Lived Experiences of Caregivers Raising Children Living with Autism in Manzini Eswatini By

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ABSTRACT

Research on autism in Eswatini is scarce, and with public awareness remaining at low levels, caregivers of children living with autism are faced with major challenges related to stigma, adverse discrimination, severe isolation, abuse and lack of supportive services. As a result, the plight of children living with autism is extremely worse, significantly because the challenges are further escalated when combined with poverty since there is no proper diagnosis nor supportive services. Based on the researcher's experience in the field of Social Work, and experiences of raising an autistic child and as a researcher, a gap was recognized in the awareness of autism in the country, seeing that it is in its inception stages. The overarching aim of the study was to explore the lived experiences of caregivers raising children living with autism in Manzini (Eswatini). The study utilized a constructionist paradigm, in order to delve into how caregivers constructs their experiences of raising children living with autism. This study followed a descriptive-exploratory research design. The size of the study sample consisted of, two males and 13 females which in total were 15 caregivers. The study utilised a purposive sampling method. Data were analysed using the Analytic Framework approach, which falls under the thematic analysis approaches for qualitative data. The findings in the study reflected that caregivers of children living with autism stress begins before the diagnosis is made and increases upon receiving the diagnosis. Significant feelings were found to be that of guilt, stress, denial, anxiety, depression, frustration, confusion, shock and fatigue; similar to the process of grief. Challenges caregivers experience is found to be lack of social support and social isolation; increasing their level of stress. Caregivers reported that their child has a positive influence on them as well as the child taught them patience, acceptance and unconditional love.

Key Words

ASD: Autism Spectrum Disorder

Autism spectrum disorder consists of a continuum of multifaceted neurological and developmental disorders presenting with deficits in reciprocal social interaction and communication, along repetitive and stereotyped interest and behaviors (Alli, Abdoola & Mupawose et al (2015)).

Primary caregiver

This term is used to describe parents, grandparents and other family members who are in charge of proving care for a child with autism.

DECLARATION

I, Makhosazana Tibuyile Hlanze (Student Number 221117413) declare that this study entitled:

Lived experiences of caregivers raising children living with autism in Manzini Eswatini

It is the result of my own investigation. I declare that this study represents my own research and it has not been submitted in part or in full for any degree or to any other University.

________________________ ______________________________ ________________________

Makhosazana T. Hlanze **Student Number** **Date**

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CHAPTER ONE: PROBLEM AND ITS CONTEXT

1.0 Introduction

According to (Centers for desease control and prevention, 2023) Autism spectrum disorder (ASD) is a neuro-developmental disorder associated with lifelong deficits in social and communicative abilities as well as ability to function independently. Some people with ASD have a known difference, such as a genetic condition. Other causes are not yet known. Scientists believe there are multiple causes of ASD that act together to change the most common ways people develop. People with ASD may behave, communicate, interact, and learn in ways that are different from most other people. There is often nothing about how they look that sets them apart from other people. The abilities of people with ASD can vary significantly. For example, some people with ASD may have advanced conversation skills whereas others may be nonverbal. Some people with ASD need a lot of help in their daily lives; others can work and live with little to no support. This chapter will provide a background and problem statement of the study.

1.1 Background and Rationale of the Proposed Study

The motivation of the study was prompted by the status of research on autism in Eswatini being scarce, and with public awareness remaining at low levels. Having noticed that while reviewing relevant studies for content, the study became attractive to engage in.

Research on autism in Eswatini is scarce, and with public awareness remaining at low levels, caregivers of children living with autism are faced with major challenges related to stigma, adverse discrimination, severe isolation, abuse and lack of supportive services (Mvubu, 2017). Thus, a number of these caregivers are faced with multiple barriers on daily basis (Mvubu, 2017). In Eswatini, in particular, the plight of children living with autism is extremely worse, significantly because the challenges are further escalated when combined with poverty since there is no proper diagnosis nor supportive services (Autism Swaziland 2013). Furthermore, in Eswatini there is some awareness among those in medical community but the degree of their knowledge is limited. In a report by Ruparelia et al, (2016), it was noted that at a conference with African country representatives there was a lack of ASD awareness in many countries. This led to many children receiving alternative diagnosis or no diagnosis at all. Such that, in Nigeria research found that, ASD was believed to be caused by supernatural causes or a mother’s wrong doing.

Consequently, as a social worker who at some stage was based in Mbabane Government hospital the main referral hospital in Eswatini, the researcher noticed that these children are either not diagnosed or misdiagnosed. This is congruent to Traci Pedersen & Erik Mayville (2022), that for ASD children each individual exhibits a unique set of symptoms at different degrees of severity. This itself makes ASD diagnosis challenging to medical community leading to incorrect diagnosis, misdiagnosis and late diagnosis. Some end up being hidden at home, or if they are lucky, are categorized alongside deaf and mentally ill children. Caregivers living in rural areas often do not have access to high quality treatment facilities in particular psychiatric hospitals as there is only one in the country. It located in Manzini, therefore they utilize local clinics with only nurses based. A request to see a medical doctor or receive occupational treatment can take more than a year waiting period. In developed countries like USA a multidisciplinary team assesses, diagnosed and develop an individualized plan for an autistic child (Autism Speaks, 2021). However, what happens in Eswatini is far from that, autistic children are hidden at home and most of them are rejected even in special schools. Eswatini is still at initial awareness stage in as far as issues of autism are concerned. Many people do not know nor understand autism as it is highly stigmatized (Mvubu, 2017). In Eswatini mothers who have autistic children, deal with immense stigma, discrimination, abuse and lack of support which they experienced on a daily basis due to lack of awareness and knowledge on autism within the society. Based on such and the realised scarcity of studies on ASD, a gap was recognized in the awareness of autism in the country and thus the need for this study to be carried out.

Personal Rational

The motivation for the study was driven by the fact that the researcher’s first born child was autistic. He was born in 2012 September, everything about him was normal according to the doctors. Everything changed when he was around one and a half years where we noticed he had developmental delays. He was diagnosed with mild Cerebral palsy; he couldn’t sit at two years. He was taken for Occupation therapy sessions on weekly basis, there was a change he managed to sit after sometime. When he was three and a half he was diagnosed with autism, but nobody explained what autism was and all about. At that time, he couldn’t stand, due to having weak muscles and at times he would miss his occupation therapy sessions due to the fact that he was a sickly child. Unfortunately, few months after diagnosis he passed away, I

did not experience to be part of the support group or him with autism because at that time my focus was cerebral palsy and him being asthmatic and sickly. Hence the interest to study on the experiences of living and raising ASD children.

1.2 Problem Statement

There is dearth of information on autism in the country and yet the number of children diagnosed with autism is increasing. Autism Eswatini Organisation started in 2013, as a response to the needs of children with autism, within a low middle income country like Eswatini (Thwala, et al., 2015). So far Eswatini has the first of its kind Autism centre based in Manzini, and it has attempted to create awareness. The centre is funded by Municipal Council in manzini, there is provision of supportive services to children living with autism between 0-12 years old (Manzini Municipal Council News letter 11 August, 2021). Most of the efforts from NGO's and Government seemed to be directed at the children with autism, and not much in relation to caregivers or parents (UN Eswatini, 2020).

In low income countries, where caregiving takes place against various socio-economic and psychological challenges, caring for an autistic child is bound to exercebate these pre-exisitng challenges. Despite this, caregivers of children with special needs, such as autism, are still expected to perform their role, at home, in the workplace, and in communities. How caregivers of children with autism experience this caring, is the focus of this study. The study, within the context of Eswatini, has never been conducted, and through it, is hoped that voices of caregivers of children living with autism would be heard (UNFPA, 2020). In countries advanced in Autism diagnosis, treatment and services like United States of America, they have treatment therapy called Applied Behavior Analysis (ABA) Therapy treatment, which consists of Specialised Autism Therapists (Behavioural Analysts and Behavioural Technicians, 2013). On the other hand, Eswatini according to Ministry of Health there are only three government hospitals with specialised support when it comes to children living with autism. In USA due to numerous research, the prevelance of autism is 1 in 160 children is autistic. On the other hand, accoording to Deputy Prime Minister's office (Disability unit), there is limited autism statistics and data in the country. A first of its kind baseline survey by UNFPA was conducted in 2020, to obtain the prevelence ASD in selected Eswatini districts (Eswatini UNFPA, 2020).

The diagram below indicates on the prevalence of autism spectrum disorder among children in Selected Developed countries as of 2020. According to (Elfein, 2020), Hong Kong had the highest prevalence of 375 per 10,000 children and Poland has the least occurrences of autism of 3 per 10,000 children.

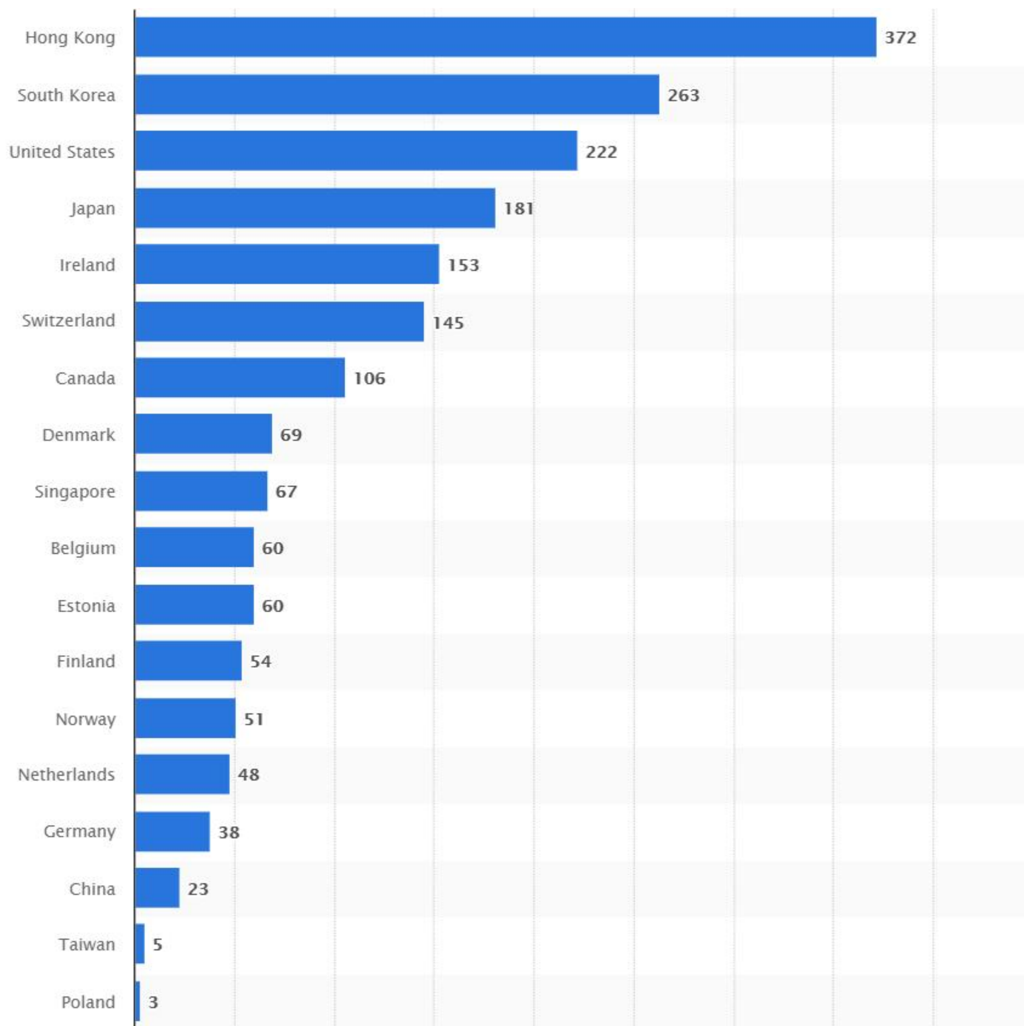

Figure 1: *No. of children with Autism in selected countries worldwide*

Source: (Elfein, 2020)

However, there is conflicting data regarding the prevalence of ASD in the sub-Saharan Africa, with different African nations reporting different numbers. The prevalence in Nigeria is 2.3%, according to Lagunju et al, in Uganda, Kakooza Mwesige observed a frequency of 0.68 %, in Libya, Zeglan discovered prevelance of 0.33%, and in Somalia, Hewitt reported a prevelance of 2.0%. According to a multi-country survey, the prevelance was 11.5% in Tunisia and 33.6% in Egypt. These disparate estmation do, however highlight the necessity of a more thorough and uniform assessment of the prevalence of ASD throughout the continent.

1.3 Purpose and Aim of the Study

The overarching aim of the study wasto learn about the lived experiences of caregivers raising children living with autism in Manzini (Eswatini).

1.4 Objectives of the Study

Objectives of the Study	**Research Questions**
To explore and analyze experiences of caregivers raising children living with autism	What are the lived experiences of care-givers in Eswatini living with autism?
To describe the coping strategies faced by caregivers raising children with autism	What are the coping mechanisms of caregivers raising children with autism?
To ascertain identified needs and supportive services required by caregivers of children living with autism	What are the needs and supportive services needed by caregivers of children living with autism?
To explore the challenges of caregivers raising children with autism	What are the challenged encountered by caregivers living and raising children with autism in Eswatini?

1.5 Significance of the Study

This study sought to make a significant contribution to research, practice and policy on education and social protection for children living with autism. Since, there is minimal research done on the experiences of caregivers of children living with autism, the study will contribute towards availing their lived experiences, which may be significant in the design of supportive programs by social workers and other helping professionals.

The study is timely and relevant within Eswatini, as it is conducted at a time when Autism awareness is receiving national attention following the launch of Autism Eswatini in 2021. In relation to research, the study will theoretically and empirically contribute to existing literature on Autism in the Kingdom of Eswatini, regionally and internationally. More specifically, the study will be significant to the caregivers, in the sense that it will give them an opportunity to speak about their experiences of raising children living with autism under the irregularity in Eswatini, and how that has affected their children.

At the national level, the study will contribute positively in education of policy makers, stakeholders, communities and Eswatini at large which will then assist in understanding of experiences of caregivers living with autistic children in Eswatini context.

1.7 Dissertation Layout

The overall structure of this dissertation takes the form of five chapters

CHAPTER ONE: Is the introductory section of the study, where the aim and objectives of the study are expounded upon

CHAPTER TWO: The second chapter presents relevant and available body knowledge regarding ASD, beginning with an overview of ASD.

CHAPTER THREE: The chapter discusses the methodology employed in this study, as well as the research design. This is followed by a detailed description of the process of recruiting the sample, along with the process of data collection. The chapter further explain the steps taken to analyse the data collected. Moreover, it explores ethical consideration relevant throughout this dissertation.

CHAPTER FOUR: The data collected is presented highlighting the themes and the findings of the study are discussed and described in detail.

CHAPTER FIVE: Concluding remarks and recommendations emanating from the discussion and limitation of the study are further explored.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

Literature review is a survey of scholarly sources providing an overview of current knowledge by allowing the researcher identify relevant theories, methods and gaps in existing research (McCombe, 2019). The literature on ASD education and awareness about the condition will be examined. Topics covered include what autism is, its causes, characteristics, types of autism, management strategies, caregiver experiences, theoretical framework, autism in global, regional and national context as well as impact faced by caregivers raising children living with autism.

2.1 Conceptualizing autism

2.1.1 Definition of autism

ASD is a lifelong neurodevelopmental disorder (Sadock & Ruiz, 2015) that was previously referred to as pervasive developmental disorder in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV). The term "spectrum" refers to the wide variance in symptomology, skill and levels of impairments in functioning that can occur in people with ASD. The variation can be seen in the amount of independent functioning, as some individuals with ASD manage daily living requirements independently, while others require significant amounts of support in basic daily living. Currently, ASD is classified in the group of neurodevelopmental disorders in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). The three most common forms of autism, which are mostly diagnosed in the pre-2013 classification system, are autistic disorder or classic autism, Asperger's syndrome and pervasive developmental disorder not otherwise (PDD-NOS). (Xu, et al., 2023) note that translating medical terms such as ASD that are difficult to understand into local language, can be difficult. The challenge frequently comes from having to communicate information that is both precise and nuanced while maintaining language and cultural relevance, which undoubtedly is the situation in Eswatini. The authors recommend working with medical professionals who are conversant in both the language and the cultural environment of their clients and caregivers.

2.1.2 Characteristics of autism

The characteristics of autism vary in each and every child depending on the severity of the case (Gutstein & Sheely, 2002). Some children may present symptoms as early as the first few months of life while others do not show sign of disorders until 2 to 3 years of age (The Centre for Diseases Control, 2014). According to the (Diagnostic Statistic Manual V, 2013) ASD varies and ranges from low - high in levels of severity, which can be divided into 3 categories. Level 1 (moderate), level 2 (mild) and level 3 (severe). In level 1 the child needs support, in level 2 the child needs substantial support and in level 3 the child needs very substantial support.

Social impairment deficits present in ASD and impact the individual's manner of developing, understanding and maintaining social relationships with others (Van der Merwe, et al., 2017). Children diagnosed with autism often face social challenges and struggle with everyday human interactions. Children may fail to respond to their name, have no interest in the people in their surroundings, resist cuddling and holding and seems to prefer playing alone retreating into his or her own world, have trouble in understanding other people's feelings or talking about their feelings, they appear to be unaware when people talk to them but respond to other sounds, they do not play pretend games (not pretend to feed a doll), they have unusual reaction to the way things smell, taste, look, feel, or sound (CDC, 2014) . Another main challenge is that, children living with autism have trouble in adapting when a routine change, this may result to difficulty in regulating emotions (APA, 2014). Someone who does not have knowledge on autism may see these emotions as "immature behavior" or inappropriate outburst. These children tend to lose control and become frustrated in many situations. When a child is frustrated, this can lead to self-injurious behaviors such as head banging, hair pulling or self-biting (APA, 2014).

Communication deficit is evident in the early year of life. This deficit is pervasive in social communication and social interaction across multiple context (Leekam, et al., 2014). Children with autism tend to face challenges related to communication, younger children diagnosed with autism are often delayed in speaking and using gestures (APA, 2013). A child with autism may exhibit poorly integrated verbal and non-verbal communication for example poor eye contact when talking or using the caregiver as a mechanical aid (using the caregivers' hand as a tool to indicate the desired object rather than vocalizing) (Leekam et al., 2014). Some significant language delays start early in an infant's life and many do not begin speaking until much later in life. Children with autism often require speech therapy to help

them improve their spoken language and communication abilities. Unfortunately, these treatments are not always affordable or easily accessible in developing countries like Eswatini. According to (Smith & Hutman, 2012) the child may either be over active or passive, they may exhibit odd or ritualistic behavior such as rocking back and forth, waving their hands, and they sometimes have an extra ordinary talent in art, music, math's, or technical area such as fixing cars.

2.1.3 Causes of autism

There is no one cause of autism. Research suggest that autism develops from a combination of genetic and non-genetic or environmental influences. These influences appear to increase the risk that a child will develop autism. (Autism Speaks, 2021)

The exact cause of autism is not known. A report from Medical Research Council commissioned by US Department of health, outlined the current of scientific knowledge about the epidemiology and causes of autism disorder (MRC, 2001). The cause of ASD mainly contains a genetic component. However, the mechanism by which this operates is not clearly understood. (WHO, 2013) continues asserting that high maternal & paternal age, genetic mutations, are considered risk factors for development of ASD. The difficulty in finding a cause for the neurodevelopmental disorder complicates the treatment process as not one single intervention can be perceived as better than the other and subsequently differs from one child to another based on the severity of their diagnosis and behavioral problems. As a result, this complex treatment process is a factor that may become extremely costly and lead to financial difficulties within the family (Autism Speaks, 2021). It is crucial to emphasize that although clinical factors play a role in autism, people frequently develop their own theories about what causes the disorder. In their South African study, (Manono & Clasquin, 2023) found that some mothers of children living with ASD held strong cultural and religious values that impacted on the diagnosing procedure, as they went to traditional healers or religious authorities.

2.1.4 Types of autism

There are five main types of autism spectrum disorders these include: Asperger's Syndrome, Rhett's Syndrome, Childhood Disintegrative Disorder (CDD), Classical Autism and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (Sadock et al., 2015)

2.1.4.1 Asperger's Syndrome

These classify people who fall under the high functioning autism spectrum. They are often intelligent and excel in academics and work life. However, their impairments lie in the lack of social skills. While they develop communication and language skills in the same was as any other developing child, their deficit become more obvious with age as they struggle to keep with expectations of their family and extended community circles (Smith & Hutman, 2018).

2.1.4.2 Rhett's Syndrome

Rhett's syndrome is a neurodevelopmental disorder that almost exclusively occurs only in girls, it is the only form of autism spectrum disorder that can be diagnosed and medically confirmed. Children with Rhett's syndrome, in the initial stages tend to show that are very much similar to early signs of autism. Girls with Rhett's syndrome suffer from significant communication impairment. Also, one of the common symptoms of Rhett's syndrome is the girl's limited ability to use their hands for regular activity. Typically, this syndrome deteriorates with the girl's age, thus requiring more support and time. Most children diagnosed with Rhett's syndrome will have slower head and brain growth which is often an early indication of the disorder. Seizures are quite common. (American Psychological Association, 2013)

2.1.4.3 Childhood Disintegrative Disorder (CDD)

CDD, also known as Heller's Syndrome, it is an extremely rare condition in which children develop normally up to an age of two and then suffer a severe loss of social, behavioral and communication skills. It is sometimes referred to as Dementia Infantilis or Disintegrative Psychosis. CDD is often overlooked initially by the parents as they tend to attribute this sudden impairment as a 'transient and temporary' phase for their child and would expect it to pass away. (American Psychological Association, 2013)

2.1.4.4 Classical Autism

Classical autism is the broadest and most predominant form of autism, among all the various types of autism. In technical terms anyone showing tendencies that satisfy the guidelines laid out by "DSM 5 autism spectrum disorder" is termed Autistic. The effect of autism in such people may range from mild to very severe. Research has shown that, the brain of autistic children has a fair number of electric impulses than any other normal brain of similar age (American Psychological Association, 2013).

2.1.4.5 Pervasive Developmental Disorder (PDD-NOS)-Not Otherwise Specified

It is a neuro-developmental disorder that impairs the growth and development of the brain. Out of the various different types of autism, diagnosing physicians consider PDD-NOS an atypical autism; this is because individuals with the disorder often do not display the typical criteria normally presented by individuals with conventional or classical autism. An often misconception of the PDD-NOS diagnosis, is that it is a milder form of autism. While a PDD-NOS diagnosis may indicate, that the individual presents some mild characteristics, other symptoms may be more severe than standard autism. (American Psychological Association, 2013).

2.2 Management of autism

There is no cure that exist for autism spectrum disorder, and there is no one size fits all treatment. As there is no known cure for ASD, treatment and intervention objectives focus on the improvement of the child's functioning (Woodgate, et al., 2008). Target of interventions include developing social, communication, adaptive, behavioral and academic skills as well as decreasing maladaptive and repetitive behaviors (Committee on Children with Disabilities, 2001, cited in Woodgate et al., 2008). With improved functioning as the goal of interventions alongside the high variance in presentation amongst individuals with ASD, there is a vast array of interventions and treatment possibilities (Karst & Hecke, 2012). Individuals with ASD and their families encounter numerous professionals and pediatricians to clinical psychologists, occupational therapies, speech therapies and educators. Some studies suggest that, prior to receiving a formal diagnosis, an average of four and a half practitioners are seen. However, in South Africa (Mitchell & Holdt, 2014) found that the number of practitioners ranged from six to eleven.

2.2.1 Medically

There is no cure for autism spectrum disorder and there's currently no medications to treat it, but some medications can help with related symptoms like depression, seizures, insomnia and trouble focusing. Studies have shown that medication is most effective when combined with behavioral therapies. Risperidone (Risperdal) is the only drug approved by the FDA for children with autism disorder, it can be prescribed for children between 5 and 16 years old to help with irritability (WebMD, 2021). (Manono & Clasquin, 2023) reported that while some participants in their study stated being overcome with the fact that there is no known treatment for autism, others showed comfort at having a term for their child's condition after

receiving the diagnosis. Consequently, feelings will surface when a person receives a diagnosis, regardless of how soon they do so.

2.2.2 Socially

Children with autism have difficulty with social interaction behaviors, including establishing and maintaining relationships, reciprocating social interactions and communicating with others. Parents/ caregivers can help improve social skills in autistic children in these five ways: Social deficits and communication difficulties were previously presented as separate categories in the DSM-V however have been combined as they are inherently inter-related (DSM-5. American Psychological Association, 2013). Commonly discussed deficits of ASD are those in the domain of social interaction and understanding. Deficits presents in ASD impact the individual's manner of developing understanding and maintaining social relationships with others (Van der Merwe et al., 2017). Given their challenges in social cognition and communication skills, children with ASD may find it particularly difficult to interact with others, which could put obstacles in the way of their relationships and interpersonal bonds; which could be more difficult for their caregivers.

2.3 Theoretical Framework of the Proposed Study

The theoretical framework is the blueprint for the entire dissertation inquiry that serves as a guide on which to build and support the study (Grant & Osanloo, 2014). This study is guided in two theories namely Family Stress Theory: ABC-X Model and Family Resilience Theory.

2.3.1 Family Stress Theory: ABC-X Model

It is the foundation of a family stress theory that was developed by Reuben Hill as an ABC-X Model. Family stress theory is a theory of human behavior that defines the family unit as a complex social system in which members interact to influence each other's behavior (Murrell Bowel, 1996). It revolves around central components which include, **A** as a stressor event faced by the family, **B** as the family resources or strengths and **C** as the family perception of the event. When a family is unable to adapt or solve the problem it can lead to a crisis, which is the **X** component (Smith & Hamon, 2012)

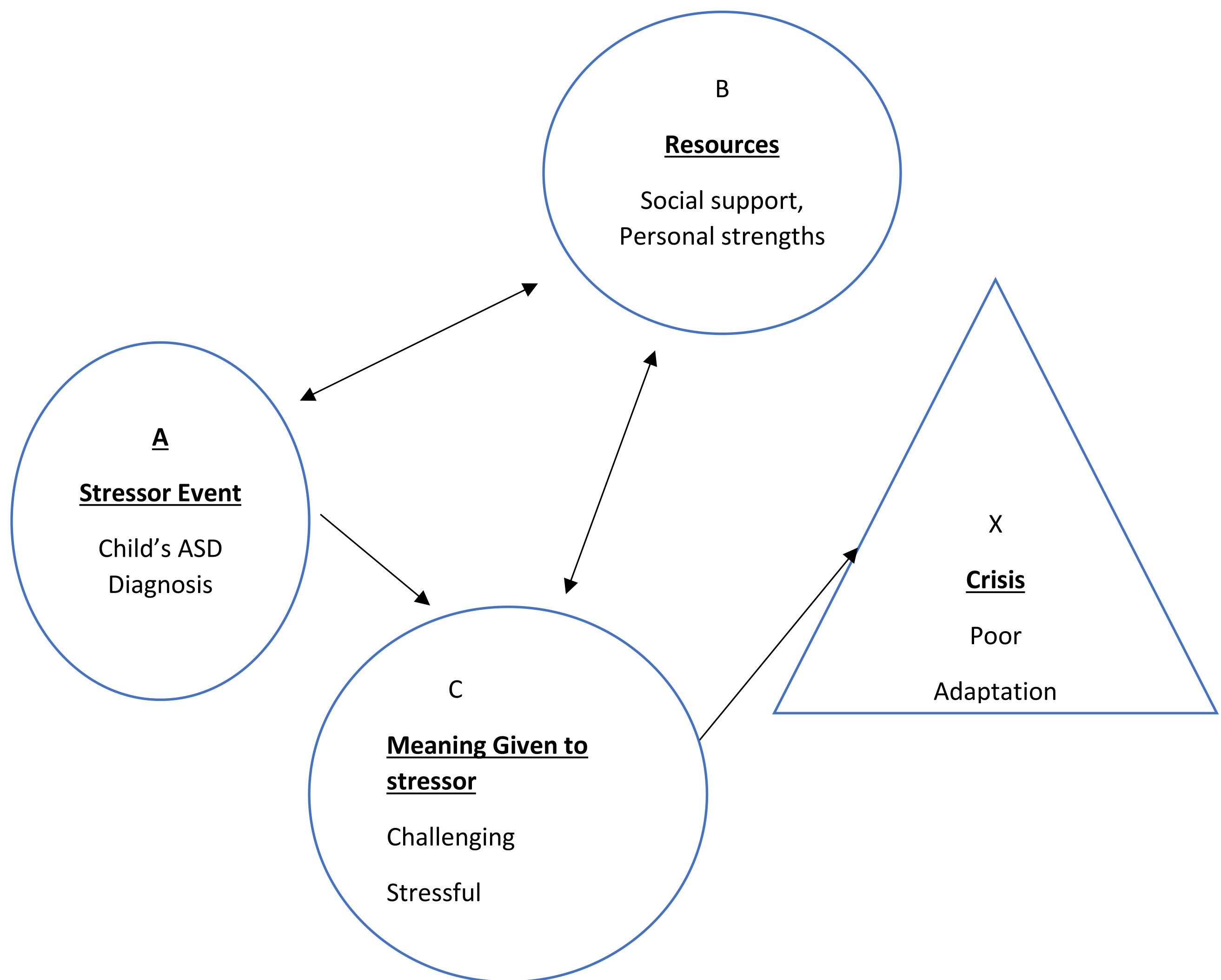

Figure 2: Hill ABCX Theory

The ABCX Model describes how parents/caregivers responds to stressors overtime, based on intercorrelation of available resources, caregiver's perception of the event or definition of the situation may result in either adaptation or crisis.

Since the study focuses on experiences of care-givers of ASD children which might be stressful to their day to day lives, family stress theory is an appropriate theory to be included in this study, due to the fact that it explores the periodic acute stressors that happens in all families taking care of children living with autism (Pozo et al., 2006; 2011)

2.3.2 Family Resilience Theory

Resilience is defined as a process of coping with adversity, change or opportunity in a manner that result in the identification, fortification and enrichment of resilient qualities or protective factors (Richardson, 2002). According to Resilience theory, an individual's resilience is determined by balancing risk and protective factors in the face of adversity (Luther et al., 2000). The main constructs in resilience theory are risk factors, protective factors, indicators or resilience and resilience outcomes.

Risk factors are factors that predispose people to physical and mental health problems because they affect how a person adapt to stress for caregivers of persons with ASD include severity of symptoms, marital quality, parents' anger and a number of children with ASD (Greene, Galambos, & Lee 2003; Smith-Osborne 2007). Protective factors promote resilience by diminishing the effects of risk and decreasing the negative reactions to it, allowing caregivers achieve positive outcomes, for caregivers of ASD children it may include social support, age of the child, time since diagnosis, locus of control, cognitive appraisal, religious beliefs and spirituality (Suresky, 2010). Indicators of resilience, these are predictors or resilience, in family members of Children with ASD include self-efficacy, acceptance, sense of coherence, optimism, positive family functioning and enrichment. Outcomes of resilience, its indicators have been found to be associated with many positive health outcomes (Van Breda, 2001). In parents/caregivers with ASD children, resilience indicators have been associated with positive indicators such as less depression, better marital quality, greater psychological well-being, and greater life satisfaction (Saman & Kaniel, 2011).

Family Resilience Theory is relevant for this study as it provides a way for caregivers of ASD children to bounce back and be resistant to stressful experiences thus developing and growing strengths that can help them deal with the situation in a positive way.

2.4 Experiences of Caregivers

Research tells us that caregivers of ASD children are particularly vulnerable to stress. High levels of stress (Davis & Carter, 2008) than parents of typically developing children. In addition, for these parents several factors also contribute to the likelihood of stress such as greater time demands associated with participation in various therapies such as speech & language as well as occupational therapies. This results in less time to attend to other matters at home and at work (Sawyer et al., 2010). Parents of children with ASD face a number of

challenges within their daily life, social life and occupational areas as well as within the community and health system (Estes et al., 2013; Huang et al., 2013).

2.4.1 Globally

ASD prevalence rates have become a global concern as they have reportedly increased considerably over the last decade (Altiere & Von Kluge, 2009; Bakare & Munir, 2011; Fewster & Gurayah, 2015; Kar Dest & Van Hecke, 2012; Malcom-Smith, Hoogenhout, Ing, Thomas, & De Vries, 2013; Meadan et al., 2010; Mitchell & Holdt, 2014). The current global prevalence rate of ASD is reportedly estimated to be 1-2% (Centres for Disease Control and Prevention, 2014; Franz et al., 2017).

In the United States, it is estimated that 1 in every 68 children is diagnosed with ASD (Centres for Disease Control and Prevention, 2014). Gender plays a role in the prevalence of Autism, with more boys being diagnosed than girls. A study was conducted, findings indicated the prevalence of ASD in males ranged from 7.3 % in Florida to 19.3% in Missouri whereas the ASD prevalence among females ranged from 1.0% to 4.9% in Arizona (CDC, 2009). In addition to gender being a factor in the ASD prevalence, ADDM indicated that ethnicity plays a role in the autism diagnosis. ASD is more prevalent in non-Hispanic white children than it is in non-Hispanic black children and Hispanic children. The results of the study were that non-Hispanic white children diagnosed with ASD ranged from 9.4%-10.4% whereas non-Hispanic black children ranged from 6.6-7.8% and Hispanic children from 5.3% to 6.6% (CDC, 2009).

Caregivers often experience stressful situations upon the initial diagnosis that relate to their child's behaviour, adapting to this new lifestyle and the complexity of finding access to the appropriate services useful to the family (Banach, Iudice, Conway, & Couse, 2010). Stressors from ASD diagnosis can cause a strain on parent's marital relationship, increase financial problem in the family, which results in caregivers socially isolating themselves from others. Findings indicated that mothers reported having more stress than fathers related to their child diagnosed with autism as mothers are usually the primary care givers of these children and are more active in the child's education (Estes et al., 2009). Learning that your child is autistic can result to scattered emotions for the caregivers. Just as the spectrum varies so does, each family's experience. Upon hearing their child's diagnosis one study found that in caregivers," 52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise and 10% felt self-blame (Banach, et al., 2010).

2.4.2 Regionally

Limited research and understanding of ASD in a South African context may have various consequences including delays in diagnosis and in turn the loss of the benefits that early intervention may have for a child with ASD (Grinker et al., 2012; Kim et al., 2011; Malcom-Smith et al., 2013; Mitchell & Holdt, 2014). In their review (Franz et al., 2017) found 28 articles that met their inclusion criteria, suggesting only 28 articles on ASD in the period from 1970 to 2015 were peer-reviewed and data based. Three studies were aimed at exploring challenges and strategies of parents of a child with ASD in South Africa (Alli et al.,2015; Fewer & Gurayah, 2015; Oliver & Ah Hing, 2009); Mitchell and Holdt, 2014) examined parent experience of the diagnosis while (Greeff & Walt, (2010) explored family resilience.

Another study examined family routines and quality of life (Schlebusch, Samuels & Dada, 2016). Two studies explored informal support sources, specifically social media (Cole, 2017; Gerber, 2014). One study explored the adolescent transition through the perspectives of parents and professionals (Meiring, Seabi, Amod, Vorster & Kern, 2016). A study by (Pottas & Pedro, 2016) explored the experiences of father carers and finally two studies involved parent perceptions of different aspects of treatment (Louw, Bentley, Sordahl, & Adams, 2013; Wetherston et al., 2017). According to Zeliadt, 2017, many caregivers resort to these extreme measures because they have no other choice. Others hide their children, fearing stigma which is pervasive in many parts of Africa and casts disabilities as the sign of a curse or possession by spirit. Many children with autism across Africa stay out of sight for another reason because few clinicians have the skills and experience to identify the condition, if they are even aware that it exists (Zeliadt, 2017). This demonstrates the need of raising awareness of ASD beyond of geographic borders and promoting a shared understanding that is felt even at the national level.

2.4.3 National

The Eswatini Observer newspaper, (Mbingo, 2016) states "Autism is very little known in the Kingdom, despite its astonishingly high prevalence and the calamitous way in which it touches the lives of those affected, particular the caregivers". It further state that, there appears to be no documented statistics, but a staggering number of children living with autism in the country and more that could still not have been diagnosed because of lack of awareness of the condition. Swazi mothers have joined hands to form Facebook and WhatsApp groups to increase awareness. According to Tryphina Mvubu, the founder of

Autism Swaziland, in Eswatini, autism affects about one in every one hundred and fifty children, but no one is sure what causes it. “Most often autism is misdiagnosed as multi-related and, in many instances, children are left untreated”, she said.

There are three government hospitals that give therapeutic services to individuals with autism in Eswatini namely, the Psychiatric centre, Mbabane Government and Mankayane Hospital. Autism Swaziland also known as Litsemba Lemliba Support Centre is the only autism centre available that specifically specialises with children living with autism. Tryphina Mvubu, Founding Director of Autism Swaziland, shares first-hand experience as a mother of a child living with autism, which made her stand up and act hence this successful organisation. But these too, have a limitation in adequately providing therapeutic services to individual with autism spectrum disorder, yet autism is on the rise in the Kingdom. There are private service providers though few. They are expensive for the masses, many of which are counted among almost seventy percent of the country’s population that lives below poverty line. Meaning that, not everyone can afford the autism specialists but can only afford the government hospitals which do not specialize in it (Mvubu, 2017).

When it comes to Autism issues in Eswatini there is Autism Eswatini Organisation, which was established in 2013, which further launched Litsemba Lemliba Support Centre as a response to the needs of children with Autism, it has attempted to create awareness and support to caregivers from all the regions. The is also a first of its kind Autism centre based in Manzini, which is a new project funded by Manzini Municipal Council, which provides support for children living with Autism between 0-12 years which officially opened in 2021 (Manzini Municipal Council) Newsletter 11 August 2021. An Autism website was launched in November 2020, to provide helpful resources for those with Autism and their families (Simelane, 2012).

As a country there is a need of increasingly effective approaches to intervention at all life stages, empowerment of families supporting a person with autism, training of non-specialist health workers and a must of an Autism one stop centre in all the regions with Specialised Autism Therapists. In as much as there is an autism centre in Manzini not all caregivers will access the services due to financial constraints this results to psychological distress (Backer et al 2005). There is a need to advocate for caregivers’ financial assistance, because even after the diagnosis they may not be able to do much about the condition. Increasing efforts need to be made to facilitate the production of policy relevant evidence and its uptake by policy

makers and advocates. It is important to ensure that, research is locally relevant, engaging both local communities as well as including people with autism and their caregivers. Finally, the country has put its most focus on Autistic children, little not much in relation to caregivers and parents hence the reason the researcher decided to do this study (Olaitan, 2023).

Despite the high prevalence rate of autism across the globe it was observed that little information is known in Africa regarding this condition, in most Developing countries the literature revealed that, autism is associated with cultural and spiritual beliefs (Gona, 2016). In Ghana, there is a belief in religion and cultural superstitions regarding children with autism as children from river or forest sent to parents who has committed some sort of sin and were being punished by God/gods for their inequalities (Ametepee & Chitiyo, 2009). Thus, the parents are stigmatised and discriminated against. In Kenya, caregivers of children with ASD have a difficulty in accepting the diagnosis, thus experience an emotional burden due to the fact that, the is a belief that ASD is caused by a woman who has forbidden cultural action or had married a certain prohibited tribe. Therefore, they belief she is punished by supernatural powers to have a child with ASD (Avoke, 2002). Studies in Eswatini have turned their attention towards understanding Autism in mainstream classroom, some on other disability like Cerebral Palsy and Epilepsy research on caregiver's experiences living with children with autism remain sparse (Takwi, 2023). The support service received by caregivers in Eswatini is limited compared to developed countries. In general, there should be social work counselling, Occupation therapy and speech therapy (Olaitan, 2023). In Developed countries like USA, they have supportive services in all their hospitals they have Autism specialist like behavioural therapists, they have organisation like Autism speaks which you access anytime in your area (Autism speaks, 2021).

2.5 The challenges faced by caregivers raising children living with autism

2.5.1 Recognition of atypical development

Parents/caregivers are often the first to notice and report concerns regarding their children's atypical development who later receive a diagnosis on autism (Charwaiska et al., 2007; Guinchant et al, 2012; Secrecy et al., 2015). Some parental concerns were the presence of challenging behavior which include sleep problems, motor concerns, medical concerns and language difficulties which are usually most common to autistic children. (Sicherman et al, 2021) further mentioned that caregivers/parents reported severe presentation in the areas of

lack of gestures and delayed language was associated with a decrease in age of diagnosis. Although parents may have recognized atypical development at different points, studies suggest that families sought guidance from healthcare professional before the child was two years of age (Altiere & Von Kluge, 2009; DePape & Lindsay, 2015; Mitchell & Holdt, 2014). Some studies found that parents saw an average of and half practitioners with a waiting period of three years or more for a diagnosis however in the study by (Mitchell & Holdt, 2014), it was found that in African countries particularly Eswatini and South Africa the number of practitioners a caregiver may have seen before diagnosis ranged from six to eleven and diagnosis varied between two and seven years.

Atypical development can be noticed by caregivers across the domains (language, social development, stereotyped/restricted behavior, and behavior/temperament) which can be visible on physical feature as illustrated on the table below

Table 1: physical feature noticed by caregivers

Domain	Physical Features
Language	Delayed speech
	No speech/vocalization
	Poor language comprehension
	Language regression
	Lack of language imitation
Social Development	Delayed social communication
	Gaze abnormalities
	Poor social integration
	Lack of response to social stimuli
	Social/nonverbal regression
Stereotyped/restricted behaviour	Need for routine/rituals
	Restricted interest
	Hypo/Hypersensitivity
Behaviour/Temperament	Lack of attention and interest

	Hyperactivity Tantrums and opposition Aggression and violence Unsettled crying and anxiety

An understanding of these abnormal behavior earliest could aid caregivers in reducing the age of diagnosis of children living with autism

2.5.2 Psycho-socioeconomic burden

Research often emphasizes on contributing factors of caregivers and parents of children living with autism to include: limited resources, obtaining a proper diagnosis from a professional, children struggling with proper education as well as financial burden. Caring for a child living with autism in a developing country like Eswatini with limited resources can be financially and emotionally draining. Caregivers of children with autism are financially drained by medically and educational obligations they have to fulfill to care for their children (Depape & Lindsay, 2014; Heiman, 2002; Myers, Mackintosh, & Goin-Kochel, 2013).

Caregivers of children with ASD consistently report more psychological stress and poorer well-being than parents of non ASD children or parents of children with other disabilities (Estes et al., 2003; Harting & Johnson, 2001; Stewart et al., 2017). Most parents/caregivers do not get therapy/counselling for psychological stress of taking care of an autistic child especially the ones who are not part of Autism Swaziland support group. Behavior that are difficult to cope with or stressful for parents are mostly centered on the child inability to function independently, inappropriate behavior in social setting and impaired ability to communicate. Another contributor which make the caregivers' situation worse, is when they have to leave their job or works fewer hours in order to take care of their autistic child. As a result, this contributes to disruption to the family system and caring for a child with autism becomes a strenuous task (Stewart et al., 2017).

On the other hand, management of autism requires important interventions that further necessitates a lot of financial resources. According to (Sharpe & Barker 2007), children with autism needs interventions from speech and language therapies to assist them with pragmatic language and social play. Occupation therapists assist autistic children with therapy to develop motor skills and activities for daily living. Dieticians are also needed to assist autistic children with a special diet and school services, since children living with autism mostly

attend in special schools which are usually expensive compared to normal schools. Utilizing all these interventions requires money, which contributes to financial and psychological burdens to caregivers from developing countries with limited resources and services like Eswatini (Fletcher, Marcoulakis & Bryden, 2012)

2.5.3 Lack of Awareness

When it comes to children living with autism lack of awareness have been identified in the following areas: education, health and the community.

2.5.3.1 Education

While parents elsewhere are able to get access to education for their children but want to play key roles in planning and discussing appropriate intervention strategies for their children (Webster et al., 2016). Caregivers in African countries especially Eswatini struggle to gain access to basic education for their children with ASD because of lack of autistic schools. The Eswatini Disability policy of 2018 affirms that children living with disabilities have a right to access education, on the contrary caregivers of ASD children are struggling to gain access for their children's education. The reason behind is limited human and material resources, lack of training of teachers, lack of co-ordination between mainstream and special education needs as well as poor acceptance by society (UNESCO, 1994). This results to children living with autism to be excluded in schools and at times they attend school but they are left unattended in class by the teachers_and some caregivers resort that their children should stay home (Thwala, 2018). However, the exclusion of autistic children can also be caused by othering. Othering refers to other learners being shunned by their peers and facing discrimination in school due to lack of awareness in autism (Bjorg & Hanssen, 2016)

2.5.3.2 Health

There is usually lack of awareness on autism in medical sector which in most cases results either in late diagnosis or misdiagnosis (Bateman, 2013; Tincani, Travers & Bout, 2009). ASD presents with diagnostic difficulties for professionals because of presentation of the symptoms which is often similar to that of other neurodevelopmental and medical conditions (American Psychology association, 2013; Midence & O' Neill, 1999). Those conditions are but not restricted to attention deficit hyperactivity disorder (ADHD), global development delay, intellectual disability communication disorder, disinhibited social engagement disorder, fragile & syndrome deafness and others. ASD can be comorbid with the above-mentioned disorders thus healthcare professionals tend to focus on the other comorbid developmental disorders instead of ASD.

Parsley and Smith 2013, found that during the diagnostic process many parents are subjected to institutional discrimination. Due to lack of knowledge on health care professionals on ASD, they usually subject caregivers to continuous and unnecessary interventions which when questioned by parents are perceived as hostile and difficult (Bateman, 2013; Paisley & Smith, 2013). Despite the early concerns of many parents/caregivers and the research suggesting early accurate diagnosis is possible there is often a long delay between the recognition of these concerns and actually obtaining a diagnosis (Estes et al., 2013; Mitchell & Holdt, 2014). On the other hand, (Crane et al., 2016), found an average of three and a half years of delay between first contact with a healthcare provider and receiving a formal diagnosis. This usually led to caregivers being frustrated and confused. However, caregivers of ASD Children in various studies try convince health professionals that the concern about further investigation on their children's ASD condition but it was brushed aside by both practitioner and friends (Altiere & Van Kluge 2009; Mitchell & Holdt 2014). But they were assured by health professionals that their children would grow out of it or alluded to poor parenting ability as the root cause.

2.5.3.3 Community and Society

It has been found that many parents/caregivers within the African context are stigmatized by their communities due to having a child with autism (Bakare & Munir 2011; Costa, Steffegen & Ferring, 2017; Costa, Steffegen & Ferring, 2017; Schlebusch & Dada, 2018). This may be attributed to not only a lack of knowledge but also cultural beliefs about the disorder (Bakare & Munir, 2011; Mavundla et al., 2009) state that the biggest contributor to mental illness stigma is misinformation and this may be alleviated through community-based education. On the other hand, Avoke 2002 asserts that in many communities in African countries the use of pejorative labels and the manner in which people with disabilities are treated to religious or magical models where evil was placed to individuals by gods for instance in Eswatini children living with autism in communities are labelled and referred to with negative expressions like "sidalwa", "crazy"," sihlangananhloko"," umhambuma"and many more ruthless names. However, this has led to parents of ASD in Ghana preferring boarding facilities for children living with autism because they use them as avenues to abandon and hide them from the public. This perpetuate negative cultural beliefs and attitudes towards disability as they can serve as avenues for exclusion of persons with disabilities from mainstream society (Lamptey, Villeneuve, Minners, & Mccoll, 2015). Contrary to Eswatini where they are no residential care facilities for disabled children, with the researcher's

experience as a Social Worker there are high cases of caregivers who are hiding their children, some even lock them in their houses so to protect them from the community members' stigmatization.

2.5.4 Spirituality, Religion & Cultural Perspective

According to (Avoke, 2002), the religious model of disability envisions disability as evil place on and individual from the gods as punishment for offense committed. It is evident in societies where superstations and eugenics are prevalent in African countries like Eswatini. Attitudes of the community of those with disabilities are largely shaped by beliefs in fear of deities and gods. Ghana is a highly religious nation, it is therefore not astonishing that persons with disabilities in this nation are sometimes considered to be a curse, hence they are shunned and stigmatized. It may be posited that lack of knowledge in conjunction with cultural beliefs surrounding the disorder may lead to many caregivers turning to alternative methods to gain assistance for the ASD children. In African countries, it is common for parents to take their children to spiritual or traditional healer explanation and interventions for ASD (Bakare & Munir, 2016; Gona et al., 2015; Ruparelia et al., 2016), this is evident in Eswatini where parents resorted to using religion methods to try and cure their children with "tiwasho" and "timbita" which are traditional herbs and drinks from traditional healers in belief that it will cure their ASD children.

In a study in Kenya conducted by (Gona et al., 2015), it was revealed that, ASD stemmed from supernatural causes such as witchcraft and evil spirits although Eswatini is no different sentiment on the same issue. On the other hand, in Nigeria research found that ASD was believed to be caused by supernatural causes or a mother's wrong doing (Ruparelia et al., 2016). In most cases caregivers continued their spiritual journey in taking care of their ASD children by connecting to Deity. However, caregivers do not know how to manage their challenge of taking care of autistic children. Instead, they move towards spirituality and their religious practices and beliefs to help them.

2.5.5 Need for support and services

Support structures are instrumental in providing the necessary formal and informal services which required by families living with individual who have a disability. The formal services include medical interventions and social services provided by government whilst informal services primarily consist of the emotional support from family, friends and community (Wetherston et al., 2017). For parents to accept their children's diagnosis it is suggested they

need to undergo a mourning process for the loss of sense of normalcy with the help of therapist. In Eswatini Organization like Autism Swaziland provide such services but only to caregivers who are members of the support group. The therapist further re-integrate, that by helping caregivers grieving for their sense of normalcy which allows the parents to come to terms and accept their children's diagnosis (Paisley & Smith, 2013)

The following are gaps identified in Eswatini

- For government offering services and decentralization of these services to meet the plight of parents raising children living with autism
- There is a gap in government making efforts to capacitate parents with skills on how to take care of autistic children
- A need for a social grant due to expenses that arises in caring for an autistic child, for example, transport to attend therapy, food since ASD children eat special diet, and medication
- Training of community care health workers "Bagcugcuteli" in communities and raising awareness through outreach in communities and church

2.5.5 Coping Strategies

Majority of the corpus of this review revealed that parents had to develop strategies like seeking medical care to manage their child's conditions irrespective of the help available to them through social systems in their respective countries. Caregiver's strain can culminate in positive or negative consequences, depending on the primary caregivers' appraisal of situation, their responses to stress and the meaning they give to their child's disability that manifest in either mal-adaptive or healthy coping behavior strategies (Tajalli et al., 2011). Adaptive or problem-focused forms of coping include seeking social support, such as family support or developing relationships with health professionals, schools and parents in similar situation (Kerr and Mcintosh, 200; Pritziaff, 2001;Tajali Hooman Ali, Afrooz Ali.& Bonab Ghobari, 2011). Social support, internal locus of control, hardiness and optimism contribute to positive coping outcomes with these parents expressing the psychological benefits from raising a child with ASD (Cappe et al., 2011).

The positive strategies implemented by caregivers included strong connection to God, managing and treating the condition, advocating for autism, planning for their child's future, accepting reality, being hopeful and relying on sense of humor as well as focus on their hobbies (Hall & Graff, 2010). Maladaptive behaviors or emotion-focused coping strategies

focus on the problems and the child's limitations, with parents viewing the seeking of social support as a weakness and blame others for the child's disability (Tajalli et al., 2011). The negative strategies implemented by caregivers was using sleeping peels, resorting to drugs and alcohol, emotions of sadness and anger to release stress by crying, screaming. In this stage the parents may not have adapted and accepted the ASD condition and the child's symptoms difficult to manage.

2.6 Summary

The literature reviewed in this study indicated that, being the caregiver of a child with ASD has been shown to involve encountering problems and demands daily that can cause substantial amount of stress, mental health and well-being negatively, more than that of parents of typically developing children or non-ASD disabilities. Prior to diagnosis caregivers face growing concern about their child's development and the task of attempting to access appropriate guidance from health care providers. Parents encounter a tumultuous journey of diagnostic delays, dismissals from practitioners regarding their concerns and a number of misdiagnoses during the lengthy and frustrating diagnosis process while they attempt to understand and managing their child's concerning and disruptive behavior. Despite these numerous challenges and stressors parents face, many report positive experiences and positive benefits of having a child with ASD. The ability to adapt and engage with the new normal life caregivers are presented with is essential on the path towards acceptance. Caregivers who were able to employ coping strategies effectively changed their perception of the situation reported greater adaptation and family harmony.

CHAPTER THREE: RESEARCH METHODOLOGY

3.0 Introduction

Methodology is a section that explains the approach which the study used to collect data as well as how data has been analysed (Bertram and Christiansen, 2014). This section provides an overview of the method of collecting data that this study used. A qualitative approach was utilised in this study to explore the lived experiences of caregivers with children living with autism in Eswatini. The overall methodology for this study is therefore discussed as follows:

3.1 Research Paradigm

Paradigms relate to a research culture with a set of beliefs, values and assumptions that a community of researchers have in common regarding the nature and conduct of research (Punch, 2013). The study utilized a constructivist paradigm, in order to delve into how caregivers constructs their experiences of raising children living with autism. Constructivism is a philosophical paradigm that ontologically emphasizes how an individual actively constructs their own notions of reality through their cognition resulting in the existence of multiple realities (Shannon-Baker, 2023) . Utilising a constructionist perspective, in the context of studying caregivers of children living with autism, was an acknowledgment of how broader social and cultural issues, such as stigma, support systems, and cultural ideas about autism, may impact caregivers' experiences.

3.2 Research Design

Research design is the overall plan for connecting the conceptual research problems to the pertinent and achievable empirical research (Creswell, 2014). Little is known on experiences of caregivers living with autistic children in Eswatini, even though the topic is researched elsewhere in the region (Bakar & Munir, 2011; WHO, 2013). In order to achieve an extensive understanding of the phenomena under the study, this study followed a descriptive-exploratory research design. The exploratory research design created a relatively new space where the caregivers in Eswatini could freely share their unique experiences of caring for autistic children; while the descriptive research design allowed the researcher to describe their experiences in an in-depth manner (Creswell 2013). These experiences are based on each caregiver’s meaning-making of the environment/world around them.

3.3 Sampling Strategies

The study utilised a purposive sampling strategy, whereby participants were purposefully chosen from Litsemba Lemliba support group, a support group of care-givers living with autistic children in Manzini Eswatini. (Cresswell & Clark 2011) asserted that, in purposive sampling, participants are selected based on how well informed and proficient they are on the phenomena of interest. This study utilised this sampling method because the researcher needed caregivers with first hand experiences on caregivers raising children living with autism. The sampling criteria was as follows:

- Participants needed to be caregivers of children living with autism, and residing in Eswatini
- Participants needed to be part of the support group

A study Population according to Cresswell (2018), is a group of individuals taken to measure the sample. On the other hand, a sample, is a small portion of the total set of objects or persons from which a representative selection is made. It allows us to study a workable number of cases from a large group to derive findings relevant to all members of the group (Barker, 2003). The researcher requested access to Litsemba Lemliba support group located in Manzini. It comprised of members from all four regions of the Kingdom, which included well-represented data for the study, a formal letter was addressed to Autism Eswatini. The study sample comprised two males and thirteen female caregivers, for a total of fifteen caregivers. The Director of Autism Eswatini issued an approval letter for the researcher to have access to the participants, refer to Annex C, which indicated that a full approval was subject to receiving a copy of ethical clearance which was subsequently sent (see Annex F). The Director of Autism Eswatini invited the researcher in one of the support group meetings to introduce her and the purpose of the research. The researcher was therefore, introduced because she had no prior relationship with the group, 15 caregivers indicated interest in the research. The researcher then provided the caregivers with informed consent forms, refer to Annex D and E (depending on the language or preference) as well as a sample of questions that were to be asked. The interview guides were available in both English and Siswati Language refer to Annex A and B.

This was done to provide the participants with relevant information for the study. The researcher contacted the support group co-ordinator to schedule for the interviews. The participant all agreed to be interviewed either after or before their support group sessions which is usually held only on Saturdays in Manzini. On the day of the interviews, the study was explained in detail and all participants were assured about confidentiality and privacy of their responses, as well as the anonymity of their interviews, as a result pseudonym was used for this study. Participants were also informed that they could withdraw from the study at any stage of the interview without any consequences.

3.4 Data collection Instruments

Semi structured interviews were used to collect qualitative data, which was the best method for the study, even though the participants were familiar with each other from the support group. The data collection tool was not pre-tested before the interview commenced. The individual interviews allowed each one of them to express their raw emotions, and thought processes as well as to speak in their voice. It also enabled the researcher to keep the process of the interview within the parameters covered by the aim of the study. This was done through the researcher asking open ended questions. The interviews lasted between 45 minutes to 1 hour. Semi-structured interviews are considered as more flexible than structured interviews as they allow the interviewer to probe further for clarity. When using semi-structured interviews, the researcher used an interview schedule that allowed the researcher to cover all overarching issues from the research questions. Interviews are a data collection tool used for gathering information about participant's experiences, views and beliefs concerning a specific research question or phenomenon of interest (McGrath et al., 2019). Semi structures interviews are less intrusive to the interviewees. They provide uniform information and draw focus from research questions. The interviews afforded the researcher an opportunity to explore in an in-depth manner, matters that are unique to the experiences of caregivers living with children with autism. The researcher conducted individual interviews with care-givers at a place most convenient to them in order to maintain confidentiality. In addition, interviews were conducted in participants' preferred language, which was SiSwati or English, since the interview guide was translated. Interviews were not tape recorded, but the researcher used a notebook to record all the information. The reason being that, the caregivers were not comfortable to be audio recorded, at some stage in a previous research

one parent mentioned that they were trending in one of the social media platforms without their concern which let them devastated since confidentially was breached.

3.5 Methods of Data Analysis

(Maree, 2007) argued that data analysis is the process by which a researcher tries to understand how participants make meaning of selected phenomena by analysing their beliefs, feelings, perception and lived experiences in an attempt to contextualize their cnstruction of phenomena. Data analysis is viewed as an ongoing nonlinear process. Phrased differently, data collection, processing and analysis are interwoven. Interviews were not audio recorded but the reseacher recorded with a note book in order to get sufficient summaries from the interviews. Data were analysed using the Analytic Framework approach, which falls under the thematic analysis approaches for qualitative data (Braun & Clarke, 2006). Thematic analysis is a qualitative method that identifies, organises and details the given data set (Braun & Clarke, 2006). This process allows patterns to emerge and be examined in parts and as a whole. Thematic analysis is viewed as a more flexible method even when working with a variety of data, as it allows for a systematic approach that yields accurate results and that is more sensitive in understanding and interpreting observed data (Braun & Clark, 2006). To partake a thematic analysis, six stages were followed, as asserted by (Braun & Clark 2006). The stages were: (1) familiarization, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6) producing the report.

3.5.1 Familiarization and immersion with data

This phase the researcher immersed herself in the data by reading and re-reading textual data till familiar with it (Braun & Clark, 2006). The researcher repeatedly read the data, searching for patterns and meaning within the data set. This enabled her to understand specific language usage and latent meanings.

3.5.2 Generating Initial Codes

Once researcher had familiarized herself with data, she then began to identify codes which are the data features that seem interesting and meaningful by identifying the common words used by the participants and ended this process by collating all the noteworthy data extracts (codes). (Braun & Clark, 2006). During this stage of data analysis, the researcher also searched for themes which involved finding similarities within the data set. This was done

uniformly across all the data collected from the interviews. This process allowed the researcher to identify data relevent to previously extracted codes.

3.5.3 Search for patterns or themes across different interviews

At this stage analysis start to take shape, the researcher then shifted from codes to themes, as the theme captures the important informatiom from the data set (Braun & Clark, 2012). The collated codes were searched to identify relevent themes for the study. These were used to group and identify major themes the findings revealed thus gradually beginning the analysis of the data gathered.

3.5.4 Review of identified themes

A deeper review of identified themes was followed, where the researcher needed questions whether to combine, refine or improve, separate or remove preliminary themes (Maguire & Delahunt, 2017). This constituted examining whether the themes worked in relation to the entire data set or coded extracts.

3.5.5 Define names and themes

Defining themes involves formulating exactly what we mean by each theme and figuring out how it helps the researcher understand the data. Naming themes involves coming up with a succinct and easily undestandable name for each theme (Jack, 2019). The researcher then provided theme names and clear working definations that capture in a concise and punchy manner the essence of each theme.

3.5.6 Producing the Report

According to (Braun & Clark, 2006), producing a report is the sixth and final step in data analysis. In this stage, the researcher transformed the analysis into an interpretable piece of writing using vivid and compelling examples of extracts to the topics, research questions and litreture (Maguire & Dalahunt, 2017). In order to convince the reader of the merit and validity of the analysis, the report must relay the results of the analysis. This step involved putting together the data extracts to form a cohesive narrative about caregivers experiences and place the narrative in relation to the existing body of knowledge.

3.6 Ethical Considerations

3.6.1 Informed Consent

Acknowledging that participants have a right to be informed about the nature and consequences of Experiement in which they are involved (Denzil & Lincolin, 2011). The

researcher then gained access to the participants based on trust and not deception. All participants were made aware of potential ethical issues by way of participant information sheet. They all showed a capacity to undestand all the information that was provided to them regarding the study including the unforeseable implications of participating, as well as the capacity to exercise consent. The participation of all caregivers of children with ASD was free from coersion. Thus, all participants were assured that they have a right of refusal or dropping out which would not negatively affect them.

3.6.2 Voluntary Particpation

Human research have granted participants a right to exercise their free will and deciding whether to participate in research activity or not (Lavrakas, 2008). Participants in this study voluntary participated in this research without any form of coersion from the resercher. Partcipants therefore, signed a consent form, refer to Annex D, attesting to know what the research was all about.

3.6.3 Confidentiality

A research project gurantees cofidentiality when the researcher can identify a given persons responses but essentially promises not to reveal that information publictly (Babbie, 2014). Confidentiality goes hand in hand with upholding the ethical value of client self determination, and this just means that, the client has a right to decide or choose who knows the information shared with the Social Worker and that is why informed consent is crucial. Limits to confidentiality can also occur in the event where the Social Worker has a duty to warn who is sharing information to an outside party in the event harm is eminent (Reamer, 2002). During the research, participants were clearly informed about the resercher's intent to keep the information gathered from them strictly confidential and this assurance encouranged participants to open up and express themselves freely.

3.6.4 Do no Harm to participants

Aknowledging that conducting research, may cause harm to participants which may include emotional or psychological distress, physical harm, legal harm or political harm (Babbie, 2014). The researcher speculated that caregivers might become distressed in the course of discussing their experiencies. All participants were made aware that in an event of any emotional distress resulting from the questions asked during the interview, psychotherapeutic services would be made available. In such an event, a referral to a Social worker from

Department of Health and Social Welfare would be arranged through a referral from the researcher who is currentely employed in the same field as a Social Worker.

3.7 Reliability

Reliability is a concept in qualitative research that has a purpose of generating understanding (Stenbacka, 2000). The study attained credibility through participants validation, participants were given transcribed data to check and confirm if the transcriptions were accurate. To attain dependability (reliability), a reflective journal was kept. Confirmability means that the findings are shaped by the participants experiences more so than the reseacher (Statistics solutions, 2020). Permission was requested from the care-givers of children living with autism to record notes while conducting the interviews.

3.7.1 Credibility

Credibilty is one of the important factors to consider as a researcher in order to establish the trustworthiness of the research findings (Guba & Lincolin, 1985). It is also the level of confidance that the researcher is able to place in the research findings, validated by rich narrative data and felt to be truly representative of the phenomena they are trying to understand (Whitemore et al.,2001). The credibility of the study attends to the question of "how congruent are the results with reality" (Pandey & Patnaik, 2014). The credibility of this study was achieved through engagement with the participants during the interviews in order to develop a rapport. This allowed participants to provide detailed and voluminious descriptions of their experiences.

3.7.2 Transferability

According to Pandey and (Patnaik ,2014), the concept of transferability concerns the applicability of the research findings to another context. It is extremely difficult to demonstrate that findings can be applied to another context. It is extremely difficult to demonstrate that the findings can be applied to another context due to the small size and the homogeniety of the sample.

3.7.3 Confirmability

The concept of comformibility is in preference to the objectivity of the researcher in positivism (Guba & Lincoln, 1985). This concept can be perceived as a degree of neutrality by the researcher, or rather the degree to which the results of the study are participants-driven and not shaped by the researcher motivation, interest or bias (Pandey & Patnaik, 2014). The

researcher ensured that neutrality was maintained throughout the process of interviews; all participants were treated in the same manner. The researcher did not allow her background (of being a parent to an autistic child) to affect what was chosen to be investigated, as well as communication of conclusion.

3.7.4 Dependability

Dependability refers to the effort and degree to which care is taken to safeguard that the research is dependable and complies with the rules and procedures of qualitative research (Flick, 2009). Dependebility shows that the results are consistent, meaning that if the study were to be repeated in the same context, with the same participants and with the same methods it would yield similar results (Pandey & Patnaik, 2014).

Chapter four provides an in-depth introduction to and of the emergent themes

CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS

4.0 Introduction

This chapter is a presentation of the results that were obtained during the analysis of data which was obtained from the interview. The study pursued to explore the experiences of caregivers of children living with autism. For the researcher to achieve this, 15 family caregivers were interviewed. A thematic analysis of interviews revealed a number of significant themes which offered insights of experiences of caregivers living with children with autism in Manzini Eswatini. However, all names have been changed and Pseudonyms have been used as indicated in the previous chapter, for all the caregivers living with ASD children. Certain SiSwati words and phrases have been used in this chapter. Meanings have been written in brackets next to them. Although some meanings appear to be straight forward it is the connotations that come with them that has led to them kept in SiSwati. This chapter has two sections; the first section presents the demographic profiles of participants and the second is presentation of themes which includes recognition of atypical development, psycho-socio economic burden, lack of awareness, spirituality & religion as well as coping strategies and sub-themes that arose from the data.

4.1 Participants Demographical Information

Table 2: Demographical profile of participants

Pseudome Names:	Age	Gender	Marital Status	Level of Education	Employment status	No. of children residing with	Region	Relationship with the child	Diagnosis age
1 Lusito	48	Male	Widower	Matric	Employed -Driver	2	Lubombo	Father	3
2 Obed	47	Male	Marri	Matric	Employed	9	Lubom	Uncle	9

			ed		-Driver		bo		
3. Wethu	70	Female	Widow	Tertiary	Retired nurse	3	Hhohho	Grandmother	3
4.Ncane	43	Female	Married	Tertiary	Self employed	4	Manzini	Mother	5
5. Thuli	80	Female	Married	Tertiary	Retired nurse	2	Shiselweni	Grandmother	4
6. Nolizwe	47	Female	Divorced	Matric	Self employed	1	Shiselweni	Mother	7
7. Philile	45	Female	Divorced	Tertiary	Employed - Accountant	4	Hhohho	Mother	4
8. Phindile	45	Female	Single	Matric	Unemployed	3	Manzini	Mother	6
9. Viwe	52	Female	Single	Tertiary	Employed -secretary	5	Hhohho	Mother	5
10. Sonto	42	Female	Single	Tertiary	Counselor	1	Manzini	Aunt	3
11 .Gugu	50	Female	Single	Tertiary	Employed -Program director	3	Lubombo	Grandmother	7
12. Pretty	37	Female	Single	Tertiary	Employed -Hotel Chef	3	Hhohho	Mother	6
13	40	Fema	Marri	Tertiar	Employed -Civil	2	Lubom	Mother	3

Zipho		le	ed	y	servant		bo		
14 Thembi	55	Female	Single	Tertiary	Employed - receptionist	4	Manzini	Mother	5
15. Busiswa	46	Female	Divorced	Tertiary	Employed -Secretary	5	Lubombo	Mother	2

Participants of the study were not selected by age nor gender but they were chosen particularly on the basis that they were caregivers of children living with autism who were part of Litsemba Lemliba support group in Manzini Eswatini. In order to better understand their experiences, both genders from the participants were involved, and their socio-economic status was imperative in order to ensure that, the study had the holistic view of the caregiver's challenges which obviously were different. The mean age of the participants from the study was estimated to 50 years ranging from 37 to 80 years. The youngest was 37 years and oldest was 80 years, due to the fact that some of the caregivers were grandmothers of the children. Based on the table above there were only two male caregivers and 13 female caregivers, this supports the fact that caregiving is perceived as a female duty. As a result, findings suggest that mothers reported more stress related to taking care of ASD children than fathers (Estes et al., 2009; Hastings 2003; Hasting et al., 2005).

However, the marital status of the caregivers was also considered by the researcher, 4 were married, 2 were widows, 3 were divorced, and 6 were single parents. Most caregivers of the study were female single parents. This is reflective of research as (Risdal & Singer, 2004), points out that, couples parenting children with ASD reports higher rates of divorce and separation than couples in the general population and parents of children with other disabilities. This therefore results in high rate of single parenting to caregivers of ASD children as reflected from the above table. All four regions were represented because the caregivers were from Lubombo, Manzini, Hhohho and Shiselweni region. All participants

were part of the advocacy and the fight to raise awareness by the virtue of being members of autism Eswatini, which prioritize advocacy of a support group.

4.2 Themes and sub-themes that emerged from the interview

The main themes and sub-themes that emerged from the data were identified and are illustrated on the table below. Themes were deliberated with reference to the narratives of the participants which some are presented verbatim and in italics. The objectives of the study included:

1. To explore and analyse experiences of caregivers raising children living with autism
2. To describe the coping strategies faced by caregivers raising children with autism
3. To ascertain identified needs and supportive services required by caregivers of children living with autism
4. To explore the challenges of caregivers raising children with autism

Table 3: Themes and sub-themes that emerged from the interview

Themes	Sub-themes
1. Recognition of Atypical Development	a) Reaction to diagnosis b) Descent wondering between what is autism and what will be with the ASD child
2. Psycho-Socio Economic Burden	a) Psychological/emotional burdens b) Impact on social systems c) Financial burden
3.Lack of Awareness	a) Education sector b) Medical awareness
4. Spirituality and Religion	a) Connecting to deity, reflecting on the failure in their struggle b) African supernatural traditional religion

5. Need for support and services	Government support a) Support services from Department of Education b) Support Services from Department of Health c) Support service from Department of Social Welfare
6. Coping Strategies	a) Positive coping b) Negative coping c) Support Groups

4.3 Theme 1: Recognition of Atypical development

Most participants mentioned that they have recognized atypical development from their children. This comprised on how caregivers described as to how the development of their child did not follow the normal expected course which included learning and social difficulties their children exhibited. The data collected indicated that the participants did notice abnormalities in the development of the child or their children. According to a number of studies this is the case for many caregivers who report distress relating to ASD prior to a diagnosis, as many report atypical behaviour and developmental delay early on (Altiere & Von Kludge, 2009; Carlsson et al., 2016; DePape & Lindsay, 2015; Estes et al., 2013; Karst & Van Hecke, 2012; Mitchell & Holdt, 2014) and began to seek professional guidance.

At 5 months he couldn't sit up, had a weak neck. I took him to Mbabane Government Hospital where I was told he had weak muscles and was referred to an occupational therapist. I was told he had delayed milestones and need to come for therapy on weekly basis. Loku kwavele kwangicedza emandla ngoba bengite kucondza kutsi kubangwe yini konkhe loku (this let me confused because I didn't know what was the cause of all these). Though it was not easy for me as a widower and alone, eventually he was diagnosed with autism. When he was 3 years because all the symptoms were visible. (Lusito), 48 years

Bodokotela basengakasibikeli kutsi nguluphi luhlobo lwesifo umtfwana wami lanaso khona bekungibikela kutsi hhayi khona, kukhona mani lokungahambi kahle kumtfwana. Benginekutibuta ngitsi ngibakhulisile bantfwana kopha lona wehlukile (Before diagnosis there was a motherly instinct that something was wrong, my child was not acting normal like children of her age). This was around age 1-2 years, and she had no speech, I notified her father who told me there was nothing to worry about since the whole family on his side acted like that including himself when they were still young. (Busiswa), 46 years

To tell the honest trust I did not understand the symptoms, when he was at a tender stage I thought my child was affected by an evil spirit. Since I am a Zionist the child was prayed for in church. But as he grew up I thought he was misbehaving, because all about him was routine based and should you change that it triggers his tantrums. (Nolizwe), 47 years

What amazed me was that at 4 years old my grandson had no speech, he couldn't even say simple word like "mama". I was so worried about him because even the health workers never explain what was wrong about his speech instead were referred to a speech therapist and occupational therapist. Kubuhlungu indlela lengaphatseka ngayo ngalelolanga ngoba naleso speech therapist ne occupation therapist kute nje lowangichazela kutsi basebentani nekutsi batongisita ngani nje sekutsiwa angiye kubo. (I was really not happy the way I was treated on that day, I was referred to speech and occupation therapists and nobody explain the reason for referral and I was not aware of their roles as well) I must say this was frustrating for all my family members, it was our first time to encounter this. (Thuli), 80 years

From the above extract it is clear to see that caregivers start to notice atypical development of their children on different ages and developmental stages due to the fact that autism is a spectrum. Therefore, no two children can be on the same spectrum, similar perhaps but never the same, every child is on a spectrum unique to them. All parents realized their child's behaviour was atypical either from early on or after a clear marker of change in their child's behaviour. The findings are consistent with those of (Haye & Watson, 2013; Lenroot & Yeung, 2013) who also found that, ASD present on a spectrum with variations in behavioural phenotypes within each domain and the type and severity of the deviation that manifest. This means that, one individual may not necessarily meet the diagnostic criteria or be impaired in the exact same way as another individual with ASD.

4.3.1 Subtheme 1: Reaction to the diagnosis

The researcher observed that there was a pattern with more than half of the participants extremely confused after receiving the diagnosis. They really had not connected to the symptoms the children were experiencing to autism spectrum disorder, perhaps because of lack of awareness of what the disorder is, and particularly within Eswatini. In addition, it is also seen that, caregivers had a different way of grieving though they were in pain in different times regarding their children's condition but they all find it truly hard. A common trend that was found amongst the participants was that their children were diagnosed with ASD at around the age of 36 months. This is reflective of research as (Koudstaal, 2010) points out that, most children are not diagnosed until they are 36 months of age. It is around this age that children display prominent signs and symptoms of ASD and parents began to worry that something is 'wrong' with their child/children.

When my child was diagnosed I was so frustrated because even though I once heard about autism but I was not aware what it was all about. For that matter, there is no SiSwati name it's just an unknown sickness. I wept tears, it was like I was told my child will die tomorrow. At that time, he was around 3 and a half years old. (Zipho), 40 years

My child was diagnosed with autism at 3 years that time she had no speech, I thought she will speak because children do not develop the same way. I did not accept the diagnosis because my first born *also developed his speech when he was 2 years. It was very hard for me. I therefore seek for a second opinion from another hospital hoping that the diagnosis would change but the result was still the same. Nangitjelwa kutsi umtfwana une autism kwakulukhuni kwemukelaloyo mbiko ngoba nalomunye umtwana wam waphuta kukhuluma, kani name make longitalako wangitjela kutsi ngephuta kukhuluma. Kimi loko beku normal ngiku ngaba nebulukhuni kukwemukela kutsi umtwana wami une autism (I was in denial to accept the diagnosis of ASD for my child in that I associated ASD with delayed speech which was normal in my family because even me my mother told me I developed speech very late and my first born as well. (Viwe), 52 years*

My pregnancy was not smooth, at 7 months I got a placenta previa I almost lost my child due to bleeding. The doctors told me it was because of having more than one abortion which was true for me just that I never disclosed it to anyone it was my secret. When my child was diagnosed with this autism thing I felt guilty because I knew it was all my fault. He was around 5 years of age when diagnosed. I was not even aware what autism was, who get it,

how do you get it and why do you get it? At the same time, I was relieved to learn what was wrong with my child after back and forth from different health professionals (Phindile), 45 years

My boy was diagnosed when he was exactly 3 years all the signs and symptoms were visible to him, I had no choice but to accept what I was told though I didn't know what was autism and I was confused. There was a sense of peace though, to know what was wrong with my child even though I didn't know about autism (Lusito), 48 years

From the above quotes most ASD children were diagnosed late when they were mostly toddlers since all the symptoms were visible. Most caregivers were not aware that their children were living with autism and some caregivers mentioned that it was their first time to know about this condition. Such that it came with a sense of relief or hope because they finally had clarity on the child's mysterious behaviour, however for others the diagnosis came as a shock they were confused which resulted to depression. This is congruent to (Kuhn & Carter, 2006) that parents often report feelings of loss, confusion, grief, sadness, denial, isolation and guilt soon after their child's diagnosis.

4.3.2 Sub-theme 2: Descent, wondering between what is and what will be

The journey of spirituality that caregivers in this study began with the wondering between what is autism and what will be the future of their ASD children. In this study endless grief and sorrow of all participants began just after the diagnosis of their children and it developed in all aspect of their lives. They also seemed confused and lost hope due to the fact that they were not aware of what will happen to their children

I cried so much when I realized my son has autism. Due to this subject I was so upset. I asked myself questions like what have I done wrong to deserve a child with this condition. I understood my baby was sick but I didn't want to accept it. I tried not to say my child was ill, though I did not want to admit it but I didn't have a choice. In my heart I believe that not to say anything about this autism thing, maybe my son will get better someday what should I say….? (Zipho) 40 years

After my son was diagnosed with autism I was so confused because first of all I didn't have any idea what autism was and secondly there is even no SiSwati name for it. It was my first time to hear the word or at all know about it. I was as confused and worried as to how I am going to manage in taking care of my child with this wired sickness. I was even wondering if there is any treatment or medication in Eswatini for it. (Ncane), 43 years

The word autism could not sift through my head, it did not match my child at all. I was so hurt and angry at the same time because I felt that why I was not told early when he was still a baby about this. (Nolizwe), 47 years

It affected me [chuckles], yah it affected me. I could always sense there was something wrong with him even though he met all his milestone but still he was not verbal. After the actual diagnose I investigated about autism, when I realised that I am not alone in this journey I eventually accepted though it was not easy at all I am telling you. (Thembi), 55 years.

Most of the participants have described the progression and pendulum of feelings they experience upon learning that their children had autism. The feelings include shock, denial, grief, guilt, anger and confusion.

From the above quotes the emotional reaction from caregivers upon diagnosis of their children included guilt, denial, confusion and frustration. One caregiver mentioned that she was in denial of the diagnosis in that she looked for a second opinion but the result came out the same. Consequently, parents of children with ASD seek out second opinions and rely on internet research in search of definitive answers (Lilley, 2011).

4.4 Theme 2: Psycho-Socio-Economic Burdens

Caregivers experiences of poor emotional well-being, as well as the despair and guilt that may have caused their children's disability, compounds the challenging experience of caring for a child with autism (Gobrial, 2018)

The second theme Psycho-Social-Economic burden encompasses of the three areas consistently being mentioned by participants to be overwhelming burdens which includes the psychological/emotional burden, impact on social system as well as the direct financial demands.

4.4.1 Subtheme 1: Psychological/emotional burdens

The main focus of this theme is the when the participants expressed their emotional feelings of how draining it can be to take care of a child living with autism for the rest of your life and you don't have a choice and the consistent worry about their children's security. Caregivers experiences of poor emotional wellbeing, as well as despair and guilt that may have caused their children's disability, compounds the challenging experience of caring for a child with

autism (Gobrial, 2018). The following quotes depict the emotional turmoil caregiver's experiences as a result of caring for a child with ASD:

I love my son so much but as a single mother at times I feel as if every day is like hell, there is actually no good day and accepting is near impossible but adjustment is possible. There was a time where it was extremely hard for me where I had to deal with my divorce and my ASD child, suicide was my option but for the sake of my boy I didn't do it, because of my worry as to who will be able to take care of him when I am gone. (Philile), 45 years

It is emotionally draining you don't know what to think and what to do about it. Most of the time you feel alone and it is like no one seems to understand what you are going through since we live in Eswatini where everyone has an opinion about the condition, be it traditional healers, you don't know how to discipline your child or you have angered the ancestors. To add on that, it was not easy for my son to get a proper diagnosis I moved from one hospital to another since he was two years but eventually diagnosed with ASD when he was three years. (Lusito), 48 years

It is very frustration because you need to deal with the child's condition and also the after effect of the medication given to the child for this condition and again the whole society and their perspective about my child's behavior I don't have control over. Emangweni bantfu bebatsi ngingumtsakatsi ngatfwala ngalomtfwana kubuhlungu kusolelwa intfo longayentanga. Nami angiticelelanga ku Nkulunkulu kutfola umtfwana lone autism, Inkhosi iyati kutsi anginacala (The community member told me I was a witch, I wanted get rich hence I sacrificed to the gods that is why my child gave birth to an ASD child, only God is my witness how can I do that to my grandchild. (Thuli), 80 years

It is however unfortunate that I have not yet had suicidal thoughts, basically it is a mixed emotion when it comes to my grandchild because I cannot leave him alone on his own due to the fact that I know he will not be able to help himself and I love him at the same time he drives me crazy. I feel helpless because he is supposed to be attending sessions with the Occupation therapist but I can't afford transport money it's too expensive to travel from Siteki to Manzini. (Gugu), 50 years

Taking care of my nephew in a country with limited resources such as Autistic schools and therapist to assist the child with his speech. I come from a rural area called Dvokolwako where there is no speech nor any other therapist. Every time I have to take him to Manzini, it is far and costly at times we don't attend the session due to lack of money for transport.

Another issue is an autistic school; my boy is not attending school he stays at home which I feel his right to education is deprived. (Sonto), 42 years

The above extract shows participants experience significant stress around taking their children to public or to the community as they feel like they have to explain everyday about the behaviour of their children. The findings of the study are reflective to research from (Firth & Dryer, 2013) that state that parents experience difficulties in managing behavioural problems displayed by ASD children which impacts on social gatherings. These behavioural problems further dominate the family life of parents of ASD children, thus restrict social and recreational activities (Neely et al., 2012) In addition is the fact that taking care of an autistic child is a lifetime journey that is emotionally strenuous with a lot of difficulties in all aspect of one's life.

4.4.2 Subtheme 2: Impact on Social Systems

The social system for this study focused on the social aspect of the caregivers living with children with autism in the family, workplace, in church and community. The social aspect had two extremes either the caregivers had a very supportive social system or they had a completely disregarding social system whereby they will either be very unaccepting and feel as though the child is given too much attention, very spoilt or very accepting and supportive.

4.4.2.1 Family

Having a child with autism impact on all aspect of family lives which may include housekeeping, finances, emotional and mental health of parents, marital relationships, and poor sibling relationship. Findings suggests that, the family functioning can be impacted both in a negative or a positive manner (Lindo et al., 2016)

Wooooo I don't want to lie I thank the Almighty God with my precious family, the support they are giving me with my nephew is so amazing. Taking care of him is not strenuous at all because it's everybody's responsibility. Angiwuva lomtfwalo wekunakekela umtfwana lokhubateke nge Autism njengobe labanye banakekeli bawuva (I really don't feel the burden of caring for an ASD child like the other caregivers. My family is a blessing from God. (Obed), 47 years

I never got any support from my husband and in-laws instead I was blamed that I have an autistic child. (Bebatsi ngite nesicalekiso ekhaya kitsi) meaning I came with the curse from my own family, hence I gave birth to an autistic child. I was told that I am the one who is

responsible to take care of the child alone because I came with the autistic genes from my family. Life was tough for me and my husband ended up divorcing me. (Nolizwe), 47 years

My family is supportive even though they at times feel I am spoiling my boy, but his condition has actually made me to put all my attention to him. (Lusito), 48 years

I give almost all my attention to my daughter due to her condition but her siblings are complaining that they feel like I don't love them. Nami ngiyatibona vele nginakekela yena kakhulu kunalalabanye ngetiwa ngulesimo sakhe noko (I give all my attention to my ASD child, more than her siblings, this is due her condition though). I thank God they are very supportive in taking care of their little sister and they all love her in as much as they feel unloved by me at times. (Viwe), 52 years

As for the family the diagnosis had an effect on the paternal side of my child's family as her grandmother was afraid of her and somewhat shun her and that kind of hurt me as a parent because I expected her to support me. Kwakungivisa buhlungu kubona make tala angamtsatsi umtfwana wam, sonkhe sikhatsi abebeka tizatfu nakumele asale naye. (It pains me to discover that my mother in-law couldn't stay in the same room with my child, she couldn't even hold or comfort her when she was crying). This actually resulted on my husband not to fully support me we separated for a year and finally divorced. (Philile), 45 years

I think it affected my family negatively as you know it's an expectation that in every family that you will have a normal child (Pretty), 37 years

Overall, it is clear that raising a child with ASD is extremely disruptive to some families causing divorce as well as an atmosphere of blame and unhappiness due to feeling burdened by taking care of a child who needs attention twenty-four hours a day. It also appears that, most couples separate after realizing the atypical development of their child and most children experience rejection from the paternal side of their family. This is congruent to Risdal and Singer, 2004 as they point out that couples parenting children with ASD report higher rates of divorce and separation than both couples in the general population and parents of children with other disabilities. However, some families are brought closer by having a common goal of taking care of their loved one who is living with autism. There is logical evidence that, having a ASD child have a negative impact on relationships, some caregivers reported strained relationships, low levels of happiness and increased conflict such that this impacts on peaceful marriage and to some parents it eventually results to divorce, DePape & Lindsay, 2015 et al.

4.4.2.2 Church

In a normal world a church set up is where one can fellowship, worship, praise and pray to the Almighty God with unity and a loving congregation. This is not the case with ASD children and their caregivers, they either get support or rejection.

My nephew sits at a corner on the right at the front every Sundays. That time we had no *understanding of his condition and the routines, every time he would find someone sitting where he sits he will simple go back home or his uncontrollable tantrum will be triggered. Our home is right next to the church, the church members are so supportive and understanding towards him. Nobody sits on his place every Sundays, even if we late. (Obed), 47 years*

At church they are completely supportive to my grandson and his condition, they normally come home to offer prayers. We have a disability support program in church and my grandchild gets support as well from that program. (Gugu), 50 years

In my church I was not getting support, I experience discrimination and rejection. Nobody will sit next to us even children do not play with him. I felt it that my child is abnormal, until I decided to attend church online. (Lusito), 48 years

My church is where I always felt my grandchild is welcome, nobody judges me of spoiling him and lacking parental skills. The children like him but it's just that he does not like to play with them. (Thuli), 80 years

To tell the honest truth, I don't like church that place is a residence where people sit on God's throne and judge you as if they themselves are angels. Lots of people use to shout at my boy, and some will tell me right on my face that am a bad parent and have poor parenting skills. Some further told me my boy need a lashing, so he can behave well since he lacks discipline. Lomunye watsi "eyi Lusito lentfo yakho yekuhlulwa bantfwana lona udzinga umshaye ngeluswati utobuya endleleni" (a church member commented that, the child needs a lashing he is naughty, the father lacks parental skills. That actually made us to stop attending church ever since my son was around five years till today. (Lusito), 48 years

Church is very supportive just that my child becomes uncomfortable when they are lots of people around him and he consistently cries and make a lot of noise. As a result, some church members tend to judge me that I lack parental skills and I am spoiling my child. (Thembi), 55 years

From the above extract the church system appears to be supportive of the child's condition with the exception of a few cases where the church members felt the child is spoilt and the caregiver is not doing enough to discipline the child. One participant mentioned that the church has even adapted to the routine of his nephew who sit on one place and chair every Sunday, in that everybody understands no one is allowed to sit on his chair because it either triggers uncontrollable tantrums or he just go back home. Some participants felt judged or perceived as incompetent parents who do not know how to discipline their children. Participants tended to receive rejection, discrimination and judgments from places where they believed they would receive support such as in church. This is congruent to Bateman, 2013 who mentioned that, as the child's behaviour is often viewed as abnormal, the parent and autistic child may be subjected to discrimination, rejection and prejudice.

4.4.2.3 Work Duty

Having a child with ASD can cause significant professional strain to parents/ caregivers. Compared to parents of typically developing children or children with other types of special needs. Parents of children living with autism report being underemployed, having more difficulty accomplishing important work task and viewed as less favourable by their supervisors (Larson, 2022). Even though the experience is not the same with all caregivers, others have supportive work experience.

Work has not been affected much as they have been extremely understanding and they are okay with me leaving in instances where I have to take my child to hospital. (Busiswa), 46 years

As a widower it is tough for me to take care of my boy I solely rely on nannies to take care of him during my absence to work, who do not last due to my son's condition. This usually at times lead me not to attend work in order to look for another baby-sitter but well…., my boss understands and he is supportive. (Lusito), 48 years

My colleagues are so much supportive, they understand that every Wednesday I have to take my child for therapy (Philile), 45 years

I lost my job because I was always absent at work due to the fact that my child is a sickly person, my employer didn't understand and I was fired. Imphilo ilukhuni ngalahlekelwa ngumsebenti angiboni kutobalula kutfola lomunye umsebenti ngoba lesimo semtfwanami angeke sishintje (Life is tough, since I have no source of income as a single mother and a

bread winner I don't think it will be easy to get another job due to the fact that my child's condition will not change). (Phindile), 45 years

I lost my first job due to the fact that baby sitters were not taking good care of my child I would find my child dirty and hungry because they were all not patient with him. This use to make me to dismiss them and look for another helper such that I had to be absent from work. My employer ended up firing me due to lack of understanding of my child's condition and that month he gave me only half of my salary. I was so hurt but there was nothing I can do I had to leave my job. Lobulukhuni bemphilo nalesimo semtfwana kwenta ube nekubalisa emoyeni wakho utsi kopha Nkhosi ngoneni lelengakakuwe konkhe loku akukangifaneli (At times i complain to myself and say but God why did you allow this painful situation in my life what did I do wrong to deserve all these) (Sonto), 42 years

According to the narratives when it comes to the work system. It appears that there are two extremes. It's either the employer is understanding or completely disregards the hardships that comes with raising a child with autism to the extent that some parents lose their jobs. This relates to how disadvantaged caregivers of ASD children are even though they require to work.

4.4.2.4 Society

It has been found that many parents within the African context are stigmatized by their societies due to having a child with ASD (Bakare & Munuir 2011; Costa, Steffgen & Ferring, 2017; Schlebusch & Dada 2018). This however results for primary caregivers reporting negative experiences, however it is not the same case with all caregivers though, some communities are supportive especially the church.

The community have no understanding of the condition. She is now 14 years and have been raped twice by community members. She was infected with HIV, and is currently on ART, the community members are taking advantage of her because of the condition she is, which is very painful. In Eswatini there are no places of safety that accommodates children living with a disability. (Nolizwe), 47 years

The public has no understanding of my child's condition, I constantly get compassion from the community members which keep on reminding me that my child is abnormal. I always ask myself "will they ever accept his condition"? (Busiswa), 46 years

Lack of knowledge and understanding from community members, some community members call him a lunatic and yet he understands this results on him to have tantrums and it is so painful to us as a family. (Lusito), 48 years

Lack of understanding and support from the community I can't even attend community gatherings anymore because he becomes the centre of attention and people say whatever opinion about him which is hurtful to me. (Labanye batsi lihlanya, sidalwa, sihlangananhloko) they call him a crazy lunatic. (Thuli), 80 years

My child was very active and was branded as naughty, such that we stopped taking him to social places like church and shopping centres. Basically to us it meant we had to keep him in-doors, as a mother I had to remain home to take care of him. The same applied to my family when I had to go to work someone had to stay home to take care of him. This means we are really grounded in all respect. (Thembi), 55 years

The community is supportive especially my church, the church of the Nazarene, they even have a program for supporting people living with disabilities. They give us food parcels every month and they even give out assistive devices to those that needs them.

From the above quotations out of all the participants the community is either supportive or not supportive to children living with autism they are either rejected, taken advantage of, name calling, public humiliation due to lack of understanding and information regarding autism. Some participants felt judged or perceived as incompetent parents who do not know how to discipline their children. Some community members are supportive though not all but some of the churches even have programs supporting people living with disabilities. Findings suggest that, as the child's behaviour is often viewed as abnormal, the parent and autistic child may be subjected to discrimination, rejection and prejudice (Bateman, 2013). This is further compounded by the interactions with different community structures such as the church and school which reinforce perceptions and beliefs that the community may have regarding the autistic child.

4.4.3 Sub-theme 3: Economic/Financial burden

Financial stability was seen as a major factor contributing to a lifestyle change in the majority of participants. 'Autism Speaks' estimated that in the United States of America (USA), autism costs society an astounding $126 billion per year (Kamaralzaman, et al., 2018). Non-medical costs were seen to account for the greatest proportion of the yearly expenditure. This

is consistent with the participant's reports that most of the costs include intervention services, medication, special schools and food as evidenced by the following quotes:

My child has sleeping difficulties due to her condition but the medication they give her calms her and she sleeps peacefully. The medication is expensive and is not available in government hospital so I always buy it on the private pharmacies. At times I am failing to buy the medication, and that means she had to skip it which affects her so bad. I always cry myself when I see her suffering, and struggling to sleep because I couldn't afford to buy her medication. (Viwe), 52 years

My grandchild is supposed to be undergoing therapy with the Occupation therapist and Speech therapist but such therapist is not available in the rural areas like the Lubombo region where we reside. They are only available in the main big towns like Mbabane and Manzini. Hence I only take my grandchild for therapy only once a month or skip some month due to expensive transport fee (Gugu), 50 years

My child is not attending therapy due to the fact that it's expensive to go to the big towns, I am based in rural areas and our hospital have no therapists. (Busiswa), 46 years

Children living with autism have a special diet, they don't just eat anything because some of the food we eat make them hyperactive. You know this is not at all easy I am struggling to buy his special food because it's expensive. At times I just give him what we have but I always pick whenever he is not okay due to the food. It pains me because I don't afford his special diet. The public assistance he is getting from the government is too little, it's only E280 on monthly basis. (Thembi), 55 years

Taking care of my nephew comes with expenses I don't want to lie, which include his medication, taking him for Occupation therapy. I tried to apply for the public assistance but he didn't qualify because the people who assess the eligibility of people living with disabilities have no skills for that. These are Government Social Workers, they just looked at my boy and I was told he is normal and not eligible. Even when I told the officer who was assisting us that the child is living with autism, I could tell that she has no understanding of the condition hence she said he does not qualify. (Obed), 47 years

The special education is not accommodative to autistic children I must say. In Eswatini there are only two government autistic schools and they are all in Mbabane. They both do not have a hostel to actually accommodate children coming from far, this means they were meant for

residents around Mbabane. These two schools are always full; the available schools are the private schools. These has led me to take my boy to a private school, and it is very expensive I can't afford it but I don't have a choice, it is his right to get education like any other children. (Philile), 45 years

According to the responses from the participant's financial burdens arise as a result of the expenses that comes with raising a child living with autism. These expenses include transport costs, taking children to special schools that requires an extra financial muscle, the cost of specialized diet & medication, and lack of disability grant. It appears that most caregivers have difficulties keeping up with the financial needs that comes with having a child living with autism. The overwhelming financial needs affects the family caregivers psychologically as the stressors keep mounting because raising a child with autism is a lifetime commitment. This is consistent with (Backer, Brookman & Stahmer, 2005) that, families caring for a child with ASD experience increased psychological distressed compared to other families.

4.5 Theme 3: Lack of awareness

Majority of the interview participants described a low level of awareness about ASD in the country. The main key areas identified within this theme were lack of awareness in the medical sector which is the first place of seeking a diagnosis for majority of the caregivers and the second sub-theme being the education sector.

4.5.1 Sub-theme 1: Lack of awareness in the medical sector

There is usually lack of awareness on autism in medical sector which in most cases result either in late diagnosis or misdiagnosis (Bateman, 2013; Tincani, Travers & Bout, 2009) as demonstrated in the quotes below.

The journey for my child to eventually get a proper diagnosis was not easy. I went to different hospitals and clinics the medical professionals were saying different things with conflicting professional explanations. I was so worried and confused. My child was eventually diagnosed very late when he was around 6 years of age. (Nolizwe), 47 years

My child had no speech he started talking when he was 5 years, all these years he was identified as a deaf and dumb child. The time he started to talk his speech was not clear, I took him to a speech therapist, who told me he has all the signs and symptoms of autism. I had no idea what was autism, it was my first to even hear about it. He was then referred to a paediatrician who diagnosed him with autism. Kubuhlungu kutjelwa kutsi umtfwanakho

unesifo lesingenalo neligama lesintfu, iautism kimi nje kwaba kutsi kusho kutsi sifo sebelungu. (Phindile), 45 years

My nephew was categorized as a mentally challenged person, by nurses in the community clinic. When I recall very well one of the nurses went for a training on autism in Mbabane when she came back, it was unfortunate that my boy had flue so I took him to the clinic. The trained nurse told me I was about to call you, during the training I pictured your nephew because all the signs and symptoms I know them from him, he has autism. At that time, he was 9 years old, since then she has been of great support to us as a family on how to take care of an autistic child. (Obed), 47 years

However, the actual diagnosis of ASD was done at age 7 for my daughter by a professor who was also a Medical doctor heading the ICU in Mbabane Government hospital. None of the doctors from Piggs Peak Government hospital and Mkhuzweni health centre where I come from could help me and yet I went to different doctors for assistance. This was so difficult and frustrating at some stage I felt alone and desperate through trying a lot of avenues and assistance with the child's diagnosis. (Nolizwe), 47 years

Findings suggests that majority of caregivers from this study faced lengthy and frustrating diagnosis processes which supports findings in previous research internationally and in South Africa (Altiere & Von Kluge, 2009; Crane et al., 2016; Estes et al., 2013; & Holdt, 2014).

From the above narratives, it is worth noting that due to the fact that autism is a spectrum, the pathway to diagnosis is not an easy one for both caregivers and the medical sector. Since autism is a spectrum it consists of a wide variation of conditions, which tend to be confusing to the medical team, as a result, children are misdiagnosed which further leads to late diagnosis. There are also commonalities that stood out, such as the experience that every participant reported was having seen multiple healthcare professional before receiving the actual diagnosis which included doctors, nurses and occupation therapists. The process for most caregivers was difficult and frustrating one during which most caregivers reported feeling alone trying as many avenues as possible to obtain the assistance they needed while attempting to cope with their child's behaviour and difficulties.

4.5.2 Sub-theme 2: Lack of Awareness in the Education sector

Children have a right to education, this is in accordance to Eswatini Child protection welfare act 2012 and the Disability act 2018, despite of any disability, and on the contrary caregivers of ASD children are struggling to gain access for their children's education. The reason

behind, is limited human and material resource, lack of training of teachers, lack of co-ordination between mainstream and special education (UNESCO, 1994). Some of the participants identified encountering difficulties in finding appropriate schools for their children to attend and changing schools for their children due to a range of problems they then encountered as illustrated below:

Education is one of the basic rights of a child, but it so painful to have a system that doesn't cater for our children or at all have an understanding of how the ASD children have to learn. This is really pathetic of our government I must say. (Zipho), 40 years

His school was not really willing to handle him; they don't have experience on how to handle him. So, they were not teaching my boy, basically I was paying school fees and he was not taught. Eventually he had to stop going to school and I decided to keep him home, because they were no difference whether he goes to school or stay at home. (Lusito), 45 years

Children living with autism are excluded in schools such that at times they attend school but they are left un-attended by the teachers and some parents resort that their children should stay at home (Twala S.K, 2018) *Lomunye thishela watsi kimi yena uhamba nalabahamba akanaso sikhatsi sekunesana nalowami umtfwana baningi kakhulu labantfwana kuleliklasi bangu foti. (Gugu), 50 years*

My child was attending school at a normal public school but the teachers always call me to inform that my child was naughty and stubborn. I remember one day we went for a disciplinary hearing I had to explain that my child was autistic. I discovered that the teachers didn't know about the condition, the head teacher indicated that she will request a workshop from their headquarters to train the teachers because my child was not the only one with the signs and symptoms of autism. (Pretty), 37 years

My child was not coping at school because the other children were bullying him and calling him with all the funny names and yet he understood. Every morning he was crying and didn't want to go to school. I went and report the matter but it was not resorted and I decided to take my child to a special school. Though it is extremely expensive but my child is happy and has improved so much with his school work. (Nolizwe), 47 years

Wuhu…….. (deep breath) my child is not coping at school he is always failing and I wish I had enough money to take my child to a special school where I will know and be satisfied all his educational needs will be met accordingly. Ngikhumbula ku open day thishela wemtfwana

wami watsi, kute lakwatiko naye uzame konkhe kumusita but uyahluleka angimuyise esikolweni lapho batokhona kumunakekela kahle khona ngalo lonkhe lusito laludzingako (Phindile), 45 years

I can be happy for my grandchild to attend a school where they are not made to feel different. In many public schools they are still made to feel different. I want him to learn, have fun and to feel welcome and enjoy schooling. (Wethu), 70 years

Education is a fundamental human right and is a privilege passage that everyone needs to undergo, though research indicate that special needs education does not address the needs of those with disabilities which will assist in their development (Hunt,2011; UNESCO, 1994). However, the participants mentioned that it is time for the Government to ensure that the children living with autism get support. For that reason, teachers need to be trained in autism issues, there is a need for autistic schools, and school children need to be capacitated on autism to avoid bullying children living with autism and to accept them as they are. It is clear that although human rights are infused in the education section, how this is implemented leaves much to be desired.

4.6 Theme 4: Spirituality and Religion

The caregivers identified that the typical beliefs among the Swazi society are that ASD or developmental disorders are spiritual problems or of a supernatural cause. Participants previously identified experiencing different challenges at church and society. However, it seems that there are mixed reactions with this theme hence no conclusion could be arrived and yet it emerged across all the interviews. At the beginning of the journey with raising a child living with ASD, some participants resorted to using tradition religion methods to try and cure their child with "tiwasho" and "timbita". Some participants gave their children traditional herbs and drinks from traditional healers in belief that it will cure them. On the other hand, some participant used their religion in a manner that is more accepting of their children in that they strongly perceived their predicament as a way of strengthening their religious faith and their relationship with God.

My grandchild was prayed for almost every Sunday for years and we even took him to popular Pastors in big towns but her condition didn't change instead she got worse. Benginekukholwa kutsi kute lokwehlula Nkulunkulu kopha imithantazo ayisishintjanga lesimo

semtfwana kuze kube ngunamuhla (Prayers did not change my grandchild's situation though I had faith that there is nothing impossible with God) (Gugu), 50 years

I come from a family with a belief of using traditional medicine for healing. Before diagnosis I thought the condition of my child was due to a curse from his father 'side. I therefore took him to a traditional healer and (tinyamatane) traditional medicine and rituals were performed but none of that healed my angel. (Pretty), 37 years

From the above interview with the participant it may be posited that lack of knowledge in conjunction with the cultural beliefs surrounding the disorder may lead to many caregivers turning to alternative methods to gain assistance for ASD children. In African countries especially Eswatini, where there is lack of awareness on autism, it is common for parents to take their children to spiritual or traditional healer explanation and interventions for ASD (Bakare & Munir, 2016; Gona et al.; Ruparelia et al., 2016). This is evident in this study where caregivers resorted to using traditional methods to try and cure their children with traditional herbs and drinks.

4.6.1 Sub-theme 1: Connecting to deity, reflecting on the failure in their struggle

Parents in this study through the initial involvement, continued their spiritual journey with connecting to deity. They didn't know how to manage their challenges and after reflecting on their failure for caring of their children they moved towards choosing spirituality and their religious practice to help them. Indeed, they came along with the disorder and becoming calm by entrusting their hearts to God.

My faith in God has actually help me to survive during hard times; it is not an easy journey taking care of an ASD child, I am satisfied with God's will. Even though some people in my church believe my child has a generational curse she needs to be delivered from it through deliverance prayer (Busiswa), 46 years

I am strong everyday my source of strength is The Almighty God, I believe I should be thankful for everything even when everything is bad and doesn't make sense. (Philile), 45 years

I always find courage in the word of God, John 9:2-3, I don't believe my child's condition is due to some sort of curse but I believe and in support of this verse that is to glorify the Lord. Though at first I was angry at God but now I know everything happen for a reason. I trust God and I thank him for the strength to love and care for my child. (Obed), 47 years

By faith I believe my child is not a burden, but a special gift from God. God is in control and has my best interest in heart. God did not give us this child to ruin our lives, for God promises to work all things for our own good. (Lusito, 48 years)

Though my angel is still autistic and there is no cure for his condition, yet by faith I trust God is still in control. Yes, my child seems a tragedy, but God's triumph is not a punishment but God's good and perfect gift. (Thembi), 55 years

From the above quotes, most participants mentioned that, children living with autism are not a curse but a blessing from God, as proclaim by the Psalmist's rule (Psalms 139: 13-14) which state that "we are fearfully and wonderfully made by the Almighty God" and supported by the participants in this study. Most caregivers joyfully acknowledge that their source of strength is God in this journey of taking care of children living with autism. It was not the same with all the participants though, Philile mentioned that in her church they believe her child has a generational curse thus needs deliverance. The findings are consistent with those of (Yih, 2013), that there are some Christians who believe that ASD children have a generational curse thus needs prayer and deliverance.

4.6.2 Sub-theme 2: Afrocentric beliefs

In Africa life is religion and religion is life (Opoku, & Ghartey, 2011). Although Eswatini is a Christian country, but there is also a strong engagement with African traditional religion (Golo & Yaro, 2013), which gives meaning and significance to Swati culture. According to the findings of the study, some of the Eswatini society accused parents of causing their children's ASD conditions.

Nginelubito lokuba sangoma kusukela ngisemncane, angizange ngiluvume bantfu emangweni batsi kungako ngitale sidalwa semtfwana ngoba ngala kulalela emadloti akitsi. (I have a calling to be a traditional healer since I was young but to date I have not accepted it, hence people from the society are blaming me for that, and I'm told that is a reason I have an ASD child, I have angered the ancestors. (Pretty), 37 years

I am married when I and my husband discovered that our child was living with ASD, I was accused by my in-laws that I came with the ASD from my genes because from their genealogy there is no one with this condition. I grew up from a family that was accused of witchcraft, there was a belief I was paying for sins from my parents as well. (Ncane), 43 years

From the above quotes, it is clear that the belief in supernatural cultural opinion influence some traditional societies when it came to the ASD children's conditions. Though findings of previous research affirm that, in African traditional societies is a bad omen either a punishment from sins of the mother or her family (Slikker, 2009). On the other hand, Zeliadt, 2017, state that, many caregivers resort to these extreme measures because they have no other choice. Others hide their children, fearing stigma which is pervasive in many parts of Africa and casts disabilities as a sign of a curse or possession by spirits. Many children with autism across Africa stay out of sight for another reason because few clinicians have the skills and experience to identify the condition if they are even aware that it exists.

4.7 Theme 5: Need for support and services

There is a clear gap in the government offering services and decentralization of the very services to meet the plight of caregivers raising children living with autism. A number of participant not receiving support from the government to mention a few, capacity building on autism issues for caregivers, a one stop centre for ASD children regionally, financial support, a residential care centre facility for ASD children and limited therapists. The following quotes portray what the participant's perspectived about governmental support:

My grandson is not attending any therapy since there is no occupation therapy in the Lubombo region. The transport to Manzini is expensive, and we can't afford, to take him there, I use to take him but I eventually stopped. It's my plea for government to decentralize the services even to rural areas where we can all have access to them. (Zipho), 40years

The public assistance we are receiving as a financial support is too little, it's about E280 on monthly basis. The government needs to ensure we get a disability grant that will be enough for us to cater for ASD children's needs. The transport is expensive and they don't just eat anything they are picky in food which is also costly, some parents had to stop working to be able to take care of the children on full time basis. (Pretty), 37 years

There are no autistic schools in the country I think we have a few in in big towns like Mbabane and Manzini. My child is not attending school; it pains me to see children of his age going to school but there is nothing I can do for him. I wish there was a sort of a skill centre where they can groom them with whatever skill they are good at from a young age till they are old rather than staying at home. My child is good at drawing; I see if he can be groomed he can be an artist in future. (Lusito), 48 years

Nobody explained to us what autism was about, my child was diagnosed with it and it was my first time to even hear about the word autism. It was not easy, I have learnt about it and I thank Autism Eswatini for constantly training us on autism issues and how to take care of our ASD children. I believe this was supposed to be done by the Ministry of Health immediately after the diagnosis. The government must capacitate the parents of the ASD children on ASD issues and maybe they must also be a support group in the communities where everyone can reach without paying transportation. (Philile), 45 years

From the above quotes it is clear that majority of the caregivers distinctly expressed their disappointments in the fact that there were no inadequate services in Eswatini to cater for autistic children. They further expressed poor satisfaction with the quality of services provided to their children by education, health, social services and emphasized on the need and importance of early identification, decentralization of services as well as social assistance.

4.8. Theme 6: Coping Strategies

This theme was divided by three sub-themes, employed by caregivers as coping strategies namely positive coping, negative coping and support groups.

4.8.1 Subtheme 1: Positive and Negative Coping

Positive Coping

The way that the caregiver responds to stress and the meaning they gave their children's disability was either maladaptive or healthy coping strategy or behaviour. Some caregivers resort to the following positive coping strategies, family support, exercising, attend to their hobbies, attending church, and self-education.

I really enjoy jogging every morning to keep fit and healthy as well as giving me my "me" time to keep away from all the family dynamics that came along with having an ASD child. (Busiswa), 46 years

Esontfweni kulapho ngifike ngive ngatsi konkhe ngemphilo yam emhlabeni kuhamba kahle, noma siphila nale simo se autism. Umdali ungiko konkhe kimi. Church is my comfort zone, when I'm there I feel like all my troubles are gone, despite the situation of living with ASD situation. God is my pillar and strength. (Sonto), 42 years

Finding a passion aside from their children and their relationship with God helped the participants to cope better. By doing something totally different help the parents to go into a

different world. This is further supported by family resilience theory framework of the study, that caregivers of ASD children are able to bounce back and be resilient to the stressful experiences of raising ASD children thus developing and growing strengths that help them to deal with the situation in a positive way.

Negative coping

The negative response to dealing with the child's behaviour displayed by the caregivers' emotions like crying, anger, screaming as well as unhealthy habits like using sleeping peels, alcohol and some drugs.

I use to cry when I looked at my child and I was very angry especially at God as to why did he gave me a child with ASD. At times i use to lose it and hit my other children for no reason. (Phindile), 45 years

When my child was diagnosed with ASD I could not sleep such that I was actually using sleeping peels to eventually rest. I tried drinking alcohol, but I will get drunk and the next day find the same situation unchanged. (Viwe), 52 years

From the above extract, the reason for all these undesirable reactions at this stage is that the caregivers may not have adapted to or accepted the ASD situation.

4.8.2 Subtheme 3: Support group

All the participants from this study are members of Litsemba Lemliba support group, from Autism Eswatini in Manzini. The caregivers meet every weekends and the following has assisted most of them to adapt. Sharing experiences and knowledge with other caregivers, advocacy work where the caregivers visits schools and organisations to share about ASD issues.

I am always at peace when I manage to help parents who have their child recently diagnosed with ASD, and still in process of adaptation to sit down and take them through the journey of ASD. We always identify some of the parents during our advocacy visits. (Zipho), 40 years

Nangicala kuba li memba laku Litsemba Lemliba ngafika nginebulukhuni, kopha ngagcina ngitfola kusitakala. Kubona labanye bananakekeli bebantfwana labaphila kulesimo se autism, kwavuka litsemba kimi. When I first joined the support group my life was in a bad state, as I learned from other caregivers with ASD children my hope came back again. (Thembi), 55 years

From the above extract most caregivers found the support group so helpful especially when it came to their mental health issues. They mentioned that, some are advocates in helping other parents with newly diagnosed children living with ASD throughout the journey. This also improved their skills to cope with all the challenges that came with raising ASD children.

4.9 Conclusion

This chapter presented the findings of the study connecting with biographic profile and analysis of the participants (caregivers). This was followed by a discussion of five emerged themes namely: Recognition of atypical development, Psycho-socio economic burden, Lack of awareness, Spirituality and religion, need for support and services as well as coping strategies. Subthemes that emerged during the engagements with the participants were also discussed. Narratives discussed in this chapter indicated as per the main themes important findings from the participant's point of view. Findings indicated that caregivers attempted to deal with a number of demands, ongoing daily stressors and psychological dynamics they also face disorganization within their family units (Holtzkamp, 2010; Greeff & Vn Der Walt 2010, McCubbin, 1993; McCubbin, Partterson, 1982; MacCubbin & Thomson, 1991; Wlsh 2003). The family dysfunction that comes with caring for an ASD child according to the findings of this study lead to divorce, separation and failure to take care of the other children within the family as a unit. In their attempt to access support services caregivers' encountered resources that were inadequately suited and incapable of assisting them in meeting the demands faced by ASD children. Lack of knowledge within the health sector resulted to either misdiagnosis or late diagnosis to children living with ASD. Finally, the coping strategies employed by the caregivers, which according to the findings was negative coping after diagnosis. Then later as they adjusted and accepted positive coping and the involvement in the support group was of great help to them. The next chapter discusses the conclusion and recommendation of the study.

CHAPTER 5: SUMMARY, RECOMMANDATION AND CONCLUSION

5.0 Introduction

The study aim was to learn about the lived experiences of caregivers living with children with autism in Manzini Eswatini at a support group called Litsemba Lemliba based in Autism Eswatini Organization. This chapter entails a discussion of the results based on the experiences of 15 caregivers, which were 13 females and 2 males, identified themselves as biological mothers, fathers, uncle, grandmothers and aunties all living with ASD children. Semi-structured interviews were used in collection of the data of lived experiences of the caregivers. The presentation of the discussions for this chapter are the summary of the key themes that emerged and are presented in order to draw conclusions in line with the aim and objectives of the study. Limitations and recommendations are discussed as well as implications for social work practice.

5.1 Summary and overview of the study’s aim and objectives

The aim of the study was to learn about the lived experiences of caregivers living with autism at a Support group based in Autism Eswatini in Manzini. The aim was accomplished by achieving the following key objectives of the study:

1. To explore and analyse experiences of caregivers raising children living with autism
2. To describe the coping strategies faced by caregivers raising children with autism
3. To ascertain identified needs and supportive services required by caregivers of children living with autism
4. To explore the challenges of caregivers raising children with autism

5.1.1 Summary of the key findings and conclusion

5.1.1.1 The daily experience of caregivers raising a child with autism

There are characteristics that are associated with several diagnoses but may be more pronounced with ASD for example behaviour related to self-regulation generally are delayed or impaired in children with ASD (Davis & Cater, 2008). These behaviours increased the time and energy demands of caring for these children thus leading to a greater likelihood of parental stress (Sawyer et al., 2010). It was evident from the data collected that, participants experience drastic changes in their day to day lives. These changes affected their careers, finances and lifestyle. They had to be always there for the child to keep him/her out of danger,

calm and so on. Working caregivers had to make adjustments of either quitting work or asking a relative or live in nannies to help who at times do not last due to the conditions of staying with the ASD child. Problem behaviour appear to be the strongest predictor of stress among caregivers of ASD children. This problem behaviour includes acts of defiance and or aggression, tantrums and public outburst (Estes et al., 2009; Hasting 2003, Lecavalies, Leone, & Wiltz, 2006). Many participants reported that, they eventually learn to accept the difficult behaviour but the judgment received as a result of lack of understanding by the public proved to be difficult for the participant to handle. One participant mentioned that, she fears taking her ASD child to public places due to being victimized, labelled as lacking parental skills, name calling directed to her child, and whenever her child throws tantrums she is labelled as a spoilt child. Some participants further mentioned that, whenever they take their children to public places they experience stares that are uncomfortable. Additionally, every time their children are out in the public without them they fear that they might be abused physically and even sexually. This makes them really stressed and often then depressed, having an autistic child is a full time job for them because the worry never stops.

Findings from previous studies state that, caregivers have several factors which increases the likelihood of a daily strain, such as greater time demands associated with participation in various therapies and daily tasks such as Occupation therapist, speech therapist, assisting in self-care, relieving other family members of duties or seeing to other children in the family. However, this results in less time to attend to other matters (Sawyer et al., 2010). Consequently, caregivers reported that they dedicate almost all their time and attention to the ASD children, this unrelenting management constituted a stressor and in turn a vulnerability for most of the family as it was a daily, ongoing occurrence that depleted caregiver's internal resources. As a result, caregivers reported being exhausted which in turn impacted their ability to cope and adjust adequately.

Mothers and fathers of children with ASD report lower relationship harmony and agreement (Gau et al., 2012). One participant explained that as a mothers she had to quit her job to care for the child whilst the father of the child remained at work to cater for financial needs of the family. This resulted on the family having only one salary which further caused financial strain and conflict within their relationship.

Inevitable, complicated psychosocial dynamics are at on high level and affect caregivers of ASD children on daily basis. One caregivers mentioned that at times you don't know whether

you are going in or out, it's just too much such that they suppress their emotions inside. From the statement one can tell that the mental health and well-being of caregivers is at risk. Previous studies found that caregivers reported feeling overwhelmed, stressed, and exhausted indicating that caring for a child with ASD left them physically, psychologically and emotionally depleted (Altiere & Von Kluge, 2009; Chong & Kus, 2017; DePape & Lindsay 2015; & Holdt, 2014; Woodgate et al., 2008)

5.1.1.2 Challenges that comes with raising a child with autism

Across studies, parents generally first became concerned about the child's development when they were between 1 and 2 years of age (Chawarska et al., 2007; Coonrod & Stone, 2004; Guinchat et al., 2012). It was evident from the study that parental distress began in the pre-diagnostic phase when it was noticed that the child was experiencing developmental delays or had not reached a certain developmental milestone. However, the caregivers became anxious and worried when the child did not develop speech and behavioural problems became difficult to manage. This made the participants of the study struggled with reconciling the child's atypical development with normality of his/her appearance.

Most caregivers in the study revealed that, due to the fact that autism is a spectrum, before their children reached the actual diagnosis they were misdiagnosed. They moved from one doctor to another and they all came with different opinions of diagnosis as a result their children were diagnosed when they were above 3 years of age. As seen in the previous studies, children with ASD generally endure lengthy and involved procedures before receiving a diagnosis (Braiden, Brothwell, & Duffy, 2010; Moh & Magiati, 2012) this process involves seeking opinions from multiple professionals, who individually attribute delays to a variety of factors. Parents further reported that prior to diagnosis their concerns about their child's functioning were dismissed by professionals and they were often left having to convince health care professionals that their concerns were valid and necessitated further inquiry (Altiere & Von Kluge, 2009; Mitchell & Holdt, 2014). Studies suggested that this may be due to a lack of professional knowledge and understanding of ASD (Franz et al., 2017; Mitchell & Holdt, 2014).

The study revealed that, having a child with autism has proved to affect families in many ways which can be destructive to a family system and can lead to conflicts, separation and divorce to the married. This has been supported by previous studies that, having a child with ASD impacted family unit functioning, overall well-being and cohesion (Hayes & Watson,

2013; DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Meadan et al., 2010; Mitchell & Holdt, 2014). Family quality time was also affected as this was over ruled by the needs of the child with ASD (Altiere & Von Klude, 2009; Meadan et al., 2010, Nealy et al., 2012; Schlebusch et al., 2016). Additionally, married couples parenting children with ASD report higher rates of divorce and separation than both couples in general population and parents of children with other disabilities (Risdal & Singer, 2004).

The study also found out that cultural constructs mostly rural areas to be precise in Eswatini have a great impact when it comes to lack of awareness in autism. In Eswatini there is a famous phrase called 'tibi tendlu' which means family secrets. Children living with autism are considered a taboo and ought to be hidden. It is not in all cases though, some participants mentioned that they keep their ASD children at home for protection and safety from the community who harm them due to lack of awareness. Congruent to this study, preceding studies discovered that the religious model of disability as an evil placed on an individual from gods as a punishment or curse for an offense committed evident in societies where superstitions and eugenics are prevalent (Avoke, 2002).

Another significant challenge revealed by the study attempts to access appropriate schools and interventions which include different therapist like speech therapists and occupation therapists. This is due to the fact that the government of Eswatini has not yet decentralized these services in a substantial way. As seen in previous research, health care and education systems were perceived as inaccessible and ill-equipped (DePape & Lindsay, 2015; Mitchell and Holdt, 2014). Parents described teachers with inadequate training and limited understanding of ASD, and schools that were unable to cope with their children's needs as well as troubling limited amount of adequate facilities and services available for children with ASD (DePape & Lindsay, 2015; Mitchell & Holdt, 2014).

5.1.1.3 Coping strategies of caregivers living with ASD children

During the study, it was observed that just like parents in the rest of the world who have children with autism. Eswatini caregivers who have children with ASD also have to devise strategies to manage their children's condition. Meanwhile, while caregivers elsewhere coped by ensuring the safety of their children, their family and property and others coped by participating in recreational activities (Owen, & McCann, 2018; Paynter, et al., 2018; Stewart, et al., 2017), Eswatini caregivers coped through other diverse means.

One of the coping strategy adapted by participants in this study, was emotion-focused which they applied in their day-day caring of their children with autism. Emotion focused coping is directed at regulating emotional response to a problem. An important coping strategy mentioned by the majority of caregivers was spiritual coping. This manifested itself in belief and acceptance that the child's condition was part of God's bigger plan and in prayers and active searching for spiritual healing. These actually made the caregivers then expressed an acceptance of this situation and it seemed to be a salient coping strategy. The results of the study were therefore consistent with the findings of the previous literature. According to (Jardin, 2008), the belief that the autistic child is part of God's plan and that God will give strength to the caregiver be able to deal with the condition of the child, appeared to be another way of accepting the child's diagnosis.

Another coping strategy from the study was the fact that they all belong to Litsemba Lemliba support group from Autism Eswatini. This is where they were equipped with information and skills, they shared their different experiences and empower each other, advice on how to deal with different professionals and their ASD children. They also consistently get counselling from the psychologist that Autism Eswatini organizes for the caregivers if they have identified a need. This emphasizes that, just like parents in other parts of the world, parents in Eswatini had to avail themselves to be educated in order to empower themselves and be part of facilitators who intervene and help to manage their children's condition (Hutton, & Caron, 2005; Depape, & Lindsay, 2014; Webster, Cumming, & Rowland, 2016). On the other hand, self-education plays a huge role in caregivers of ASD children in Eswatini, in the study some of the care givers revealed that they have taken it upon themselves to read, listen and watch educative programs about ASD. This therefore, helps them to be well informed and be in a better position to help their children.

Alternatively, the findings of the study revealed that, due to limited support system caregivers in Eswatini who have children living with ASD also relied on their families to help them cope with their children's condition. This confirms existing research that asserts that, parents of children living with autism rely on family to compensate for the lack of support (Glazzard & Overall 2012; Thomas, Badoe, & Owusu, 2015; Paynter, et al., 2018; Stewart, et al., 2017). One caregiver revealed that, due to her son's condition, baby sitters could not cope, they will stay for few months and leave. These result mean that, caregivers relied on their family for babysitting their ASD children since some baby sitters are failing to cope with the ASD children's conditions.

Additionally, it is evident that parents who have children with autism in Eswatini retreat from or disregard negative social attitudes as a way of coping with their children's condition. Caregivers reported that they are influenced by socio-cultural ideologies and religious beliefs, such that they and their children are stigmatized and discriminated in their communities. Therefore, their way of eliminating the stigma and its consequences on their lives like being emotionally stressed is to disregard the society's negative attitude towards them and their children and concentrate on loving their children and living a happy life. These revelations confirm that in their quest to cope and manage their children's condition, parents look on the bright side of life by thinking positively about their children and disregarding negative public behaviour towards them (Depape and Lindsay, 2014; Glazzard & Overall, 2012). These highlight the fact that society's action and beliefs have immense influence on caregivers who have children with autism, and these attitudes forces these them to take drastic decisions for their wellbeing and that of their children.

Conclusively, a study conducted by (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005), on coping mechanisms employed by caregivers of children with ASD found four reliable dimensions of coping: (1) problem-focused, for example, seeking help to mediate the situation, (2) avoidance coping, for example, making use of drugs/alcohol to get by, (3) religious coping, for example finding comfort in faith, (4) positive coping, reframing in a positive manner. However, this was consistent to the finding of this study which some of the participants employed as coping mechanism in order to manage their children's condition.

5.1.1.4 Need for support and services

Research by (Jack, 2016) emphasized on several needs for social support and services on children living with autism which include limited resources or services, obtaining a proper diagnosis from professionals, struggling with proper educational programs, as well as financial burdens. Support for caregivers as well as services for children living with ASD in Eswatini are mostly found in towns, which becomes a challenge to the ones staying in rural areas to access the services. Majority of the participants of this study expressed their disappointments on inadequate services in the country as well as the poor satisfaction with the quality of services provided for their children.

Findings suggests that the majority of the parents in this study faced lengthy and frustrating diagnosis process which supports findings in previous research internationally, South Africa and Eswatini (Altiere & Kluge, 2009; Crane et al., 2016; Mitchell & Holdt, 2014).These

result from the study meant that, health professionals were perceived as lacking lack of professional experience and knowledge impacting parent appraisal of the potential resource. Their failed attempt at acquiring a diagnosis and in turn some form of validation of their concerns seem to leave many of the caregivers internalizing these failures of their parenting ability impacting their sense of self and their resolve to continue seeking assistance for their child. According to a number of studies, a lack of access to 'gold standard' assessment tools has resulted in the lack of appropriate diagnosis of the majority of children with ASD and African countries like South Africa and Eswatini due to inadequate services and resources such as appropriate and accessible primary, secondary and tertiary assessment and intervention facilities (Bakare & Munir, 2001; Franz et al., 2017; Mubaiwa, 2008).

Majority of participants in this study were directly impacted after many failed attempts to access appropriate schooling and intervention, often with little guidance as to the needs of their children. As seen in previous research, education system was perceived as inaccessible and ill-equipped (Depape & Lindsay, 2015; Mitchell & Holdt, 2014). Caregivers in the study described teachers in Eswatini schools with in adequate training and limited understanding of ASD, and schools that were unable to cope with their children's needs as well as troubling limited amount of adequate facilities and services available for children with ASD

Lastly, caregivers in this study reported, feeling financially strained due to the expensive nature of ASD, despite the majority of the families occurring above the low socioeconomic status. These arise from the high cost of medication, private special education, cost of professional care for the ASD child include occupation therapy, speech and language therapy, parent inability to keep the job due to the demands of their children's condition. Congruent with this study (Ghanizadeh et al., 2009) indicated that a high number of families of children with ASD usually have a lower level of income. Consequently, they often need additional income to cover the costs of their children's medical care. This is ironic since, according to (Sharp & Barker, 2007), even those caregivers who enjoyed steady employment are forced to reduce working hours in order to meet the needs of children with autism spectrum disorder. (Sharp & Barker 2007), further stated that those who are not working are finding it hard to get employment due to the challenges they face in caring for their children with ASD.

5.2 Recommendations

In considering the findings from this study, the following recommendations are offered in terms of social work practice and future research

5.2.1 Recommendation for social work practice

In the view of the challenges that ASD children and their caregivers face, should be taken into consideration that caring for ASD children includes increased vulnerability to depression, anxiety, as well as the negative impact it has on the quality of family life. It is recommended that well trained designated social workers on complexity of the nature of autism spectrum disorder, must provide counselling to both ASD children and their caregivers. This will also assist in developing of support groups for children living with autism within their communities, as well as support groups for caregivers of ASD children which can be accessible even in rural communities. This will further enable social workers to provide education and training to rural health motivators (bagcugcuteli) in communities, since their roles is to respond to key public health challenges. There is a need for social workers to be involved and initiate more research in this area of study, where autism is becoming more prevalent with more cases on clients and family members living with an autism diagnosis. On the other hand, social workers need to find a role in the multidisciplinary team of professionals working with ASD children. This study provides personal experiences and coping strategies of caregivers of ASD children which in turn social workers can reiterate to them whenever they encounter such cases in their field of practice. Advocating for a need and importance of early identification, a centre for children living with autism, decentralizing of services as well as disability grant since currently ASD children are receiving a public assistance grant which is too little. A data base for all children living with autism in all the Social Welfare offices regionally, in order for their needs to be catered for accordingly. Since social workers in Eswatini have a slot on the National Radio station every Thursdays, issues on ASD should be addressed and discussed in order to bring awareness to the Swazi nation.

5.2.2 Recommendation for Government

The following are recommendations for the government of Eswatini:

- That government and relevant stakeholders create employment opportunities for parents of children living with ASD
- To raise funding of more research on ASD and awareness campaigns on autism in schools, communities, public places.
- To decentralize services for children living with autism spectrum disorder
- To create programs that will train and capacitate young adults living with autism spectrum disorder for vocational skills and using this study to identify area of priority to assist children living with autism spectrum disorder and parents.

- Prioritize providing food assistance to families with a family member with ASD and raise awareness about the special food sensitivities and needs common with autism.
- For Ministry of Education and training-to review curriculum in primary, high school and tertiary to be considerate to children living with ASD and to build autistic schools and hostels regionally. Training of teachers to better be able to deal with ASD children in classroom, as well as to employ teaching assistants in mainstream classrooms to assist the main teacher with attention on ASD children.
- For Ministry of Health to develop (or adapt from existing tools) a culturally appropriate and context specific diagnostic tool for Eswatini (observation/or interview based). By putting systems in place, interventions to facilitate early identification of children with ASD including training of health professionals on administering the Eswatini specific autism diagnostic tool to enable them to accurately diagnose ASD earlier.
- There is a need for the government to increase awareness in the general public about what autism is and what the symptoms are, and how to treat people with autism with dignity and reduce the stigma. A radio communications campaign could help increase awareness at a low cost.
- For the government to Institute a country-wide policy that allows caregivers of a person with ASD in queues with a person with autism to jump to the front of government service queues, especially in healthcare and home affairs.

5.2.3 Recommendation for Policy Makers

It is recommended that policy makers review the following policies the Education sector policy of 2018, the National disability act of 2018 and the Health sector policy in order to ensure inclusion and accessibility of resources to children living with ASD. This will in turn increase awareness and thus reducing stigma and discrimination to children living with ASD and their families in Eswatini.

5.2.4 Recommendations for future research

ASD research remain limited in Eswatini despite growing interests in expanding the research base within this context. This research study provided the opportunity for in depth exploration of caregivers raising children living with autism in Eswatini setting. The findings highlight the value further research in this area could hold and therefore emphasizes the need for further exploration. It is hoped that this study will bring about the awareness and knowledge of what caregivers of children living with autism face in their struggle to obtain

relevant information, coming to a full understanding of the diagnosis, finding effective early intervention and receiving sufficient support from education and health facilities. It is recommended that a study which explores the mental health of parents/caregivers would be beneficial as it has been indicated that caregivers/patents of ASD children present with a greater risk of developing mental illness such as depression.

5.3 Limitations of the study

A lack of comparable literature was a limitation of this study, as the researcher found few articles relating to ASD within Eswatini context and even smaller amount relating to experiences of caregivers of children living with autism. The majority of the published articles were conducted in different social and cultural contexts, providing a limited source of comparison.

The other limit of this study, which is documented in the literature about qualitative studies such as this one, is its generalizability (Cresswell & Poth, 2017). The findings however, do allow the reader to get a subjectivity account of caregivers' lived experiences and how they eventually cope with adversity, which can be viewed as an indication of shared experiences (Ludlow et al., 2012).

5.4 Conclusion

The findings of the study reflect that caregivers of children living with autism stress begins before the diagnosis is made and increases upon receiving the diagnosis. Participants' experience various emotions throughout the process of caring for a child living with ASD. Significant feelings were found to be that of guilt, stress, denial, anxiety, depression, frustration, confusion, shock and fatigue; similar to the process of grief. The family stress theory which is a framework of the study, asserted that, on the difficult and stressful experiences that came with challenges caregivers experience is found to be lack of social support and social isolation; increasing their level of stress. Despite the limited resources from the government for ASD children some parents have ways to provide for their children raising a child with ASD have been found to have a significant impact on parental wellbeing as well as siblings, extended families and peers, it is also financially costlier than expected as it entails lifelong costs. Although raising a child with Autism Spectrum Disorder is found to be very challenging, many caregivers reported that their child has a positive influence on them as well as the child taught them patience, acceptance and unconditional love. Congruent

to that, the family resilient theory which is also another framework of this study, affirms that various caregivers were resilient despite the numerous difficulties and stressors they encountered. Such that some reported good experiences and benefits of rising ASD children. In that they were able to employ coping strategies effectively, that changed their perception of the situation which resulted in greater adaptation and harmony.

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APPENDIX A: INTERVIEW GUIDE

Name & Surname:

Age:

Gender:

Marital status

Employment status:

Educational level:

No of children (including other children in household):

1. Please tell me how old your child was when you realized they were living with autism?

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2. How did you make sense of the symptoms before diagnosis and afterwards?

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3. When was the diagnosis confirmed and by whom?

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4. Tell me, what the diagnosis mean to you and those around you.

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5. Describe for me, how you would say you have accepted and adjusted to caring for a child living with autism.

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6. Please share with me your coping strategies as a caregiver of a child living with autism?

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7. How has your social world (which includes your community, family relations, church work) been impacted in the journey of raising a child living with autism?

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8. What would you say is the emotional impact of raising a child living with autism?

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9. How could you describe the access to services for children living with autism in Eswatini?

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10. In terms of support, tell me more about supportive services in your journey of raising your child?

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11. What could you recommend for the government to offer as assistance for caregivers of children living with autism?

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12. Tell me more about what you consider the strengths or positive factors to this journey?

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APPENDIX B: INTERVIEW GUIDE (SISWATI VERSION)

IMIBUTO NCOCISWANO LECONDZISAKO

Libito nesibongo:…………………………………………………………………

Umnyaka:…………………………………………………………………………….

Bulili:……………………………………………………………………………..

Simo sakho semshado:…………………………………………………………

Indlela yekucasheka:……………………………………………………………

Lizinga lemfundo:…………………………………………………………………

Linani lebantfwana (lokufaka ekhatsi labanye bantfwana labangaphansi kwaloluphahla (lwendlu):………………………………………………………………………………………

1. Ngicela ungitjele kutsi abeneminyaka lemingakhi lomntfwana nawusola noma umbona kwekucala kutsi uphila nekukhubateka kwe autism?
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2. Wacabangani ngaletibonakaliso (timphawu) usengakammikisi kuyohlolwa phindze nangalesikhatsi sewumhlolile?
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3. Kunini lapho loluhlolo tetinsolo ngalesimo tatfolakala kutsi tingito? Ngubani lolowenta lesiciniseko setinsolo talokucilongwa kutsi tingito?

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4. Ngitjele, wena nalabo labadvute nawe nikutsatsa njani lolokushiwo ngulolucilongo lelentiwa?

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5. Ngichazele kutsi ungatsi ukwemukele njani loku, nekutsi wenta njani kulungela kunakekela umntfwana lophila nale *autism*?

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6. Ngicela ungihlephulele kutsi usebentise tiphi tindlela kute ungatsikabeteki ekunakekeleni umntfwana lophila nekukhubateka nge-*autism*?

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7. Itsikabeteke njani nje imphilo yakho nebantfu ikakhulukati emmangweni, budlelwane emndenini, esontfweni, nasemsebentini kulokukhulisa umntfwana lophila nekukhubateka nge-*autism*?

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8. Ungatsini ngekutsikabeteka nangekutsintseka kwemoya (umphefumulo) ekukhuliseni umntfwana lophila ngako kukhubateka nge *autism*?

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9. Ungachaza kutsi lusito loludzingwa bantfwana lababphila ngalokukhubateka nge *autism* lutfolakala njani eveni laseSwatini?

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10. Ngalokutsintsa kusekeleka, ngicela uchaze kabanti ngekusekeleka ekukhuliseni umntfwana lophila ngekukhubateka nge *autism*?

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11. Ngutiphi tiphakamiso noma tincomo Hulumende langatiletsa tibelusito, kulabo labanakekela bantfwana lababphila ne *autism*?

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12. Ngitjele kabanti ngalocabanga kutsi kungiko lokungaba ngemandla kulolohambo lwekukhulisa umtfwana lophila ngekukhubateka nge-*autism*?

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APPENDIX C: LETTER FROM AUTISM ESWATINI

Focusing on Facilitating Autism and other Neuro-Developmental Disorders Support; Rehabilitation, Awareness,
Advocacy, Research, Protection, Psycho-Social Support and Spiritual Nurturing for Children/Individuals & Affected Families

Box. C1997, Hub, Eswatini
(+268) 7603 7577 | autismswaziland@gmail.com
Plot 175, Ngwane Street,
Christian Media Centre, Office No: 3, Manzini Eswatini.

20 April 2022

MS. MAKHOSAZANA HLANZE

Student NO: 22117413

The University of Kwazulu Natal

South Africa

Dear Madam

<u>RE: Permission to Interview Caregivers Support Group for Research Purposes in Partial Fulfillment of the Master of Social Science Degree</u>

This letter serves as a response to your letter dated 25 March 2022 requesting permission to interview Caregivers Support Group.

Autism Eswatini grants the permission to conduct this research with the Caregivers. Hoping that the findings of the study will also be shared with the organization.

Wish you all the best in this Research.

Yours Faithfully

<u>Tryphinah Mvubu</u>
Executive Director

Autism Eswatini

APPENDIX D: INFORMED CONSENT

25 September 2022

Dear Caregiver/Parent

My name is Makhosazana Hlanze, a Masters student in the Department of Social Work at the University of KwaZulu-Natal contact 0026876918446 or, email 221117413@stu.ukzn.ac.za

You are being invited to consider participating in a study that involves research on the lived experiences of raising children living with autism in Manzini Kingdom of Eswatini. The aim of the research is to learn about the experiences of caregivers who are part of the Litsemba Lemliba autism support group. A sample size of 15 caregivers will be utilized, which will require an individual interview session that will last for 45 minutes. Participation is completely voluntary and can be withdrawn at any stage of the study.

Some of the questions to be discussed may be sensitive hence you may feel uncomfortable sharing such information. Please note that it is fine if you do not wish to answer or discuss any topic that makes you uncomfortable. We hope that the study will enable caregivers' voices to be heard and draw attention of relevant stakeholders, the government and motivating policy makers to enact laws that would outline support and interventions centers for caregivers. It will also help Social Workers to be able to provide relevant support and guidance to caregivers, however the study will provide no direct benefits as a result of participation.

Since the research could potentially involve risk, Social Workers from Manzini Social Welfare will be available to provide psychosocial support. This study has been reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee, approval no.

The information collected from the research will be stored in a lockable cabinet, it will be only the researcher and the supervisor will have access to it. This may be disposed and destroyed in 3-5 years.

In the event of any problems or concerns/questions you may contact the researcher at 0026876918446 or email 221117413@stu.ukzn.ac.za or the HUMANITIES & SOCIAL SCIENCES

RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govern Mbeki Building

Private Bag X54001

Durban

4000

KwaZulu Natal, South Africa

Tel: 27312604557 Fax: 27312604609

Email: HSSREC@ukzn.ac.za

CONSENT

I ____ have been informed about the study Live experiences of caregivers raising children living with autism by Makhosazana Hlanze.

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

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

I have been informed about any available compensation or medical treatment if injury occurs to be as a result of study related procedures.

If I have any further questions or concerns/queries related to the study I understand that I may contact the researcher at 0026876918446 or email 221117413@stu.ukzn.ac.za

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

I hereby give consent to:

Audio record my interview/ focus group discussion YES/NO

RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govern Mbeki Building

Private Bag X54001

Durban

4000

KwaZulu Natal, South Africa

Tel: 27312604557 Fax: 27312604609

Email: HSSREC@ukzn.ac.za

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Signature of Participant Date

APPENDIX E: INFORMED CONSENT (SISWATI VESION)

Liphepha Lelwati

25 September 2022

Mtali

Ligama lami ngu Makhosazana Hlanze. Ngingmfundzi we Masters in Social Work eNyuvesi yaka Zulu Natali, inombolo yami yamahlalekhukhwini ngu 0026876918446, likheli lami le email ngu 221117413@stu.ukzn.ac.za.

Uyacelwa kutsi ube yincenye yalesifundvo lesilucwaningo lwekutfola lwati kabanti loluhlangabetwa banakekeli nomake batali labakhulisa baphindze banakekela bantfwana labaphila ngekukhubateka kwe autism. Injongo yalolucwaningo kufundza kabanti kanye nekutfola lwati kubanakekeli bebantfwana labaphila nekukhubateka kwe autism labayincenye ye Litsemba Lemliba autism support group lese dolobheni ka Manzini Eswatini. Lolucwaningo lubukete kubanenkhulumo ncociswano nebanakekeli bebantfwana labalishumi nesihlanu (15), lencociswano itotsatsa sikhatsi lesingaba ngemashumi lamane nesihlanu 45 minutes umuntfu ngamunye. Sincumo sekuba yincenye yalolucwaningo sikuwe ngalukuphelele, kungenteka kungobe ngusiphi sigaba selencociswano utive ungasakhoni kuchubeka nayo, uvumelekile kuyekela ungasachubeki.

Leminye imibuto yalolucwaningo ingakuvusa kukhatsateka lokungakwenta ungabi nekukhululeka ngekwabelana ngalolwati. Yati ngalokuphele kutsi awukaphoceleleki kuchubeka nekwaba lwati esihlokweni lesikwenta ungabi nekukhululeka. Sineletsemba kutsi lesifundvo sitokwenta liphimbo lebanakekeli nomake batali balabantfwana livakale, kuhulumende, nalababambe lichaza lelifanelekile, nalababhala imitsetfo, babhale imitsetfo letofaka kunakekeleka kwebatali bebantfwana labaphila nalokukhubateka kwe autism. Loku kutophindze kube lusito kulababuke tenhlalakahle (social workers), ngekuveta kwesekeleka kubatali, kodvwake kute lusito lolungaba ngumvuzo wekutimbhandzakanya nalolucwaningo.

Njengoba kungenteka lolucwaningo livuse kukhatsateka nje, bosonhlalakahle ehhovisini letenhlalakahle khona ka Manzini, batimisele ngekukusita kulashwa kwemoya mahhala kunoma ngubani lototimbandzakanya nalolucwaningo wase uhlukumeteka umoya. Konkhe kuIenkhulumo ncociswano kutobhalwa phansi, kugcinwe kuyimfihlo efayeleni lelitoba

sendzaweni lekhiywako nalephephile iminyaka lesihlanu, besekuyashiswa ngemlilo njenge kwemigomo yeNyuvesi.

Uma kwenteka noma nguyiphi inking, nomake unekukhatsateka ngemibuto ungatsintsana nemcwaningi ku 0026876918446 noma 221117413@stu.ukzn.ac.za noma ikomidi letokuhlaliswa ngekuhlaliswa ke Buntfu ne Social Science yase UKZN, iminingwane yokuchumana kanje

HUMANITIES & SOCIAL SCIENCE RESERCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govern Mbeki

Private Bag x54001

Durban

4000

KwaZulu Natal, SOUTH AFRICA

Tel: 27312604557-Fax: 27312604609

Email: HSSREC@ukzn.ac.za

Incwadzi yekuvuma kubayinye yelucwaningo

Mine____ (Bhala emagama akho ngalokuphelele), ngichazelekile ngelwati nenhloso yaloluphenyo ncociswano, ngu mcwaningi Makhosazana Hlanze. Ngivuma ngalokucondzekile kutsi sincumo sami kuba yincenye yalolucwaningo, futsi ngivumelekile kuyekela kuchubeka nalolucociswano noma ngabe ngusiphi sikhatsi. Ngiyitfolile yonkhe imininingwane nenchazelo mayela nelusito lolukhona, nakwenteka ngitsikameteka umoya ngenca yalolucociswano.

Ngaloko ngiyavuma kuba yincenye yalolucwaningo ngalokuphele.

Nginiketa Imvume:

Yekutimbandzakana naloluphenyo Yebo/Cha

____

____

Sayina Lapha Lusuku

APPENDIX F: ETHICAL CLEARANCE

26 July 2023

Makhosazana Tibuyile Hlanze (221117413)
School Of Applied Human Sc
Howard College Campus

Dear MT Hlanze,

Protocol reference number: HSSREC/00005690/2023
Project title: Lived experiences of caregivers raising children living with autism in Manzini, Eswatini
Degree: Masters

Approval Notification – Expedited Application

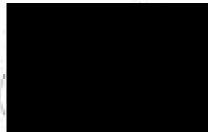
This letter serves to notify you that your application received on 05 June 2023 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**.

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

This approval is valid until 26 July 2024.
To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

HSSREC is registered with the South African National Health Research Ethics Council (REC-040414-040).

Yours sincerely,



Professor Dipane Hlalele (Chair)

/dd