illness in the African context is adapted from Edwards (2011).

2.4.2.3.1. *Treatment for animistic causation*

If ASD symptoms are believed to be caused by elder displeasure, treatment would require that a ritual to appease the ancestors be performed. This ritual is known as *umsebenzi* and serves as a means of re-establishing a relationship with the elders. Edwards (2011) additionally notes that an alternative way that the symptoms could be treated involves the child receiving a calling to become a diviner (*sangoma*). Another way that treatment occurs is through a ritual referred to as *ukubuyisa*. This ritual is performed in instances where the child's symptoms are believed to be caused by the possession of an alien spirit of a person who died and was not integrated with body of family ancestral spirits (Edwards, 2011).

2.4.2.3.2. *Treatment for magical causation*

Illnesses caused by magical causation refer to those whose aetiology is believed to be from malicious humans aiming to cause destruction. This is known as *ubuthakathi* (Edwards, 2011). If the child's ASD symptoms are believed to be caused by *ubuthakathi*, Edwards (2011) notes that treatment is performed by a traditional healer and involves the ritual of re-establishing all relations between spiritual, human and environmental relationships. Various rituals are performed to establish the required balance (Ngubane, 1977). These are rituals such as *isidlo* and *ukuchela*, both of which aim to reconnect the family with the ancestors.

2.4.2.3.3. *Treatment for mystic causation*

According to Berglund (1976, cited in Edwards, 2011) *ukubethelela* refers to a ritual performed by means of heavenly herds aimed at protecting the family home and the promotion of family health. This ritual is performed when the child's ASD symptoms are believed to be caused by contagion or pollution associated with stresses of major life and death events. Through this ritual, health is promoted and illnesses prevented if the required moderation and abstinence is practiced during the ritual. A second ritual to treat the illness is known as *ukuchela*. This ritual has a similar purpose as *ukubethelela* as it also aims to fortify the home. However, the *ukuchela* ritual requires sprinkling and spreading of medicine by the family herbalist as a means of

fortification (Edwards, 2011). Set down below is a tabled summary of treatment protocol for ASD symptoms in the African context, particularly among the Nguni people of South Africa as highlighted above.

TABLE 2		
TREATMENT FOR ASD SYMPTOMS IN AFRICAN CULTURE		
Animistic causation	Magical causation	Mystic causation
Cleansing ritual to appease ancestors (umsebenzi)	Re-establishing spiritual, human and environmental relationships by performing rituals to protect and strengthen the vulnerable individual, family and community as well as promote their future health, well-being and fortune (Edward, 2011).	<i>ukubethelela</i> to fortify the home against danger, e.g. sorcery
Cleansing ritual to free spirit of a deceased family member (ukubuyisa)	<i>isidlo</i> the beer ritual· communication with shades through eating and drinking	<i>ukuchela</i> fortifying the homestead through sprinkling and spreading of medicine by the family herbalist
Receiving a calling to become a diviner (<i>sangoma</i>)	<i>ukuchela</i> fortifying the homestead through sprinkling and spreading of medicine by the family <i>inyanga</i>	

2.5. Synthesis and Summary of Literature Review

The above literature review has provided some valuable insights which are relevant to this study. The review, for instance, showed that the two major approaches that guide action in mental health practice, namely, universalism and relativism, recognize the impact of culture on human life. Yet one distinguishing characteristic assumption of the Uniiversalist approaches involves the belief that Eurocentric approaches to understanding mental disorders should be applicable to the experience and life of people from non-Western cultures. Challenging such an assumption, numerous studies reviewed were unanimous in their view that cultures differ from one another, such that what is applicable in one culture may have no relevance in another culture. This caveat was interpreted to mean that Uniiversalist approaches to mental health practice developed in Europe and North America should not be applied indiscriminately across cultures.

It was noted that when the Eurocentric approach is allowed to dominate practice, cultural bias will set in, giving rise to opportunity for promotion of misunderstanding, misdiagnosis and irrelevant treatment of mental health illnesses of people from African cultural backgrounds. The implication of this was believed to be counter-productive to overall interest of the person seeking help, an anomaly that is neither justifiable nor ethical.

In contrast, the relativist perspective approaches mental illness through a consideration of the culture within which the mental illness is experienced. In this way, the premise of the relativist approach stems from the understanding that culture is the lens through which people make sense of their lives. As a result, it is suggested that a client's culture always needs to be taken into consideration when providing care, in order to prevent the crisis of cultural bias and to ensure equitable relevance in the care that is provided.

2.6. Conceptual Framework

This study assumes that many Africans living in South Africa continue to hold onto African cultural belief systems, even though the South African mental health system is predominantly embedded in the Eurocentric paradigm. The literature reviewed for the study demonstrated that the European and African worldviews differ significantly, and that this has implications in the way that mental health disorders are understood, diagnosed and treated in most places in contemporary Africa. The research further assumes that Africans who are rooted in the African belief system may find themselves in a conflicted position when faced with mental health problems because of the significantly different ways of viewing mental illness within the European and African cultural traditions. The study therefore hypothesized that this conflict would result in cognitive dissonance for the caregivers where they would experience psychological distress. Additionally, the study hypothesized that the dissonance that caregivers would experience would result in an inadequate implementation of the treatments recommended by health practitioners for their child's ASD symptoms.

In the next section, Leon Festinger's Theory of Cognitive Dissonance (Festinger, 1957) will be reviewed. This will help in understanding the type of cognitive stress that become the burden of caregivers who are made to accept, without question, a mental health procedure that

disagrees with their cultural beliefs on the matter. This will be followed by a discussion of the health belief model, intended to highlight the conditions that must be fulfilled before caregivers will be motivated to implement any interventions recommended to be followed in the service of their child's ASD symptoms by Western-trained mental health practitioners.

2.6.1. Festinger's Theory of Cognitive Dissonance

Festinger's theory of cognitive dissonance postulates that a person who holds two beliefs or views which are in contrast, will experience a state called cognitive dissonance. According to Festinger (1957, p. 3) cognitive dissonance is an "antecedent condition which leads to activity oriented toward dissonance reduction". Since Festinger first coined this term, many scholars have come up with alternative variations of its meaning. Griffin and Moorhead (2011) define cognitive dissonance as a distressing mental state caused by inconsistency between a person's two beliefs or a belief and an action. Dickens, Kuhns, and Sheets (2013) on the other hand, define this state as a person's conflicting thoughts or ideas which directly cause changes in behaviour or attitudes associated with those thoughts or ideas. A common thread between these formulations is the view that when a person is confronted with contrasting beliefs, she or he faces the risks of developing a state of psychological discomfort should she or he be expected to act in favour of any one of these beliefs at the expense of the other.

According to Festinger (1957) there are five ways in which a person faced with adjusting to the call of two contrasting beliefs could reduce the resulting cognitive dissonance. This could be through altering the importance of the issue or the elements involved, changing one or more of the cognitive elements, adding new elements to one side of the tension or the other, seeking consonant information, and distorting or misinterpreting dissonant evidence (Festinger, 1957; Littlejohn & Foss, 2005; O'Keefe, 2002). A linear model of cognitive dissonance that could face caregivers of children with ASD symptoms in this context of this study could therefore be illustrated as follows:



Figure 1. A linear model of cognitive dissonance for the study

The above indications can be interpreted to mean that, in the African context, when a parent presents a child with ASD symptoms for treatment in a modern health facility that recommends only the use of the Western biomedical approach to healing, the parent may be thrown into the condition of cognitive dissonance if the parent tends to believe that the ASD symptoms are a product of ancestral anger rather than a medical problem. It would therefore be interesting to explore the extent to which such a negative state of affairs could be verified among the caregivers involved in this study.

2.6.2. The Health Belief Model

According to Burke (2003) the Health Belief Model (HBM) is an intrapersonal theory that is used extensively in the design of health intervention programs. The reason why the HBM is considered to be an intrapersonal theory stems from its conceptual basis. This theory is founded on Lewin's (1943) concept that it is perceptions of reality rather than objective reality that influence the behaviour of people. From this perspective, a health behaviour will be carried out because of the person's desire to attain good health, and also by their belief that the recommended action will achieve this. Therefore the implementation of an action for a positive health outcome is determined by the person's perception of the situation and not the actual situation or factual evidence. According to Burke (2003) the HMB suggests that an action occurs with the existence of the following perceptions:

Perceived susceptibility: A person must believe that they are at risk of being affected by the health condition.

Perceived severity: A person must be convinced of the seriousness of the condition and the seriousness of its impact.

Perceived benefits of an action: A person must believe that the proposed action will be effective in reducing the risk or that it will result in additional benefits.

Perceived barriers to action: A person considers and weighs the benefits with the cost of taking action to determine whether taking action will be worth the while.

While the perceived susceptibility and perceived severity of the condition are internalized, the HBM indicates that there are modifying factors which are external and these may also influence how the person at risk feels about taking action for the condition presenting a threat. These modifying factors are perceived threats, environmental factors and cues to an action (Burke, 2003). Additionally, the balance between benefits and costs may suggest the person's likelihood of acting and their preferred course of action, but these do not necessarily determine that they will act. Rather, if benefits are closely balanced against costs, the person may experience anxiety (Burke, 2003).

For this study, the HBM was tested to ascertain whether the presumed cognitive dissonance arising from the contrasting worldviews confronting caregivers would have an influence on whether the caregivers implemented the interventions recommended for their child's ASD symptoms.

2.6.3. George Kelly's Theory of Constructive Alternativism

George Kelly's theory of constructive alternativism proposes that people do not always stick to one thing but are in constant search of discovering options that will meet their needs. As people's needs change, so do the methods that they use in finding solutions. This theory states that while there is only one true reality, reality is always experienced from one or another perspective, or alternative construction, this perspective is additionally not fixed and people alternate between different realities to find a solution for their difficulties. The way African

caregivers went by to search for treatment options for their child's symptoms shows patterns of moving back and forth between biomedical and traditional methods.

2.6.4. Conceptual Map of the Study

Overleaf is a conceptual map of the study. The diagram below summarizes both the literature reviewed and the hypothesis of the research. Such a conceptual map aims to describe how the ideas of the study are related to each other.

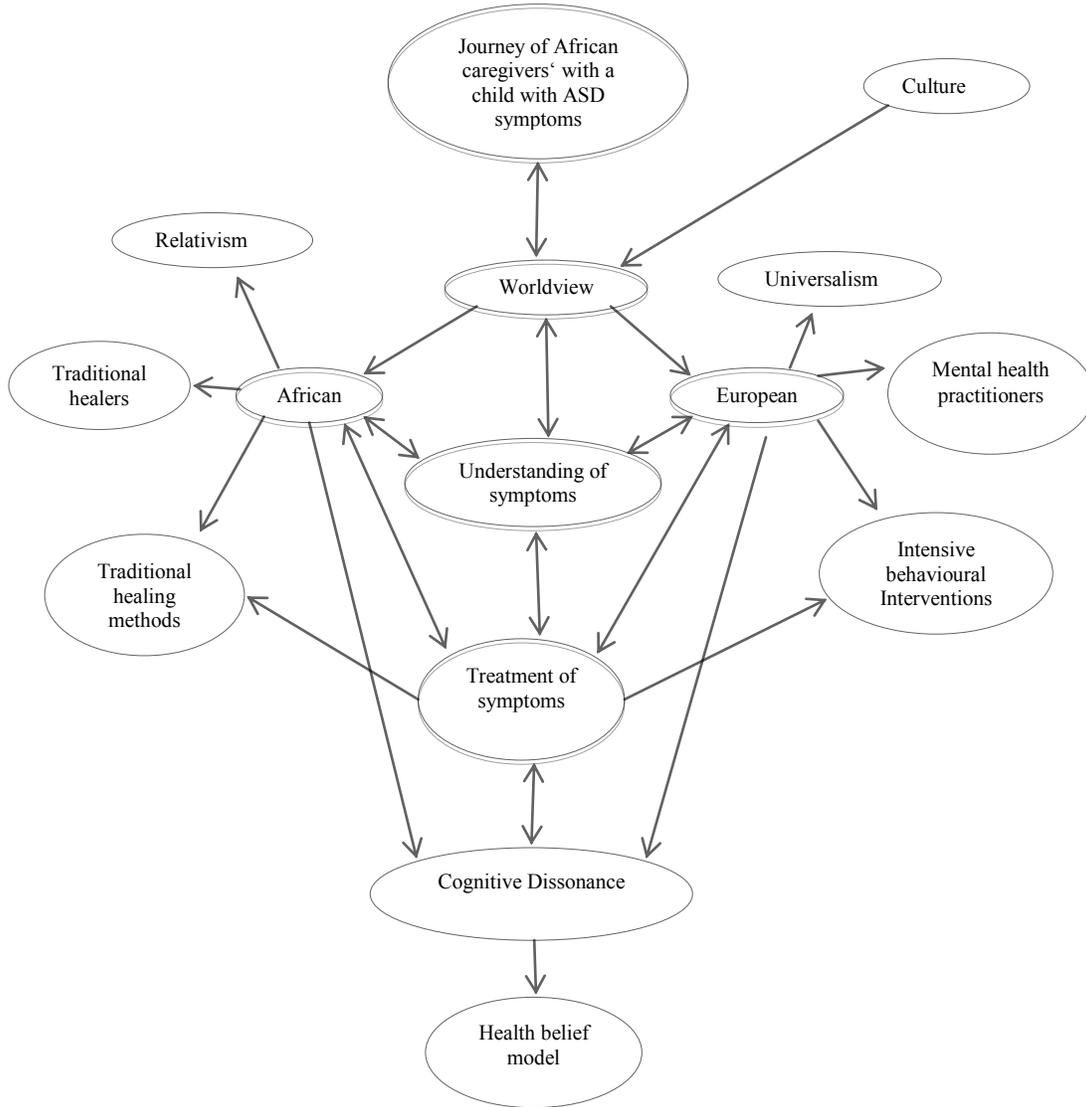


Figure 2. Conceptual Map of the Study

This conceptual map draws all the elements of this study together to visually present how the research has been conceptualized by the researcher.

CHAPTER THREE: METHODOLOGY

3.1. Introduction

In this chapter, the methodology for the study is presented. The chapter therefore discusses the design of the study, the study location, the study population, and sampling techniques and sample size. In addition, the research instrument is described and its validity and reliability are discussed. Following this, steps employed to analyze the data are described. The chapter concludes with ethical issues which were considered while the research was being carried out.

3.2. Design of the Study

This study aimed to collect reliable and valid information on the journey of African caregivers with a child with ASD symptoms. To accomplish this, the researcher invited the caregivers to share their narratives. For this reason, a qualitative research design was chosen for the study. A qualitative research design was preferred since the study was targeted at capturing the subjective meanings that caregivers attributed to their journeys (Neuman & Robson, 2004). A qualitative design also facilitated the opportunity for the researcher and caregivers to engage in in-depth discussions of the narratives and descriptions that were related by the caregivers (Ulin, Robinson, Tolley, & McNeill, 2002). Hence a narrative research approach was used in the study.

According to Ollerenshaw and Creswell (2002) a narrative approach requires an interpretation of the human experience from a subjective perspective. In light of this, a phenomenological approach was also utilized. Willig (2013) notes that phenomenology as a research framework resonates with how people experience their world by drawing on their own understandings and perceptions of the issues under investigation. Babbie and Mouton (2013) describes phenomenology as a means for studying the perspectives of the world of participants. It also attempts to provide detailed descriptions of the participants' consciousness, while grasping the diversity of their experiences and ultimately making the meanings of these experiences intelligible. In relation to the present study, phenomenology was therefore used to describe what the phenomenon of the study was, according to the caregivers' descriptions of it.

3.3. Location of the Study

The study was conducted at a school that caters for children with special needs which is located in Durban in the KwaZulu-Natal province of South Africa. The school caters for children with a range of physical and mental disabilities. The school was chosen as the research site as the majority of the caregivers who participated were recruited on the basis of their child attending this school for their ASD symptoms. By holding the interviews at the school the caregivers had easy access to the research site and were additionally provided familiarity of the environment.

A schedule was drawn up of the different dates and times that the interviews would be held. The research interview appointments were negotiated with the caregivers. The interviews took place over three Saturdays where two interview sessions on average were conducted each Saturday. On the final day of the interviews, three caregivers were interviewed as there was a total of seven caregivers.

Since the interviews were of a sensitive nature, it was planned that the interviews would be held in a private setting where the caregivers would feel psychologically safe to share sensitive information about their journeys. An office which is used by the school guidance teacher was set as the interview venue. This venue was located at the end of the staff section and provided seclusion from the rest of the school building. In addition, there was not much activity at the school over the weekends that interviews were held. Consequently, the secluded location of the venue ensured that, should there be persons passing by, information resulting from the conversations would not be overheard. It was believed that this would impart a sense of psychological safety and information confidentiality to the caregivers. The interview sessions lasted between 45 to 60 minutes and were conducted in either English or Isi-Zulu depending on the preference of the participant.

3.4. Study Population

The study population consisted of seven caregivers. All of the caregivers were of African descent and lived in KwaZulu-Natal. The ASD symptoms of the caregivers' children varied. The study population is summarized in Table 3 below.

TABLE 3				
DESCRIPTION OF STUDY POPULATION				
Participants	Primary Caregiver	Child's Gender	Child's Age	Child's Symptoms
Caregiver 1	Mother and Father	Male	8	Asperger's Syndrome
Caregiver 2	Mother	Male	10	Autism
Caregiver 3	Mother	Female	3	Childhood disintegrative disorder
Caregiver 4	Aunt	Male	11	Atypical Autism
Caregiver 5	Mother	Male	4	Autism
Caregiver 6	Grandmother	Male	15	Asperger's Syndrome
Caregiver 7	Grandmother	Male	7	Autism

3.4.1. Inclusion and Exclusion Criteria

According to Manning et al. (2013) there are no biological markers for ASD. ASD symptoms are commonly diagnosed based on their identifying features which are based on behavioural and cognitive elements. The current best practice of identifying these markers is carried out by experienced clinicians who employ methods such as detailed history taking and direct observation. According to Manning et al. (2013) in the diagnosis of ASD symptoms these clinicians comprise of psychologists, psychiatrists, physicians, paediatricians, and sometimes developmental specialists such as speech and language pathologists and occupational therapists. Given this, the inclusion criterion was based on having attained a professional diagnosis for an ASD symptom disorder from any one of the above-listed clinicians (Mitchell & Holdt, 2014).

A study conducted by Chamak et al. (2011) indicated that in some instances mental health practitioners were reluctant to give a diagnosis for ASD symptoms even when the child presented with ASD symptoms. This reluctance resulted from the complexity presented by ASD symptoms in that they did not manifest themselves in the same way for all children but varied from child to child (Chamak et al., 2011). Based on this, it was those caregivers whose mental health professionals had confirmed that their child's problems were the result of ASD symptoms who were included in the study, even though an official diagnosis had not been attained. The children of these caregivers were continuously under direct observation for ASD

symptomatology for an extended period ranging from six months to 3 years. However, the caregivers who participated in the study were those who had received a diagnosis for their child, within the last ten years or less. This allowed caregivers to recall their journeys as accurately as possible, as longer periods of time may have interfered with memory recall.

The last criterion that the caregivers had to meet was that of being from an African cultural background. A distinction was not made between the languages that the caregivers spoke. This was on the basis that the traditional worldview of Africans living in South Africa was similar, and the dissimilarities only lay in the names that were given for traditional treatments. Even though there was no language discrimination, all the caregivers who participated were Isi-Zulu speaking as the people in the province where the sample was recruited were predominantly Isi-Zulu speaking.

As a precautionary measure, caregivers who had suspected that their child's symptoms were ASD in nature but had not interacted with mental health practitioners were not included in the study. It was considered that relying on the professional opinion on mental health practitioners was a more reliable index than relying on the caregivers' assumptions. Similarly, in instances where a diagnosis had been received for the child more than 10 years ago, these caregivers were not considered for participation as the journeys that they engaged in would not be recalled as readily as those which had been more recent.

3.5. Sample Techniques and Sample size

Caregivers were selected using a purposive sampling technique. This non-probability sampling technique allowed for a convenient access of participants as they were approached on the basis of being relevant caregivers of children in a class tailored for ASD. The sample size initially consisted of nine caregivers; however two caregivers were unable to continue with participation due to personal circumstances. The final sample size consisted of seven caregivers.

3.6. Research Instrument

The research instrument consisted of an interview schedule (Appendix 1) which is composed of nine questions and served as a guide only in driving the data collection process.

Probing questions were used to further explore the narratives of caregivers during the interview process. The interview questions were constructed by drawing on ASD literature, in collaboration with the supervising professor of the research and the hypothesis of the study. Given that all caregivers were Isi-Zulu speaking, the research instrument was translated from English, the language which it was devised, into Isi-Zulu (Appendix 5). Translating the interview schedule to suit the home-language of caregivers enabled the interviews to be conducted in either English or Isi-Zulu depending on the preference of each caregiver.

3.6.1. Credibility and Reliability

According to Silverman (2008) there is no golden key to validity in qualitative research. However, Silverman (2008) provides a guide on how qualitative research which is genuinely based on critical investigation can be conducted. Anecdotalism is a term used for research which is based on using a few well-chosen examples from the data collected, thus excluding collected data which does not support the hypothesis presented. According to Silverman (2008) anecdotalism presents a threat to the credibility of the study as it interferes with objectivity. To improve the credibility and reliability of the study, the bias of anecdotalism was therefore avoided. In addition, to avoid subjectivity, this research used the principle of refutability and the constant comparative method.

Popper (1959, in Silverman, 2008) indicates that the principle of refutability requires that the evidence that supports the hypothesis that has been gained through data collection should be subjected to critical rationalism. The process of critical rationalism aims to refute any assumed relations between the phenomena being studied (Silverman, 2008). In this research, critical rationalism was achieved by falsifying or carefully excluding invalid correlations. By doing so, the research aimed to offer objectivity by including deviant cases in the research, which meant using data which both supported and refuted the hypothesis. As such, all data collected from the caregivers' narratives have been included in the study.

A second method which was used to achieve credibility was the constant comparative method (Silverman, 2008). This method involved finding another case through which an

alternate hypothesis is tested (Silverman, 2008). This method was applied by starting with a small selection of the data for analysis and steadily expanding. By so doing the entire emerging hypothesis could be identified. By applying both these processes, the threats of anecdotalism were minimized as the research aimed to present all the narratives from caregivers. The research aimed to achieve reliability by including descriptions which are low-inference in the research. Low inference descriptors are items which provide actual observations from the data collection process such as actual accounts of what the caregivers said (Morse, Barrett, Mayan, Olsen & Spier, 2008).

In this research, audio recordings of participants' narratives were transcribed verbatim and analyzed according to what and how the caregivers related their narratives by quoting their words rather than providing summaries or reconstructions of their accounts. By using low inference descriptors, the research aimed to achieve actual, concrete and detailed information which did not represent the researcher's personal representation of the meanings contained in the data.

3.7. Data Analysis

In keeping with the exploratory and descriptive aim of this study, the thematic analysis (TA) technique was used as a method for data analysis. This technique was used from the essentialist perspective which explains the meanings, experiences and reality of participants. In addition, the study used a semantic approach. This approach meant that themes would be identified from the data collected and involved moving beyond mere description to interpreting the findings.

The study therefore followed the six steps of TA as described by Braun and Clarke (2006):

Stage One: Reading and reading the data, and emerging ideas noted down to allow the researcher to familiarize herself with the data.

Stage Two: Coding the data. This was effected through systematic coding of all interesting features of the collected data while grouping the data that fell within each code.

Stage Three: Looking for themes that existed in the data and organizing these according to potential themes that could be explored.

Stage Four: Reviewing the themes to check if they fitted the coded extracts as well as entire data sets. This process was followed by the generation of a thematic map of the analysis.

Stage Five: Defining and naming the resulting themes. This stage proved to be an on-going analysis which refined the specifics of each theme and also served to paint an overall picture provided by the analysis.

Stage Six: Producing a report of the findings of the data which incorporate extracts from the narratives of caregivers. This report is presented in Chapter Four of this thesis.

3.8. Ethical Considerations

The present study falls under the category of sensitive research. According to McCosker, Barnard and Gerber (2001) research is considered to be sensitive when it has the potential to invoke emotions laden with feelings of dread. Liamputtong, (2006) additionally suggests that sensitive studies are those where there are potential significant emotional, physical and spiritual consequences for persons involved. In this study, caregivers were requested to relate their narratives associated with to their child's illness. As noted by Hutton and Caron (2005) being a caregiver is a complex task, however being a caregiver of a child with difficult symptoms complicates this task further. Given the sensitive nature of the study, several steps were taken to ensure that participants would not be subjected to any harm due to participation.

At the initial stage, ethical clearance was requested from the Ethics Review Committee (ERC) of the University of KwaZulu-Natal for evaluation as to whether the research possessed any harm for the participants. After the ERC evaluated the methodology, location and ethical information, the research was approved.

A second measure that was implemented to ensure that the research was ethical was the safeguarding of participants from potential emotional distress that could arise when asked to narrate their journeys. In attending to this, a registered Counselling Psychologist was present at the research site so as to intervene should any participants experience emotional distress. In

addition to safeguarding the psychological safety of participants, the four principles guiding ethical research were implemented (Wassenaar, 2006). These principles are informed consent, confidentiality, beneficence and non-maleficence.

Informed consent: Participation in the study was voluntary. Caregivers were informed of their right to withdraw from the study at any point without any harm to them if they wished to do so.

Confidentiality: The aim of the study was explained to the caregivers and they were assured that no personal or identifiable information would be mentioned in the research findings or in any research publication in peer reviewed journals arising from participation. Furthermore, caregivers were requested to provide written informed consent (Appendices 4 and 7) for their participation to demonstrate that their participation was free of coercion. Permission to audio-tape the interview was also requested from the participants. This was granted.

Beneficence: There were no direct benefits for participation that the caregivers received. However, the caregivers were informed that their participation would be of benefit to the literature that is available on ASD symptoms and South Africans. Some caregivers indicated that they wished they could benefit by receiving treatment for their child in exchange for their participation. When it was explained that this was not a resource that the researcher could avail, the caregivers continued with participation and felt that even contributing by sharing their narratives would be beneficial to the mental health system of finding means to alleviate their children's symptoms if not cure them completely.

Non-Maleficence: This principle ensured that the study would not harm the participant in any way either psychologically or methodologically, or through issues pertaining to the subject matter. The ethical clearance for the study that was received from the ERC of the University of KwaZulu-Natal indicated that the study did not pose a risk to the participants.

CHAPTER FOUR: RESULTS OF THE STUDY

4.1. Introduction

This chapter presents the results of the study. The presentation is organized according to the research questions investigated. It begins with a detailed descriptive analysis of the caregivers and their children. Although the interviews were conducted with only caregivers and they are the only respondents, the relevance of describing their children is based on the fact that it is the child that is affected by ASD symptoms and hence the journeys undertaken by the caregivers were associated with the child's symptoms. Following this analysis, the results are presented by showing the themes that emerged for each of the research questions. This chapter concludes with a summary of the findings.

4.2. Descriptive Analysis of the Caregivers

4.2.1. Caregiver's relationship to the child

The complete sample of participants predominantly consisted of females with one of the caregivers being accompanied by her husband, however the relation that the caregiver had with the child differed. This relationship is indicated below.

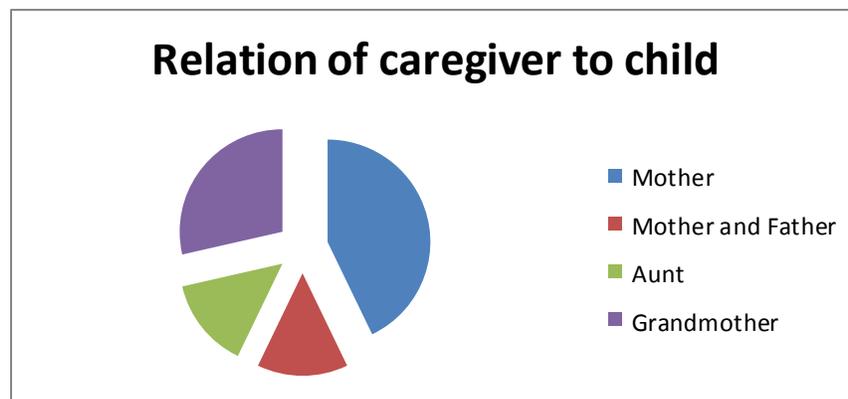


Figure 3. Caregivers' relationship to the child

4.2.2. Gender of the child

The majority of the caregivers' children were male; hence affected female children were a minority in the sample. The percentage distribution of the children's gender is illustrated below.

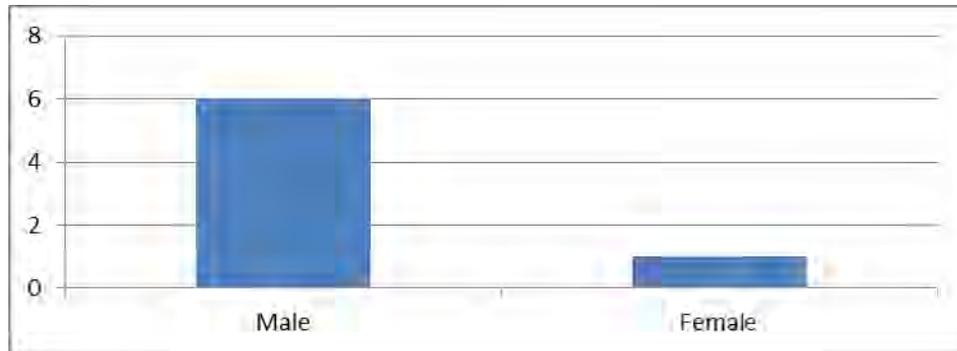


Figure 4. Distribution of children's gender

4.2.3. Ages of the children

The ages of the children implicated in the study ranged from three to fifteen (3-15) years.

4.2.4. Presenting symptoms of the child

The presenting symptoms of the child are indicated in Figure 5 below.

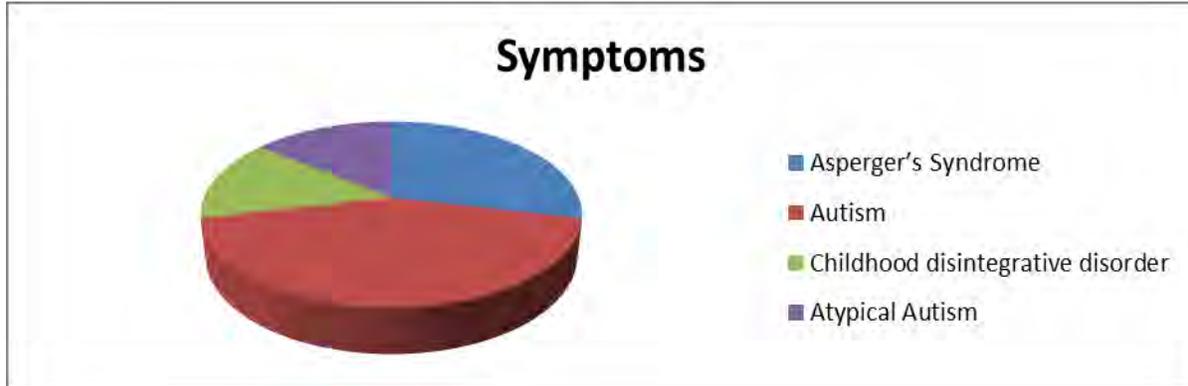


Figure 5. The Children's Types of ASD Symptoms

Information highlighted in Figure 5 above revealed that the dominant symptom of the children whose caregivers were involved in the study was Autism disorder followed by Asperger's syndrome.

4.3. Presentation of Results Research Question by Research Question

As indicated in Chapter One of this study, the present research aimed to answer the following three questions:

1. How do African caregivers interpret and understand the origin and meaning of their ASD symptoms?
2. What journeys or experiences do African caregivers undergo to obtain help and treatment for their child with ASD symptoms?
3. In what specific ways are African caregivers affected by the journey of attaining help for their child's ASD symptoms?

Presented below are the results of this study in relation to these questions. The results attained under Research Question One are presented immediately below in themes which pinpoint the patterns that emerged.

The first theme relates to the symptoms that the child displayed which led the caregiver to initiate attaining help. The second theme addresses how caregivers understood their children's symptoms.

4.3.1. Theme One: Symptoms that initiated the journey

Among the most notable cause for concern that caregivers reported were key three issues. These issues related to their child displaying inadequate social interaction, not reaching their developmental milestones, and caregivers having a sense that something just did not feel right.

4.3.1.1. Inadequate social communication

The most commonly identified symptoms that alerted caregivers about their children's problems were linked to problems with social interaction and communication. Commenting in this regard, one caregiver noted:

"...when he was 2 (years old), I could tell that something was wrong, even before that I was worried because he was not looking at me in the eye".

The same caregiver went on to state concerns about her son's speech:

"He wasn't also making baby talk, you know, like a child making sounds".

Another caregiver related similar concerns connected to the issue of eye contact and the manner in which her child communicated:

"He didn't look at me, he was always looking down... but when I spoke to him, he will repeat everything I say ... I could tell that he was not understanding"

The repetition of words mentioned by Participant 2 is not an uncommon ASD symptomatology. This repetitive speech pattern is known as *echolalia*. Verbal children who express ASD symptoms are often echolalic which means they do use words however their word choice is based on a memorized patterns rather than actual understanding.

Commenting on her sons symptoms, another participant observed:

“We could see that my son had sometimes done unusual things like spinning around and around but we weren’t worried until he didn’t talk.”

For some caregivers, however, it was the child’s overly cooperative behaviours which were the cause of concern. A caregiver who was looking after her grandson noted:

“People used to compliment his mother saying, “You have a king of a child.” He was never troublesome. No crying, nothing. Even when he was hungry or waking up, it didn’t make a difference.”

Even though the child did not present symptoms which are generally deemed as problematic, this in itself became a cause for concern. As with participant 7, this caused feelings of panic:

“My cousin showed me that the child is not alone. There is a shadow that is with the child. Then in a week my grandmother came from Transkei. She said to me, “Where is the boy?” Then I gave her the child and she immediately started screaming, saying “Kodwa baba, senzeni?” (But father what have we done?)

4.3.1.2. Problems with reaching developmental milestones

Caregivers also cited the problem of their children not reaching some developmental milestones as being what alerted them that their child might be experiencing illness. In this regard, one caregiver stated:

“When we went to the clinic they said he was developing slowly, his muscles were not forming according to where he should be at 9 months.”

Another caregiver whose child was diagnosed with childhood disintegrative disorder expressed what caused her initial sense of concern:

“She was about 3 (years of age), all of a sudden, she couldn’t speak like she was before but we didn’t think anything of it... We also started noticing that it was getting worse and worse. Then just like that she started dropping things on the floor, her hands were becoming weak, also her walking. Eventually we took her to the doctor...”

4.3.1.3. Problems related to sensory issues

Concerns for Participant 4 were raised when her child exhibited sensory problems:

“He didn’t want me to carry him, so I would put him in a carry cot to calm him. If I tried to hold him, he would be restless until I left him alone.”

Participant 4 further noted how the child’s sensory problems became exacerbated by clothes and human touch:

“Once I put his vest on he would cry like there was no tomorrow... Even rubbing Vaseline on his body was as if I’m hurting him.”

4.3.2. Theme Two: How caregivers’ understood their children’s symptoms

Caregivers assigned various understandings to their children’s symptoms. Some caregivers accepted understanding the symptoms from the perspective of mental health practitioners who had given their child a diagnosis:

“They said its Asperger’s syndrome, I have to accept that.”

When the caregiver was asked what Asperger’s syndrome was, she answered saying:

“It’s an illness which is like what’s happening to my son. He’s not good with socializing with other people, even children his age. He doesn’t like people. He just likes to play his own things, from the time he was born.”

A second caregiver who had similarly received a diagnosis for her child explained her child's symptoms in medical terms. This caregiver had received a diagnosis for classical autism from a clinical psychologist:

"The psychologist informed us that he is nonverbal, meaning that his speech problems mean he can't talk because of the autism. Also with his other problems it was because of the autism."

Both these caregivers were further interviewed to ascertain whether their understanding of the children's symptoms could be explained in cultural terms. Although these caregivers indicated an awareness of cultural explanations of ASD and associated with people who thought their child's problems were of supernatural causes, they themselves did not subscribe to this belief system:

"Of course some people say that. But for me, I don't believe in that."

Another caregiver who did not subscribe to the African cultural belief system related as follows:

"His grandmother, from his father's side was insisting that this illness is from the elders (ancestors) but me and my husband, we believe what the doctor says."

Unlike the two caregivers above, however, other caregivers understood the symptoms from both a medical and a cultural perspective. For instance, one of the caregivers reported:

"The teachers at school told me to take him to the doctor, but the doctors can't help him because this is a family problem. His father did not perform a ritual for spoiling my daughter, the ancestors have turned their backs on the child, they do not know him."

This caregiver went on to say:

"When he (the father of the child) appeases the ancestors, then the doctors will be able to help him (the child). For now, it's pointless taking him there."

Other caregivers who understood ASD symptoms from both cultural and European perspectives reported understanding their child's symptoms as follows:

"It's not the first time that bad things happen with this child... The doctor said it's a disorder but we know that this disorder is a punishment from the elders.

And:

"Even though we do cleansing, it's only because my relatives say it's something necessary, we do it. I don't want to upset them and bring bad blood but for me, this thing is what the doctors say. It's autism, not a curse."

The above presentation shows that the caregivers' explanations of how they understood their child's ASD symptoms fell into two categories. On the one hand, there were caregivers who followed the biomedical explanation of ASD symptoms. On the other hand, there were caregivers who understood the symptoms from both the European and the traditional African worldview. Although these caregivers viewed both systems as working together, some of the caregivers tended to assign more power to cultural beliefs. Others were in-between.

4.3.3. Theme Three: Routes taken by caregivers to get help for ASD symptoms

An analysis of caregivers' routes to seek help for their child indicated that the process of attaining help was not straight forward. From the interviews, it emerged that the majority of the caregivers alternated their worldviews when getting help for child's symptoms. It seemed that some caregivers used both biomedical and traditional help providers. This was with the exception of two caregivers who did not subscribe to African traditional beliefs. The paths that the caregivers used are tabled below.

Participant	Diagnosis	Help Provider According to the Order in which they were Consulted				
		First	Second	Third	Fourth	Fifth
Caregiver 1	Asperger's Syndrome	Pediatrician	Clinical Psychologist	Speech Therapist	Occupational Therapist	Physiotherapist
Caregiver 2	Autism	General Doctor	Psychiatrist	Educational Psychologist	Speech Therapist	Audiologist
Caregiver 3	Childhood Disintegrative Disorder	Herbalist (Inyanga)	Faith Healer (Umthandazi)	Nurse	General Doctor	Faith Healer (Umthandazi)
Caregiver 4	Atypical Autism	General Doctor	Occupational Therapist	A Diviner (Isangoma)	Faith Healer (Umthandazi)	
Caregiver 5	Autism	Clinic	General Doctor	Herbalist (Inyanga)		
Caregiver 6	Asperger's Syndrome	Nurse	Faith Healer (Umthandazi)	Diviner (Isangoma)		
Caregiver 7	Autism	Herbalist (Inyanga)	Clinic	Herbalist	Diviner (Isangoma)	

Data summarized in the above table show that the routes which caregivers took when seeking help for their children varied. The majority of caregivers tended to start by visiting biomedical practitioners. These practitioners consisted of pediatricians, general doctors and nurses. The caregivers who started their help seeking using the traditional route in the first instance visited a herbalist. What is noticeable about the caregivers' paths is that irrespective of whether the caregiver started off using the biomedical or the traditional medicine route, their help seeking process often involved some kind of vacillation, with most of them having the need to visit both types of healing systems in the course of their attempt to secure relevant attention for their children. However, two of the caregivers' routes deviated from the trend of the majority. These caregivers indicated that they did not believe in the traditional system of healing and therefore their paths involved seeking help only from biomedical practitioners.

To find out why the other caregivers had approached the help providers the way they did, namely trying to make use of the two systems in the course of their help-seeking process, they (the caregivers who used both the biomedical and the African traditional healing systems) responded as follows:

“I want my child to be healed so I go to both the doctors and traditional healer.”

And:

“Maybe the doctor’s way can be quicker but I can’t leave the way of the elders because things can get even worse.”

The two excerpts above showed that the overall feelings expressed by caregivers were that they believed doctors could cure their child’s symptoms. At the same time, however, the reasons attributed to seeking help from traditional healers seemed to lie in finding out the cause of the symptoms, which in turn would charter the path required for the lasting cure of their symptoms.

4.3.2. Research Question 2: What journeys or experiences do African caregivers undergo to obtain help and treatment for their children with ASD symptoms?

This research question sought to explore the caregivers’ experiences or journeys undertaken and how they felt about the help and treatment that they received for their children. Information collected from the interviews was grouped into the following four main themes, namely, help providers not being able to cure the child’s symptoms, personal conflict regarding treatments, lack of culturally relevant help from mental health practitioners, and the heavy financial implication of treatments.

4.3.2.1. Help providers not being able to cure the child’s symptoms

Analysis of the interview data with the caregivers indicated that some caregivers felt disappointed that the help providers, which included both mental health practitioners and

traditional healers, were unable to cure their children's symptoms. For instance, a caregiver expressed her frustration regarding social skills training as follows:

"They told me to take him for social skills training, but it's not working. Okay, I see a difference, but it's so small."

Another caregiver expressed a similar dissatisfaction with the time it took for the symptoms to be alleviated:

"We've seen a lot of specialists, we've been going for three years now, the progress is just slow."

And:

"I've used many herbs and also rituals, but I still have to continue."

As noted by the caregiver above, another significant difficulty expressed by caregivers related to the high number of help providers they had consulted:

"It's doctor after doctor after doctor, but there is no cure."

Another caregiver related:

"If I had to say how many specialists we went to, I wouldn't even be able to count."

The same caregiver went on to express the helplessness of the situation:

"The sangoma (diviner) said the child needs to be united with his elders, we should do a cleansing ritual. We have done it but for now we haven't seen a considerable change."

In addition to the frustration that caregivers experienced with minimal improvement of their child's symptoms was the fact that despite consulting numerous help providers, caregivers indicated that they felt significantly challenged when trying to obtain a diagnosis. In particular, as regards the question of receiving a diagnosis for the ASD symptoms, caregivers were troubled by mental health practitioners' reluctance to provide a diagnosis:

“He (the doctor) wouldn’t be straightforward and tell us what’s the problem. He says it seems to be autism, but to tell us straight, no.”

According to a caregiver, this reluctance implied that it was still possible for parents to access services even if the parents had not received a diagnosis for their child. The caregiver related:

“He (the doctor) said we don’t need a diagnosis, we can take him to a speech therapist ... even without it.”

According to this same caregiver, a diagnosis would have provided a more reliable way to plan the child’s treatment:

“If we knew for sure, if he told us for sure then he would tell us what to do but because he’s not saying it, it’s like he’s not sure, so how can the child be treated?”

In some instances, caregivers felt that mental health practitioners tended to minimize their concern about their children’s development by encouraging them to wait for their children to grow out of their problems. Commenting in this regard, one caregiver stated:

“When he was 18 months, he used to spin himself round and round on the floor. When we told the doctor he said that we must not worry too much because sometimes kids outgrow their quirks.”

Some of the caregivers noted that they needed to be persistent if they were to get a diagnosis for their child:

“What helped the situation, I guess, was not giving up. It was such a difficult time.”

The majority of comments made by the caregivers concerning their feelings about the help attained showed evidence of enormous feelings of frustration and unmet expectations. However, some caregivers had positive narratives. These caregivers attributed their frustration to their child’s illness rather than mental health practitioners:

“It’s the disorder that’s the problem but the doctors mostly have been effective. In the beginning it was a struggle, a real struggle of seeing specialist after specialist because they are expensive. It’s not cheap, you know, all the travelling and taking time off work, but when we had a diagnosis, he started therapy. Even though he’s still having a lot of problems, he’s getting better. We can see the improvement. It’s slow but we can see it.”

Another caregiver who similarly expressed positive sentiments noted that the treatment her child was receiving gave her hope for her child’s future wellbeing:

“From the time he started ABA, it gave us hope that one day he’ll be able to have a life like other children, you know. Even with him, he’s more manageable now”.

Only two of the caregivers obtained a diagnosis for their child’s ASD symptoms. It was also remarkable that these two caregivers, who obtained a diagnosis, despite being of African background, had not consulted traditional cultural methods. These diagnoses were obtained from a clinical psychologist and a paediatrician.

4.3.3. Research Question Three: In what specific ways are African caregivers affected by the journey of attaining help for their child’s ASD symptoms?

4.3.3.1 The financial implications of getting treatment for the child

Many of the caregivers complained of the financial implications that accompanied the process of attaining help, as well as implementing the recommended treatments. These costs included transportation, visits to mental health practitioners and traditional healers, as well as paying for the services that they were given. Commenting in this regard, one of the caregivers said:

“It was so expensive to get help because we had to take four taxis return to go to the psychologist. We had to take another two taxis return to go to the faith healer. Even when we arrived there, we paid.”

Another caregiver went on to say:

“The whole family had to put in money to help because I’m not working, but when nothing was raising her up, it looked like the damage was too great and we gave up. But at least the sangoma told us where to look.”

One caregiver who used ABA as an intervention for her daughter noted the following about the financial burden that attaining help resulted in:

“It was very expensive, me and my husband we had to make a lot of sacrifices to continue ABA treatments for her.”

And:

“You know, it’s never easy. But you do all that you can for your child. You love them, they yours. Even if it means all your money is going there.”

As a result of the high costs of treatment, caregivers often abandoned many treatments that they had been using for their child and opted to use one. In this regard, one caregiver noted:

“We eventually stopped (doctors’ visits) and started going more regularly to the faith healer.”

All in all, most of the caregivers interviewed were unanimous in their view that treatment that they were given for the ASD symptoms placed a considerable financial burden on them. In cases where caregivers could no longer afford concurrently using both biomedical and traditional healing, one of these fell away. The interviews revealed that most caregivers felt that treatments from traditional healers were less expensive than those from mental health practitioners.

4.3.3.2. Personal conflict regarding treatments

Another issue that came to light during the interviews was the internal personal conflict that some of the caregivers seemed to experience regarding the treatment options that were offered. For example, some of the caregivers felt challenged regarding which treatment to implement. One caregiver in this regard noted as follows:

“The doctors tell you something else, the sangoma tells you something else, you end up not knowing which one to do because you cannot ignore the cultural practices.”

In a similar vein, another caregiver related:

—It reached a point where I could not sleep and I started losing weight thinking about what I must do. Because my family were against using ABA, they were saying, “What ABA? Just take the child to the diviner.”

In certain instances caregivers felt that mental health practitioners lacked an understanding of their cultural perspective of illness and these clashed with how they believed their child’s symptoms should be cured. This contributed to their internal conflict. In this regard one of the caregivers noted as follows:

“The doctors can’t see the reason, they can’t tell you what’s causing the illness. They can only see the signs of it... For me this was difficult because the way we know, we should treat the root of the problem not just the symptom.”

And:

—Traditional rituals are very important. If you do not follow them, there will be bad consequences, but the doctors they don’t tell you that.”

And:

—I grew up in the traditional practices. I cannot question many things in the traditions but our traditional beliefs do not mix with the way we understand African things.”

And:

“When the relatives were saying I must focus more on the traditional herbs so things can go well for the family, but deep inside, I felt I must also try therapy”

And:

“I didn’t know which treatments to use first so I did both of it at the same time but it was too expensive so sometimes I would take him for social skills, and treat him using imphepho, just alternating the two.”

And:

“I don’t really know which one was working, because I used both of them at the same time.”

4.4. Summary of Findings

ASD symptoms manifested themselves in the same way as that defined by the DSM-V. The dominant symptoms were social communication, developmental lag and sensory problems. This study revealed that the way the caregivers understood the symptoms was mixed. Thus while the majority of the caregivers (five of the seven studied) ascribed them to supernatural causes they also subscribed to the biomedical approach for treating the symptoms. Two of the caregivers opted to understand the symptoms solely from a biomedical perspective and did not believe in traditional cultural explanations.

Given the above variation in the caregivers’ explanations and understanding the symptoms, the routes that caregivers followed in their journey to find help for their children’s symptoms also varied. Only two of the caregivers stuck to using the help of the mental health practitioners in this process, while five of the seven caregivers saw need to consult both the mental health practitioners and the traditional healers in this regard. The mental health practitioners that both groups engaged were noted to consist of medical doctors, nurses, psychologists, psychiatrists, audiologists, speech therapists and occupational therapists. Traditional healers that were consulted consisted of herbalists, diviners and faith healers. From the accounts given, most of these caregivers alternated between the two categories of help providers, African and Western.

Narratives from caregivers provided insight into how they felt about the help and treatment that they were offered. From these, it was noted that the caregivers had an expectation that consulting a help provider would either result in getting their child’s symptoms cured or in receiving a diagnosis. When this expectation was not met, the caregivers felt frustrated and demoralized. This explains why most of the caregivers consulted more than one specialist. Most caregivers cited their reason for consulting traditional healers as including the idea that it was something that could not be avoided since the biomedical model was incapable of dealing

decisively with the symptoms. As part of their growing up they have been brought up to believe that certain symptoms that could not be remedied through the Western medical process could be remedied by means of traditional medicine, through consultation with traditional healers.

Likewise, it was discovered from the interview process that caregivers were affected badly by the challenge of having to care for their children with ASD symptom presentation. The key challenges included high capital expenditure and intensive and endless walking to and from the help providers. The overall psychological impact of all these was the demoralization suffered by the caregivers. The next chapter will discuss and interpret these findings.

CHAPTER FIVE: DISCUSSION AND CONCLUSION

5.1. Introduction

In this chapter, the findings of the study presented in the last chapter are discussed research question by research question. The aim of this is to indicate how the main research questions formulated in the introductory chapter have been answered. The findings of the study will also be interpreted, and an attempt will be made to relate them to the results of other similar studies in the literature reviewed. Implications of the findings and recommendations for policy and practice issuing from the present study will also be made. Finally, the study limitations and areas for further research will be delineated.

5.2. Discussion of Results Research Question by Research Question

5.2.1. Research Question One: *How do African caregivers interpret and understand the origin and meaning of their children's ASD symptoms?*

The results of the present study in relation to the above question have been presented in Section 4.3. of Chapter Four. According to information highlighted in that section, most of the caregivers studied interpreted and understood the origin and meaning of their children's ASD symptoms from the point of view of the Western biomedical model as well as according to the framework of the African traditional worldview. In responding to this finding, the first step is to recall that the extant literature from European and African traditional understanding of mental illness indicated that the two systems had different ways of explaining health problems (Hammonde-Tooke, 1989). The conclusion arrived at in reviewing this literature showed that when confronted by a difficult illness, African caregivers did not subscribe entirely to the Eurocentric worldview, which tends to explain all illnesses and diseases from a biomedical or biopsychosocial perspective. Consistent with this understanding, most of the caregivers who participated in this study saw ASD symptoms as a result of interactions between the family system, the community and the ancestors, and this was in addition to their faith in the possibility that the biomedical model would provide them with a full diagnosis of their children's illnesses.

Hence, the differential journeys undertaken by African caregivers in search of help for their children who have ASD symptoms can be understood from the perspective of the theory of constructive alternativism credited to George Kelly (1955). According to this theory, people do not have only one particular way of looking at and understanding the world. They approach the world from multiple perspectives. In this way, when they are challenged with a problem in the world, they try to follow alternative approaches to circumvent it. The way in which this preposition can be seen was reflected in the behaviours of African caregivers in the context of this study as the double perspective with which the majority of the participant caregivers approached the understanding of the ASD symptoms of their children. Five out of seven of the caregivers studied described their children's illnesses as ukufa kwabantu, which means that in their view the cause of their children's disorders can be explained according to the indigenous perspective which sees the illness as a response to a withdrawal of protection by a supernatural spirit, god or ancestor (Edwards, 2011). On the other hand, the same five caregivers also felt the need to consult the expertise of mainstream mental health practitioners, who operated from the biomedical model of the DSM-V, in search of an answer for their children's ASD symptoms.

This dualism in the manner of African caregivers approaches to their children's illnesses is consistent with Kelly's (1955) theory which also posits that peoples experiences, thoughts, feelings and behaviours, referred to in that theory as their construction system, vary as people interpret the unfolding of events. This point can be interpreted to mean that when things do not occur in the manner expected based on previous efforts made to resolve the problem, be they indigenous or modern, the result is that people make an effort to engage in some kind of adaption aimed at drawing from an alternative approach to looking at the issue under consideration. This is known as the experience corollary and refers to the change in the behaviours that people engage in when dealing with life challenges. In the context of the present study, having a child with an illness usually involves an extensive process of searching for viable, decisive help. Based on previous cultural experience, caregivers recollected that illnesses believed to be of supernatural causation are treated through traditional healing methods. However the way

caregivers started help seeking varied, as revealed in the present study. In this way, they did not subscribe rigidly to one action plan. This was because it was not all seven caregivers who initially consulted either a faith healer, diviner or herbalist, although cultural experience would suggest that they should follow this option. Rather, in the first instance, three caregivers consulted practitioners from the biomedical system, and thereafter utilized traditional healing methods.

Two approaches can be used to explain this. The first relates to how the symptoms were first identified. Initially three caregivers did not know what the cause of their children's illness was. Consequently, they started engaging in consultation with medical practitioners, and then saw that they would not be able to pin point what the child's illness was. With this turn of events, that is, with the inability of the medical practitioners to explain the illness, they then had to turn to traditional healing methods for a possible alternative option. On the other hand, caregivers who initially suspected that the illness was of supernatural cause, for instance one of the caregivers indicated that a relative immediately believed that the child was "not alone and a shadow had been cast over them", were the ones that initially sought help from traditional healing methods. According to Kelly (1955) the experience corollary means that when things do not occur in the manner expected based on previous experience, people adapt and change their behaviour. The previous experiences of caregivers could be that when seeking help from a medical doctor, there would be identification and a lasting healing of the illness. When this was not forthcoming, the tendency to try consultation with the traditional model was put into sharp relief. Similarly, for the caregivers whose initial consultation was with traditional healing, previous experience would indicate that this would lead to accurate identification and the curing of the illness. However, when the help that the caregivers received from either traditional healers or medical doctors did not heal their child, they resorted to alternative ways of seeking help and healing. Only two of the caregivers persisted and stuck with searching for help through one of the two worldviews noted above. In that case, for those two caregivers, Kelly's theory of constructive alternativism did not apply.

5.2.2. Research Question Two: *What experiences or journeys do African caregivers undergo to obtain help and treatment for their children with ASD symptoms?*

Data relating to this question was summarized in section 4.3.1 in Chapter 4. Information in this section revealed that having a child with complex symptoms of illness is a stressful matter. This is consistent with the results of a similar study by Glass (2001). According to Glass (2001) a childhood illness is demanding and challenging for caregivers and this challenge is further exacerbated when ASD symptoms are the problem. This is because such an illness is complex and its nature is not easily understood. Similarly, the results of the present study revealed that caregivers also faced personal internal stress regarding decisions on which treatment to use for their child. Ultimately, the financial implications of consulting both mental health practitioners and traditional healers impacted caregivers' feelings when it came to treating their children's symptoms.

Congruent with literature, caregivers in the present study faced high levels of stress and frustration when help providers could not cure their children's ASD symptoms. Studies that have examined caregivers' experiences of seeking help for ASD symptoms indicate that there is a tendency for help givers to minimize caregivers' concern about their children's development by encouraging them to wait for their children to grow out of their problems (Goin-Kochel, 2006). Similarly, some of the caregivers in the present study felt frustrated by the reluctance of mental health practitioners to provide a definitive diagnosis for their children's symptoms. This trend corroborates with the result of the study conducted by Chamak et al. (2011) where French psychiatrists were reluctant to give a diagnosis for ASD symptoms citing that it was still possible for caregivers to access health care services even if the caregivers had not received a diagnosis for their children.

The results of this study were also consistent with the finding in a UK survey which showed that caregivers were not satisfied with the diagnostic process even though children were being diagnosed earlier than in previous years given that they were still experiencing lengthy delays before finally obtaining a diagnosis (Chamak et al., 2011). Thus, whilst research has shown that it is possible to diagnose ASD symptoms accurately before the age of two years, the results of the present study showed that the majority of the caregivers still found themselves

faced with a slow and frustrating period of uncertainty and worry (Goin-Kochel, 2006). In the present study, for example, five caregivers out of the seven studied consulted both mental health practitioners and traditional healers in the process, with the hope of receiving a diagnosis as well as a cure or an alleviation of the children's uncomfortable symptoms. Unfortunately, these caregivers reported the experience of being frustrated by their inability to receive the dependable diagnosis they sought. Most of them complained that even though in some instances there was a reduction in the children's symptoms, they still felt that such exceptions were not sufficient to result in satisfaction. Only two of the caregivers in the present study received a diagnosis for their child. The caregivers who received a diagnosis had consulted only mental health practitioners, and had implemented behavioural interventions as a treatment choice. Both of these caregivers, although not feeling completely satisfied with their children's progress, indicated higher levels of satisfaction in comparison with the five caregivers who had not received a diagnosis. This trend is in line with the results of similar studies by several researchers (Leonard et al., 2010; Matson, Nebel-Schwalm and Matson, 2007). Like trends reported in these other studies, caregivers in the present study who had received a diagnosis felt that this provided them with the opportunity to understand the illness affecting their children which in turn provided them with a framework for treatments to be used.

5.2.3. Research Question Three: *In what specific ways are African caregivers affected by the journey of attaining help for their children's ASD symptoms?*

The results of the present study in relation to this question were again reported in chapter 4. The trend of the study findings showed that there were altogether four major ways that both singly and in combination specifically affected the caregivers in their journey of attaining help for their children's ASD symptoms. These included the stress and demoralization of having an ASD symptom presenting child, epistemological uncertainty and the associated problem of unpredictability about how to obtain a lasting cure for the problem leading to the problem of emotional restlessness arising from lack of closure in the caregivers' journey, intensive and morale-sapping walks, back and forth from the healing agencies (African and

modern) in search of appropriate understanding and lasting cure for their children symptoms, and the excessive financial burden involved in trying to find a solution to this problem.

The results of the present study were therefore consistent with the findings of much of the previous literature on this theme. For instance, the notion of the excessive financial burden complained of by the participant caregivers as one of the major ways they were negatively affected by the challenge of having to attend to their children with ASD symptoms has been documented in numerous studies (Mitchell & Holdt, 2014). Thus as noted by Shacar (2006) because of the varied treatments needed or the complicated nature of the ASD symptoms, caregivers often find themselves overwhelmed by the financial strain they must bear.

Similarly, in line with the findings of the present study, is the result of a study conducted in South Africa which investigated caregivers' experiences of having a child with ASD symptoms, where it was reported that the expense of getting help and treatment was frightening (Mitchell & Holdt, 2014). This trend was interpreted to arise from the many types of medications and therapies, multiple transportations to and from the various help providers needed, plus expenses for anxiety medication, occupational therapy as well as behaviour-based interventions. Also, apart from traditional healing costs being high in South Africa, Karim et al., (1994) indicated that these fees were neither fixed nor standardized, and varied according to the nature of treatment and the severity of the illness. However, Case et al. (2005) reported that the fees that traditional healers charge averaged R433.00 then, which is significantly lower than therapies provided by mental health practitioners. All of these comments on the financial burden show that although the findings of the present study do not conclusively indicate whether the primary basis for caregivers' choice of traditional treatments over biomedical treatments in the long run were because of cultural reasons or financial implications, the general outcome was that when caregivers could no longer afford using treatments of mental health practitioners alongside those of traditional healers, they opted for traditional healing.

These results mean that the participant caregivers were affected in multiple ways, particularly economically and psychologically, and experienced low dissonance reduction arising from persistent conflicting worldviews confronting their need for achieving an accurate

understanding the problem of their children's illnesses in the journeys they took towards finding a respite for the crisis faced by their children presenting with ASD symptoms.

5.3. Summary of the Study

The major purpose of the present study was to explore the experiences of South African caregivers with children that present with ASD symptoms. The specific objectives were, inter alia, to discover how these caregivers interpreted and understood their children's symptoms, and the kind of help providers, whether African and/or Western, they approached in search of diagnosis and healing for their children's illnesses, and the critical ways their efforts impacted on their lives.

To implement the study, a qualitative survey design was chosen. A purposive sampling technique was used in drawing participants into the study. The study was qualitative in that it collected narratives of caregivers' experiences in their journey of searching for and obtaining a modicum of cure for their children's illness. The participants consisted of seven caregivers whose children presented with ASD symptoms. The instrument for data collection consisted of a structured interview schedule, aimed at facilitating the emergence of enriching dialogue with the caregivers, designed to help the researcher to capture the complex experiences of the participants in relation to the journeys they had to undertake in finding a cure for their children's ASD symptoms. The data collected were analyzed by means of thematic analysis, including an attempt to present multi-voiced impressions of the participants' raw or direct responses to questions put to them, in the presentation of the results. This was intended to give voice and originality to their views on the issues studied, and in that way to improve the believability of the study report.

The findings show that the participating caregivers were severely and negatively affected in four main ways in their journey towards obtaining an understanding and a cure for their children's ASD symptoms. Among these negative effects were, firstly, the stress and the demoralizing experience of having to discover that they had children with ASD symptoms.

Secondly, there was the problem of emotional restlessness and the strain of lack closure that comes with knowing that there is no predictable way of finding a lasting solution to their children's illnesses. Thirdly, there was the crisis of conflicted epistemology of healing that came with discovering that neither of the two worldviews for explaining people's illness, indigenous or western, was able to give a decisive and conclusive guidance in the intervention to be given, forcing most of them to engage in multiple and emotionally draining journeys to consult with help givers from alternative epistemologies of healing. Finally, there was the damaging impact of the excessive financial burden that goes with the challenge of having to engage in multiple and alternative journeys in search of solution for the problem of their children's ASD symptoms.

Implications of these results were examined and found to be consistent with the results of most of the similar studies carried out elsewhere aimed at discovering the kind of experiences undergone by parents of children with ASD symptoms.

One of the theories that was proposed when the research was conceptualised was the Health Belief Model as a way to explore and determine which treatments the caregivers would use and what their reasons for doing so would be. Initially, it was postulated that their cultural perspective might serve as a barrier to using biomedical treatment and therefore they would stick mostly to traditional treatments. However, the study revealed that caregivers were not limited by their cultural experience when selecting treatments for their child. Caregivers alternated, and moved back and forth from both biomedical and traditional options. The lack of consistency in applying biomedical treatments such as IBI therapies was rather attributed to limited resources whereas traditional treatments were more affordable and easier to access. It can therefore be said that the Health Belief Model does not explain caregivers' inconsistency in using biomedical treatments.

A second theory that was proposed at the outset of the research was Festingers theory of cognitive dissonance to explain how caregivers would feel and react to the treatment options that they would be offered for their child's symptoms. From this theory it was proposed that, caregivers might find themselves experiencing feelings of discomfort when having to adjust to the call of two contrasting healing systems, that with foundations in African tradition and the more mainstream system grounded in Western culture. With the discomfort it was expected that this would lead caregivers to alter their beliefs and attitudes by either seeking consonant

information or distorting or even misinterpreting dissonant evidence reduce feelings of discomfort. What the research revealed was contrary. The caregivers accepted both systems as alternatives to finding a cure for the child's symptoms. Their acceptance of both the African and Western as seen in how they moved back and forth between practitioners offering both methods.

When looking at the trends and patterns of the caregivers' journeys in trying to attain help for their child, it is George Kelly's theory of alternative constructivism that best explains their journey. Caregivers' constant use of the different options they were presented with indicated that their reality was not viewed from one fixed state but shifted between different perspectives. These perspectives were influenced by whether they felt satisfied with the treatment, the ease of access to treatments as well as factors such as affordability. Furthermore, as stated by this theory, caregivers' motivation for alternating between different realities was simply based on finding a solution for the difficulties with which they were faced.

5.4 Conclusion: Implications of the Study

The results of the present study suggest that it is a great tragedy to have a child with ASD symptoms in which there is no definite approach to getting the aetiology, diagnosis and conclusive care for the children affected. The situation therefore compels the need for dialogue to be put in place between cultural African healing perspectives and the European mental health system that the caregivers of such children have to resort to. The lack of mutual understanding between both of these worldviews has serious implications for the treatment of mental illnesses.

Similarly, given the excessive financial burden faced by caregivers of children with ASD symptoms, it would appear that something needs to be done at the national policy level to promote institutional sympathy in support of these caregivers. This could mean that medical insurance may need to be sought and put in place in support of such parents so that they do not have to suffer alone the double burden of having children with ASD symptoms and the full brunt of having to underwrite the total and cumulative costs of providing care to these children.

5.5. Recommendations for Policy and Practice

Based on the above, the following recommendations for policy and practice are made: First, early intervention for children with ASD symptoms is strongly recommended. The existing literature and the views of the study participants who obtained early diagnosis of the problem show that the prognosis of the illness improved with early intervention, all of which has been shown to contribute positively to the emotional state of both the child and their family. This area needs special attention given that South Africa is a multicultural country. Not only will such attention encourage early intervention and improve the quality of life of persons living with ASD symptoms, but it also will contribute in alleviating the psychological problems associated with the illness, such as the stress and frustration experienced by families of those with ASD symptoms.

Second, there is a need to integrate indigenous healing methods into mental health. This is because the present study has demonstrated that the use of traditional methods has continuously been used by persons of African culture despite living in a system that promotes the use European-centred treatments when confronted with children with ASD symptoms. Similarly, the South African Department of Health (2004) indicated that 70% of the South African population made use of healing based on cultural beliefs. To formalize and accommodate the people's tendency in this regard, it is recommended that more mental health practitioners be educated in the principles and practices of this traditional approach, and, following such multicultural learning, authorities should be encouraged to keep updated records of certified traditional healers to whom they can make referrals when confronted with the needs of children with ASD symptoms that fail to respond successfully to biomedical treatments. This suggestion is in line with recommendations from studies conducted by the World Health Organisation (WHO) which estimated that treatment based on cultural models was three to four times more commonly used than conventional medicine (Kubukeli, 1999).

5.6. Limitations of the Study

One limitation of this study relates to the fact the African cultures of Black South Africans were grouped together to provide a general overview of the phenomena. This study did

not deal with each culture individually, yet it is known that illness beliefs among various cultural groups in South Africa do vary.

A second limitation relates to the sampling technique used in the study. A specific sample was required for this study which included caregivers of children who had ASD symptoms. This non-probability sampling technique allowed for a convenient access of participants as they were approached on the basis of being caregivers of children in a special needs school, in the class tailored for ASD. Additionally, this sample consisted of only seven participants. It is feared that the results are specific to these caregivers and cannot be generalized to the larger community of African caregivers who have children with ASD symptoms.

5.7 Recommendations for Future Research

Given the above limitations and other implications arising from the present study, it is recommended that future research should be carried out that would look at how collaboration could be established between traditional healing practitioners and mental health care professionals in order to provide culturally relevant treatment to persons of differing cultures in the area of ASD symptoms.

It is also recommended that another study be carried out to investigate the help-seeking experiences of other cultural groups, other than Africans, confronted by children with ASD symptoms. This would help to identify challenges that are commonly experienced, which are not limited to the caregivers from African cultural backgrounds. This research could yield beneficial insights which would go towards providing assistance and treatment in the most efficient and effective way possible to caregivers of all traditions.

It is also recommended that a follow up study be conducted that would focus on the two care-givers who persisted in their use of the biomedical model in the care of their children. This is necessary to see if they were able to achieve a better prognosis for their children in sticking with the biomedical practice, and to see what lessons can be drawn from their experiences for the edification of future caregivers.

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APPENDICES

Appendix 1: Semi-structured interview questions

1. What symptoms did your child have that concerned you?
2. How old was the child when they first presented these symptoms?
3. What did you feel caused these symptoms?
4. What routes did you take to get help for these symptoms?
5. Who did you consult?
6. What did they say was causing the problem?
7. What interventions has the child been exposed to?
8. How do you feel about these interventions?
9. Have any of these interventions helped?

Appendix 2: Letter to the gatekeeper



01 March 2013

To: The Director of (Name Removed)

Re: Permission to access the support group to conduct research

I am a Masters student in Psychology at the University of Kwa-Zulu Natal and I am conducting a research study as part of my research project. The purpose of the study is to explore how Autism Spectrum Disorders (ASD) are understood from an African perspective by African caregivers. My research sample therefore consists of African caregivers who have a child with ASD symptoms. Insights gained from this study may assist mental health professionals understand how traditional African parents understand ASD which may lead to culturally informed interventions.

The study will require that caregivers, if they wish, to participate, to attend individual interview sessions with a researcher which will last an hour long. Participation is completely voluntary and participants may withdraw at any stage of the study. The questionnaires will be kept for five years in accordance with the University's regulations and will thereafter be disposed of using a shredder.

In order for this study to take place, I would like to request for written permission for the researcher to access the property in order to recruit participants that will be willing.

Your help with this matter would be greatly appreciated and will be invaluable to the research study that is going to be undertaken.

Please feel free to contact either myself or my supervisor for any further clarification regarding this study.

Yours sincerely,

Supervisor: Prof A Nwoye

Contact: 0332605100

Research student: Zinhle Mthombeni

Contact: 0836330316

Appendix 3: Letter requesting participation



01 March 2013

Dear Participant

Re: Request for participation in a research study

I am a Masters student in Psychology at the University of Kwa-Zulu Natal and I am conducting a research study as part of my research project. The purpose of the study is to explore how Autism Spectrum Disorders (ASD) are understood from an African cultural perspective by African caregivers'. My research sample therefore consists of African caregivers who have a child with ASD symptoms. Insights gained from this study may assist mental health professionals understand how traditional African parents understand ASD which may lead to culturally informed interventions. This study will require you to attend an individual interview sessions which will last an hour long. Participation is completely voluntary and can be withdrawn at any stage of the study.

Your help with this matter would be greatly appreciated and will be invaluable to the research study that is going to be undertaken.

Please feel free to contact either myself or my supervisor for any further clarification regarding this study.

Research Supervisor: Prof. A. Nwoye

Contact: 0332605100

Research Student: Zinhle Mthombeni

Contact: 0836330316

Appendix 4: Consent form to be completed by participant

I hereby agree to participate in the study concerning how Autism Spectrum Disorders are understood from an African perspective. I understand that my participation is voluntary and I may withdraw from participation at any point of the study. The purpose of the study has been explained to me.

In addition to the above, I agree to do an audio recording of this interview to enable data to be accurately recorded. I understand that no personally identifiable information will be released and that the audio record of the interview will be kept confidential.

Signature of participant

Date

Appendix 5: Imibuzo ye interview (Interview Questions Translated into IsiZulu)

1. Yiziphi izinkomba ezenza ukuthi ukhathazeke ngengane yakho?
2. Yayingakanani ingane ngesikhathi iqala ukubonisa lezi zonkimba?
3. Ucabanga ukuthi lezi zinkomba zabangelwa yini?
4. Yiziphi izinyathelo owazithatha ukuze uthole usizo?
5. Wabona bani ukuthi akusize?
6. Bathi lezi zinkomba zazibangelwa yini?
7. Yiluphi usizo ingane esike yaluthola?
8. Uzizwa kanjani ngalolusizo?
9. Uzizwa ukuthi liku sizile lolusizo oye waluthola?

Appendix 6: Incwadi yesicelo ukuba ube ingxenye yocwaningo (Letter Requesting Participation Translated into IsiZulu)



01 March 2013

Ibhokiselwe kulowo oyifundayo

Isicelo sokuba ube ingxenye yocwaningo

Ngingumfundi esikoleni seSayikholoji eNyuvesi yakwa-Zulu Natal. Ingxenye yezifundo zami kulonyaka iphoqa ukuthi ngenze ugwaningo. Inhloso yalolucwaningo ukuhlola ukuthi abazali noma abanakekeli bezingane ezine Autism Spectrum Disorders (ASD) basiqonda kanjani lesisifo.

Abazibandakanya kulolucwaningo badinga ukuba abantu abakhuluma isiZulu, futhi baphinde babe umzali noma umnakekeli wengane ene ASD noma izinkomba zayo. Ulwazi oluzotholakala kulesisifundo lungasiza abasebenza nezingane ezine ASD baqonde ukuthi ngokwesizulu ama ASD asho ukuthini futhi alashwa kanjani.

Lolugwaningo luzodinga ukuba ube ingxenye yenkulumo ezoqoshwa, ezoba yihora elilodwa. Ukuba ingxenye kuya ngokuzithandela futhi akuphoqiwe. Ngaphezu kwalokho, uma uzizwa ufisa ukuyeka ukuba inxenye yalesisifundo, ukhululekile ukuyeka nanoma isiphi isikhathi ngaphandle kwemibandela.

Usizo lwakho lubalulekile kakhulu kulolugwaningo. Sicela uzizwe wamukelekile ukuthintana nami noma nosupervayza wami ukuze uthole ukwaziswa okwengeziwe.

uSupervayza: Prof A Nwoye

Umfundi: Zinhle Mthombeni

Inombolo: 0332605100

Inombolo: 0836330316

Appendix 7: Isivumo sokuba ingxenye yogcwaningo (Consent Form Translated into IsiZulu)

Ngiqinisekisa ukuthi ngiyavuma ukuba ingxenye yogcwaningo mayelana nokuthi ama ASD aqondwa kanjani ngokwesiZulu. Ngियाqonda ukuthi ukuba kwami ingxenye kungokokuzithandela futhi ngingahoxa kulesisifundo noma yinini. Ngiye ngachazelwa ngenhloso yalesisifundo.

Ngiyavuma ukwenza i-interview eqoshiwe ukuze ukwazisa kuqondwe kahle lapho sekubhalwa. Ngियाqonda ukuthi Imininingwane yami ngeke ivezwe.

Isignitsha

Usuku