

**EXPERIENCES OF CAREGIVERS FOR CHILDREN DIAGNOSED WITH AUTISM
SPECTRUM DISORDER IN THE EHLANZENI DISTRICT, MPUMALANGA PROVINCE.**

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**A mini- dissertation submitted in partial fulfilment of the requirements for the degree of
Masters of Public Health in the Department of Public Health at the University of Venda**

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DECLARATION

I, **Nomfundo Mazibuko** student number 15006895 declare that the mini-dissertation for the Masters degree in Public Health at the University of Venda, School of Health Sciences has not been submitted at this or any other University, and that it is my own work in design and in execution. All the sources that I have quoted and cited have been indicated, acknowledged and referenced.

Signature.....

Date.....

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DEDICATION

I dedicate this study to my late grandmother, Mrs B.S. Malambe.

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LIST OF ABBREVIATIONS

ASD: Autism Spectrum Disorder

CDC: Centre for Disease Control and Prevention

WHO: World Health Organisation

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ABSTRACT

Autism spectrum disorder (ASD) is a life-long neurodevelopmental disorder, which does not affect the child only but the caregiver more. ASD characterized by impairments in social interactions, communication and repetitive behaviour. Therefore, caring for a child diagnosed with ASD can be a very challenging experience for caregiver especially when knowledge about the condition is limited. The aim of the study was to explore experiences of caregivers for children diagnosed with ASD in the Ehlanzeni District, Mpumalanga Province. The study adopted a qualitative approach, wherein data was collected using face-to-face semi-structured interviews, in which an interview guide was used. Participants were selected purposively from the three different schools and data was analysed using thematic content analysis. Twelve (12) participants were interviewed for the study. The caregivers' children were aged 5-12 years. Ethical considerations and measures to ensure trustworthiness were adhered to throughout the study. The study findings indicated that caregivers for children diagnosed with ASD experienced psychological stress, social isolation and stigma, financial burden, lack of family support, services for children with ASD were perceived not to be accessible and available. The findings also indicated that there is limited knowledge of ASD amongst caregivers, health professionals and the community at large. Therefore, more awareness campaigns need to be done on ASD to increase knowledge on the condition. Furthermore, the study recommends that support groups for caregivers of children diagnosed with ASD should be formed and that information regarding a range of inexpensive interventions and educational programs should be made available for caregivers and their children, as well as continuous dissemination of information amongst caregivers. However, limited statistical information on ASD is available on the South African context.

KEYWORDS: Autism spectrum disorder, caregivers, experience, autism, children

CHAPTER 1

INTRODUCTION

1.1. BACKGROUND OF THE STUDY

There is an increasing number of children diagnosed with autism spectrum disorder (ASD) worldwide. This calls for health concerns and further research. With the growing number of children with ASD, there is also an interest in the experiences of caregivers living with children diagnosed with ASD, so that further support may be given to the caregivers. Therefore, the researcher explored the experiences of caregivers for children diagnosed with ASD. According to DePape and Lindsay (2015), ASD is a neuro-developmental disorder which is characterized by impaired communication, repetitive behaviours, impaired social functioning and restrictive interest. ASD is also a condition that can be stressful for both the child and the caregiver, particularly the caregiver. Their whole lives change completely. A normal day for them would comprise of a structured and set routine that they have to adhere to on a day to day basis (Mthimunye, 2014). Caregivers of children diagnosed with ASD also have to deal with the stigma and public isolation because of the child's behavioural problems (DePape & Lindsay, 2015). The signs and symptoms start showing during the first three years of life.

Caring for children diagnosed with ASD comes with higher demands, requires more time, effort and patience, which at times is strenuous for caregivers. All these might lead to psychological and mental health problems, such as stress, anxiety and depression. Financial problems might also arise, as some of the caregivers may be unemployed or not earning enough income to sustain the children's health, which requires constant treatment from health specialists. However, knowing the experiences from a caregiver's point of view could perhaps decrease the burden of caring for children diagnosed with ASD. This can be achieved by having appropriate services offered to the caregivers in different facilities and support from family members (Hoefman, Payakachat, Van Exel, Kuhlthau, Kovacs, Pyne & Tilford, 2014).

According to Mthimunye (2014) in developed and developing countries, women are regarded as the main caregivers for children with ASD. Furthermore, women are most likely to give up their jobs to take care of their children with ASD. Hence, the researcher saw the need to focus on female caregivers for children diagnosed with ASD, instead of male caregivers.

According to the World Health Organization (WHO) (2017), 1 in 60 children has ASD. Its prevalence varies across studies. Some studies may report a much higher figure. Abubakar, Ssewanyana and Newton (2016) contend that global estimates are that, one in every 160 people are living with ASD, which is contributing to the 7.6 million disability life adjusted years. Lai and Oei (2014) also confirm that recent epidemiological studies show an increase in the prevalence of children diagnosed with ASD worldwide. Furthermore, Bateman (2013) highlighted that ASD has increased rapidly worldwide with estimates of 1 in 50 children in the United States of America being affected. Martins, Walker and Fouche (2013) further reported the prevalence of ASD to be 6.7 children in every 1000 in the United States of America. Other countries such as Europe and Denmark have also reported a high prevalence of children diagnosed with ASD.

According to Abubakar et al. (2016) the prevalence of ASD in African countries is still unclear. As a result, it is quite difficult to estimate the number of children diagnosed with autism spectrum disorder in low and middle countries, more especially African countries. This is because the knowledge and awareness is still low, leading to late diagnosis (Bakare & Munir, 2011). The prevalence of ASD in Africa is unknown. In South Africa, the epidemiology of ASD is also still unknown. Thus, more research needs to be done in this area (Malcom-Smith, Hoogenhout, Ing, Thomas & de Vries 2013). Chambers, Wetherby, Stronach, Njongwe, Kauchali and Grinker (2017) further added that “there is no prevalence of ASD in South Africa or indeed in Sub-Saharan Africa as a whole, due to lack of standardized screening and diagnostic tools validated for African populations and limited access to appropriate intervention in the public health and educational sectors in Africa and South Africa in particular”. Furthermore, the prevalence in African and South Africa have not been adequately articulated.

1.2. PROBLEM STATEMENT

The present researcher once volunteered as a school counsellor at a special school in the Ehlanzeni District, Mpumalanga Province for a year. While at the school, the researcher observed that there were children diagnosed with ASD. The researcher also observed that these children have many high needs when it comes to caring for them. Furthermore, it is very difficult to understand how they are feeling because they have deficits in their social and communication skills. As a result, they exhibit many of behavioural problems, such as violent behaviour in most cases. With this background, the researcher saw the need to explore the experiences of caregivers for children diagnosed with ASD. While reviewing the literature, the researcher found that there is gap in terms of the prevalence of ASD and the experiences of caregivers in the Ehlanzeni District, Mpumalanga Province.

1.3. RATIONALE OF THE STUDY

The rationale for the study arose from realisation that studies on the experiences of caregivers for children diagnosed with ASD are limited in the Ehlanzeni District, Mpumalanga Province. Therefore, the researcher focused on the experiences of caregivers for children with ASD. As a result, this study provided evidence-based information on the topic and gained deeper insight into the phenomenon.

1.4. SIGNIFICANCE OF THE STUDY

The rate of children diagnosed with ASD is increasing at an alarming rate; it is estimated that 1 in 160 children were diagnosed with ASD globally (Abubakar et al., 2016). The results of the current study may impart some knowledge to other caregivers who have children with newly-diagnosed ASD, on how to take care of them and what is expected of them when caring for such children.

The study might also help caregivers deal with the high needs that the children have and to cope with stress, anxiety and depression and could be utilised as educational guidance to assist caregivers that are based at special schools. The study findings can also be used as a reference for further research on ASD. The results of the study could also assist the Department of Health to disseminate information to the public, especially during awareness campaigns, such as during the World Autism Awareness Day, and to assist health practitioners to pay more attention to the early diagnosis of the condition.

1.5. PURPOSE AND OBJECTIVES

1.5.1. PURPOSE

The purpose of the study was to explore the experiences of caregivers for children diagnosed with autism spectrum disorder in the Ehlanzeni District, Mpumalanga Province.

1.5.2. OBJECTIVES OF THE STUDY

- To determine caregivers' knowledge regarding autism spectrum disorder.
- To explore the experiences of caregivers for children diagnosed with autism spectrum disorder.

1.6. DEFINITION OF TERMS

Caregiver

“A caregiver can be defined as a person who looks after a sick, elderly or disabled person on a regular basis. A caregiver can be either a family member or a paid individual” (Van Rooyen, 2016). In this study, a caregiver is a female individual who is responsible for providing day to day care to a child diagnosed with autism spectrum disorder.

Experience

“Experience is the knowledge of an event gained through direct involvement of the activity or event” (Van Rooyen, 2016). For the purpose of the study experience is what caregivers go through on a day to day basis when caring for children diagnosed with autism spectrum disorder.

Children

“Children are defined as any persons under the age of 18 years” (Children’s Act 38 of 2005). For the purpose of this study children are defined as individuals who are aged 5-12 years.

Autism spectrum disorder

“Autism spectrum disorder (ASD) is a behaviourally manifested neurodevelopmental disorder that affects individuals across their lifespan” (Van Rooyen, 2016). In this present study, autism spectrum disorder is a disorder that affects social and communication skills of children who are aged 5-12 years.

1.7. Outline of Research Methods

The research study adopted a qualitative approach, with the use of an explorative, descriptive and contextual designs. Data was collected using face to face semi-structured interviews, in which an interview guide was used. Purposive sampling method was used to select participants and data was analysed using thematic content analysis. Twelve (12) participants who met the inclusion criteria were interviewed until data saturation. Ethical considerations and measures of trustworthiness were adhered to throughout the study. The study was approved by the University of Venda Higher Degrees Committee and ethics approval was obtained from the University of Venda Ethics Committee (Project no: SHS/18/PH/08/1505).

1.8. CONCLUSION

This chapter presented the introduction and the background of the study and statement of the problem regarding the experiences of caregivers for children diagnosed with autism spectrum disorder. It further presented the rationale of the study, significance of the study, purpose and

objectives of the study and last but not least the definition of terms as well as outline of research methods. The next chapter presents the literature review.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

This chapter presents reviews of previous literature on the study. The purpose of this chapter is to present what other authors have found regarding the experiences of caregivers for children diagnosed with autistic spectrum disorder. This is an attempt to bring out a theoretical background of the study and to identify knowledge gaps and issues that relate to the study.

2.2. AUTISM SPECTRUM DISORDER DIAGNOSTIC CRITERIA

According to the DSM-5, (American Psychiatric Association, 2013) the following criteria should be met when diagnosing a child with ASD:

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive: see text):
 - Deficits in social-emotional reciprocity, for example from abnormal social approach and failure of normal back and forth conversation, to reduced sharing of interests, emotions or affect, to failure to initiate or respond to social interactions.
 - Deficits in non-verbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and non-verbal communication, to abnormalities in eye contact and body language or deficits in understanding and use gestures, to a total lack of facial expressions and non-verbal communication.
 - Deficits in developing, maintaining and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts, to difficulties in sharing imaginative play or in making friends, to absence of interest in peers.
- B. Restricted, repetitive patterns of behaviour, interests or activities, as manifested by at least two of the following: currently or by history (examples are illustrative, not exhaustive: see text):
 - Stereotyped or repetitive motor movements, use of objects or speech (for example, simple motor stereotyped or repetitive motor movements, use of objects or speech

(for example, simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or non-verbal behaviour (for example, extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same routine or eat same food every day).
 - Highly restricted, fixated interests that are abnormal in intensity or focus (for example, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 - Hyper – or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment (for example, apparent indifference to pain/ temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights and movement).
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capabilities, or may be masked by learned strategies in later in life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

2.3. PREVALENCE OF AUTISM SPECTRUM DISORDER GLOBALLY

The global prevalence of ASD has dramatically increased over the past years. It is also the most common developmental disorder (Malcom-Smith et al., 2013). According to Kincaid, Doris, Shannon and Mulholland (2017) “the prevalence of autism spectrum disorder is estimated to be one percent of the population”. It is evident that children diagnosed with ASD are predisposed to other mental difficulties and co-morbidities. Poovathinal, Anitha, Thomas, Kaniamattam, Melempatt, Anilkumar and Meena (2016) contended that an epidemiological survey was carried out in several countries across the globe, in order to determine prevalence of ASD, which was estimated to be 61.9/10000.

Bateman (2013) noted that the recent Centre for Disease Control and Prevention (CDC) reports indicate a clear rise in the prevalence of ASD in recent years. Some reports have even referred to it as an autism epidemic because of its rapid increase, with the recent CDC estimates suggesting that 1 in 110 children aged 8 years have ASD. When prevalence rates are considered against year of publication, there is indeed clear support for the claim of an increase in prevalence reported for autistic disorder over time. Lai and Oei (2014) argued that this pattern has caused much controversy because it has generated confusion as to whether the rise in prevalence can be attributed to a rise in incidence. "Prevalence is the proportion of individuals in a population who suffer from a defined disorder at any point in time, while incidence is the number of new cases occurring in a population over a period. Incidence does not include individuals already diagnosed or treated for the condition, only the new cases occurring during a certain time" (Lai & Oei, 2014).

As ASD is a behaviourally defined disorder, determining its prevalence is more challenging than for any disorder, where clear biological markers exist. The symptoms of ASD vary in severity and may present differently in children with a mixture of cognitive abilities.

According to Hoefman et al, (2014) recent studies have showed that the prevalence rate for ASD is approximately 90-120/10,000. Males consistently outnumber females by approximately 5:1 for broader ASDs.

2.4. PREVALENCE OF AUTISM SPECTRUM DISORDER IN SOUTH AFRICA

According to Malcom-Smith et al. (2013) ASD in South Africa is relatively unknown. Furthermore, resources for diagnosis and intervention in services are often scarce or unavailable. The study also revealed that standardised assessment tools are not available in several languages, which makes it difficult for healthcare practitioners to diagnose it. Furthermore, "doctors may not refer cases from disadvantaged communities for assessment, due to lack of available services, compounding lack of care".

Chambers et al. (2017) also added that there are no prevalence studies for ASD in the country because the standardised screening and diagnostic tools for African populations is missing. As a result, literature on ASD is scarce in South Africa. However, Mthimunye (2014) stated that "the estimated population of South Africa is approximately 50 590 000; with 19.48 babies being born to every group of 1000. It would suggest that, in the year 2012, an average of 955 493 children were born in South Africa, of whom 11 198 were likely to develop ASD on estimates. This indicates that approximately 933 new cases of children will be diagnosed each month, 216 cases per week

and 31 cases per day. Therefore, one can conclude that every 45 minutes in South Africa a child is born, who will develop ASD”.

2.5. CAREGIVERS' KNOWLEDGE OF AUTISM SPECTRUM DISORDER

Gona, Newton, Rimba, Mapenzi, Vijver, and Abubakar (2016) have stated that although awareness about autism has increased in developed countries, more than in developing countries, ASD remains poorly understood by most South Africans, especially those in remote areas and in areas where research is limited. It is evident that little is known about the condition because there is no prevalence data on children diagnosed with ASD in the Ehlanzeni District, Mpumalanga Province. Mthimunye (2014) reported that there is lack of knowledge and understanding about ASD and disorders associated with ASD in our communities, especially in our African communities. This is because some people in the African community still believe that a disorder such as ASD only occurs among western communities (Mthimunye, 2014). Healthcare practitioners may diagnose a child with ASD but many caregivers lack the knowledge about the condition, and this may lead to anxiety and raise much concern. Healthcare facilities lack a significant number of trained professionals to provide care and support to caregivers upon diagnosis. This is a major problem in public healthcare facilities. Lastly society may stigmatize the condition because of poor knowledge, which makes it even more challenging for the caregiver (Mthimunye, 2014).

2.6. EXPERIENCES OF CAREGIVERS WHEN CARING FOR CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER.

Gona et al. (2016) stated that research on the experiences of caring for a child with ASD is mostly reported from Europe, North America and Australia, and little is known about experiences of caring for a child with ASD in African countries in the literature. ASD is a developmental disorder characterized by poor communication and social skills, and behavioural problems. The study revealed that caregivers must come to terms with caring for a child who has a lifelong developmental disability. In addition, autistic children have many needs. Therefore, caregivers often experience many challenges in dealing with the needs of children with ASD. These include mental health problems, financial burden, lack of support system, availability and accessibility of services (Aylaz, Yalmaz & Polat, 2012).

ASD is a generally misunderstood developmental disorder. Some people do not even know what it is or know how to deal with the challenges caregivers experience on a day to day basis. Lack of awareness limits access to appropriate services that may improve the quality of life and prognosis in children affected by autism. In addition, caregivers of children with autism experience

challenges such as single parenting or divorce, childcare needs and lack of financial resources, all of which have negative effects (Gona et al., 2016)

The stress of caring for a child with ASD can affect the psychological and emotional wellbeing of caregivers. This aspect is worsened by the poor prognosis of ASD. Caregivers of children with ASD have been reported to experience increased personal stress, problems in interpersonal relationships and increased isolation. Caregiving stress has a negative impact on the mental and physical health of the caregivers themselves. According to Malcom-Smith, et al. (2013) factors that contribute to elevated stress in caregivers of children with ASD include the child's behavioural problems, lack of adequate professional support, and social attitudes towards the child with ASD. The study revealed that the lives of persons in families that have children with ASD often revolve around dealing with the child's unusual behaviours. These behaviours may adversely impact the family function.

In another study, DePape and Lindsay (2015) reported that giving care to children with ASD is seen as a stigma and is one of the most difficult aspects of public encounters experienced by the caregivers. A stigma is a social construct defined as a mark of shame or discredit, characterized by guilt or disgrace. Components of stigma include labelling, stereotyping, separation, status loss, and discrimination. Caregivers of children with ASD often experience stereotyping and negative public reactions. Therefore, it is quite difficult to walk around with the children without being stigmatized by the public.

2.7. CONCLUSION

This chapter reviewed literature on the experiences of caregivers for children diagnosed with ASD. It covered aspects such as diagnostic criteria of ASD, global prevalence of ASD, national prevalence of ASD, caregivers' knowledge of ASD as well as experiences of caregivers for children diagnosed with ASD.

CHAPTER 3

METHODOLOGY

3.1. INTRODUCTION

This chapter outlined the research methodology that the researcher used in the study. The following aspects were discussed in this chapter: the approach of the study, design of the study; setting of the study; population and sampling procedure of the study; research instrument; pre-testing; method of data collection; data management and analysis; measures for ensuring trustworthiness; ethical considerations; scope and limitations of the study as well as dissemination of the results.

3.2. RESEARCH APPROACH

The study adopted a qualitative approach. This approach enabled the researcher to be closer to the people and the situation being studied. According to De Vos, Strydom, Fouche and Delpont (2011) when a researcher is “describing and understanding the phenomena from the respondents’ point of view, qualitative approach is used to answer questions about the complex nature of phenomena”. In this case, the researcher explored the experiences of caregivers for children diagnosed with ASD. Grove, Gray, and Burns (2015) further note that in qualitative research people are studied in their natural setting, to discover the social world of cultures. This approach gave the researcher the opportunity to find out the experiences of caregivers for children diagnosed with ASD in the Ehlanzeni District, Mpumalanga Province.

3.3. RESEARCH DESIGN

According to Maree (2016) a research design is a “plan or strategy that moves from underlying philosophical assumptions to specifying the selection of participants, the data gathering methods to be used and data analysis to be done”. In this study, exploratory, descriptive and contextual designs were used, through these designs the researcher was able to gain insight into the phenomenon under study and it also afforded the researcher the opportunity to probe and observe non-verbal communication cues from the participants during the interviews.

3.3.1. EXPLORATORY DESIGN

Exploratory research is defined as a design that attempts to lay ground work that will lead to future studies. Exploratory research is conducted in order to gain a clear understanding on what is currently being studied (Neuman, 2011). The researcher laid the ground of the study and explored the experiences of caregivers for children diagnosed with ASD and gained a clear understanding of the phenomenon.

3.3.2. DESCRIPTIVE DESIGN

According to Pilot and Beck (2014) a descriptive design refers to a study that has as its main objective the accurate portrayal of the characteristics of persons, situations or groups. Descriptive research allows the researcher to describe specific behaviour as it occurs in the environment (Maree, 2016). The researcher evaluated the caregivers' knowledge on ASD and gave them the opportunity to describe their experiences of caring for children with ASD. Furthermore, the researcher observed any specific behaviour during interviews and recorded the interviews.

3.3.3. CONTEXTUAL DESIGN

Contextual studies define and describe the setting in which the research actions occur. The aim of contextual studies is to understand events within the context in which they take place (Babbie & Mounton, 2016). The study was contextual in nature because it was conducted in the Ehlanzeni District where the phenomenon took place.

3.4. STUDY SETTING

According to Maree (2016) a setting is the location where the researcher intends to conduct the study, the setting should be suitable and feasible. The study was conducted in three different schools in the Ehlanzeni District, Mpumalanga Province. The Ehlanzeni District has a total of three schools that accommodate children with ASD, two of which are private schools and one is a public school. These schools do not only cater for children with ASD but also accommodate children with other disabilities.

Ehlanzeni District is one of the three district municipalities located in the North-Eastern part of Mpumalanga Province. The capital city of Ehlanzeni District is Mbombela, previously known as Nelspruit. It has a total population of 944 665 people. Most people in this district speak Siswati language. Ehlanzeni District is bordered by Mozambique and Swaziland in the east, Gert Sibande District in the south, Mopani and Sekhukhune Districts of Limpopo in the North and Nkangala District Municipality in the west.

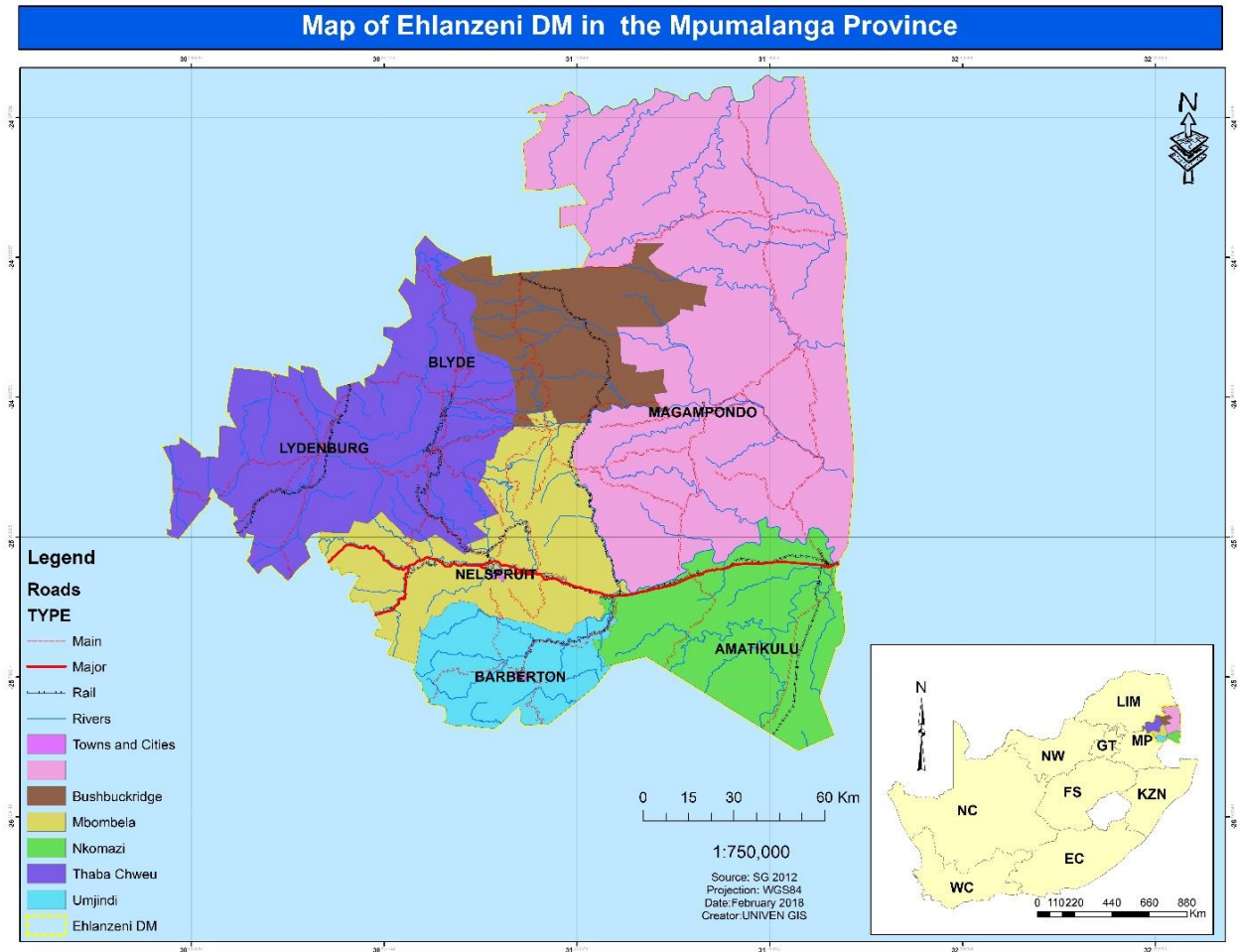


Figure 3.4.1. Map of Ehlanzeni District

3.5. STUDY POPULATION AND SAMPLING

3.5.1. POPULATION OF STUDY

A population is any group that is the subject of research interest (Goddard & Meiville, 2014). According to Pilot and Beck (2014) a target population is the entire population in which the researcher is interested. The target population of the study were caregivers of children with ASD in the Ehlanzeni District. The children were 5-12 years. An accessible population is the portion of the target population that is accessible to the researcher (Pilot & Beck, 2014). The accessible population of the study were caregivers of children diagnosed with ASD, whose children were attending at one of the three schools that accommodate children with ASD in the Ehlanzeni District.

3.5.2. STUDY SAMPLE AND SAMPLING

A sample is defined as the selected group of people or elements (Grove, Gray & Burns, 2015). LioBiondo-Wood and Haber (2014) defined a study sample as the group of people that the researcher will interview or observe in the process of collecting data to answer the research questions. A sample of a study should represent an identified population of people. In qualitative research a sample is determined by data saturation (LoBiondo & Haber, 2014). The researcher interviewed twelve (12) participants from the three schools who met the inclusion criteria of the study.

Pilot and Beck (2014) maintained that sampling involves selecting a portion of the population to represent the population. Maree (2016) defines sampling as a systematic selection of a pool of participants. In the current study, non-probability sampling procedure was used. Non-probability sampling is a way of selecting individuals that are not known because the researcher does not know the population size or the members of the population (De Vos et al., 2011).

In non-probability paradigm, each member in a sampling frame does not have an equal chance of being selected for that study. Under non-probability sampling, the researcher used purposive sampling technique. According Maree (2016) “in purposive sampling members of a sample are chosen with a purpose to represent a phenomenon, group, incident or type in relation to a key criterion”. Pilot and Beck (2014) further added that purposive sampling is based on researchers’ knowledge about the population.

The study focused on caregivers of children diagnosed with ASD in the Ehlanzeni District, Mpumalanga Province. Twelve (12) caregivers who were accessible on the day of data collection were interviewed. The researcher used purposive sampling which enabled the study to fulfil the research aim in that the characteristics of the participants fit with the aim of the research.

3.5.2.1. INCLUSION SAMPLING CRITERIA

Grove, Gray and Burns (2015) maintained that inclusion sampling criteria are the characteristics that the participants should have in order to form part of the study. In this study the sample was all female caregivers of children diagnosed with ASD, whose children were aged 5-12 years in the Ehlanzeni District, Mpumalanga Province.

3.5.2.2. EXCLUSION SAMPLING CRITERIA

Exclusion sampling criteria involves characteristics that will exclude participants from being part of the study (Grove, Gray & Burns, 2015). In this study exclusion criteria was male caregivers of children diagnosed with ASD, and children who were not aged 5-12 years.

3.6. RESEARCH INSTRUMENT

Pilot and Beck (2014) defined a research instrument as a device or tool used to collect research data. The instrument that the researcher used in the study was an interview guide. According to LoBiondo-Wood and Haber (2014), an interview guide is a set of pre-coded questions to produce quick, cheap and easy questions. An interview guide provides the researcher with a set of predetermined questions to be asked during the interview (De Vos et al., 2011). In this study, the interview guide (see appendix E) was developed in English.

3.7. PRE-TESTING

According to Babbie and Mouton (2016) pre-testing is the stage that involves the testing of data collection tools. A pre-testing study on three caregivers residing in the Ehlanzeni District and who met the inclusion criteria was conducted. These caregivers did not form part of the final study. This helped to pre-test the feasibility and applicability of the instrument used in the final study. This helps in checking whether the objectives have been covered or not. Pretesting confirmed that questions in the interview guide were accurate, fair and reliable. In addition, the pre-test helped in testing concepts or general issues and to spark ideas.

3.8. DATA COLLECTION

According to Creswell (2013) data collection basically means seeking and gaining permissions, conducting a good sampling strategy, developing ways of recording information on a voice recorder and taking notes and lastly considering ethical issues that may arise. The data in this study was collected using an interview. Maree (2016) asserts that an interview is a two-way conversation in which the interviewer asks the participant questions, to collect data and to learn about the ideas, beliefs, views, opinions and behaviours of the participant.

In this study, the researcher used a semi-structured interview. In a semi-structured interview, the interviewer has a list of questions or key points to be covered and works through them in a methodical manner (Maree, 2016). Semi-structured interviews help researchers to clarify concepts and problems and allow for the establishment of a list of possible answers and solutions. Semi-structured interviews facilitate the elimination of unnecessary questions and reformulation of unclear ones. Semi-structured interviews also allow for the discovery of new aspects of the

research problems by exploring in detail the explanations supplied by the participants (Maree, 2016).

When collecting data, the researcher provided a brief introduction and background of the study and explained what was expected of the participants. The researcher then explained the consent letter to the participants, to make them aware of the ethical considerations and gave them the consent form to sign. Thereafter the researcher asked the participants for permission to use a voice recorder. A voice recorder was used to record the interviews, to ensure that data was transcribed verbatim, for data analysis purposes, without missing any information. Handwritten notes were also used to support the recordings.

3.8.1. PREPARATION FOR DATA COLLECTION

Once the study was approved by the University of Venda Higher Degrees Committee, it was then explained to the schools' principals and participants. A trusting relationship was established by developing a rapport with the participants. The researcher was then granted permission to contact the participants telephonically prior to the interviews.

3.8.2. RECRUITMENT PROCESS

According to Given (2012) "recruitment refers to the process whereby the researcher identifies and invites (recruits) participants to join the study. These participants must meet the inclusion criteria of the study" (Given, 2012).

In this study participants were recruited through the schools' social workers. Once permission was obtained from the Mpumalanga Department of Education and the principals of the schools. After recruitment of participants, the researcher had a formal meeting with the participants to discuss dates of the interviews. Data was collected on the school premises as it was a familiar environment for the participants.

3.9. DATA MANAGEMENT AND ANALYSIS

According to Borghi, Abrams, Lowenberg, Simms and Chodacki (2018) the term data management refers to storage, organization, documentation and dissemination of data. In this study data was collected using a voice recorder then stored and kept in a safe place. The data will be stored for one year for future research referrals. Creswell (2013) contends that "data analysis in qualitative research involves preparing and organising data analysis". This process is a systematic way of reducing data into themes then representing data in a discussion form. Data in the proposed study was analysed qualitatively. Qualitative data was analysed thematically, in line with the aim and objectives of the study. Furthermore, a thematic analysis helped the

researcher gain a deeper understanding of the participants' knowledge of ASD and experiences of caring for children with ASD. Data was processed and analysed according to the initial research questions.

According to Vaismorad, Turenen and Bondas (2013) thematic analysis is a qualitative analytic method for analysing materials of life stories and reporting patterns (themes) within the data. It minimally organises and describes data set in rich detail. However, frequently it goes further than this, and interprets various aspects of the research topic. The researcher used the following processes to analyse data, as outlined by Braun and Clarke (2006) adapted from Vaismorad, Turenen and Bondas (2013):

Phase 1: Becoming familiar with the data

This phase involves transcribing data verbatim (transcribing data into text, word for word) the information from interviewing the caregivers. The collected data was read and re-read until it was satisfactory to continue with the initial phase of analysis. Important initial ideas were be noted down.

Phase 2: Generating initial codes

In this phase coding of data took place; that, is the researcher organised the data into meaningful groups and highlighted meaningful phrases, statements or words that were related to the phenomenon under study.

Phase 3: Searching for themes

The researcher then collected and organized codes into potential themes and determined the relationship among codes. Themes were identified from the content or statements.

Phase 4: Reviewing themes

The researcher revised and reworked on the initial themes identified and clustered.

Phase 5: Defining and naming themes

The researcher identified common and similar themes and clustered them under one group.

Phase 6: Producing the report

The researcher finalized the reviewed themes and began with the process of writing the final report and decided on themes that made meaningful contributions to answering research questions.

3.10. TRUSTWORTHINESS

Maree (2016) defined trustworthiness as the way in which the enquirer can persuade the audience that the findings in the study are worth paying attention to and the research is of high quality. Creswell (2013) on the other hand defines trustworthiness as the acid test of your data analysis, findings and conclusions. The researcher needs to be familiar with the procedures that can be used for assessing the trustworthiness of the data analysis constantly in mind. These procedures include field notes and voice recorder when collecting data and making sure that the researcher's beliefs do not affect the research process.

When enhancing trustworthiness during the study the researcher used four concepts from Lincoln and Guba (1985) of the criteria of trustworthiness adapted from Maree (2016):

3.10.1. CREDIBILITY

In order to ensure credibility, the researcher adopted well-recognised research methods, debriefing respondents and describing the phenomenon under study (Maree, 2016). The following were measures of credibility for the study:

- Credibility was achieved by verbally paraphrasing the participants' responses and they confirmed their responses.
- The researcher built a trusting relationship with the participants and created a familiar environment that allowed them to fully express themselves in their preferred language.
- Probing and asking follow-up questions took place and sought clarity from the responses given.

3.10.2. TRANSFERABILITY

According to Maree (2016) transferability does not involve generalised claims but invites readers of research to make connections between elements of a study and their own experience or research. Measures of transferability in the study are as follows:

- The researcher provided a brief description of the data collection method that was used.
- The researcher mentioned the number of participants in the study (sample size) and the number of researchers involved in the study (in this case the researcher conducted the study with the guidance of a supervisor).
- The length of the interviews was also outlined (approximately 30-45 minutes).

3.10.3. DEPENDABILITY

Dependability refers to the researcher's ability to account for changes in and around the phenomena being studied (Lincoln & Guba, 2012). Dependability in the study included the following components:

- The researcher used field notes when transcribing data.
- A voice recorder was used to ensure that the researcher does not miss any information when collecting data.

3.10.4. CONFIRMABILITY

According to Lincoln and Cuba (2012) confirmability is linked to the question of objectivity. Confirmability is all about whether data help confirm the general findings and lead to the implications. To enhance confirmability, the researcher did the following:

- Semi-structured interview, using an interview guide was conducted until data saturation was reached.
- The findings of the study were compared with existing literature.

3.11. ETHICAL CONSIDERATIONS

The term ethics implies preference that influence behaviour in human relations, conforming to a code of principles, the rules of conduct, the responsibility of the researcher and the standard of conduct of a given profession (De Vos et al., 2011). Ethical Considerations is the principle of respect for person, beneficence and justice (Burns & Grove, 2015). For the purpose of this research the following ethical issues were adhered to, permission to conduct study, informed consent, confidentiality, Anonymity and discontinuance.

3.11.1. PERMISSION TO CONDUCT STUDY

The research proposal was presented to the School of Health Sciences Degrees Committee and later to the University Higher Degrees Committee for quality assurance and approval. After approval by University Higher Degrees Committee, the researcher applied for ethical clearance from the University of Venda research committee to conduct the study. As soon as the ethical clearance was obtained, the researcher sought permission to conduct study from the Mpumalanga department of education and principals of the three different schools.

3.11.2. INFORMED CONSENT

According to LoBiondo-Wood and Haber (2014) informed consent implies that research participants have the right to understand the implications of participating in the study and should give informed consent to participate in the study, this basically means that the researcher should fully inform research participants about what is expected of them and the nature of the study. The researcher informed the participants on the background of the study, by explaining to them what the study entailed and what is required of them. Before conducting the interviews with the participants, the researcher first sought the participants' permission to do so.

3.11.3. CONFIDENTIALITY

Confidentiality is a pledge that any information provided by the participants will be kept strictly in confidence and will not be made accessible to others (Pilot & Beck, 2014). The researcher gave the participants an assurance that any information which is deemed life-threatening, or which, may disturb the participants' economic, social, physical, health, and psychological make-up, will not be readily made available to anyone else.

3.11.4. ANONYMITY

Anonymity involves protecting the participants' identity so that they remain unknown (Maree, 2016). Participants who feel that their identity should not be revealed were taken into consideration. A representation of the participants was made in the form of numbers or pseudo names to protect their identities. The researcher made sure that the true identities of the participants were not revealed to anybody, to protect them from potential victimisation

3.11.5. DISCONTINUANCE

Discontinuance is the termination, cessation, ending, giving up (Hickson, 2008). The participants were assured that they are free to discontinue at any stage of the interview, if they feel uncomfortable. The researcher gave the participants an assurance that they are free to discontinue with their participation at any time without being required to offer an explanation.

3.11.6. THE RIGHT TO SELF-DETERMINATION

The principle of self-determination means that prospective participants have the right to decide voluntarily whether to participate in the study, without risking any penalty or prejudicial treatment (Pilot & Beck, 2014). The researcher allowed participants to ask questions, made them aware that they could refuse to give information and withdraw from the study at any given stage.

3.11.7. RISK BENEFIT RATIO

According to Rid and Wendler (2017) risk entails to the likelihood of harm occurring whereas benefit refers to positive event or experience. Therefore, risk benefit ratio is a process of accessing a research study's risks and potential benefits. The researcher informed participants that there would not be any direct benefits and risks by participating in the study.

3.12. SCOPE AND LIMITATIONS OF THE STUDY

This proposal outlined the overview of the study which included introduction and background, problem statement, rationale, significance, objectives, literature review, research methodology and methods, trustworthiness and ethical considerations. This study focused on an anticipated minimum number of 10 caregivers for children diagnosed with autism spectrum disorder until data saturation was reached.

3.13. DISSEMINATION OF RESULTS

The final report of the study will be submitted to the University of Venda Library and the findings might be published in accredited journals.

3.13. CONCLUSION

This chapter focused on the methodology that was used in the study and it covered aspects such as research approach, research design, study setting, study population and sampling method and procedure that was used to gather information. It also presented the instrument that was used, method of data collection and analysis and ethical clearance used to ensure participants' rights were not violated in the study. The next chapter presents the findings and discusses the results of the study.

CHAPTER 4

PRESENTATION AND DISCUSSION OF THE FINDINGS

4.1. INTRODUCTION

This chapter seeks to present and discuss the results of the data that was collected and analyze it. The aim of the analysis was to identify themes from the meaningful data collected. The themes are illustrated using extracts from the data. Data was collected for the purpose of exploring caregivers' experiences of caring for children diagnosed with autism spectrum disorder (ASD) in the Ehlanzeni District, Mpumalanga Province. The aim of data analysis is to transform, bring order, structure and meaning to masses of collected data (De Vos et al, 2011). Three main themes emerged from qualitative data that was collected through individual semi-structured interviews with the participants, namely: caregivers' knowledge of ASD, caregivers' experience of caring for a child with ASD and coping mechanisms used in dealing with the challenges of caring for a child with ASD, each major theme has some subthemes.

4.1.1. DEMOGRAPHIC INFORMATION

A maximum of 12 participants were interviewed for the study, only female caregivers participated. The caregivers were caring for children aged of 5-12 years, diagnosed with ASD. The sample size was determined by data saturation. Ten participants were the biological parents of the children diagnosed with ASD and two mentioned that they had adopted the children. The table below illustrates the demographic information of the participants. Ten participants were African women and two were White women. Their age ranged between 25-49 years. Participants were from low and middle-income families. Their marital status indicated the categories single, married and divorced.

Table 4.1.1. Participants' demographic information

| Participant | Age | Marital Status | Highest Qualification | Occupation | Relationship with the child | Age of the child |
|--------------------|------------|-----------------------|------------------------------|-------------------|------------------------------------|-------------------------|
| 1 | 38 | Single | Diploma | Sensory Therapist | Biological son | 6 |
| 2 | 48 | Divorced | Matric Certificate | Buyer | Biological son | 9 |
| 3 | 48 | Married | Honours' Degree | Teacher | Adopted son | 12 |
| 4 | 25 | Single | Diploma | Administrator | Biological son | 5 |
| 5 | 32 | Married | Diploma | IT Specialist | Biological son | 10 |
| 6 | 49 | Single | Bachelor's Degree | Teacher | Biological son | 9 |
| 7 | 36 | Married | Advanced Certificate | Teller | Biological son | 11 |
| 8 | 32 | Single | Matric Certificate | Unemployed | Biological son | 6 |
| 9 | 47 | Married | Bachelor's Degree | Teacher | Biological son | 9 |
| 10 | 32 | Married | Matric Certificate | Unemployed | Adopted daughter | 10 |
| 11 | 29 | Single | Matric Certificate | Unemployed | Biological son | 7 |
| 12 | 38 | Single | Grade 11 | Domestic worker | Biological son | 5 |

4.2. FINDINGS

Table 4.2.1 summarises the themes and subthemes identified after data analysis. The themes are; caregivers' knowledge of ASD, caregivers' experience of caring for a child with ASD and coping mechanisms used in dealing with the challenges. The themes and subthemes are discussed in detail below, evidenced by verbatim quotations in italics.

Table 4.2.1. Findings of the study

| Themes | Subthemes |
|--|---|
| 1.Caregiver's knowledge of ASD | 1.1. Disorder |
| | 1.2. Lack of Knowledge |
| | 1.3. Cultural Beliefs |
| 2.Caregivers' experience of caring for a child diagnosed with ASD | 2.1. Psychological Stress |
| | 2.2. Social Isolation and Stigma |
| | 2.3. Financial Burden |
| | 2.4. Lack of family support |
| | 2.5. Accessibility and Availability of services |
| 3.Coping mechanisms used in dealing with challenges for a child diagnosed with ASD | 3.1. Prayer |
| | 3.2. Strong support system |
| | 3.3. Acceptance |

4.3. THEME 1: CAREGIVERS' KNOWLEDGE OF ASD

According to Mthimunye (2014) ASD is still a misunderstood condition, caregivers, health care professionals and communities' at large still lack knowledge about ASD. In addition, caregivers are not informed about the disorder until the day of diagnosis, some experience confusion even after diagnosis. Participants' knowledge, understanding and how they view autism differs from one caregiver to the other. However, most of them expressed that it is a developmental disorder. Some were still struggling to understand what it is and still lacked information about the condition.

A few participants believed that ASD has much to do with witchcraft because they mentioned that their children developed well during the first year of life, then changed. The sub-themes identified under this theme are, disorder, cultural beliefs and lack of knowledge. The subthemes are discussed below as follows.

4.3.1. Sub-theme 1.1.: Disorder

Most of the participants caring for children diagnosed with ASD, reported that ASD is a disorder that affects mostly the development of their children. This is supported by the following:

“My understanding of autism is that the children on the spectrum have a neurological disorder, so it impairs them, it depends on the child you have, it impairs their social skills, impairs language development to the extent where some of them are physically impaired”. (Participant 10)

“It’s a neurological disorder, it affects their development basically some of them are able to reach some milestones and some of them are delayed so it’s basically about developmental issues in terms of growth”. (Participant 12)

“Okay, I understand it’s a disorder whereby the child will have difficulty communicating also repetitive activities and the development of his own way of doing things and wanting to stick to it whether it’s right or wrong and having no understanding of the world as we know it”. (Participant 6)

“Hmmm it’s a slow developmental disorder which makes the child to behave in a different way from the normal children”. (Participant 8)

The researcher had an opportunity to also interview a professional in the field of ASD. This participant is a sensory therapist at one of the schools that caters for children with autism and she has two children with ASD. She expressed her understanding of ASD as follows.

“.....it’s a neurodevelopmental disorder in which the brain struggles to process certain information and inputs from outside through the sensors. The information gets disorganized. Also, you have a lot of fine motor and gross motor difficulties and it’s also a social and emotional impairment, so it’s basically in all developmental areas there is an impairment or a dis-regulation of some sort and it’s also not a set or a fixed kind of affliction so all children different from one another they all have different profiles, it’s never exactly the same thing every time but yes mainly it gets characterized by social irregularities and misunderstanding struggling to cope with social scenarios” (Participant 3)

According to Bashir, Bashir, Lone and Ahmad (2014) ASD is a complex neurological disorder that affects the brain function which causes impairments in several areas of development such as social interaction, communication deficits and behavior. DePape and Lindsay (2015) also indicated that ASD is “developmental disorder involving abnormal communication repetitive behavior, restrictive interest and social functioning”.

4.3.2. Sub-theme 1.2.: Lack of knowledge

Some participants mentioned that they still have no idea what ASD is, even though they have children on the spectrum. The following quotes show how little some caregivers' knowledge was on autism spectrum disorder.

“Uh, actually, when it comes to autism I don't have much information but what I know is that most of the children who suffer from autism struggle a lot when it comes to speech and they also don't see things the way we see them, like everything around them is loud. That's what I understand about autism”. (Participant 7)

“Autism...what I understand about it, is that we had a bond with the child, I didn't know about autism. I still can't describe it.....” (Participant 2)

The current findings are in line with Madlala (2014), who reported that there is still a gap in knowledge about ASD among parents, communities and health care professionals. This is further supported by Mthimunya (2014), who reported that some parents are not adequately informed about ASD and that they had never heard of it until the day of diagnosis. Even after diagnosis some participants reported that were still not too clear about it.

4.3.3. Sub-theme 1.3.: Cultural Beliefs

Two participants expressed the view that they understand ASD and that it has something do with witchcraft because they had watched their children developing well during the first year of their life, then everything changed. Therefore, they saw it as witchcraft. They also indicated that they had taken their children to sangomas and traditional healers to seek help. This is supported by the following statements.

“Uh...autism...I think sometimes it has a lot do with witchcraft because my child at first he was talking but after 2 years he stopped talking, so I thought maybe he was bewitched, hence I took him to almost every sangoma in my area and even outside my area...” (Participant 1)

“Eish...uh I was hurt because this is my child and I want the best for her in life, it was difficult I didn't take it well, I even took her to several sangomas, as I thought maybe she's bewitched

because it is not normal for a child to just stop doing things she used to do before..." (Participant 2)

In the African culture, a child diagnosed with ASD is linked to a potential message from their ancestors or as a sign of lack of goodwill from neighbors. Therefore, they seek traditional healing systems (Madlala, 2014). This is consistent with Kovita, Ruparelia, Abubakar, Badoe, Bakare, Visser, Chugani, Chungani, Donald, Wilmshurst, Shih, Skuse and Newton (2016) who reported that some parents regard ASD to have supernatural causes, precipitated by angered ancestral spirits, sinful wrong doing or action of the devil. Further, in the African culture it is common for children to be taken to traditional healers first before seeking medical assistance, and this delays the diagnosis.

It is evident from the above findings that there is limited knowledge surrounding ASD, merely among caregivers and the community at large. It is also evident that how caregivers view and understand ASD is greatly influenced by cultural beliefs, as some expressed that when a child is diagnosed with ASD is as a results of angered ancestral spirits and witchcraft. Therefore they sought traditional healing methods.

4.4. THEME 2: CAREGIVERS' EXPERIENCE OF CARING FOR CHILDREN DIAGNOSED WITH ASD

Parents in Hoefman et al. (2013)'s study indicated that they experienced a number of challenges when caring for a child with ASD. Giving care to a child with such a disorder can also be very strenuous, leading to stress on both the caregiver and the child but more especially the caregiver. It also leads to poor psychological well-being on the caregiver. Similarly, caregivers in the current study reported that caring for a child with ASD requires time, efforts and patience. Furthermore, participants reported that they experienced many challenges when it came to caring and raising the child with ASD. They mentioned that they experienced psychological stress, social stress, as well as financial burden because children with ASD have many financial needs to be catered for. Some mentioned that accessibility and availability of health care services was a problem. One participant indicated that she had no support system at all. The subthemes that emerged under this theme are discussed below.

4.4.1. Sub-theme 2.1.: Psychological stress

According to Da Paz, Wallander and Tiemensma (2018) psychological stress refers to the emotional and physiological reactions experienced when an individual is faced with a situation beyond their coping measure. The signs and symptoms of psychological stress are anxiety,

depression, feeling overwhelmed, constant worry and restlessness. The majority of participants mentioned that they experienced psychological stress when it came to caring for a child diagnosed with ASD. Some participants also stated that they could not cope with everything, it became overwhelming to them that they ended up failing to coping with their situations. The following quotes depict how the participants experience psychological stress.

“It’s not easy, it is difficult because even now he still wears pampers and people think I have not potty-trained him and I can’t always be explaining his situation. That really affects me psychologically and I’m not really coping”. (Participant 4)

“It’s very hard because he’s constantly on my mind. He times me so I have to rush home, if I stop somewhere he knows and he performs, he gets angry when I’m late. I can’t just be impulsive and do what I want; also, I am the main purpose in his life so, if had to go away and something happened to me, nobody would want him, nobody would understand him the way I do, so psychologically, it does play on your mind very much and you always worry if you leave him with people, you can’t just leave him with anybody because he’s got to be protected...” (Participant 3)

“In terms of psychological experience, it’s really hard, some days are good, someare bad, especially with me and my surrounding...” (Participant 8)

“...So, psychologically, I can say that it pains me because of the spectrum...they are not really teachable, at home you want him to be independent and self- reliant...” (Participant 11)

“Psychologically sometimes it’s hard for me because I want him to do things like normal kids but he won’t even reach that point that disturbs me a lot. Sometimes I become very emotional and end up crying, sometimes I become stressed...” (Participant 1)

According to Lai, Goh, Oei and Sung (2015) “parents of children with ASD have been reported to have poorer psychological outcomes”. This correlates with Hoffman (2012) who noted that parents caring for children diagnosed with ASD experience higher levels of psychological stress than parents who were caring for children without ASD. The findings of the current study correlate with the findings of Lai et at. (2015), Hoffman (2012) as well as (Al-Dujaili and Al-Mossawy, 2017) report that most caregivers of children with ASD suffer a great deal of psychological stress.

4.4.2. Sub-theme 2.2.: Social isolation and stigma

Participants indicated that social isolation and stigma is a problem and that it is a contributory factor to their psychological problems. They also complained that society does not accept or understand their children, as people often stared at their children and that became stressful for

them. The participants stated that they believe society lacked knowledge on ASD. This statement is supported by the following.

“...when we take him to town someone will come to him and say we are going to call the police and he doesn’t even understand. Some will say you are not a good parent because your child is shouting and you keep quiet, he’s spoiled and so forth. They really lack knowledge on autism, and that is also stressful” (Participant 7)

“Socially, I would say not a lot of people understand him; some would want to greet him and he would not respond or say anything. This one time we were at Mr Price and my child was greeted by another child and he did not respond properly. So, the other child said to him, “you can’t talk but you are old”. So, I sometimes keep quiet or respond and explain to them his situation. Sometimes, it depends on the parent of the other kids” (Participant 5)

“...the things that he says are not really language; so, a lot of people turn and stare and start saying that this child is old but can’t talk properly...” (Participant 2)

“Socially, I prefer staying at home because at first he could say one or two words but then he started speaking this other language that you don’t understand and people would start starring and then they would start asking questions. As a parent, you are still struggling because some of the things you don’t understand. He wants something but you don’t know what he wants and then he will start screaming and shouting, then people think you don’t discipline your child. I can’t take him anywhere because he easily gets frustrated and people stare at him. Only family understand him so, it’s not nice” (Participant 5)

One participant reported that she could not even let her child to go out and play with other children because they mocked him and the parents of these children were not doing anything to make their children understand that he is different. So, she believed that it is best that she kept him in the house, in order not to stress about the whole situation. This is evident in the following statement.

“The problem with the children around my neighborhood is that most of them do not understand his condition; so they ostracize him. He’s marginalized; they don’t accept him; they boo him, they laugh at him and that can be very disturbing, even to a parent, especially when you look at their parents and realize they’ve not done anything about it hence; I think the parents are also encouraging that because they are supposed to talk to their children and say no, he’s just a child, it’s just that he’s differently abled, but he’s a normal child, like you...you don’t have to treat him

differently. They are not handling the situation properly; so instead of me fighting with them, I would rather keep him to myself or in the house, entertaining him with his toys. He likes phones..." (Participant 9)

According to DePape and Lindsay (2015) parents of children with ASD often receive criticism from strangers when they were out in public, strangers believe that their children were acting out and should be disciplined. Furthermore, parents believed that this could be a result of ASD being an invisible disorder while some parents ignored such strangers and educated them about the nature of ASD. Fletcher, Markoulakis and Breyden (2011) reported that parents with children diagnosed with ASD experience public stigma as a result of their children's condition and they would assume that the inappropriate behavior was due to poor parenting skills.

4.4.3. Sub-theme 2.3.: Financial Burden

Participants reported that children have many financial needs which at times they cannot cover. Most of the participants mentioned that their children did not eat what other people ate in the house and some of the children used nappies because they could not talk and did not have a sense of what was happening around them. The participants further indicated that they also spent much money paying for therapists and buying medication as some of the things were not available in government hospitals and their school fees were also expensive. This is supported by the following statements.

"Financially, it is very taxing because, to start with I'm not even happy with him being in a government school. I feel like I'm being a bad parent, it's just that I cannot afford to enroll him at a private school because it's too expensive and I won't be able to meet all the demands of that particular school. That is why he's in a government school but really it is expensive, even the therapy sessions that I take him to, the medical aid does not cover all the costs, so, I have to pay the shortfall". (Participant 1)

"...the thing with them is that there are specific foods that they eat, so you cannot just buy any type of food. They are very choosy and very sensitive about things, for instance, before my son eats he will smell whatever you give him to eat. So, you need to buy the things that he wants, you cannot just buy any food; for example with cereals he only eats cornflakes, so you need to buy just cornflakes. He doesn't like bread and they are saying bread is not good for them, so all those special foods are expensive and soya milk is very expensive. So, it is very strenuous when it comes to finances". (Participant 5)

“...financially, it’s quite hard because we wanted to take him to this other private school that has a lot of resources which would assist him because they have a built-in speech machine therapy They also have a lot of things for them. The problem is that it’s too expensive for us to take him there; so, we have no choice but to take him to Dasha Foundation, which is okay but if I had my way I would have liked to take him to the other school”. (Participant 7)

“He’s still on nappies, just a pack of 13 costs R160; which takes 4 days; so how do we cope financially with that?? He eats non-stop everything goes to the mouth of course he’s got his own likings and preferences; so financially it’s a huge burden”. (Participant 11)

“Financially, you really spend a lot when you have a child with autism. School fees are too high; there’s specific food, paying for occupational and speech therapists is expensive, it’s just too much”. (Participant 6)

“...uh special foods and he doesn’t eat this and now he only eats this, so it’s costly all this gluten-free products are very expensive” (Participant 4)

The current findings are supported by Matenge (2012), who noted that ASD has serious financial implications for the caregiver, considering the costs involved in managing the disorder and associated problems, such as therapy, doctors’ fees, special dietary requirements (this entails that children diagnosed with ASD have selective eating behavior, they have certain food choices such as eating gluten free products) and special education for a child with ASD. Bashir et al (2014) contend that ASD causes a financial strain on families in several ways, such as spending a lot of money on therapists and treatment, as in some cases medical aid does not cover all the costs. Further “intervention strategies are expensive and require one on one interaction with a trained professional or use of costly food and drug supplements”.

According to Hoefman, et al (2014) many parents face financial problems because of extra financial expenses for the child, underemployment and unemployment. This is further supported by Ludlow, Skelly and Rohleder (2011) who notes that financial costs of raising a child with ASD are high. “The total costs of raising a child with a disability is estimated to be approximately three times greater than the costs of raising a normally developing child”.

4.4.4. Sub-theme 2.4.: Lack of family support

One participant reported that she does not have support from her family. She mentioned that her family members were not helping her at all. It should be noted that the family is regarded as the primary support system and lack of support from immediate family members could mean that the

participant does not have someone to lean on during difficult times. This is evident in the following statement:

“...but another thing is that I’m not coping really well because I don’t get support from my family....uh I am neglected by my own family. I’m paying someone to look after my child so that I can be able to go to work because my sisters want nothing to do with my child...” (Participant 2)

The current findings correlate with Hoefman et al. (2013) who indicated that some family members and friends never show any support in their children’s situation. Hence they distance themselves from such people. This correlated with Madlala (2014)’s findings, which showed that a few parents mentioned that they were finding it hard to cope with their children because of the poor support they were receiving from their families. They also mentioned that they were discriminated because of their child’s invisible disorder.

4.4.5. Sub-theme 2.5.: Accessibility and availability of services

Participants indicated that accessibility and availability of services were a challenge in the district. Some of the participants mentioned that at times medication for their children was not available in public hospitals around the district. They also reported that they had to go as far as Steve Biko Hospital in Pretoria to access medication and they had to travel with their children for such long distance. The participants also stated that it is tiring for them and their children travelling long distances especially for their children, because they were not used to confined spaces. Further, the participants reported that there are not enough government schools that cater for children with disabilities. The participants added they had struggled first to find a school for their children. Participants also stated that there are not enough health professionals who know about autism; hence they often sent them to Steve Biko Hospital in Pretoria. The following quotes show the challenges that the participants faced in terms of accessibility and availability of services.

“He’s also on medication but we get the medication in Pretoria at Steve Biko but transport is arranged and paid for us by the hospital we just carry food to eat along the way”. (Participant 9)

“uh he’s on medication and we fetch the medication at Steve Biko Hospital, and transport is arranged by the hospital it’s just that he doesn’t like being in one place for too long. So he gets tired travelling a long distance, sometimes he throws tantrums”. (Participant 10)

“So, right now the government structure overlooked our children’s situation because the schools for children with mental illnesses are not enough, it’s like they have written them off because they think they won’t amount to anything in life which is not always the case...” (Participant 1)

“...schools...I don’t think the government really understand what autism is because yes our children are impaired but it doesn’t mean that we write them off”. (Participant 4)

Similar results were obtained in DePape and Lindsay’s (2015) study which found that parents experienced challenges when trying to access services for the children with ASD. Some expressed that the challenges experienced led them to pay out of their pockets for treatment and some had to travel long distances to access services. Mthimunye (2014) further stated that few schools accommodate children with ASD and the few schools that do so have certain criteria for admission such that a child may not be successful sometimes, thus, forcing them to stay at home. This correlates with Hoffman (2012) who found that parents expressed concern about the lack of support from the state, especially that ASD is on the rise; there are few public schools that cater for children with ASD.

4.5. THEME 3: COPING MECHANISMS USED IN DEALING WITH CHALLENGES OF CARING FOR CHILDREN DIAGNOSED WITH ASD.

According to DePape and Lindsay (2015) problem-focused coping strategies such as problem solving are very important in dealing with the challenges of caring for a child with ASD. Therefore, participants in the current study mentioned prayer and going to church as some of the most important aspects of their lives when it comes to coping and dealing with challenges of caring for a child with ASD. In addition, they stated that communicating their problems to God gave them hope that everything will be fine. The participants reported that having family, friends and professionals that understand what they were going through helped them alleviate stress therefore, they were able to cope with their challenges. Lastly, they stated that accepting their children’s situation was the best they could do and it was very important for coping. The subthemes are discussed as below.

4.5.1. Sub-theme 3.1.: Prayer

Prayer could be considered the core of faith and is seen by many as a being helpful coping strategy. People have contended that in many cases prayer and having faith in God are the strategies that they used to cope with their personal problems (Bade & Cook, 2010). The participants in the current study reported that prayer really helps them in times of distress and to cope with the challenges of raising and caring for the child. They stated that God knows best, so they left everything in God’s hands and hoped for the best. This is evident in the following quotes.

“...praying a lot help, sometimes you just reach a point where you have to understand that whatever situation you are facing is not a surprise to God, as He knew that it was going to happen in your life and he’s got a better plan for you. I always put my trust in God” (Participant 2)

“I believe that when you raise an autistic child, you should treat them normally and also pray. God really helped me a lot when it comes to me raising the child. So prayer really helped me a lot to cope and deal with this condition”. (Participant 7)

The findings correlate with Madlala (2014), as he also reported that caregivers rely on religious practices such as prayer, going to church and seeing their spiritual leaders as means of coping with their children’s condition and further said that it helps them to understand and accept the child.

4.5.2. Sub-theme 3.2.: Strong support system

Most of the participants mentioned that having a strong support system helps relieve stress. The participants indicated that getting support from family, friends and professionals such as teachers and healthcare professionals were an effective means of coping with difficulties. This statement is illustrated by the following.

“I think I’m lucky that I’ve got people around me, I’ve got my son’s teacher...shame she’s a God sent, that woman she’s really God sent, she’s so kind, she’s spiritual so she helps me a lot and also his occupational therapist they are just really great women who are helping me with my son”. (Participant 10)

“...my family also, when I need something I know I can go to them and ask for help and when I just need to be away from my child because sometimes it’s gets a lot...I know I can send him off to my sisters and she can take care of him because she works with children with special needs and that makes me feel like I’m not abandoning him but I’m just taking out time for myself”. (Participant 10)

“...so I also have my friend who is a colleague and a teacher so she loves my child so I can say he’s got a second mother with her so most of the time when I have to go on workshops or when I want to have my time she offers to take my child and be with him and there are also other three colleagues who can help me with my child and he’s very comfortable with them that also helps me to cope”. (Participant 12)

“currently, there is a group on whatsApp wherein his teacher added me, so they share challenges that they come across and whenever they have a discovery of some sort about autism they share on the group” (Participant 7)

“I think my family, especially my mother, and my sister, are the ones that understand more even my husband sometimes he would go and attend the sessions when I’m busy”. (Participant 6)

“...the support groups also help especially now that we can see that he’s getting better, so they help us cope. The support groups and family help a lot”. (Participant 2)

“I get a lot of support from my other son and his nanny and the whole family, it’s really supportive”. (Participant 1).

“...but now that I get support from the school; it’s better. I also attend support groups at the hospital and that helps me understand that he’s not the only one and that he has improved in a lot of things and that he can do most of the things by himself...” (Participant 4)

“...but his speech therapist has been helping me a lot to cope lately so yeah, at least...” (Participant 11)

The above quotations show that the participants have the necessary support from both the family, peers and school that help them cope with the challenges of caring for their children with ASD. This is asserted by Hoffman (2012), who found that strong support system is critical in reducing the negative psychological effects of caring for a child with ASD. The findings in Hoffman (2012) study also indicated that a strong support system is very important for families with a child with ASD and it is an integral part of the coping milieu. Similar findings were made by DePape and Lindsay (2015), who indicated that it is important that caregivers of a child with ASD receive the kind of support that they need from family members as well as the community. The findings further reported that parents with this kind of support have a positive psychological well-being (DePape & Lindsay, 2015). Terry (2016) indicated that the “problem that parents experience in their daily live and the lives of their children is the reason why they participate in support groups”. The author also found that parents believed that support groups help them cope with the challenges because they shared their experiences with someone who is in the same situation (Terry, 2014).

4.5.3. Sub-theme 3.3.: Acceptance

The participants reported acceptance as a way of coping with the challenges. The participants mentioned that as soon as they started accepting the way their children are, they tended to cope better with their children’s condition. This is evident in the following statements.

“....accepting that he’s different but most importantly knowing that he’s your child at the end of your day even if he was an able child, he will still need your guidance. You must also accept that they are not going to excel in everything they will still need you to hold their hand”. (Participant 8)

“Hmmm now it’s not much of a stress because I think we have accepted him the way he is so it’s more or less like we ok”. (Participant 6)

In a study by Mount and Dillion (2015) the mothers of children diagnosed with ASD considered accepting their children’s diagnosis as a coping strategy. This correlates with the findings of the present study as well as findings of DePape and Lindsay (2015), who reported that “caregivers accepted their children with ASD, such that they could not imagine their family without the disorder. They regard accepting as a coping strategy”.

4.6. CONCLUSION

This chapter outlined themes in accordance with the data that was collected by the researcher. Several themes and subthemes emerged from the participants’ responses. The chapter also discussed the findings of the study and compared the findings with other studies. The next chapter outlines the limitations, recommendations and conclusion of the study.

CHAPTER 5

Summary, Limitations, Recommendations and Conclusion

5.1. Introduction

The previous chapter encapsulated the responses of caregivers with regard to their experiences of caring for a child with ASD. The responses were analyzed and discussed in the context of relevant literature on the study. The objectives of the study were to explore the experiences of caregivers for children diagnosed with ASD and to determine caregivers' knowledge of ASD. This chapter provides a summary, limitations, recommendations and conclusion of the study.

5.2. Summary

The study sought to explore the experiences of caregivers for children diagnosed with ASD in the Ehlanzeni District, Mpumalanga Province. Therefore, this chapter presents the limitations of the study, provide detailed recommendations and the conclusion.

5.3. Limitations

The following limitations were identified when exploring the caregivers' experience when caring for children diagnosed with ASD:

- The research only focused on female caregivers. It would have been ideal if male caregivers were also interviewed. This would have made the findings more representative and generalizable to a wider population. Furthermore, the researcher only interviewed those who were residing in the Ehlanzeni District and excluded those that were not in the proximity.
- Time was also a significant factor because there was not enough time to interview each and every participant and to finish exactly at the allocated time. This is because some participants did not manage to come to the interview on time, which made the researcher start with the interviews a little late.
- Literature was limited, as not many studies have been conducted that focuses on the experiences of caregivers for children diagnosed with ASD.
- Finding ASD statistics in South Africa was a significant problem. The statistics are unknown, therefore, the study focused more on international statistics.

- Lastly, there was a problem with ethnicity of the participants, only two white female caregivers were interviewed as well as ten black caregivers. It would have been ideal to conduct interviews with other ethnicity groups, considering the cultural diversity of South.

5.4. Recommendations

The following recommendations were made in relation to the health system, education system and research.

- It is evident in the study findings that there is limited knowledge regarding ASD, merely among caregivers and the community at large. Therefore I recommend that the Department of Health conduct more awareness campaigns on ASD, to increase knowledge about the condition.
- Health care professionals should be trained more on early interventions for children diagnosed with ASD to avoid late diagnosis.
- Availability and accessibility of services, such as medicine should be within the province/district to avoid caregivers travelling long hours to access services.
- Caregivers should have more information regarding the range of inexpensive interventions and educational programs available for their children. Therefore, continuous dissemination of information on ASD is essential amongst caregivers.
- The study findings can be used as a reference for further research studies on ASD.
- Support groups for caregivers of children with ASD should be formed.

5.5. Conclusion

The following conclusions were drawn from the study:

- It is evident from the findings that little is known about ASD in the country. This is because ASD is still stigmatized in our communities.
- Some caregivers reported that they experienced lack of support from family, friends and community members. This resulted in them being socially isolated.
- Caregivers for children diagnosed with ASD complained that caring for such children is an expensive exercise, hence they experienced financial burden, psychological stress, social stigma and so forth.
- A wide range of support services available to caregivers can help decrease the burden of caring for a child with ASD.
- Support groups are vital for caregivers because they help them cope with the challenges of caring for a child with ASD.

- Family is often the cornerstone for caregivers, hence support from family members is very essential.
- Health care professionals should offer support at all times to the caregivers.

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LIST OF APPENDIXES

APPENDIX A: INFORMED CONSENT

RESEARCH ETHICS COMMITTEE

UNIVEN Informed Consent

LETTER OF INFORMATION

Title of the Research Study : Experiences of caregivers for children diagnosed with Autism Spectrum Disorder in the Ehlanzeni District, Mpumalanga Province.

Principal Investigator/s/ researcher : Ms N. Mazibuko, Bachelor of Arts Honours in Psychology

Co-Investigator/s/supervisor/s : Prof. N.H Shilubane (PhD)
Mr. B. S Manganye (MPH)

Brief Introduction and Purpose of the Study: There is an increasing number of children diagnosed with autism spectrum disorder (ASD) worldwide. This calls for a health concern and further research. ASD is a neurodevelopmental disorder which is characterized by impaired communication, repetitive interest. ASD is also a condition that can be stressful for both the child and the caregiver, particularly the caregiver. Their whole lives change completely. A normal day to them would comprise of a structured and set routine that they have to adhere to on a day to day basis. Therefore the purpose of the study seeks to explore the experiences of caregivers for children diagnosed with autism spectrum disorder in the Ehlanzeni District, Mpumalanga Province.

Outline of the Procedures: The researcher will interview a minimum of ten participants, using a semi-structured interview with an aid of an interview guide. A voice recorder will be used will be used to record the interviews to ensure that data is transcribed verbatim and without missing any information. The interviews will take approximately 30-45 minutes. However the researcher will

establish a trusting relationship by developing a rapport with the participants. The researcher will contact participants telephonically prior to the interviews. The interviews will take place within the school premises since it is a familiar environment to the participants. The inclusion criteria of the study will be female caregivers for children diagnosed with autism spectrum disorder, whose children are aged 5-12 years in the Ehlanzeni District, Mpumalanga Province. The exclusion criteria of the proposed study will be male caregivers of children diagnosed with autism spectrum disorder and children who are not aged 5-12 years.

Risks or Discomforts to the Participant: There is no risk in participating in the study.

Benefits: There will be no direct benefits to any participants.

Reason/s why the Participant May Be Withdrawn from the Study: Participants may be withdrawn at any stage of the study if they feel uncomfortable about certain aspects of the study.

Remuneration: Participants will not receive any remuneration or monetary.

Costs of the Study: Participants will not be expected to cover any costs towards the study.

Confidentiality: The researcher will give the participants an assurance that any information which is deemed life-threatening, or which, may disturb the participants' economic, social, physical, health, and psychological make-up, will not be readily made available to anyone else. The researcher will make sure that the true identities of participants are not revealed to anybody, pseudo codes will be used to identify participants.

Research-related Injury: Should there be a research-related injury or adverse reaction, the researcher will be held accountable.

Persons to Contact in the Event of Any Problems or Queries:

(Prof. N.H Shilubane, Department of Advanced Nursing Science, School of Health Sciences, Email Hilda.Shilubane@univen.ac.za) Please contact the researcher (073 566 2514/ Email: nomfundomazibuko2@gmail.com), my supervisor (082 536 7441/ 015 962 8713) or the University

Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

General:

Potential participants must be assured that participation is voluntary and the approximate number of participants to be included should be disclosed. A copy of the information letter should be issued to participants. The information letter and consent form must be translated and provided in the primary spoken language of the research population

CONSENT

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, (Ms. N Mazibuko), about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number (18/PH/08/1505).
- I have also received, read and understood the above written information (*Participant Letter of information*) regarding the study.
- I am aware that the results of the study, including personal details regarding my age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant

Date

Time

Signature

I,

.....

.....

.....

(Ms. N Mazibuko) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher

Ms. Nomfundo Mazibuko

.....

Date.....

Signature.....

Full Name of Witness (If applicable)

.....

Date

Signature.....

Full Name of Legal Guardian (If applicable)

.....

Date.....

Signature.....

Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level- use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counseling (Department of Health, 2004)

If the potential participant is unable to read/illiterate, then a right thumb print is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. a wrong date or spelling mistake, a new document has to be completed. The incomplete original document has to be kept in the participant's file and not thrown away, and copies thereof must be issued to the participant.

References:

Department of Health: 2004. *Ethics in Health Research: Principles, Structures and Processes*

<http://www.doh.gov.za/docs/factsheets/guidelines/ethnics/>

Department of Health. 2006. *South African Good Clinical Practice Guidelines*. 2nd Ed. Available at:

http://www.nhrec.org.za/?page_id=14

APPENDIX B: ETHICAL CLEARANCE CERTIFICATE

**RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR**

NAME OF RESEARCHER/INVESTIGATOR:

Ms N Mazibuko

Student No:

15006895

PROJECT TITLE: Experiences of caregivers for children diagnosed with Autism Spectrum disorder in the Ehlanzeni District, Mpumalanga Province.

PROJECT NO: SHS/18/PH/08/1505

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

| NAME | INSTITUTION & DEPARTMENT | ROLE |
|-------------------|--------------------------|------------------------|
| Prof NH Shilubane | University of Venda | Supervisor |
| Mr BS Manganye | University of Venda | Co - Supervisor |
| Ms N Mazibuko | University of Venda | Investigator – Student |

ISSUED BY:

UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: May 2018

Decision by Ethical Clearance Committee Granted

Signature of Chairperson of the Committee:

Name of the Chairperson of the Committee: Senior Prof. G.E. Ekosse



University of Venda

PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 FAX (015) 962 9060

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APPENDIX C: INTERVIEW GUIDE

Section A: Demographic Information

1. How old are you?
2. What is your marital status?
3. What is your highest qualification?
4. What is your occupation?
5. How is the child related to you?

Section B: Research Questions

1. What is your understanding of autism spectrum disorder?
2. How did you know that your child has autism spectrum disorder?
3. How did you feel about the diagnosis?
4. How is your experience of caring for a child diagnosed with autism spectrum disorder (in terms of psychological, financial, social and physical experiences)?
5. What coping mechanisms do you use in dealing with challenges of caring for a child diagnosed with autism spectrum disorder?

APPENDIX D: LETTER TO THE MPUMALANGA DEPARTMENT OF EDUCATION

The Head of Department
Department of Education
Government Boulevard

Building 5

Nelspruit

1200

Dear Mrs. MOC Mhlabane

REQUEST TO CONDUCT A RESEARCH STUDY IN THE MPUMALANGA DEPARTMENT OF EDUCATION.

I'm a registered student for Masters of Public Health, under the School of Health Sciences at the University of Venda. As part of my studies I'm required to complete a research study on **Experiences of caregivers for children diagnosed with autism spectrum disorder in the Ehlanzeni District, Mpumalanga Province.**

I therefore, wish to apply for permission to conduct research study at the kamagugu Inclusive School. Furthermore, I request your permission to conduct interviews with caregivers of the children diagnosed with autism spectrum disorder (see attached research proposal).

It will be much appreciated to receive a letter of acceptance for the finalization of ethical clearance.

I hope my request will be attended to

Yours truly,

Ms. N Mazibuko

Cell: 073 566 2514

Email address: nomfundomazibuko2@gmail.com

APPENDIX E: LETTER TO DASHA FOUNDATION

The School Principal

8 De Kock Street

Nelspruit

1200

Dear Sir/Madam

REQUEST TO CONDUCT A RESEARCH STUDY AT DASHA FOUNDATION

I'm a registered student for Masters of Public Health, under the School of Health Sciences at the University of Venda. As part of my studies I'm required to complete a research study on **Experiences of caregivers for children diagnosed with autism spectrum disorder in the Ehlanzeni District, Mpumalanga Province.**

I therefore, wish to apply for permission to conduct research study at Dasha Foundation. Furthermore, I request your permission to conduct interviews with caregivers of the children diagnosed with autism spectrum disorder.

It will be much appreciated to receive a letter of acceptance for the finalization of ethical clearance.

I hope my request will be attended to

Yours truly,

Ms. N Mazibuko

Cell: 073 566 2514

Email address: nomfundomazibuko2@gmail.com

APPENDIX F: LETTER TO PRO GRATIA LEARNING CENTRE

The School Principal

Hermansburg Road

Plot 4

Nelspruit

1200

Dear Sir/Madam

REQUEST TO CONDUCT A RESEARCH STUDY AT PRO GRATIA LEARNING CENTRE

I'm a registered student for Masters of Public Health, under the School of Health Sciences at the University of Venda. As part of my studies I'm required to complete a research study on **Experiences of caregivers for children diagnosed with autism spectrum disorder in the Ehlanzeni District, Mpumalanga Province.**

I therefore, wish to apply for permission to conduct research study at Pro Gratia Learning Centre. Furthermore, I request your permission to conduct interviews with caregivers of the children diagnosed with autism spectrum disorder.

It will be much appreciated to receive a letter of acceptance for the finalization of ethical clearance.

I hope my request will be attended to

Yours truly,

Ms. N Mazibuko

Cell: 073 566 2514

Email address: nomfundomazibuko2@gmail.com

APPENDIX G: APPROVAL LETTER FROM MPUMALANGA DEPARTMENT OF EDUCATION



education
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Building No. 5, Government Boulevard, Riverside Park, Mpumalanga Province
Private Bag X11341, Mbombela, 1200.
Tel: 013 766 5552/5115, Toll Free Line: 0800 203 116

Litika le Temfundvo Umnyango we Fundo

Departement van Onderwys

Ndzawulo ya Dyondzo

Ms Nomfundo Mazibuko
PO Box 684
Kabokweni
1245
Email: nomfundomazibuko2@gmail.com
073 566 2514

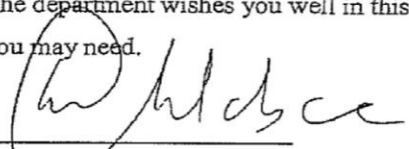
RE: APPLICATION TO CONDUCT RESEARCH: NOMFUNDO MAZIBUKO

Your application to conduct research study was received and is therefore acknowledged. The title of your research project reads: “Experience of caregivers for children diagnosed with autism spectrum disorder in the Ehlanzeni District, Mpumalanga province”. I trust that the aims and the objectives of the study will benefit the whole department especially the beneficiaries. Your request is approved subject to you observing the provisions of the departmental research policy which is available in the department website. You are requested to adhere to your university’s research ethics as spelt out in your research ethics.

In terms of the research policy, data or any research activity can be conducted after school hours as per appointment with affected participants. You are also requested to share your findings with the relevant sections of the department so that we may consider implementing your findings if that will be in the best interest of the department. To this effect, your final approved research report (both soft and hard copy) should be submitted to the department so that your recommendations could be implemented. You may be required to prepare a presentation and present at the departments’ annual research dialogue.

For more information kindly liaise with the department’s research unit @ 013 766 5476/5148 Or a.baloyi@education.mpu.gov.za

The department wishes you well in this important project and pledges to give you the necessary support you may need.


MRS MOC MHLABANE

HEAD: EDUCATION

24, 07, 18
DATE



APPENDIX H: APPROVAL LETTER FROM DASHA FOUNDATION



DASHA FOUNDATION

SCHOOL & CENTRE FOR DISABLED CHILDREN

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CHILDREN



VIR ONTWIKKELINGS-GESTREMDE
KINDERS

NPO 000 - 436

Head/Hoof: Shirley J. Parsons B.A.

PBO 930001186

2nd November 2018

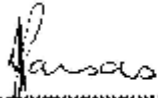
TO WHOM IT MAY CONCERN:

This is to confirm that Ms Namfundo Mazibuko, did have contact with the Parents of our learners on the Autism Spectrum during this year.

She was given permission by the Principal Ms S J Parsons to conduct interviews and interact with both parents and children during this period.

We trust the experience and interaction will be beneficial to her as she completes her studies.

Yours sincerely,



Ms S J Parsons
Principal

8 de Kock
Street

P.O. Box 810 Nelspruit
1200 Tel. 013 741 4039

Fax no.: 0866369259
E-mail: dashaschool@telkomsa.net

APPENDIX I: APPROVAL LETTER FROM PRO GRATIA LEARNING CENTRE



Pro Gratia Learning Centre for Special Educational Needs

Hermansburg Road
4 Magiesdal
Nelspruit, 1200
PO Box 21025, Nelspruit, 1200
NPC Reg number

Tel: 061 481 5532
Fax: 086 615 6392
Email: info@progratia.co.za
Website: www.progratia.co.za
2015/374300/08

Fides Spes Caritas

1 Corinthians 13:13

And now: These three remain, faith, hope and love... But the greatest of these is love!

17 July 2018

To Whom It May Concern:

This is a letter to confirm that Nomfundo Mazibuko received permission from Pro Gratia Management to conduct a research study with Pro Gratia and she was given permission to interview the parents of the children on the spectrum.

We are always in need of more information regarding the learners on the spectrum and we value the studies conducted on this challenge.

We hope that we could have been of assistance for these particular studies and we are looking forward to hearing the outcome of it.

Kind Regards

Mrs. W. Bezuidenhout

Finance and Admin Director



APPENDIX J: PARTICIPANTS' TRANSCRIPTS

Demographic Background

- 38
- *Single*
- *Grade 11*
- *Domestic worker*
- *Biological son*

Question 1

What I understand about autism is that most kids who are affected by it are boys. The signs of autism are observed among them...for example mine doesn't talk and for him not talking was one of the signs of autism, so sometimes they become hyperactive but he doesn't cope well at school. I was advised that autism affects boys more than girls. Since I started knowing about autism, there is only one child that I know who has it.

Question 2

I started realizing that there was something wrong with my child after I realized that his development was slow. So I took him to the clinic and the nurse also noticed that there was something wrong with him, so they referred me to the hospital, and that's where they made the diagnosis... he was 1 year 8 months when they made the diagnosis.

Question 3

Hmmm after they told me that he has a problem, it was initially very hard for me to accept, it even now it's not nice, it's really painful because no one cares to ask me how I feel about my child's condition. And I don't have anyone to share my burdens with and the problem overwhelms me.

Question 4

It's not easy, it is difficult because even now he still baby nappies and people think I haven't potty-trained him and I can't always be explaining his situation to people. So, that really affects me psychologically and I'm really not coping. Financially, it's difficult, I don't earn much as a domestic worker and children with autism have a lot of needs, some of which I cannot cover with my salary. At least I get his medication at the hospital. Socially he doesn't like spaces where there

are a lot of people most of the time he prefers us to be in the house and not go anywhere and he doesn't like noise. Sometimes when we do go out people would come up at and say as old as he is he still wears pampers so that affects me a lot but I sometimes try to explain some understand and some say if he was mine I was going to give him a hiding so yeah it's bad.

Question 5

What makes me cope is that most of the time when I'm with someone, just like when I'm talking to you right now and you are willing to listen and understand my situation, it makes me feel better. But another thing is that I'm not coping really well because I don't really get support from my family....umh; I am neglected by my own family. I'm paying someone to look after my child so that I can be able to go to work because my sisters want nothing to do with my child. It was also a bit better when his father was still alive because at least I used to get support from him but then he passed away recently and now I'm stuck in this situation alone. But his speech therapist has been helping me a lot to cope lately, so yeah at least but still....it's painful that I don't get support from my family, so my situation is really sad.

APPENDIX K: LETTER FROM THE PROOF-READER

SCHOOL OF HUMAN AND SOCIAL SCIENCES

11 March 2019

Department of Health Sciences
University of Venda
Thohoyandou
0950

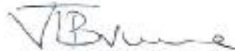
Sir/madam

This serves to certify that I have proof-read Ms N. Mazibuko's mini-dissertation titled, "Experiences of Caregivers for Children Diagnosed with Autism Spectrum Disorder in the Ehlanzeni District, Mpumalanga Province".

The proof-reading entailed editing some parts from it; for example, to avoid wordiness, redundancy; sub-dividing sentences, and so on, to make the document more understandable. However, I have not tampered with the content of the document, except where this constituted repetition or made the document confusing.

The mini-dissertation is presently ready for examination.

Sincerely



V.T. Bvuma
083 423 9227



University of Venda

UNIVERSITY OF VENDA

PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 562 8172 FAX (015) 562 8416
E-mail: Vincent.Bvuma@univen.ac.za

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