

**CARING FOR CHILDREN WITH CEREBRAL PALSY: EXPERIENCES OF  
CAREGIVERS IN VHEMBE DISTRICT, LIMPOPO PROVINCE**

**By**

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

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**2019**

## DECLARATION

I, **DUPPY MANYUMA**, hereby declare that this mini-dissertation submitted for Masters of Public Health Degree, at the University of Venda, is my own work, and has not been previously submitted for a degree, at this or other institution. All reference materials contained herein have been duly acknowledged.

**SIGNATURE:**..... **DATE:**.....

## DEDICATIONS

I would like to dedicate this study to my lovely parents, siblings and relatives who have been supporting me during my studies. And all the people who are providing care to persons with disability.

## ACKNOWLEDGEMENTS

I would like to direct my sincere gratitude to the following people who through their effort and support, made it possible for me to reach my goal.

- My parents Mr. D.T Manyuma and Mrs. M.H Manyuma for their love and support throughout my studies
- My research supervisors Dr. Maluleke M and Mr Manganye B.S for their guidance, dedication and improving my knowledge in research.
- All members of the winning research team for their ideas and contribution to my work.
- My younger brother (Itumeleng) and elder sister (Jeanert Ndivhuwo Manyuma) for their support and love.
- My aunt Gladys Ngwani and her son Pfarelo Ngwani for staying with me at night when doing my school work.
- My spiritual parents (Pastor M.P and Dr. N.L Maila) for always encouraging me to go to school, their prayers and support.
- My friends (Mashudu Muthambi, and Fhatutshedzani Fungisani) for their encouragement, support and love. You have been wonderful to me.

## ABSTRACT

Cerebral palsy is a condition which affects the normal functioning of children. Most children with this condition rely on other people for the execution of basic skills on a daily basis. The study aim was to explore the experiences of caregivers for children with cerebral palsy in Vhembe District, Limpopo Province. A qualitative approach using explorative, descriptive, and contextual design was used for this study. Simple random sampling was used to sample eight caregivers. Data was collected using semi-structured in-depth individual interviews which were pre-tested in Vhembe District, using two caregivers who did not form part of the study. Data was analysed using thematic analysis approach. Credibility, dependability, conformability and transferability were upheld to ensure trustworthiness of the study. Ethical considerations were adhered to throughout the study. Two main themes emerged during data analysis, namely: positive experiences of caregivers and challenges faced by caregivers. The study recommends: development of a model to support caregivers in caring for children with cerebral palsy; and the investigation of the prevalence of back-pain amongst caregivers of children with cerebral palsy in Vhembe District.

**Key words: Caregiver, Caring, Cerebral palsy, Children, Experience**

## LIST OF ABBREVIATIONS

CP : Cerebral Palsy

DOH : Department of Health

DSD : Department of Social Development

HCS : Health Care System

SA : South Africa

WHO : World Health Organisation

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## CHAPTER 1

### ORIENTATION OF THE STUDY

#### 1.1. INTRODUCTION AND BACKGROUND TO THE STUDY

Cerebral palsy (CP) is a developmental disability commonly found amongst children, and it affects their motor functioning, which in most cases result in damaged motor behaviour and oral dysfunction (Olawale, Deih & Yadaar, 2013). Since CP affects many parts of the human body, people living with this condition need someone to help them with day to day activities, such as bathing, feeding, using the toilet and moving from one place to another. (Kakooza-Mwesige, Tumwine, Eliasson, Namusoke & Forssberg, 2015). South Africa (SA) does not have enough institutions that provide services for persons living with cerebral palsy, and these people are left with no option but to remain in the care of their relatives; the majority of those looking after persons with CP are mothers.

Despite supporting home backgrounds being regarded as platforms wherein children with a disability can feel free to express themselves, caring for such children has never been an easy task to the caregivers (Debuse & Brace, 2011). Deepthi and Krishnamurthy (2011), also believe that caregivers who are caring for persons with a disability were reported to be having reduced quality of life as compared to other people of their age, who are not looking after children with a disability.

According to a report by the World Health Organisation (WHO) (2011), the estimated number of children who were living with a disability globally was 95 million which is considered to be 5.1% of the global population, while 13 million (0.7%) were said to be living with a severe disability. According to Oskoui, Coutinho, Dykeman, Jette and Pringsheim (2013), the condition of cerebral palsy is estimated to be 2-2.5 per 1000 live births globally. Donald, Samia, Kakooza-Mwesige and Bearden (2014) have estimated that the condition of cerebral palsy occurs in 2-10 cases per 1000 births. Findings from a study which was conducted by Christianson, Zwane, Manga, Rosen, Venter, Downs and Kromberg (2009), which aimed to determine the commonness of cerebral disability in rural Bushbuckridge Limpopo, indicated that 8.4% of children

amid the 35.6/1000 children who are suffering from an intellectual disability have cerebral palsy.

Lawal, Anyebe, Obiako and Garba (2014), report that a high percentage of persons providing care to children living with a disability are mothers, and they are viewed to be people with the first-hand information about the life, needs and health of their children.

Caring for a person who is living with a disability can be traumatic to the people providing care to them on a daily basis. (Deepthi & Krishnamurthy, 2011). According to Dambi et al., (2015), the majority of caregivers became psychologically disturbed by the circumstances of the children that they are looking after and their mental well-being becomes endangered (Byrne, Hurley, Daly & Cunningham, 2010).

### **1.1.1 Types of Cerebral Palsy**

- **Spastic Cerebral Palsy**

Spastic cerebral palsy is considered to be the most prevalent type of cerebral palsy; it is estimated to be present in 70% of all cerebral palsy cases. Those having spastic cerebral palsy have rigid muscles, which can lead to difficulties in movement and shuddering at times, which is as a result of increased muscle tone (Smith & Kurian, 2012). Smith and Kurian (2012), explain that spasticity occurs after a collection of neurons in the brain and spinal cord, referred to as corticospinal tracts and corticobulbar tracts, have been injured. According to O'Shea (2008), the upper limbs (arms and hands) can be affected, whereby the person might have difficulties in dressing him or herself, bathing and toileting, and manipulating objects. In a case where the lower limb (legs) are affected, the person might experience difficulties in stand or sitting straight, changing positions while sleeping, running and walking. Smith and Kurian (2012), found that spasticity can also be found in the tinier muscles such as the tongue, vocal folds or facial muscles, which will affect the oral movement and speech of a person.

- **Athetoid Cerebral Palsy**

Katz and Johnson (2013), state that athetoid is a type of cerebral palsy which is symbolised by unintentional squirming and shaking movements, and it is estimated to be present in 20% cases of cerebral palsy, it is as a result of injury to the basal ganglia in the form of lesions which takes place during brain development. According to Smith and Kurian (2012), this is marked by hypertonia and hypotonia, due to the inability of a person to manage the muscle tone. Athetoid cerebral palsy can be further classified into two categories, the first being choreo-anthetoid, which is symbolised by uncontrolled movements mainly found in the face and the limbs (arms, hand and legs), and the second category being dystonic, which is marked by gradual, tough contractions, which strike locally or cover the whole body (Katz & Johnson, 2013).

- **Ataxic Cerebral Palsy**

Ataxic refers to a type of cerebral palsy which is depicted by lack of co-ordination and weakness and it is estimated to be present in 10 percent of cases of cerebral palsy. This type of cerebral palsy is as a result of injury to the cerebellum, which is a segment of the brain that assists managing co-ordination and tone movement (O'Shea, 2008). Ataxic cerebral palsy can have an impact on both the upper limbs and the lower limbs. Katz and Johnson (2013), report that in a case where only the upper limbs are affected, a person might have difficulties with performing small tasks, such as writing and clapping, due to the vibration that occurs in the hands and arms as a result of the lack of co-ordination and erroneous movement, while in a case where only the lower limbs are affected, a person might experience challenges in walking.

### **1.1.2 Experiences of Caregivers for Children with Cerebral Palsy.**

- **Physical health**

Byrne, et al. (2010), state that continuous lifting of heavy loads on a daily basis can be detrimental to the health of caregivers, since this can lead to postural imbalances, which could result in low back pain and various musculoskeletal illnesses in the long run. Tonga and Duger (2008), also found that the factors contributing to back pain

across caregivers of person who are living with disability were associated with persistent lifting of the person, bearing in mind that they may carry a person who weighs more than 20 kilograms for a number of times in a day. Sharan, Ajeesh, Rameshkumar and Manjula (2012), point out that when the children grow, their weights are also expected to increase, lifting a heavy child increases the pressure in caregivers' low back and continuous engagement in this exercise worsens the condition. Tonga and Duger (2008), also believe that caring for a person with any form of disability has can be regarded as one of the factors that cause back -pain across both genders.

- **Access to health care services**

Bourke-Taylor (2010), states that caregivers have difficulties in accessing services and often complain about the quality of the services that they receive from the public institutions. Golden and Nageswaran (2012), also indicate that caregivers take up the role of an activist at health centres for their children to receive the services that they need. Dambi, et al., (2015) also state that caregivers feel that the services which are being offered at the health centres do not address the health challenges that they face together with the children that they are looking after. Singogo, Mweshi and Rhoda (2015), argue that not getting enough funds to cover for the child's medical costs can increase the caregivers' stress, which could lead to further effects on their health.

- **Financial issues for caregivers**

According to Yilmaz, Erkin and Ezke (2013), providing care to a person who is living with a disability is a complicated and demanding task, which needs one to be fully focused, and thus it reduces the caregivers' opportunity of getting permanent jobs. Mu'ala, Rabati and Shwani (2008), also believe that caregivers who assume the role of caring at a younger age will in most cases, not finish school, and their chances of getting good paying jobs can be compromised. According to Yilmza, et al., (2013) the majority of caregivers in a study conducted a Canada were found to be unemployed due to lack of proper qualifications which could afford them an opportunity to participate in high paying jobs; as a result they end up having lesser earnings.

According to Davis, Waters, Cook and Davern (2009), children with cerebral palsy, just like those with other forms of disability, might require medical attention from time to time, and this can result in most families' finances being negatively affected, since they have to spend money for their children to get the medical services that they need. Pakula, Van Naarden and Yeargin-Allsopp (2009), also confirmed that children with cerebral palsy need constant medical check-ups because they might be suffering from various impairments at the same time. Davis, et al., (2009) believes that accessing high quality medical services needed by the children with a disability can overstretch the budgets of caregivers

- **Psychological and Emotional issues for caregivers**

According to Cheshire, Barlow and Powell (2010), providing care to a person who is living with a disability for a longer time can affect the mental health of caregivers and can result in various mental health issues, such as stress, anxiety, and depression. Singogo et al., (2015) also argue that dealing with the daily needs of a person who is suffering from CP from time to time can be harmful to the physical and emotional well-being of caregivers.

According to Dambi and Jelsma (2014), children with cerebral palsy suffer from various types of impairments, which can affect their sleeping patterns, for example, due to the stiffness of the bones and body of children with CP, they can experience pain at any time and during their sleep, which will, in turn, result in abnormal sleep patterns, and this might affect the caregivers, especially those who are residing in small houses. Ketelaar, Volman, Gorter and Vermeer (2008), have also stated that the majority of minors with cerebral palsy have oral dysfunctions which could lead to speech problems, and for them to be unable to send message to the caregiver that they need something or that they are not comfortable, they have to cry and this can affect the caregivers' sleeping patterns (Dambi & Jelsma, 2014).

- **Social life and relationship issues for caregivers**

Having a child with cerebral palsy can cause unnecessary tensions between couples/parents of the child, which could even lead to marital separation. It is common for one parent (usually the father) to not accept the condition that the child

is in (Dambi, et al., 2015). According to Wegner and Rhoda (2015), CP is often regarded as a condition that is influenced by spirits. However, Ambikile and Outwater (2012), believe that sometimes, the parents are regarded as the cause of the child's disability.

Skinner and Weisner (2007), also hold the belief that spousal clashes begin when couples/parents blame one another for the disability of the child. In traditional views in Zambia, like in other parts of Africa societies, women are perceived to be the only cause of the child's condition. This is supported by Lawal, et al., (2014) when they mention that most societies on the African continent believe that women give birth to children with disability as a punishment for engaging in activities which are unacceptable. Dambi, et al., (2015) argue that matrimonial complications can result from the changes in the roles that partners have to assume when providing care to the new child in the family who is living with a disability.

According to a study by Singogo, et al., (2015) caregivers reported that they are not getting enough support from their spouses, friends and the community when it comes to caring for the child with CP, and this has led a majority of caregivers being cut off from social relationships with a fear of other people not accepting the children. Adegoke, Adenuga, Olaleye and Akosile (2014), also found that the response from the society causes parents of children living with a disability to isolate themselves and keep their children at home. Sandy, Kgole and Mavundla (2013), believe that the way in which the society behaves towards children with a disability and their caregivers, based on their traditional perspectives, has taken a lead in perpetuating issues of unfair treatment in most communities.

Davis, et al., (2009), state that most caregivers find it hard to sustain the friendships that they started before the child came into their lives, mainly because their friends do not know how to relate to the child with a disability. In most cases, caregivers are unwilling to mingle with other people because they express pity for them and they get depressed by the sympathy they receive (Narekuli, Raja & Kumaran, 2011). This however contradicts with Borst (2010), who states that caregivers of children with cerebral palsy are able to build new relationships and get to know other people because of the child's disability. Caregivers of disabled children meet at the support groups or health facilities, where they share their experiences and challenges with

regard to the children's disability. Davis, et al (2009), argue that, it is difficult for fathers of children with disabilities to meet and make friendships.

According to Deepthi and Krishnamurthy (2011), children with cerebral palsy demand more attention than children without any special need; the majority of caregivers devote their time to providing care to the children and have less time to do things which make them happy, like going out to parties with other women and attending functions. Apart from having time to themselves. Huang, Kellett, and St John (2010), state that the time given to those children without special needs in a household where there is a child with cerebral palsy is minimal, and other children feel unwanted and often develop anger towards their parents.

## **1.2. STATEMENT OF THE PROBLEM**

Cerebral palsy affects the motor functioning of the children, and those children are unable to look after themselves; there must be a person who is available to provide care for the child who is having CP on a daily basis (Debusse & Brace, 2011). In results from a study which was conducted by Dambi, Jelsma and Mlambo (2015), looking at the experiences of Zimbabwean caregivers who were providing care to children living with cerebral palsy, they have stated that looking after a child with such an impairment poses economic hardships to them, since these children have a lot of needs compared to other children within a family who are living with no disability. Apart from encountering economic hardships, caregivers may experience a variety of issues ranging from poor physical health, social isolation and stigma, lack of accessing to health care services (HCS), poor transportation systems, matrimonial conflicts, and failure to get employment (Singogo, et al., 2015). Even though research has been conducted on the experiences of caregivers of children with cerebral palsy, there is no sufficient information pertaining to the experiences of caregivers in the Limpopo province, particularly in the Vhembe District, which is considered a rural area.

In December 2016, the principal investigator was invited to a year-end function which was organised for those who were attending cerebral palsy groups during the year at Musina Hospital. During the function he observed that most children could not sit on their own and for them to move, they had to be carried by someone. Most caregivers

were struggling to lift the children on their own and they had to request other people to assist them. The principal investigator became curious as to what the caregivers encounter everyday as they care for children with cerebral palsy, since most of these children are cared for at their homes, due to the lack of centres which could accommodate them in the Vhembe District. This prompted the researcher to conduct a study in this area. It is significant to conduct this study about the experiences of caregivers of children with cerebral palsy in the Vhembe District, which might contribute more knowledge to the body of science.

### **1.3. SIGNIFICANCE OF THE STUDY**

The findings of the study might benefit the Department of Social Development (DSD), in developing programmes which aim to support people who care for persons with a disability, because most programmes only benefit those persons living with a disability and do not pay much attention to those providing care for persons with a disability.

The findings of the study might be beneficial to the Department of Health (DoH), by highlighting some of the assistive devices that might help caregivers when they are looking after children with a disability. Based on the researcher's findings and recommendations, new research areas might emerge, leading to future research studies.

### **1.4. AIM OF THE STUDY**

The aim of the study was to explore the experiences of caregivers caring for children with cerebral palsy in the Vhembe District of the Limpopo Province

### **1.5. RESEARCH QUESTION**

This study was guided by the following research question.

What are the experiences of caregivers caring for children with cerebral palsy in the Vhembe District of the Limpopo Province?

## **1.6. OBJECTIVES OF THE STUDY**

The following were the objectives of study:

- To explore the experiences of caregivers caring for children with cerebral palsy in the Vhembe District of the Limpopo province, and
- To describe the experiences of caregivers caring for children with cerebral palsy in the Vhembe District of the Limpopo province.

## **1.7. STUDY METHODOLOGY**

### **1.7.1. Research Design**

Brink, Van de Walt and Van Rensburg (2016), define research design as a procedure which the researcher has to follow throughout the study, from sampling, through data collection and the approaches that the researcher will use when analysing data.

Since the study is focusing on the experiences of caregivers for children with cerebral palsy, the following research approaches were applied in the study: qualitative, explorative, descriptive and contextual. The design will be discussed in detail in chapter 2 of the study.

### **1.7.2. Setting of the Study**

This study was conducted in the Vhembe District, which is located within the Limpopo province. Limpopo is one of the nine provinces in South Africa, and consists of five districts, namely: the Vhembe District, the Mopani District, the Sekhukhune District, the Capricorn District and the Waterberg District. A detailed description of the study setting will be outlined in chapter 2.

### **1.7.3. Population and Sampling**

- **Target population**

The population targeted for this research study, consisted of individuals who are responsible for providing care to the children with cerebral palsy.

- **Sampling method**

The hospitals which were used to access the caregivers who are providing care to children with CP were sampled through a purposive sampling method, and the caregivers were sampled through a random sampling method. The detailed sampling procedure will be clearly explained in chapter 2.

### **1.7.4. Data Collection**

Data was collected from the caregivers through one-on-one in-depth interviews which the researcher conducted with the caregivers who are responsible for providing care to children with cerebral palsy, at the homes of the caregivers.

### **1.7.5 Data Analysis**

The following qualitative data analysis steps by Creswell (2013) were used to analyze the information that the researcher gathered from the caregivers during the interviews:

- Step 1: Organize and Prepare,
- Step 2: Reading through the data,
- Step 3: Begin detailed analysis with a coding process,
- Step 4: Use the coding process to gather people as well as categories for analysis,
- Step 5: Advance how the descriptive and themes will be presented, and
- Step 6: A finalized step in data analysis involves making an interpretation of the data.

### **1.7.6. Measures to Ensure Trustworthiness**

In this study, the researcher ensured trustworthiness through the following measures, which will be clearly explained in chapter 2:

- Credibility,
- Conformability,
- Transferability, and
- Dependability.

### **1.7.7. Ethical Consideration**

The following ethical principles were adhered to during the study, the principles will be explained in full in chapter 2:

- Permission to conduct the study,
- Informed consent,
- Principle of Non-maleficence,
- Principle of Justice,
- Confidentiality,
- Analysis and reporting, and
- Anonymity.

## **1.8. DEFINITION OF CONCEPTS**

### **1.8.1. Cerebral palsy**

Cerebral palsy is defined as a set of unending disorders of the development of movement and posture, which prevents a person from being independent for the accomplishment of daily living activities (Olawale, Deih & Yadaar, 2013). In this study, cerebral palsy refers to a condition wherein a child is unable to move and perform other duties on his or her own.

### **1.8.2. Children**

Children refers to persons who are under the age of 18 years and fully dependent upon other people for their own survival (Children's Act no: 38 of 2005). In this study, children refers to those individuals with cerebral palsy who are being cared for by other people.

### **1.8.3. Caregiver**

Caregiver refers to a person who is responsible for providing care to a child or any other person who cannot do certain things for him or herself (Dambi & Jelsma, 2014). In this study, caregiver is a person who is responsible for providing day-to-day care for a child with cerebral palsy.

### **1.8.4. Caring**

Caring is defined as a process of looking after another person (Olawale, Deih & Yadaar, 2013). In this study, caring refers to an ongoing act of assisting a child with cerebral palsy to execute daily activities.

### **1.8.5. Experience**

Experience is defined as a practical knowledge that is acquired through direct practice in an event or activity (Eunson, 2012). In this study, experiences refers to the bad and good things that caregivers encounter everyday as they care for children with cerebral palsy

## **1.9. THEORETICAL FRAMEWORK**

This study was conceptualized within Leininger's Sunrise Transcultural Health-Care model (Leininger, 1991). The model takes into consideration individuals and groups, their beliefs and value systems and these specific cultural practices form the basis or the means through which the delivery of satisfactory health care to the people can be accomplished. The goal of this theory is to provide cultural- congruent care. Leininger states that if one studies the meanings, forms and expressions of cultural care, one can better understand care and predict the health or well-being of

individuals and families. This theory is relevant to this study since it focuses on what caregivers go through daily as they take care of children who depend on them fully.

The study was conducted at the homes of the caregivers where caring of children takes place. This is in line with the theory since the theory contends that from the client's worldview, social structure component and environmental factors three modes of culture-care decisions and actions can be predicted to guide nursing care.

Through the use of Leininger's Sunrise model the researcher discovered meanings attached to what people taking care of children with cerebral palsy go through. People's cultural knowledge and skills also contributes to the way in which caregivers proved care for children with cerebral palsy.

### **1.10. OUTLINE OF DISSERTATION**

The chapters in this study are arranged as follows:

- Chapter 1: Orientation of the study
- Chapter 2: Research designs and Methodology
- Chapter 3: Discussion of results
- Chapter 4: Evaluation, Conclusion, Recommendations and Limitations

### **1.11. CHAPTER SUMMARY**

In this chapter, the following were presented: Introduction and background of the study based on the experiences of caregivers who are caring for children with cerebral palsy, a statement of the problem, the significance of the study, the aim of the study, the research question, the objectives of the study, a brief description of the methodology that was adopted in the study, definitions of concepts, as well as the theoretical framework in which the study was conceptualised. Chapter 2 of study will present a detailed description of the research designs and methodologies used in the study.

## CHAPTER 2

### RESEARCH DESIGNS AND METHODOLOGY

#### 2.1. INTRODUCTION

Chapter 1 of this study outlined the introduction to the study. This chapter presents the research methodologies that were employed, in order for the study to be successful. The following aspects are addressed in this chapter: design of the study, the setting in which the study was conducted, the population sample and sampling procedures that were to select the participants, the method which was used to collect data from the caregivers of children with cerebral palsy, measures which were adopted to ensure trustworthiness of the study, and ethical principles that were adhered to during the study.

#### 2.2. RESEARCH DESIGN

Brink, Van de Walt and Van Rensburg (2016), define a research design as a procedure which the researcher has to follow throughout the study, from sampling, data collection and the approaches that the researcher will use when analysing data.

This study focused on the experiences of caregivers for children with cerebral palsy in the Vhembe District, of the Limpopo Province. A qualitative approach using explorative, descriptive and contextual designs was adopted for this study.

##### 2.2.1. Qualitative approach

The study made use of a qualitative research design. A qualitative research design gathers information from the participants in the form of words; it allows the researcher to have a deeper understanding of the subject under investigation since it describes how events unfold, and how one event can lead to another (Maree, 2012). Qualitative research allows the participants to express themselves fully, without being limited by the researcher or research questions, due to its nature of asking open-ended questions. It can further be defined as a research method which focuses on the participants narratives to gain a better understanding of their perceptions and

views regarding the subject under study and also to gain more knowledge of how the participants construct meaning based on their previous and current experiences. (Swartz, de la Rey, Duncan & Townsend, 2011).

A qualitative approach was suitable for this research study, since the aim of the study was to explore the experiences of caregivers who are caring for children with cerebral palsy, which could not be captured in numbers. Making use of a qualitative research approach gave the caregivers an opportunity to express their feelings, and narrate their lived experiences with regards to caring for children with cerebral palsy. Caregivers were awarded enough time to respond to questions which the researcher posed to them, without any limitations. The approach was relevant for this study due to its nature of reporting detailed views of the caregivers in their natural setting.

### **2.2.2. Exploratory design**

Exploratory studies are those research projects which the researcher conducts in order to gain a clear understanding of an emerging subject. They are mostly conducted when little information is available about the phenomenon and gives the researcher a chance to explore more (Brink, et al., 2016). The researcher explored the experiences of caregivers who are caring for children with cerebral palsy. He learnt what the caregivers go through in their day-to-day lives as they are providing care to a child with cerebral palsy in the Vhembe District.

### **2.2.3. Descriptive design**

Descriptive studies are usually research projects which the researcher conducts with an aim of describing how the phenomenon under investigation are related to one another, they can clearly indicate how two or more events are linked (Neuman, 2011). The researcher gave the caregivers who are caring for children with cerebral palsy an opportunity to describe their experiences with regards to caring for those children.

#### **2.2.4. Contextual design**

Contextual studies are those research projects which allow the researcher to be in the actual setting where the participant spends much of their time, in order to have a deeper understanding of their situation, and only focusing on those aspects which are related to the phenomenon under investigation, without the researcher losing focus (Maree, 2012). The researcher focused only on those caregivers who are caring for children with cerebral palsy in the Vhembe District. Other forms of disabilities and issues which were not aligned to the purpose of the study, were not entertained during the study. The study was contextual since interviews were conducted at the homes of the caregivers who are caring for children with cerebral palsy, where the actual caring takes place.

#### **2.3. SETTING OF THE STUDY**

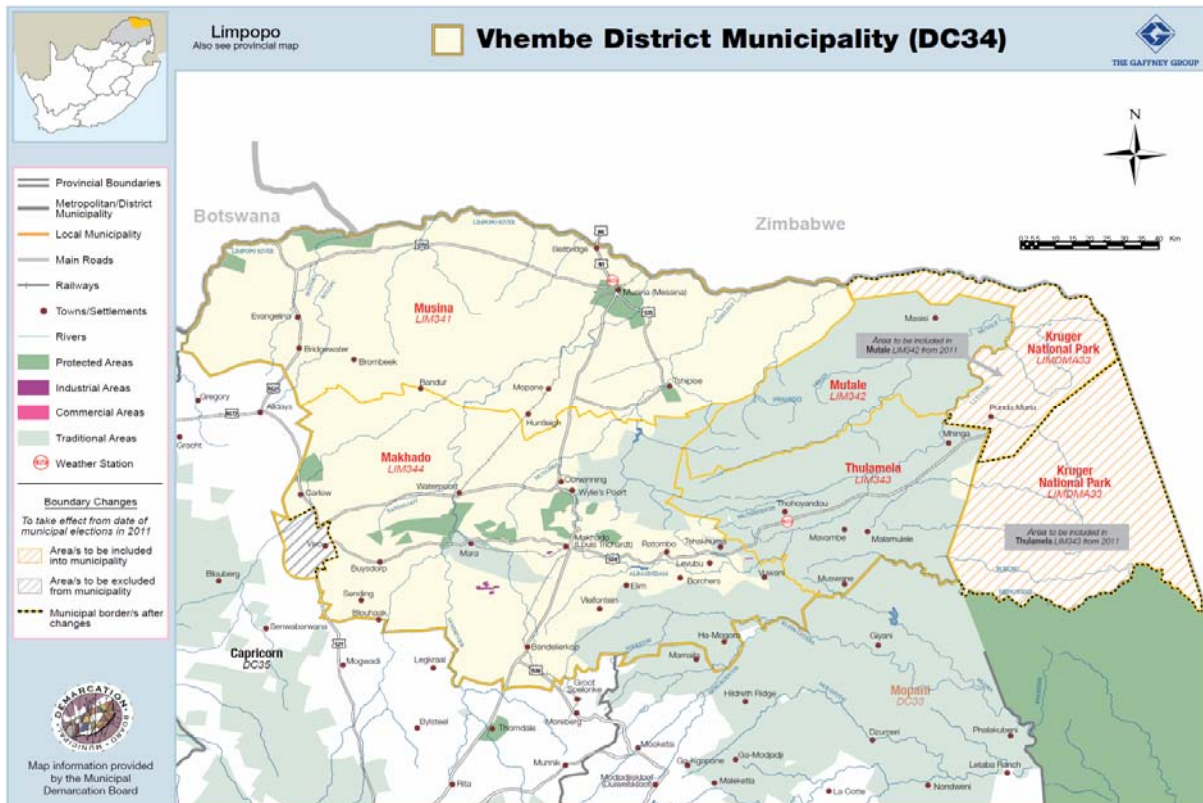
This study was conducted in the Vhembe District, which is located within the Limpopo province. Limpopo is one of the nine provinces in South Africa, and consists of five Districts, namely: the Vhembe District, the Mopani District, the Sekhukhune District, the Capricorn District and the Waterberg District. The Vhembe District is situated in the north of the Limpopo province (Department of Cooperative governance & traditional affairs, 2011).

The Vhembe District has an estimated population of about 1 232 218 to 1 302 113, with 53.3% Females and 46.7% Males. The approximation of languages spoken in the district are as follows: Tshivenda 69%, Xitsonga 27%, Sepedi 2%, Sesotho 1%, Afrikaans 1%, and other languages apart from the ones mentioned 1%. About 90% of the population resides in rural areas and do not have access to clean water (Department of Health, 2012).

In the Vhembe District, 93.6% of the entire population is uninsured and relies on the public sector for health services. Services for people with cerebral palsy are rendered at hospitals and clinics within the district. In the Vhembe District, there is 1 Regional Hospital (Tshilidzini), 6 District Hospitals (Donal Fraser, Siloam, Malamulele, Elim Messina and Louis Trichardt), 8 community health centres, 22 mobile services, 1 Specialised Psychiatric Hospital (Hayani Hospital), and 115

Clinics. Figure 2.1 gives a map of the Vhembe District (Department of Cooperative governance & traditional affairs, 2011).

**Figure 2.1**



## 2.4. POPULATION OF THE STUDY

### 2.4.1. Target population

The target population is the entire group of individual or elements which the researcher can use in the study as the source of information. The group to be studied will be defined on the basis of the study topic and aim, since it must consist only of those who have information regarding the subject under investigation (Brink, et al., 2016). The population that was targeted for this research study, consisted of individuals who are responsible for providing care to children with cerebral palsy, since the researcher aimed at investigating the experiences of the caregivers who are caring for children with cerebral palsy.

## **2.5 SAMPLING METHOD AND PROCEDURE**

### **2.5.1. Sampling method**

Sampling refers to a method used by the researcher to select participants from the larger population which is the target as the sources of information for the study under investigation (Gray, 2009). In this study, sampling occurred in two phases: Hospitals were sampled through purposive sampling and participants were sampled through simple random sampling.

### **2.5.2. Sampling of hospitals**

In this study, hospitals were selected through purposive sampling. Purposive sampling can also be referred to as judgemental sampling (Giddens, 2011). Purposive sampling allows the researcher to make judgements about the characteristics which the participants or elements to be studied poses and their ability to produce relevant information (De Vos, Strydom, Fouche & Delport, 2013).

Hospitals were used to access caregivers of children with cerebral palsy, since they were the easiest way to access them. In the Vhembe District there are seven (7) hospitals which render cerebral palsy support, namely: Tshilidzini Hospital, Donald Fraser Hospital, Siloam Hospital, Malamulele Hospital, Elim Hospital, Messina Hospital and Louis Trichardt (Memorial) Hospital. From the seven hospitals, the researcher selected three (3) hospitals with the highest number of children with cerebral palsy cases

### **2.5.3 Sampling of participants**

In this study, caregivers were sampled through simple randomly sampling. According to De Vos, et al., (2013) simple random sampling refers to a method of selection which awards all samples an equal chance of being selected from the bigger population, without being biased.

Caregivers who met the criteria for inclusion, and whose names were appearing on the list from the hospitals were approached and the researcher informed them about the study. Those who agreed to form part of the study, had their names written on

identical small pieces of papers and placed in a container. The researcher then randomly selected five caregivers per hospital from the three hospitals that were selected.

#### **2.5.4. Sampling size**

The actual number of individuals who have been selected by the researcher as the representatives of the target population are referred to as the sample size (Swartz, et al., 2011). Due to data saturation, eight (8) caregivers who are caring for children with cerebral palsy at home in the Vhembe District, were interviewed.

### **2.6. CRITERIA FOR INCLUSION**

Caregivers who were selected to form part of the study were 18 years and above, and is responsible for providing care to a child with cerebral palsy. They all resided in the Vhembe District, their names appeared on the register of people who attend cerebral palsy support groups, and they all gave consent to participate in the study.

### **2.7. PRE-TESTING**

Pretesting is about verifying the ability of the research instrument to collect data and ensuring that the instructions on the instrument are clear (Brink, et al., 2016). Prior to the actual data collection process, the researcher selected two caregivers from Musina Hospital and interviewed them to check if the question was phrased in a manner which they understood. The researcher realised after interviewing the first caregiver that the question was not clear, because the responses of the caregiver were not in relation to the research topic. The researcher then consulted with the research supervisors and phrased the question in a different way, before interviewing the second caregiver; after the interview, the researcher could see some improvements from the caregiver's responses. During the interviews with the two caregivers, the researcher realised that he was not probing enough to get the caregivers to talk more (**Refer to Appendix M**).

## **2.8. DATA COLLECTION**

Neuman (2011), define a data collection method as a part of any research design which gives a clear description of the kind of data that will be collected and how this would be done. A data collection method is a clear explanation of processes and elements that the research will make use of in the field when collecting information from the sampled participants (Neuman, 2011).

### **2.8.1. Preparation of participants**

The researcher made appointments with the caregivers telephonically before the interviews, visited the homes of the caregivers and clearly explained to them that they are relevant sources of information for the study that is being conducted and that their participation in the study will give them an opportunity to talk about their experiences regarding caring for children with cerebral palsy. The caregivers were given the consent forms to read and sign before they could be interviewed, they were also informed that if they did not want to sign, they can give verbal consent. The researcher then made appointments with the caregivers for the days and times of the interviews, depending on their availability.

Caregivers were informed that their participation in the study is voluntary, there would be no payments from the researcher for taking part in the study. The researcher also informed the caregivers that they were allowed to withdraw their participation from the study, even if they have already signed the inform consent, and that they will not be questioned for their reason to stop participating in the study.

All caregivers were informed that the interviews will be recorded, only if they allow the researcher to do so; the researcher also explained to the caregivers that if there is something that they want to talk about which they do not want to be recorded, the recorder will be stopped until the caregiver tells the researcher to continue with the recording.

### 2.8.2. Data collection instrument

The researcher conducted one-on-one in-depth interviews with the caregivers. The interviews were conducted in a manner which allowed the caregivers to share their experiences regarding caring for children with cerebral palsy, without limitation, they were conducted at the homes of the caregivers. Each interview ranged between 30 and 40 minutes long. The interviews were directed by the following open-ended question, which the researcher constructed under the supervision of research promoters.

- *Kindly share with me about what you encounter everyday as you are providing care to the child with cerebral palsy.*

Interviews were conducted in Tshivenda, translated into English then transcribed verbatim (**Refer to Appendix L & M**). The researcher also served as a research instrument during data collection, by probing the responses of the caregivers to get more clarity on what they were saying while answering the question. Probing can be defined as a method of scrutinising the responses of caregivers by the researcher without being influential in their early answers (Maree, 2012).

### 2.9. DATA ANALYSIS

Monette, Duane and Dejong (2008), define data analysis as a process of assembling and arranging information which has been collected from the participants and drawing meaning out of the large data which the researcher has. Data analysis assists the researcher to reduce the large batch of information to smaller bits of information, by taking only what is relevant to the study and coming up with themes into which data can be classified (Wellman, Kruger, & Mitchell, 2005).

The qualitative data analysis steps by Creswell (2013) were used to analyse the information that was gathered from the caregivers during the interviews.

- **Step 1: Organize and Prepare**

The researcher went to the field and collected data from the caregivers of children with cerebral palsy at their home. After collecting data from the caregivers, the researcher played the voice recording and transcribed verbatim.

- **Step 2: Reading through the data**

The researcher read through the transcribed data, and compared it with the voice recording, to ensure that nothing has been missed or changed. Reading through the transcribed data assisted the researcher to have a general idea about what all the caregivers were saying during the interviews.

- **Step 3: Begin detailed analysis with a coding process**

After the researcher read through the transcribed data, points which were raised by caregivers were highlighted, using different colored markers, and later arranged according to their similarity. The arranged data was then used to form categories and subcategories, and labelled using the words of the caregivers. The research supervisor was given an opportunity to cross-check the categories and sub-categories.

- **Step 4: Use the coding process to gather people as well as categories for analysis**

After developing and arranging data into various subcategories and categories, the researcher came up with themes which appear to be the major findings of the study. The themes are reported under separate heading in chapter 4, where the findings of the study are being discussed in detail.

- **Step 5: Advance how the descriptive and themes will be presented**

The findings are presented in tables in chapter 4. The tables have three columns, which cover the: themes, categories and sub-categories that emerged during data analysis researcher is presenting.

- **Step 6: A finalized step in data analysis involves making an interpretation of the data**

The interpretation of findings is based on a discussion of the actual phrases which were made by the caregivers, and supported using existing literature on cerebral palsy and disability.

## **2.10. MEASURES TO ENSURE TRUSTWORTHINESS**

### **2.10.1. CREDIBILITY**

Credibility refers to the context of ensuring that information is being collected from the relevant people who are informative about the phenomenon under investigation; ways of ensuring credibility are prolonged engagement with the participants, persistent observation, and member checks (Babbie & Mouton, 2010).

#### **Prolonged engagement**

The caregivers were visited at their homes prior to the interviews, in order for the researcher to build trust and rapport with caregivers, so that they could feel free to share their experiences with the researcher during the interviews. Maintaining contact with the caregivers before data collection assisted the researcher in ensuring that the individuals who have been identified as sources of information can provide relevant information that will assist in achieving the purpose of the study.

#### **Persistent observation**

The researcher observed all the non-verbal communications made by the caregivers during the interview sessions, to see if their responses were in relation to their body language. The use of a tape recorder, made it easy for the researcher to observe the non-verbal gestures of the caregivers because he did not put much of the focus on writing notes.

## **Member checks**

After each interview, the researcher played back the tape recording for the caregivers to verify if what is in the record is actually what they said. The researcher also probed during the interviews, in order to have a clear and deeper understanding of what the caregivers were saying. Some of the statements which the caregivers made during the interviews were repeated using different words, to ensure that the researcher and the caregivers had the same understanding of what was being said.

### **2.10.2. CONFORMABILITY**

Conformability refers to the level which the interpretation of the research study can be traced back to their original source and that they do not represent the ideas of the researcher but those of the participants (Babbie & Mouton, 2010). The information which was recorded during the interviews was transcribed without changes. The researcher did not influence the responses of the caregivers.

### **2.10.3. TRANSFERABILITY**

According to Babbie and Mouton (2010), Transferability refers to the point in which the same kind of study can be repeated by other people and yield similar results with what the previous researcher obtained. The research design, setting of the study, target population, and sampling procedure are clearly explained, to allow the same study to be replicated by other researchers. It also enables the findings of the study to be generalised.

### **2.10.4. DEPENDABILITY**

Dependability ensures that the information that is being presented by the researcher is accurate, and people can depend on that information for future use (Babbie & Mouton, 2010). Others who are experts in the field of research were consulted to cross-check the codes, to see if they will code the data the same way as the researcher has coded. The caregivers were visited after data analysis, to verify that what is written is actually what they meant and said during the interviews.

## 2.11. ETHICAL CONSIDERATION

According to De Vos, et al., (2013), research ethics can be explain as the normal and acceptable standard of behaviour which governs how the researchers should conduct themselves when carrying out a research project. They are designed to protect the right of participants and to clearly define the responsibilities of researcher. The following ethical principles were adhered to throughout the study:

### 2.11.1. Permission to conduct the study

- The research proposal was submitted to the School of Health Sciences Higher Degree Committee for quality assurance and approval.
- After the school gave approval for the study, the proposal was then forwarded to the University Higher Degree Committee (**Refer to Appendix A**) and the University of Venda Research Ethics Committee, for final approval and issuing of ethical clearance (**Refer to Appendix B**).
- A letter which allowed the researcher to sample participants from the hospitals was obtained from the Provincial Department of Health (**Refer to Appendix C & D**).
- The Vhembe District Department of Health also gave the researcher a letter which allowed him to have access to the data at the hospitals (**Refer to Appendix E & F**)

### 2.11.2. Informed consent

Informed consent ensures that the participants fully understand the research project that they are going to participating prior to the commencement of the research study (De Vos, et al., 2013). The aim of the study, duration and its significance, was clearly explained to the caregivers before they could give consent to participate in the study. The researcher also explained to the caregivers that there are no perceived risks in the study. The caregivers were also informed that they can withdraw from the study at any time and they would not be questioned about their actions. Those who could write were requested to sign the consent form, but some only gave verbal consent

because they were not comfortable with signing the consent forms. (**Refer to Appendix G & H**)

### **2.11.3. Principle of Non-maleficence**

The principle of non-maleficence prohibits the researcher from posing a threat to the overall well-being of those who are participating in his study (Swartz, et al., 2011). The researcher avoided asking questions which could harm the emotional and psychological well-being of the caregivers during the interviews. The researcher also ensured that caregivers use their money, instead, they were followed up at their homes and the researcher was the one to call them; they were requested to send call message for the researcher to call them if there was something which they would like to discuss with the researcher concerning the study.

### **2.11.4. Principle of Justice**

The principle of justice strives to ensure that all those who are taking part in the study are treated equally and fairly (Swartz, et al., 2011). The principle of justice was upheld throughout the study by not discriminating caregivers based on their socio-economic status, educational level and age. All caregivers were treated in the same manner.

### **2.11.5. Confidentiality**

Confidentiality is a research ethic which ensures that the information which has been provided by those who are used as the source of information for the study is made available only to the researcher and prohibits the discussion of such information with other people (Monette, et al., 2008). Information which was provided by the caregivers during the interviews was kept in a safe place, where other people who were not part of the study could not access it. Caregivers were also informed that their information will not be shared with others, except for the research promoters.

### **2.11.6. Analysis and reporting**

This ethical principle strives to ensure that the researcher does not misrepresent the information that was provided by the participants (Swartz, et al., 2011). The

information which was provided by the caregivers was not changed during data analysis or when reporting the findings, to suit the objectives of the study.

### **2.11.7. Anonymity**

Anonymity prohibits the researcher from making available any information which can lead to the identification of the research participants (De Vos, et al., 2013). The real names of the caregivers were not used during the study, instead the researcher labelled the caregivers numerically, such as 'Caregiver 1'; only the researcher knows the real names of those caregivers.

### **2.12. DISSEMINATION OF RESULTS**

- A copy of results will be made available at the University of Venda library.
- The Department of Social Development and the Department of Health will also be provided with a copy of the results.

### **2.13. CHAPTER SUMMARY**

This chapter of the study presented the following aspects: the design of the study, the setting in which the study was conducted, the population sample and sampling procedures that were to select the participants, the method which was used to collect data from the caregivers of children with cerebral palsy, measures which were adopted to ensure trustworthiness of the study, and ethical principles that were adhered to during the study. Chapter 3 will present the discussion of the results of the study.

## CHAPTER 3

### DISCUSSION OF RESULTS

#### 3.1. INTRODUCTION

In chapter 2 of this study, the design, setting, population sample and sampling procedure, method of data collection, measures of ensuring trustworthiness and ethical considerations were described in detail. This chapter presents the findings on the experiences of caregivers who are caring for children with cerebral palsy in the Vhembe District, of the Limpopo Province. Data was collected through individual in-depth interviews, analysed thematically and is arranged according to the themes, categories and subcategories that emerged during data analysis. The sample description and demographic information of participants are presented first.

#### 3.2. SAMPLE DESCRIPTION

The sample of this study as described in chapter 2, consisted of 8 caregivers for children with cerebral palsy from the Vhembe District, who were recruited through cerebral palsy support groups from three hospitals within the district, aged 18 years and above.

#### 3.3. DEMOGRAPHIC INFORMATION OF PARTICIPANTS

Table 3.1 presents the demographic information of caregivers who were interviewed in this study.

Table 3.1

Number of caregivers	Relationship to the child	Number of caregivers per hospitals		
		A	B	C

7	Mothers	3	3	1
1	Grandmothers	1	0	0

All caregivers were females and the majority were mothers of the children who have Cerebral Palsy, only one caregiver was the grandmother to the child. All participants were sampled from Hospitals in the Vhembe District.

### 3.4. DISCUSSION OF STUDY FINDINGS

Data was analysed using Creswell's (2013) six steps of qualitative data analysis. Two themes were identified from the analysed data, namely: positive experiences of caregivers, and challenges faced by caregivers. The presentation of data is done according to each theme and is discussed separately.

#### 3.4.1. Theme 1: Positive experiences of caregivers

Table 3.2 indicates the theme, categories and subcategories

Theme	Categories	Subcategories
1. Positive experiences of caregivers.	1. Support from family members.	<ul style="list-style-type: none"> <li>• His father gives me money every month</li> <li>• His brothers play with him when am busy with something</li> <li>• I can take him to my mother</li> </ul>

#### Discussion of theme 1: Positive experiences of caregivers

The analysed data indicates that participants encounter various things while providing care to children with cerebral palsy. This theme emerged from data showing that caregivers also have positive experiences in caring for the child.

## 1.1. Support from family members

Some of the caregivers indicated that they get support from their family members, which makes it easier for them to provide care for the child with cerebral palsy. The caregivers stated that the child's father 'gives them money every month', 'his brothers play with him when I am busy with something', 'I can take him to my mother'. The following quotes show how caregivers of children with cerebral palsy get support from their family members.

*"I make sure that I buy my child many toys all the time because his father gives me money every month end, you see that big chair under the tree, I bought it R2000 and many children come here to play with him because of the toys"*

*"His brothers play with him when I am busy with something, when am done they go and play with their friends, you will see him laughing when he is with his brothers"*

*"When I want to go to the stokvel I leave my child with my mother if she is around, she doesn't have a problem if I talk to her some few days before, but if she won't be around on that day she tells me, like when she is going to Moria"*

The findings of this study reveal that some caregivers enjoy the support from their family members, and the support given to the caregivers makes the role of caregiving easy. These findings are consistent with what was reported by other authors. According to Palamaro Munsell, Kilmer, Cook and Reeve (2012), in most cases, family members become united, and work together to ensure that the needs of the child with disability are met at all times. Huang, Kellett, and St John (2010), also believe that emotional support that caregivers receive from their family members is more important than that they get from general support groups. Sandy, et al., (2013), state that even though it is not easy for family members to work together, the disability of the child in the family fortifies family relationship. A family that works together creates a conducive environment for the upbringing of the child, and reduces the burden of caring for the one who is actively involved in caring for the child with the disability (Palamaro Munsell *et al.*, 2012).

On the contrary, the findings of a study conducted by Singogo, et al., (2015) show that caregivers lack support from their families and friends, and this forces them to

cut themselves off from various social engagements, due to the fear of other people not accepting the children and their conditions.

### Conclusion of theme 1: Positive experiences of caregivers

One subcategory emerged under theme 1, namely, support from family members. The findings reveal that some caregivers are not alone in their roles of caring for children with CP. They get the support that they need from their family members, and that makes the role of caring for the child easier.

### 3.4.2. Theme 2: Challenges faced by caregivers

Table 3.3 indicates the theme, categories and subcategories

THEME	CATEGORIES	SUBCATEGORIES
1. Challenges faced by caregivers	1. Economic problems	<ul style="list-style-type: none"> <li>• I have to buy him food that is different from what other children eat.</li> <li>• I can buy soup and say he will eat and he doesn't eat</li> <li>• I am forced to use a taxi even if it is expensive</li> <li>• I was using money for transport and am not working</li> <li>• -With transport I don't have a problem with money, because in a month from his money I save knowing that on a certain date I have to take him to the group</li> <li>• From the money that I will be holding, because when you look at the money that I get, it is not used for the child alone</li> </ul>

		<ul style="list-style-type: none"> <li>• When I buy pampers I have to buy two packets and they don't even finish the month</li> <li>• If I go to work who will take care of my child</li> <li>• When I take this child to the clinic for exercise, that man doesn't do anything</li> </ul>
	2. Physical access	<ul style="list-style-type: none"> <li>• If I don't get a lift I will have to walk for that distance with this child on my back</li> <li>• I am always late for the hospital, because there is no transport these side</li> <li>• We use bakkies when we want to go to town</li> <li>• I am forced to stand inside the taxi with the child on my back</li> <li>• I have one problem, because you see we use taxis and they are for everybody</li> <li>• I have to walk to the main road to get a taxi</li> </ul>
	3. Health issues	<ul style="list-style-type: none"> <li>• I have an operation, If I carry this child</li> <li>• There is a pain that I know, when it's cloudy like today I will have a pain on my back, because am talking about a person who is going to turn 6 years.</li> </ul>

		<ul style="list-style-type: none"> <li>• My back is always painful because this child is now big and heavy</li> <li>• They told me that he is not sick and they didn't give him medicine</li> <li>• Those nurses don't know how to talk to people. I am older than them they must respect me</li> <li>• At the hospital I don't have a problem</li> </ul>
	<p>4. Maltreatment of caregivers by community members</p>	<ul style="list-style-type: none"> <li>• There are some people who insult me about my baby, because I already have two cases</li> <li>• When they see their children coming here, they start calling them</li> <li>• Here in the village we are not treated like other parents who gave birth like others, people talk somehow about us</li> </ul>

### Discussion of theme 2: Challenges faced by caregivers

The analysed data reveals that caregivers encounter various challenges while providing care to children with cerebral palsy. Four categories pertaining to challenges encountered by caregivers emerged under this theme, namely, economic problems, physical access, health issues, and maltreatment of caregivers by community members. The categories will be discussed and supported by quotes below.

## 1.1. Economic problem

Children with cerebral palsy have many needs, which caregivers are expected to meet on a daily bases. Almost all caregivers in the study indicated that they are facing economic problems as a result of caring for children with cerebral palsy. Since the children do not eat what others eat in the house, they have to buy pampers for the children, the grant money that they are getting is not enough, they cannot work because they have to look after the children and they have to use transport when going to the clinic or hospital. The following quotes depict how caregivers are affected economically:

*“I have to buy him food that is different from what other children eat, he can’t chew anything. He wants soft food like potatoes, butternut and soft-porridge”.*

*“I can buy soup and say he will eat and he doesn’t eat, am forced to go and buy other things. I will buy food and they will be many, when I feed him, he will be refusing, like the Ace instant soft porridge, when I feed him he refuses, sometimes I buy one favourite (sic) and he doesn’t eat he refuses”*

*“When I take him to the hospital I can’t use the bus, even though it’s cheaper because the seats are next to each other and my child won’t be comfortable. I am forced to use a taxi even if it is expensive, so that my child can be comfortable”*

*“Someday I went to the clinic, going to take his chair, and I was told to go back, I might have been returned 4 times, telling me that they are renovating, and it was boring me because I was using money for transport and am not working”*

One young mother indicated that she does not have any problem with transport money, she saves money for transport based on the date that the child will be going to the hospital.

*“With transport I don’t have a problem with money, because in a month from his money I save knowing that on a certain date I have to take him to the group, then I save the money for transport, but the problem is when am inside the taxi, there are other people who don’t accept”*

Some of the younger caregivers indicated that the disability grant money that they receive on behalf of the child is not enough to meet the needs of the children; the whole family depends on the grant, since they cannot work because they have to look after the children.

*“He is getting that grant of disability...From the money that I will be holding, because when you look at the money that I get, It is not used for the child alone, we have to eat, we have to, everything is looking at the money of this child”*

*“My child is now big, when I buy pampers I have to buy two packets and they don’t even finish the month, and you must know that I am not working”*

*“It is difficult for me to work, If I go to work who will take care of my child? Another person won’t understand him like I do”*

The findings of this study show that almost all caregivers who participated in the study experience economic challenges. The findings are similar to what other authors found during their studies. Mu’ala, et al., (2008), believe that caregivers who assume the role of caring at a younger age will in most cases not finish school, and their chances of getting good paying jobs would be compromised. According to Davis, et al., (2009), children with cerebral palsy, like other children with disabilities might require medical attention from time to time, and this can result in most families’ finances being negatively affected, since they have to spend money for their children to get the medical services that they need.

According to Mweshi, Amosun, Ngoma and Nkandu (2011), caring for children with disabilities includes extra costs related to children’s trips to clinics and hospitals for treatment or rehabilitation, specific food that they have to eat, and the purchase of throwaway nappies/diapers. Diseko (2017), argues that despite the government supporting children with disabilities through Disability grants, it is regarded as little, since in most families, the money has to cater for the needs of all people in the household, and a little amount is directed towards the needs of the child with CP. Pakula, et al., (2009), confirm that children with cerebral palsy need constant medical check-ups because they might be suffering from various impairments at the same time. Davis, et al., (2009), believe that accessing high quality medical services needed by the children with disability can overstretch the budgets of caregivers.

## 1.2 Physical access

Some of the caregivers in the study are facing challenges with regards to physical access. They indicated that they have to walk for a distance to access health services, they are always late at the hospital because of transport, they use bakkies as their transport and they have to wait for them to be full, they are forced to stand inside the taxi with the child on their back, they have to walk to the main road to access transport. The following quotes depict the caregivers' challenge of physical access.

*"Our nearest clinic is in Madimbo, so when the child is sick, I have to put him on my back and go there, if I don't get a lift I will have to walk for that distance with this child on my back"*

*"I am always late for the hospital, because there is no transport these side, sometimes my child does not get attended to because when I get there if find that the group is out"*

*"We don't have taxis, we use bakkies when we want to go to town. And we have to wait for it to be full"*

*"This side we use taxis that are coming from Musina or Thohoyandou, and when they come here you will find that they are full of people. And am forced to stand inside the taxi with the child on my back. But if I find people with good hearts they give me a seat"*

*"Our roads are not good, and taxis don't come here. I have to walk to the main road to get a taxi, carrying this child and it is a long distance from here"*

*"I have one problem, because you see we use taxis and they are for everybody. Because there are other people who do not accept, he will be kicking and you see when am sitting on a seat with other people he will be kicking and hurting them, it's not everybody who have the same hearts, some people get bored, others understand how the child is"*

The findings of the study reveal that physical access is a challenge to some of the caregivers. Due to the nature of CP, a child with this condition has to be taken to

clinics or hospitals for treatment or rehabilitation. The findings of this study are consistent with the results of other studies which have been conducted previously. According to Tonga and Duger (2008), there is limited transportations that caters for children with disabilities; they lack space for wheel chairs, and caregivers are forced to carry their children, often, when travelling for long distances and this leaves most parents worried about the safety of their children.

Steadman (2015), states that public transport is not well designed to carry people who use wheelchairs; there is a lack of well-equipped taxis and buses in the developed and developing countries force caregivers to hire private transport, or use their own cars to transport their children. Urimubenshi and Rhoda (2011), argue that lack of proper transport can result in caregivers and children with cerebral palsy withdrawing from public engagements.

Sandy, et al., (2013) believe that there are few centres available that offer services that are most needed by persons with cerebral palsy, particularly in the African continent. The findings of a study conducted by Singogo, et al., (2015), shows that almost all mothers who participated in the study had challenges regarding roads that do not have sidewalks, small doors which make it difficult for a wheelchair to pass through, as well as buildings that have no ramps and lifts.

According to Urimubenshi and Rhoda (2011), the geographical location can be one factor that hinders caregivers from accessing health services and other services that might be essential for the survival of children with CP. Dambi and Jelsma (2014), believe that the physical environmental challenges can perpetuate the physical stress that caregivers undergo as a result of carrying the children.

### **1.3 Health issues**

The majority of caregivers in this study indicated that they encounter various health challenges as they are providing care to the children with cerebral palsy. They stated that when they take the children to the hospital they do not get assistance, they have back pains because of lifting the children, and the nurses do not know how to talk to people. The following quotes depict how caregivers experience health challenges.

*“I have an operation, If I carry this child, I know that am going to sleep when I come back because he is having...I know that tomorrow there will be clouds even when it's hot like this because of this operation”*

*“It pains me because if he is like this and not sleeping, it means I will carry him on my back when am doing everything, if it's doing my washing, cleaning and sweeping, everything he will be on my back. There is a pain that I know, when it's cloudy like today I will have a pain on my back, because am talking about a person who is going to turn 6 years. He will be hurting me, I will be feeling pains”*

*“This child cannot do anything on his own. I have to carry him always. My back is always painful because this child is now big and heavy”*

*“I once took my child to Folovhodwe clinic, he was very sick, when I got there the nurses took my baby's clothes off and pressed his stomach, then they told me that he is not sick and they didn't give him medicine. I came back and went to the main road to as for a lift to take my child to Madimbo clinic, when I got there my child was given medicine, I don't take my child to Folovhodwe anymore. There is no service”*

*“When I take this child to the clinic for exercise, that man doesn't do anything. He will put the child on the table and he will just stand on the other side and call the child. If the child looks at him, you will hear him saying, don't worry your child will be fine. I want Doctors to check my child, because that one is not doing anything”*

One caregivers who is looking after her grandchild indicated that the nurses don't know how to talk to people, they were shouting her at her saying she doesn't look after her grandchild.

*“One day I went to that house (pointing the house with a finger), this child was sleep and my husband was plastering the house that side (pointing at the side), when I came back I found the nurses who work around the villages with other nurses from Musina, they started shouting at me telling me that I am not taking care of my child's child, those nurses don't know how to talk to people. I am older than them they must respect me”*

One caregiver indicated that she does not have any problem when it comes to the health services, mentioning that her child gets attended to whenever she takes him to the hospital.

*“At the hospital I don’t have a problem, because if I go with him to the group they stretch him the way they are stretching others, looking at what his problem is if now because he is not sitting and they want him to sit they stretch him so that he can sit, they do everything that they are supposed to do, I cannot say I come across challenges”*

The findings of this study show that the majority of the caregivers are experiencing challenges with regards to health issues. The findings of the study are similar to the findings of other previous studies. Byrne, et al., (2010), state that continuous lifting of heavy loads on a daily basis can be detrimental to the health of caregivers, since this can lead to postural imbalances, which could result in low back pain and various musculoskeletal illnesses in the long run. Tonga and Duger (2008), also found that the factors contributing to back pain across caregivers of persons who are living with disabilities were associated with persistent lifting of the person, bearing in mind they carry a person who weighs more than 20 kgs for a number of times in a day

Bourke-Taylor (2010), states that caregivers have difficulties in accessing services and often complain about the quality of the services that they receive from the public institutions. Golden and Nageswaran (2012), indicate that caregivers take up the role of an activist at health centres for their children to receive the services that they need.

#### **1.4 Maltreatment of caregivers by community members**

Some of the caregivers in the study indicated that they are not treated well by other community members where they are staying. They state that there are people who insult them using their children, some neighbours do not want their children to play with the child who has CP. Caregivers are excluded from other services in the villages because they receive the grant for the child and they eventually isolate themselves from other people. The following quotes show how caregivers of children with cerebral palsy are not treated well.

*“In the community it is difficult, there are some, because I already have two cases which I reported to the chief, because we had some misunderstanding and those people insulted me using my child’s disability. I went to the police and they indicated that the people should ask for forgiveness. The first one agreed while we were still at chief when she was been asked and she accepted that she said it and she said she is asking for forgiveness. The second one refused and said she should be taken anywhere, it was then taken to the police station they talked to the person and she asked for forgiveness. It not good if I don’t agree on something with the person and that person end up involving the child”*

*“When they see their children coming here, they start calling them. I think they don’t want their children to play with my child because he once bite another child’s finger”*

*“Here in the village we are not treated like other parents who gave birth like others, people talk somehow about us. If they say there are people who are registering to get things for the orphans, you will hear them saying a person who is getting the big grant is not supposed to get this. We tried to say people all over, they must first see how a person is living. Someone said a person who has a child like this is not supposed to be given anything because the child is getting the big grant. The community here is not treating us right as people. They talk things, you even feel scared of walking around because when you come this side someone will be saying some things. It’s better to stay at home and look after the child, and only go out when am taking the child to the hospital”*

The findings of this study indicate that some of the caregivers for children with cerebral palsy are not being treated well by other community members due to the condition of the child. The findings of the study are consistent with the findings of previous studies. Sandy, et al., (2013), believe that the way in which the society behaves towards children with disabilities and their caregivers, based on their traditional perspectives has taken a lead in perpetuating issues of unfair treatment in most communities.

Davis, et al., (2009) state that caregivers find it difficult to sustain the friendships that they started before the child came into their lives, mainly because their friends do not know how to relate to the child with disability. Adegoke, et al., (2014) also argue that

the response from the society causes caregivers of children with cerebral palsy to isolate themselves and keep their children at home. Narekuli *et al.*, (2011) believe that in most cases caregivers are unwilling to mingle with other people because they feel pity for them and they get depressed by the sympathy they receive.

### **Conclusion of theme 2: Challenges faced by caregivers**

Four categories emerged under theme 2, namely: Economic problems, physical access, health issues, and maltreatment of caregivers by community members. The findings of the study reveal that caregivers for children with cerebral palsy in the Vhembe District encounter various challenges on a daily bases, as they are providing care to children with CP.

### **3.5. CHAPTER SUMMARY**

This chapter presented the sample description, demographic information of participants who were interviewed, as well as the discussion of study findings, where two themes emerged namely: positive experiences and challenges faced by caregivers. One subcategory emerged under theme 1 and four categories emerged under theme 2. Chapter 4 will present the evaluation of the study, conclusion, recommendations and limitations of the study.

## CHAPTER 4

### EVALUATION, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

#### 4.1. INTRODUCTION

Chapter 3 of this study presented the findings on the experiences of caregivers who are caring for children with cerebral palsy, themes, categories and subcategories that emerged during data analysis; as well as the sample description and demographic information of participants. This chapter of the study presents the conclusion about the experiences of caregivers who are caring for children with cerebral palsy in the Vhembe District, of the Limpopo Province. The chapter outlines the risks, limitations, interpretation of the research findings, recommendations and further research.

#### 4.2. EVALUATION OF THE STUDY

This study is evaluated according to the purpose and objectives, as set in chapter 1.

The purpose of the study was to explore the experiences of caregivers who are caring for children with cerebral palsy in the Vhembe District, of the Limpopo Province. The purpose of the study was achieved through in-depth individual interviews which were conducted with the participants. The interviews were guided by one open-ended question, which was constructed under the supervision of the research promoters “*Kindly share with me about what you encounter everyday as you are providing care to the child with cerebral palsy*”. Participants were sampled through simple random sampling, and the hospitals were sampled through purposive sampling. Data that was collected from the participants was analysed using six the steps of qualitative data analysis by Creswell (2013).

The objectives of the study were to:

- Explore the experiences of caregivers who are caring for children with cerebral palsy in the Vhembe District, of the Limpopo Province
- Describe the experiences of caregivers who are caring for children with cerebral palsy in the Vhembe District, of the Limpopo Province.

The objectives of the study were achieved, as the experiences of caregivers who are caring for children with cerebral palsy were explored and described in detail. Probing skills were used to explore the experiences of caregivers and to make them narrate their lived experiences with regard to caring for children with cerebral palsy. The following narrative depicts how the caregivers were narrating their experience

*“In the community it is difficult, there are some, because I already have two cases which I reported to the chief, because we had some misunderstanding and those people insulted me using my child’s disability. I went to the police and they indicated that the people should ask for forgiveness. The first one agreed while we were still at chief when she was been asked and she accepted that she said it and she said she is asking for forgiveness. The second one refused and said she should be taken anywhere, it was then taken to the police station they talked to the person and she asked for forgiveness. It not good if I don’t agree on something with the person and that person end up involving the child”*

### **4.3. CONCLUSION OF STUDY FINDINGS**

Two themes emerged from the study; namely, positive experiences of caregivers and challenges faced by caregivers.

#### **4.3.1. Theme 1: Positive experiences of caregivers**

One category emerged under the theme of positive experiences of caregivers, namely: support from family members.

- **Support from family members**

The findings of the study reveal that the caregivers get support from their family members, which makes it easier for them to provide care to the children with cerebral palsy. Caregivers can leave the children in the care of some of the family members when they are going somewhere or when they are busy with things at home, and they also get financial support from the father. The narratives below indicate how caregivers for children with cerebral palsy are supported by their family members.

*“His brothers play with him when am busy with something, when am done they go and play with their friends, you will see him laughing when he is with his brothers”*

*“When I want to go to the stokvel I leave my child with my mother if she is around, she doesn’t have a problem if I talk to her some few days before, but if she won’t be around on that day she tells me, like when she is going to Moria”*

#### **4.3.2. Theme 2: Challenges faced by caregivers**

Four categories emerged under theme 2-Challenges faced by caregivers, during data analysis, namely: economic problems, physical access, health issues and maltreatment of caregivers by community members.

- **Economic problems**

The findings of the study reveal that caregivers experience economic problems as a results of providing care to a child with cerebral palsy. The caregivers are unemployed because there is no one to take care of the children when they are at work, children do not eat everything, and there are specific foods that they prefer, which differ from what others in the family eat. Since these children cannot take themselves to the toilets, the caregivers uses nappies for them and they complain that the nappies are expensive and the grant money is too small. Once in a month, these children have to be taken to the hospital for cerebral palsy support groups and caregivers stated that they do not have money for taxi fares. The two narratives below depict how caregivers are affected financially when caring for children with cerebral palsy.

*“I have to buy him food that is different from what other children eat, he can’t chew anything. He wants soft food like potatoes, butternut and soft-porridge”*

*“I can buy soup and say he will eat and he doesn’t eat, am forced to go and buy other things. I will buy food and they will be many, when I feed him, he will be refusing, like Ace instant soft porridge, when I feed him he refuses, sometimes I buy one favourite (sic) and he doesn’t eat he refuses”*

- **Physical access**

The findings of the study reveal that the caregivers experience challenges with regard to physical access. The caregivers expressed that they have to travel long distances to access health services for the children, since the clinics are far from where they are staying. The findings further reveal that caregivers have to walk long distances with the children on their back to access transport, the seats in the buses are next to each other, and they cannot sit properly with the children. The narratives below indicate how physical access is a challenge to caregivers for children with cerebral palsy.

*“I am always late for the hospital, because there is no transport these side, sometimes my child does not get attended to because when I get there if find that the group is out”*

*“Our nearest clinic is in Madimbo, so when the child is sick, I have to put him on my back and go there, if I don’t get a lift I will have to walk for that distance with this child on my back”*

*“This side we use taxis that are coming from Musina or Thohoyandou, and when they come here you will find that they are full of people. And am forced to stand inside the taxi with the child on my back. But if I find people with good hearts they give me a seat”*

- **Health issues**

The findings of the study reveal that caregivers experience health challenges when they are providing care to children with cerebral palsy. The caregivers experience back-pains and chest-pains as a result of lifting the children who cannot move or walk on their own, when they travel with them, they have to put them on their back. The findings further reveal that caregivers experience negative attitudes from health professionals. The narratives below indicate the health issues that affect caregivers for children with cerebral palsy:

*“I cannot leave this child alone in the house when am cleaning outside or doing other thing. I have to put him on my back even when am cleaning the house and he is*

*heavy, imagine carrying a seven years old person on my back. I always feel pains on my back”*

*“I once took my child to Folvhodwe clinic, he was very sick, when I got there the nurses took my baby’s clothes off and pressed his stomach, then they told me that he is not sick and they didn’t give him medicine. I came back and went to the main road to ask for a lift to take my child to Madimbo clinic, when I got there my child was given medicine, I don’t take my child to Folvhodwe anymore. There is no service”*

- **Maltreatment of caregivers by community members**

The findings of the study reveal that caregivers are not treated well by other community members because of the condition of the children, because if the caregiver and the community members are fighting, they end up involving the disability of the children. The caregivers also expressed that they are discriminated against in the village, whenever people are being registered to receive certain services, they are told that they cannot get anything because the child is getting the grant. The narrative below indicates how caregivers for children with cerebral palsy are treated by local community members.

*“Here in the village we are not treated like other parents who gave birth like others, people talk somehow about us. If they say there are people who are registering to get things for the orphans, you will hear them saying a person who is getting the big grant is not supposed to get this. We tried to say people all over, they must first see how a person is living. Someone said a person who has a child like this is not supposed to be given anything because the child is getting the big grant. The community here is not treating us right as people. They talk things, you even feel scared of walking around because when you come this side someone will be saying some things. It’s better to stay at home and look after the child, and only go out when am taking the child to the hospital”*

## **4.4. RECOMMENDATIONS**

### **4.4.1. Recommendations for practice**

Based on the findings of the study:

- It is recommended that a cerebral palsy support group should be facilitated at clinics, so that caregivers can save the money they use for transport to the hospitals for group sessions.
- Medical Doctors should form part of the cerebral palsy group, to ensure holistic rehabilitation of the children with CP during the groups.

### **4.4.2. Recommendations for body of knowledge**

- Based on the findings of this study, the researcher recommends a study to develop a model to support caregivers in caring for children with cerebral palsy.
- The researcher further recommends that a study be conducted to investigate the prevalence of back-pain amongst caregivers of children with cerebral palsy in the Vhembe District

## **4.5. LIMITATIONS OF THE STUDY**

- All participants who were interviewed were females, the researcher did not get to hear about the experiences of male caregivers regarding caring for children with cerebral palsy.
- The findings of this study cannot be generalised to a broader population, since a small number of participants were interviewed. And the experiences of caregivers might be influenced by the geographical areas or cultural factors.

## **4.6. CONCLUSION OF THE STUDY**

This study was divided into 4 chapters. In chapter 1: Orientation to the study, the following were presented: Introduction and background of the study based on the experiences of caregivers who are caring for children with cerebral palsy, statement

of the problem, significance of the study, aim of the study, research question, objectives of the study, brief description of methodology that was adopted in the study, definition of concepts, as well as the theoretical framework in which the study was conceptualised. Chapter 2: Research designs and methodology, presented designs of the study; setting in which the study was conducted; population sample and sampling procedures that were to select the participants; method which was used to collect data from the caregivers of children with cerebral palsy; measures which were adopted to ensure trustworthiness of the study and ethical principles that were adhered to during the study.

Chapter 3: presented the sample description, demographic information of participants who were interviewed, as well as the discussion of study findings, where two themes emerged namely: positive experiences and challenges faced by caregivers. One subcategory emerged under theme 1 and four categories emerged under theme 2.

Chapter 4 presented the evaluation of the study based on the aim and objectives as set in chapter 1, and they were all achieved. Limitations; conclusion based on the themes, categories and subcategories as well as the recommendations for practice and the body of knowledge that has been discussed.

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## Appendix A: UHDC approval letter

### UNIVERSITY OF VENDA

#### OFFICE OF THE DEPUTY VICE-CHANCELLOR: ACADEMIC

TO : MR/MS D. MANYUMA  
SCHOOL OF HEALTH SCIENCES

FROM: SENIOR PROFESSOR L.B KHOSA  
DEPUTY VICE-CHANCELLOR: ACADEMIC

DATE : 23 FEBRUARY 2018

#### **DECISIONS TAKEN BY UHDC OF 23<sup>RD</sup> FEBRUARY 2018**

Application for approval of Master's research proposal in Health Sciences: D. Manyuma (11622663)

Topic: "Caring for children with Cerebral Palsy: Experiences of Caregivers in Vhembe District, Limpopo Province."

Supervisor	UNIVEN	Dr. M. Maluleke
Co-supervisor	UNIVEN	Mr. B.S Manganye

**UHDC approved Masters proposal**



**Senior Professor L.B. Khoza**  
**ACTING DEPUTY VICE-CHANCELLOR: ACADEMIC**

## Appendix B: Ethical clearance certificate

RESEARCH AND INNOVATION  
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:  
**Mr D Manyuma**

Student No:  
**11622663**

PROJECT TITLE: **Caring for children with cerebral palsy: Experiences of caregivers in Vhembe District, Limpopo Province.**

PROJECT NO: SHS/18/PH/05/0405

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr M Maluleke	University of Venda	Supervisor
Mr BS Manganye	University of Venda	Co - Supervisor
Mr D Manyuma	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 DIRECTOR RESEARCH AND INNOVATION 2018 -05- 07 Private Bag X5050 Thohoyandou 0950
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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: Letter of permission (Provincial Department of Health)

CARING FOR CHILDREN WITH CEREBRAL PALSY: EXPERIENCES OF CAREGIVERS IN VHEMBE DISTRICT, LIMPOPO PROVINCE
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P.O Box 637  
Musina  
0900  
28 May 2018

Limpopo Department of Health  
Private Bag X 9302  
Polokwane  
0700

Dear: Sir/Madam

### **Requisition for permission to conduct research: Limpopo Province Department of Health Ethical Committee**

I **MANYUMA DUPPY** a Masters student at the University of Venda hereby request for permission to conduct research at the hospitals in Limpopo Province, Vhembe District.

The title of the study is “**caring for children with cerebral palsy: experiences of caregivers in Vhembe District, Limpopo Province**”

#### **The purpose of the study**

The study aims to explore the experiences of caregivers caring for children with cerebral palsy in Vhembe District. This will be achieved through exploring and describing the experiences of caregivers when providing care to children with cerebral palsy.

#### **The significance of the study**

- The findings of the study might benefit the Department of Social Development (DSD) in developing programmes which aims to aid people who care for persons with disability, because most programmes only benefit those persons

living with disability and does not pay much attentions to those providing care for persons with disability.

- The findings of the study might be beneficial to the Department of Health (DOH), by highlight some of the assistive devices that might aid caregivers when they are looking after children with disability.
- Based on the researcher's findings and recommendations, new research areas might emerge, leading to future research studies.

### **Target population**

The population that is being targeted for this research study, consist of individuals who are responsible for providing care to the children with cerebral palsy, who attend cerebral palsy support groups in Vhembe District Hospitals, since the researcher aims at investigating the experiences of the caregivers for children with cerebral palsy.

### **Selected Hospitals**

The researcher wishes to sample participants from the following hospitals in Vhembe District, Tshilidzini Hospital, Siloam Hospital and Musina Hospital.

Ethical clearance has been sought from the University of Venda.

### **Contact person**

If you have any queries on the matter which is not reflected in this correspondence, the contact details are as follows:

Researcher : Manyuma D

Cell number : 072 455 9474

E-mail : [duppy.manyuma@gmail.com](mailto:duppy.manyuma@gmail.com)

Thank you in anticipation

## Appendix D: Approval letter: (Limpopo provincial Department of Health)



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

### DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650)

Ref:LP\_ 2018 07-005

Manyuma D  
University of Venda  
Private bag X5050  
Thohoyandou


Greetings,

RE: Caring for children with cerebral palsy : Experiences of caregivers in Vhembe District, Limpopo Province

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
  - Research must be loaded on the NHRD site (<http://nhrd.hst.org.za>) by the researcher.
  - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
  - In the course of your study there should be no action that disrupts the services, or incur any cost on the Department.
  - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
  - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
  - The above approval is valid for a 3 year period.
  - If the proposal has been amended, a new approval should be sought from the Department of Health.
  - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

  
Head of Department

20/06/2018  
Date

Private Bag X9302 Polokwane  
Fidel Castro Ruz House, 18 College Street, Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.  
Website: <http://www.limpopo.gov.za>

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## Appendix E: Letter of information (Vhembe District Department of health)

CARING FOR CHILDREN WITH CEREBRAL PALSY: EXPERIENCES OF CAREGIVERS IN VHEMBE DISTRICT, LIMPOPO PROVINCE
---

P.O Box 637  
Musina  
0900  
14 August 2018

Vhembe District Department of Health  
Private Bag X 5009  
Thohoyandou  
0950

Dear: Sir/Madam

### **Information of permission to conduct research: Vhembe District Department of Health**

I **Manyuma Duppy** a Masters student at the University of Venda would like to inform you that I have received permission to conduct research at the hospitals in Vhembe District, from Limpopo Province Department of Health.

The title of the study is **“caring for children with cerebral palsy: experiences of caregivers in Vhembe District, Limpopo Province”**

### **The purpose of the study**

The study aims to explore the experiences of caregivers caring for children with cerebral palsy in Vhembe District. This will be achieved through exploring and describing the experiences of caregivers when providing care to children with cerebral palsy.

### **The significance of the study**

- The findings of the study might benefit the Department of Social Development (DSD) in developing programmes which aims to aid people who care for persons with disability, because most programmes only benefit those persons

living with disability and does not pay much attentions to those providing care for persons with disability.

- The findings of the study might be beneficial to the Department of Health (DOH), by highlight some of the assistive devices that might aid caregivers when they are looking after children with disability.
- Based on the researcher's findings and recommendations, new research areas might emerge, leading to future research studies.

### **Target population**

The population that is being targeted for this research study, consist of individuals who are responsible for providing care to the children with cerebral palsy, who attend cerebral palsy support groups in Vhembe District Hospitals, since the researcher aims at investigating the experiences of the caregivers for children with cerebral palsy.

### **Selected Hospitals**

The researcher wishes to sample participants from the following hospitals in Vhembe District, Tshilidzini Hospital, Siloam Hospital and Musina Hospital.

Ethical clearance has been sought from the University of Venda.

### **Contact person**

If you have any queries on the matter which is not reflected in this correspondence, the contact details are as follows:

Researcher : Manyuma D

Cell number : 072 455 9474

E-mail : [duppy.manyuma@gmail.com](mailto:duppy.manyuma@gmail.com)

Thank you in anticipation

## Appendix F: Approval letter (Vhembe District Department of Health)



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

### DEPARTMENT OF HEALTH VHEMBE DISTRICT

Ref: S5/6  
Enq: Muvuri MME  
Date: 14 August 2018

Dear Sir/ Madam:

**PERMISSION TO CONDUCT RESEARCH ON** MANYUMA D

1. The above matter bears reference
2. Your letter received on the 14/08/2018 requesting for permission to conduct research in our facilities is hereby acknowledged
3. The District has no objection to your request.
4. Permission is therefore granted for the request to be conducted within Vhembe District.
5. You are however advised to make the necessary arrangements with the facilities concerned.
6. Wishing you success in your research in the Vhembe health facilities.

  
.....  
CHIEF DIRECTOR

15/08/2018  
.....  
DATE

Private Bag X5009 THOHOYANDOU 0950  
OLD parliamentary Building Tel (015) 962 1000 (Health) (015) 962 4958 (Social Dev) Fax (015) 962 2274/4623  
Old Parliamentary Building Tel: (015) 962 1848, (015) 962 1852, (015) 962 1754, (015) 962 1001/2/3/4/5/6 Fax (015) 962 2373, (015) 962 227

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## Appendix G: Memorandum of understanding (Tshilidzini Hospital)

### TSHILIDZINI HOSPITAL ETHICS COMMITTEE

#### Memorandum of understanding

Tshilidzini Hospital Ethics Committee with DUPPY, M. at their meeting resolved to sign a Memorandum of Understanding after the two parties have agreed on the following information:

1. Reasons for making a research at Tshilidzini hospital.  
The study targeted group visits the hospital for CP group. They can easily be accessible from Tshilidzini.
2. What will be the benefit of the entire hospital community out of your findings?  
The findings of the study might highlight what services the hospital can offer to caregivers of children with CP.
3. Who to meet in conducting your research  
The caregivers of children with cerebral palsy, who will be attending CP groups.
4. What do you do with your findings?  
A copy of findings will be submitted to the Province. The findings will not be published, they are for academics purpose.
5. We will require the hard copy of your research  
Yes.
6. We do not anticipate any information to be divulged to all types of media without the knowledge of the Ethics Committee and Hospital Board.
7. Memorandum of understanding should be signed by both parties.

Signed by: [Signature]

Date: 05/09/2018

[Signature]  
Researcher

## Appendix H: Approval letter (Siloam Hospital)



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH  
SILOAM HOSPITAL**

Confidential

Ref : S4/2/1/1/3  
Enq : Mushaphi N.T: HRD  
Date : 07 September 2018

DEPARTMENT OF HEALTH SILOAM HOSPITAL HUMAN RESOURCE 2018 -09- 07 P/BAG X 2432, MAKHADO, 0920 LIMPOPO PROVINCE
---

TO: MANYUMA DUPPY

RE: PERMISSION TO CONDUCT RESEARCH: YOURSELF.

1. The above matter refers.
2. The Hospital highly acknowledges the receipt of your letter dated 14/05/ 2018 regarding the above matter.
3. Kindly note that the institution is granting you permission to come and conduct research in "Caring for children with cerebral palsy.
4. You are kindly requested to adhere to the conditions as set out in your approval from the Provincial Office.
5. Hoping you will find the above in order

  
P. Duhan  
Chief Executive Officer

07/09/2018  
Date

Private Bag X2432. Makhado, 0920  
Tel (015) 973 0004/5/6, 015 973 1447/8, 015 973 1977, 015 973 1892/4/9 Fax (015) 973 0607.

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## Appendix I: Approval letter (Messina Hospital)



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OF HEALTH  
MESSINA HOSPITAL**

REF: S5/4/1/2  
ENQ: Mulaudzi P  
DATE: 11 September 2018

FROM: HUMAN RESOURCE DEVELOPMENT

TO: MANYUMA D  
P O BOX 637  
MUSINA  
0900

RE: CARING FOR CHILDREN WITH CEREBRAL PALSY: EXPERIENCES OF  
CAREGIVERS IN VHEMBE DISTRICT, LIMPOPO PROVINCE.

1. The above matter has reference.
2. This office wishes to inform you that your application has been approved as per conditions stipulated on the approval letter by Head of Department. You are requested to liaise with office of the Chief Executive Officer on your commencement date.
3. Your co-operation will be highly appreciated.

  
.....  
CHIEF EXECUTIVE OFFICER

*2018-09-13*  
.....  
DATE

P.O. Box 60 Musina 0900  
Tel: 015 534 0446 Fax 015 534 0819

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## Appendix J: Information sheet

CARING FOR CHILDREN WITH CEREBRAL PALSY: EXPERIENCES OF CAREGIVERS IN VHEMBE DISTRICT, LIMPOPO PROVINCE
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### Participant information sheet

**Title: Caring for children with cerebral palsy: experiences of caregivers in Vhembe District, Limpopo Province**

#### **Purpose:**

The study aims to explore the experiences of caregivers caring for children with cerebral palsy in Vhembe District. This will be achieved through exploring and describing the experiences of caregivers when providing care to children with cerebral palsy.

#### **Objectives:**

The objectives of this study are to:

- To explore the experiences of caregivers caring for children with cerebral palsy in Vhembe District, Limpopo province.
- To describe the experiences of caregivers caring for children with cerebral palsy in Vhembe District, Limpopo province

#### **Significance of study:**

- The findings of the study might benefit the Department of Social Development (DSD) in developing programmes which aims to aid people who care for persons with disability, because most programmes only benefit those persons living with disability and does not pay much attentions to those providing care for persons with disability.
- The findings of the study might be beneficial to the Department of Health (DOH), by highlight some of the assistive devices that might aid caregivers when they are looking after children with disability.

- Based on the researcher's findings and recommendations, new research areas might emerge, leading to future research studies.

### **What are the risks?**

There are no risks anticipated except that you may get tired as I interview you leading to some discomforts as you share your experiences with regard to providing care to a child with cerebral palsy.

### **Whom you should contact**

Your participation in this project is appreciated, if you have any queries, please contact the researcher on the number or email listed below:

Researcher : Manyuma D

Cell number : 072 455 9474

E-mail : [duppy.manyuma@gmail.com](mailto:duppy.manyuma@gmail.com)

## Appendix K: Informed consent

CARING FOR CHILDREN WITH CEREBRAL PALSY: EXPERIENCES OF CAREGIVERS IN VHEMBE DISTRICT, LIMPOPO PROVINCE
---

Informed consent

I \_\_\_\_\_ on this the \_\_\_\_\_ days of \_\_\_\_\_ 2018 hereby consent to:

1. Being interviewed by \_\_\_\_\_ on the topic “Caring for children with cerebral palsy: experiences of caregivers in Vhembe District, Limpopo Province”
2. The interviews will be audiotaped

I also understand that:

1. I am free to end my involvement or to recall my consent to participate in this research any time.
2. Information given up to the point of my termination of participation could however still be used by the researcher.
3. No reimbursement will be made by the researcher for information given or my participation in this project.
4. I may refrain from answering questions should I feel these are an invasion of my privacy.
5. By signing this agreement I undertake to give honest answers to reasonable question and not to mislead the researcher.

I hereby acknowledge that the researcher/interviewer has:

- 1 discussed the purpose and objectives of this research project with me
- 2 informed me about the content of this agreement
- 3 informed me about the implications of signing this agreement

As I sign this agreement the researcher undertake to:

- 1 Maintain confidentiality, and privacy regarding the interviewee's identity and information given by the interviewee;
- 2 Arrange in advance a suitable time and place for an interview to take place; and
- 3 Safe guard the duplicate of this agreement.

(Interviewee)\_\_\_\_\_

DATE:\_\_\_\_\_

(Interviewer)\_\_\_\_\_

DATE:\_\_\_\_\_

## Appendix L: Transcript

### TRANSCRIBED DOCUMENT

#### CAREGIVER 6

**R= Researcher**

**P= Participant**

---

R: Morning.

P: Good morning

R: My name is Duppy Manyuma

P: Mmmh

R: I am studying for a masters at the University of Venda, am doing research about the things that the caregivers for children with CP experience every day, what you do as a person who is caring for a child. Do you understand?

P: Yes, I hear you

R: So, another thing is that your names won't be used, so that even if someone finds this paper, the person should not know who said this, you see. So if there are questions that I will ask and you feel that you don't want to answer, you can tell me that no I don't want to answer that one, let's skip, then we will skip. Another thing is that...uhm... we will record our interview, but if there are things that you don't want to be recorded, you can say and you don't want them to be recorded you can say hai don't record, I don't want this to be recorded. Then we will just talk, when you are fine you will tell me that you can continue recording. Do you understand?

P: Mmmh

R: So your names and the names of the child will not be used here

P: Mmmmh

R: Is there something you would like to ask maybe before we start?

P: No, there is nothing

R: Ok, so as a person who is caring for a child, what is it that you come across every day when you are taking care of your child?

P: My problem is that when I care for this child, I do work. I have a problem “Kha muthu wa u sala naye, ha thu to dowela munwe muthu” he wants me all the time

R: Mmh

P: And other people don't know how to feed him, when I go to work I leave him at the crèche, they fail to feed him, I saw that because at the crèche they are failing, it's better to find someone, even with that they fail to feed him “ nga uri thi di muthu ono dzula atshi kho dziba” Ee, they are forced to stop, thinking he doesn't want, whereas he wants “vha vha vhatshi kho to balelwa ngaye”

R: Mmh

P: Mmh

R: Ok... You can continue

P: He is getting that grant of disability

R: Mmmh

P: But checking (She giggles) the things that he wants are many

R: Mmmh

P: From the money that I will be holding, because when you look at the money that I get “ I vha I songo to sedzana na ene a ethe” we have to eat, we have to, everything is looking at the money of this child

R: Maybe because you said he wants many things, can you maybe mention the many things

P: Like the food that he eats, he doesn't eat everything thi

R: Mmmh

P: Ee... I can buy soup and say he will eat and he doesn't eat, am forced to go and buy other things. I will buy food and they will be many, when I feed him, he will be

refusing, “sa mukapu wa Ace, when I feed him he refuses, sometimes I buy one favourite (sic) and he doesn’t eat he refuses

R: Mmh

P: “Nda fhambanyisa” and it seems better, I can’t say what he likes because most times he refuses what I will be giving him

R: Mmmh

P: Ee, if “a takalela mafhi namusi” tomorrow when I give him milk he refuses, and give him soup (she giggled) and he refuses, “ a vha atshi kho toda muthotho”

R: Mmmh

P: Mmmh...So the needs are many

R: Ok...

P: Mmmh... I have one problem, because you see we use taxis and they are for everybody. Because there are other people who do not accept, he will be kicking and you see when am sitting on a seat with other people and he is kicking “ U vha atshi kho vha vhaisa” it’s not everybody who have the same hearts “ vhanwe zwia vha bora, mar vahnwe vhaya zwi kondelela zwina avha a zwone” With transport money I don’t have a problem with money, because in a month from his money I save knowing that on a certain date I have to take him to the group, then I save the money for transport, but “ thaidzo I vha musu ndo no namela” there are other people who don’t accept

R: Mmmh... any other thing?

P: At the hospital I don’t have a problem, because if I go with him to the group “ vha mu onyolosa nga ndila ine vha kho onyolosa ngayo, vho sedza uri thaidzo ya hone ndia mini, vha mu onyolosa vho sedza na zwezwo” if now because he is not sitting and they want him to sit “Vha mu onyolosa zwo no ita uri a dzule” they do everything that they are supposed to do, I cannot say I come across challenges”

R: Okay... I understand

P: Another thing, if have to go the club, am forced to find someone who is very close, who will be able to take care of the child “a re na mbilu ya u kondelela” because if I

say am taking him to the crèche, it comes out at three and I might come back late from the club, where will he be if they come out at three, who will be with him? So when I leave, I have to find someone “ a ne a nga kondelala zwine a vha zwone” like my sister or my mother, when they are around I can leave them with my child, when there is no one, am forced not to go to the club

R: Mmmm

P: In the community it is difficult, there are some, because I already have two cases “dze ra vhuya ra isana musanda, ro to fhambana nga maipfi ha swika he vhanwe vhatshi kho amba vha amba nga ha nwana” I went to the police and they indicated that the people should ask for forgiveness. The first one agreed while we were still at Musanda when she was been asked and she accepted that she said it and she said she is asking for forgiveness. The second one refused and said the it should be taken anywhere, it was then taken to the police station they talked to the person and she asked for forgiveness. It not good if I don't agree on something with the person and that person end up involving the child.

R: I hear you...

P: It pains me because if he is like this and not sleeping, it means I will carry him on my back when am doing everything, if it's doing my washing, cleaning and sweeping, everything he will be on my back. There is a pain that I know, when it's cloudy like today I will have a pain on my back, because am talking about a person who is going to turn 6 years. He will be hurting me, I will be feeling pains. Even with walking, I have to walk for a distance, let's say taking him to a place like the group or the clinic, we use only one clinic and is a distance or if they say the mobile clinic is coming, from here to the community is too far, at the gate there. Carrying him there and back. It hurts me.

R: Apart from what we have discussed, is there something else that you would like to share regarding caring for the child?

P: Ah, what I can say is that the day we had a party, I talked about the bakkie and he was measured and they said I didn't bring everything, so I forgot what they said they wanted

R: Okay, is there any other thing?

P: No

R: Alrigh...Thank you for your time. Like I told you when we started, everything that we talked about will not be shared with others, except for my spervisors

P: Ok

R: Your name and the name of the child will not be used when I write my finding.

P: (Silent)

R: If there is anything that I might need clarity on after analysing my data, I will contact you so that we can arrange for a appointment.

P: It's fine

R: Thank you for your time and allowing to seeing me. Bye, we will see each other

## Appendix M: Pre-testing transcript

### TRANSCRIBED DOCUMENT

#### PRE-TESTING

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R: Morning

P: Good morning

R: How are you?

P: Am fine

R: I am Manyuma Duppy, a Masters student at the University of Venda

P: Mmh

R: Like I mentioned to you over the phone, am conducting a research about the experiences of caregivers of children with cerebral palsy

P: (the participant stared at the research in silence)

R: Your name or the child's name won't be mentioned during the study, and the information that you share with me won't be given to another person.

P: Ohoo (Looking down)

R: You are allowed to not answer some of the questions that you don't feel comfortable with and you can withdraw from the study anytime.

R: Is there anything you would like to ask me before I ask the question?

P: Hai ahuna

R: Ok, so my question is what are your experiences when providing care to the child?

P: (Silent) Uhm, experience? Like "zwine zwa nkondela?"

R: Everything, the bad and the good

P: Ah experience, it is that “Ndo mudowela, ndi kale ndi naye”, I can wash him and give him food “uhm, na u mu isa dzi nyonyolosoni”

R: Mmmh

P: The problem is that he is big, “hatsha hwaleya and thi tsha kona u mubeba” when I put him on my back when taking him to the crèche, he cries until I get to where am going. Taking care of a child “wa so” is not easy “kha masheleni”.

R: (coughs) Mmmh

P: Sometimes this child gets sick and am not able to go to work when he is sick, and I have other children. Like now, he is in the hospital, he was admitted “mbamulovha” I received a call from granny “vha crèche” saying he is sick and I had to go and take him to the hospital. Now I sleep at the hospital, and I asked another girl who stay next to us to look after my other two children

R: You said taking care of a child with disability is not easy financially

P: Ee, I am unemployed, “ndi to di shuma” and this child does not eat what other children eat, like I have other children who are older than him “Zwia konda kha siya la masheleni” because I have to buy him food that is different from other children. When he is sick “u fana na zwino” I don’t go to the market, where will I get the money?

R: Yah neh!

P: Even the other children, “azwi vha fari zwavhudi” that I do things for this one first, “zwavho zwada nga murahu” it is just that they understand that our mother has another child “a songo dzulaho zwavhudi”

R: Mmmh!

P: “Ndi zwezwo”

R: Ok, so you mentioned that the child cries when you put him on you back, what do you think makes him cry?

P: “Thi zwino marambo awe o oma, u vha atshi kho upfa vhutungu” sometimes he cries because he is sick. “Mara ene ha to dina” even during the night he doesn’t wake up or cry unless he wants something.

R: Ok, thank you. You said that you it is not easy financially when taking care the child, he is heavy to carry, and you are unable to go to the market when he is sick, is that right?

P: Ee

R: Is there something else that you would like to tell me that is related to your experience when it comes to caring for the child?

P: Uhm, hai ahuna

R: Ohoo. Thank you for your time, it was nice meeting with you.

P: You know what “ndi to livhuwa crèche heila ine nwna a zhen a yone” it is difficult for me to go out this days, but when I go to work, I take him to the crèche and they look after him. But on Sunday I go with him to church. “ungari zwo fhela”

R: Ok. If something comes up, I might come back

P: Ok

R: like I said, the information that you shared with me, will be kept safe and your name won't be attached to the transcript

P: (Silent)

R: Ok, have a good day and thank you for your time.

P: “Ndi zwone” go well