

**CHALLENGES FACED BY COMMUNITY-BASED REHABILITATION CAREGIVERS
FOR PERSONS WITH DISABILITIES IN VHEMBE DISTRICT, SOUTH AFRICA.**

By

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DECLARATION

I, **MURENDENI MAPHUTHA**, hereby declare that this Mini-dissertation titled “*Challenges faced by Community-Based Rehabilitation caregivers for persons with disabilities in Vhembe District, South Africa*” is my original work and has not been submitted for any degree at this university or any other institution; and that all citations, materials and sources used have been duly acknowledged by complete references.

Signature..... **Date**.....

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DEDICATION

This mini-dissertation is dedicated to all CBR caregivers, more especially those who care for persons with disabilities in Vhembe District. They are playing a huge role in their communities and in the lives of persons with this disabilities. This study is also dedicated to my two little princesses Pembelani and Mutondi, they are my inspiration.

ABSTRACT

Background: Globally, more than one billion people, or approximately 15% of the world's population are living with some form of disability and 80% of them are found in developing countries. There are different types of disability; these include sensory, neurological, physical, intellectual, cognitive and psychiatric disabilities. Persons with disabilities may require specialized care, resources and commitment which place a very high demand of time and responsibilities on the one caring for them. Therefore, Community-Based Rehabilitation (CBR) was promoted by the World Health Organisation (WHO) as a strategy to respond to the needs of persons with disabilities, through the provision of basic services at community level, particularly in developing countries with limited resources.

Methodology: The purpose of this study was to explore and describe the challenges faced by Community-Based Rehabilitation caregivers for persons with disabilities in Vhembe District, South Africa. A qualitative phenomenological design was used to explore and develop an in-depth understanding of the CBR caregiver's challenges. The study was conducted in three Community-Based Rehabilitation centres located within Vhembe District with a sample size of six caregivers who were purposively selected. An interview guide was developed as an instrument for data collection. Data was collected through in-depth individual interviews and analyzed using thematic analysis.

Results: Six main themes emerged from the data which shed light on the CBR caregiver's challenges, namely; Poor relationships between caregivers, government

department and families, unavailability of material and human resources, poor funding system, caregivers' well-being, education and training and the coping strategies of CBR caregivers

Conclusion: This study pointed out that there is a need for intervention from different stakeholders such as government departments, family members of persons with disability, and the community members as well for CBR caregiver's challenges to be resolved or minimized.

Key words: Caregivers, Challenges, Community Based-Rehabilitation, Disabilities

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LIST OF ABBREVIATIONS AND ACRONYMS

CBR	Community-Based Rehabilitation
CRW	Community Rehabilitation Workers
DoH	Department of Health
DSD	Department of Social Development
DWCPD	Department of Women, Children and People with Disability
EPWP	Expanded Public Works Programme
HBC	Home-Based Care
HPCSA	Health Professions Council of South Africa
IDP	Integrated Development Plan
INDS	Integrated National Disability Strategy
NGO	Non-Profit Organization
SANABP	SA National Association of the Blind and partially sighted Persons
UNICEF	United Nations Children’s Fund
WCPT	World Confederation of Physical Therapy
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND TO THE STUDY

Globally, more than one billion people, or approximately 15% of the world's population live with some forms of disability and 80% of them are found in developing countries (World Health Organization, 2014). About 10% of the world's young population are born with a disability or become disabled before the age of 19 (Philpott and McLaren, 2011). In Australia, approximately 11% of the population is living with disability, of which 4% have profound disabilities and 7% have moderate disabilities (ABS, 2010b), as cited by Kevanagh, Krnjacki, and Kelly (2012). In Tanzania over 9% of the population is living with disability, including children (McNally and Mannan, 2013). According to Statistics SA (2014a) on Profile of persons with disabilities, 7, 5% of the population 5 years and older are living with disabilities.

The research summary on disabilities and inequality by Kevanagh, Krnjacki, and Kelly (2012) reveal that, the degree and types of disabilities vary according to people's circumstances. There are different types of disability. These include sensory, neurological, physical, intellectual, cognitive and psychiatric disabilities. There are some forms of disabilities which are hidden, like epilepsy while others, such as cerebral palsy may be visible. Persons with disabilities may require specialized care, resources and commitment which place a very high demand of time and responsibilities on the one

caring for them (Selepak, 2009). However, it depends on the severity of disability to link the demand of caring. Therefore Community-Based Rehabilitations comes in as a strategy for community development and social integration of all persons with disabilities.

In the mid-1970s, Community-Based Rehabilitation (CBR) was promoted by the World Health Organisation (WHO) as a strategy to respond to the needs of persons with disabilities, through the provision of basic services at a community level, particularly in developing countries with limited resources (Kuipers and Doig, 2010; WHO, 2011). It is implemented through the combined efforts of persons with disabilities themselves, their families, organizations, communities, and the relevant governmental and non-governmental health, education, vocational, social and other organizations (Caleridge and Hartley, 2010).

In economically developed countries, Community Based approaches often exist across service sectors and complement inpatient and traditional rehabilitation services which include hospitals, medical clinics or institutions (Kuipers and Doig, 2010). In Australia government and other agencies in developed countries, are paying attention to addressing issues affecting the caring of persons with disabilities. There are also policies and the *Carers Recognition Act* of 2004 which are aimed at benefiting carers for persons with disabilities in Australia and Western Australia (Geere, Gona, Omondi, Kifalu, Newton, and Hartley, 2012)

In developing countries, Community-Based Rehabilitation plays an important role in trying to alleviate the impact of impairments on participating in the daily life activities on

persons with disabilities in their communities (WHO, 2011), as cited by Wegner (2015). The World Confederation for Physical Therapy (WCPT) (2003) reported that CBR caregivers for persons with disabilities act as local advocates on behalf of persons with disability and their families with the health services personnel. Furthermore, they provide continuity of care in the community on behalf of professionals. In East Africa, such as Kenya, equipment and therapy are used in caring for persons with disabilities. However, it is not easy to access them, particularly for poor people and those from rural areas. Some caregivers experience a challenge of physical dysfunction due to their caregiving activities (Geere et al, 2012).

In South Africa, Rehabilitation services were rendered in hospitals, focusing on the deficits of persons with disabilities. However, such services often failed to meet the needs of persons with disabilities in terms of availability and appropriateness. The Department of Social Development (DSD) and the Department of Health (DoH) have developed a strategy whereby individuals and groups are encouraged to volunteer and develop programmes within their communities for which they will be receiving funding in order to respond to the needs of persons with special needs. According to Statistics South Africa (2014b), there are approximately 57 603 persons with disabilities in Vhembe District. Their disability varies, some have a problem with sight, hearing, physical and mental disabilities and others have difficulty in self-care. Persons with physical disabilities need assistive devices as tools to overcome their barriers, such as wheelchairs, waling frames, crutches (Whitehead, 2004). The important enabling mechanisms for persons with visual impairment are independence training, assistive devices such as a white cane, braille writing tools, specialized computers, personal

assistance in the form of guide dogs, and access to reading materials in braille (DSD, 2009). Community volunteers who are known as CBR caregivers are responsible for caring for persons with profound disabilities, such as being unable to do anything for themselves, such as eating and drinking, dressing themselves, getting up from lying, or even moving around (Loveday, 2006). Additionally, caregivers in the CBRs also providing care for those who can do something on their own (Kevanagh, Krnjacki, and Kelly, 2012). According to the results from the study conducted by Akinsola, Mamabolo, Ramakuela, and Tshitangano (2013), there is a shortage of manpower and resources which seems to be affecting CBRs in Vhembe District for people with disabilities. Hence, the study is aiming at exploring and describing the challenges faced by CBR caregivers.

1.2 PROBLEM STATEMENT

The researcher has observed that caregivers in the CBRs do not stay longer in their positions they drop out and they do not volunteer in numbers. Dropping out of caregivers from the CBRs may have a negative impact on the health of persons with disabilities as there will be no one to take care of them. It will also be a challenge if the drop-out rate increases, as it will lead to the closing of the CBR. This will not reflect well for the Department of Health and Social Development and the Vhembe District as a whole for failing to sustain CBRs. The researcher was therefore interested in finding out from the current caregivers what challenges were they faced with.

1.3 RATIONALE FOR THE STUDY

Several studies have been conducted on the challenges of caring for persons with disability. However, fewer studies focusing on the challenges faced by Community-Based Rehabilitation caregivers have been done in South Africa. However, the researcher has not yet found a documented study which specifically focused on the challenges faced by CBR caregivers for persons with disabilities in Vhembe District. It is therefore important to explore and describe challenges faced by CBR caregivers for persons with disabilities in Vhembe District, South Africa.

1.4 SIGNIFICANCE OF THE STUDY

The results of this study may be used to formulate recommendations which may benefit the following stakeholders: communities, community caregivers, policy makers, donors, persons with disability, CBR managers, future researchers, and relevant departments. Communities might be aware of the challenges and come up with the strategies to assist caregivers where they can. Caregivers' conditions that interfere with their participation in CBR could be improved and other challenges might be resolved. Policy makers might draw up a policy which addresses the strategies to meet the needs of caregivers for persons with disability. Donors might offer support to caregivers and persons with disabilities, which could enhance their quality of life and improve the CBR itself in terms of resources. Managers of CBR might become aware of the challenges that are encountered by caregivers and try to seek help from other stakeholders. The results might also assist future researchers who might be interested in doing their studies based on the related topic as they may use results and recommendations to identify research gaps. The relevant departments working with CBRs for persons with

disabilities might gain an insight and understanding on how important is CBR and assist caregivers.

1.5 PURPOSE OF THE STUDY

The purpose of this study was to explore and describe the challenges faced by CBR caregivers for persons with disabilities in Vhembe District, South Africa.

1.6 STUDY OBJECTIVES

- To explore the challenges faced by CBR caregivers for persons with disabilities in Vhembe District.
- To explain the coping strategies for CBR caregivers for persons with disabilities in Vhembe District.

Research questions

- What are the challenges faced by CBR caregivers for persons with disabilities?
- What are the coping strategies for caregivers in CBR, in Vhembe District?

1.7 DEFINITIONS OF KEY TERMS

Caregiver

An individual who assists in identification, prevention of an illness or disability (American heritage, 2016). In this study, caregiver was be a paid or not paid person whom his/her job description is to provide care to persons with disabilities with their daily activities in Vhembe District.

Challenges

A new or difficult task that tests somebody's ability and skills (Hornby, 2015). The task or experience which hinders CBR caregivers from participating their full potential in caring for persons with disabilities.

Community-Based Rehabilitation

“CBR is strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services” (Philpott, 2006). CBR is a strategy developed within communities whereby individuals and group establish programme to persons with disabilities with the aim of providing care, in combination of disabled people themselves, their families, appropriate health, education, vocational and social services.

Disabilities

World Health Organisation (2015) defined disabilities as an umbrella term, covering impairments, activity limitations, and participation restrictions. Disability is any continuing condition that restricts individuals from participating in their everyday activities in this study.

CHAPTER 2

LITERATURE REVIEW

2.1 OVERVIEW OF COMMUNITY-BASED REHABILITATION

CBR is usually provided in natural community settings rather than formal service delivery settings such as hospitals. Its core is on the active engagement of clients, family and even community members in service delivery. CBR seeks to equip, empower and educate persons with disabilities and all stakeholders involved towards the goal of independence and community participation. CBR was established to assist persons with disabilities to contribute to their own communities, and to encourage community members to promote and respect human rights. CBR does not address disability in the acute stages of illness or injury, but assists people whose disabilities require long-term rehabilitation and care. The needs of clients, the presence of disability support, environmental resources including availability of generic services in the community, the availability of skills and expertise, practical feasibility, and the availability of funding, determines the nature of CBR services (Kuipers and Doig, 2010).

2.2 CHALLENGES FACED BY CBR CAREGIVERS FOR PERSONS WITH DISABILITIES

Community-Based Rehabilitation caregivers help in meeting the needs of persons with disability and helping them in rehabilitating them, so that they can do things on their own without assistance. Providing care for persons with disability may need more commitment and resources than for people without disability. However, those

Rehabilitation caregivers are faced with some challenges. The challenges vary from one CBR to the other. Some of the challenges include the following: unavailability of resources, caregiver's poor health, lack of training and education and lack of funding. However, the above challenges might not be the only challenges in all CBRs.

2.2.1 Unavailability of resources

The resources needed in the CBRs are human resources, material resources, and financial resources. Human resources are resources such as managers, CBR personnel, administrators, assistants and drivers, material resources include equipment, office space, furniture, computers, mobile phones and vehicles. However, the resources needed in a CBR may not be always available (Khasnabis et al 2010). The field staff face various challenges in performing their roles, both material and non-material of origin. According to Rozing (2015) study findings, a high workload of CBR workers is challenges to most managers and caregivers. The causes of the workload is due to shortage in human resources. However, a high workload among CBR caregivers is associated with less job satisfaction and performance motivation, the human resource shortage is likely not only influencing the number of persons who are supported, but also the quality of provided support by caregivers.

CBR Caregivers need to call specialists for help when the needs of persons with disabilities are beyond their expertise. However, they often do not get adequate support. Such specialists are in short supply, especially in low-income areas. The most underused resource in CBRs and communities in most parts of the world are persons with disabilities themselves. Some CBRs are faced with some challenges when it

comes to the availability of water and sanitation (UNICEF, 2013). Lack of resources tends to lead caregivers and persons with disabilities in sharing the same toilets with no adequate hygiene. A study conducted by Luruli, Netshandama, and Francis (2016) revealed that assistive devices provided to the CBRs are of poor quality which means that material resources is a challenge.

In rural India, female individuals with disabilities do not access rehabilitation services due to lack of female caregivers to assist them. Female caregivers were available but they are just dropping out and this leads to lack of human resources (Mannan, MacLachlan, and McAuliffeH, 2012a). According to Mannan, et al. (2012b), information on human resources for rehabilitation is inadequate in many countries. In Uganda, there is a shortage of health personnel, particularly orthopaedic surgeons, physiotherapists and psychiatric nurses. This leads to corrective surgery having to be undertaken outside the district, which affects the access and increasing the cost. Human and material resources are also limited (Musoke, 2010). A research paper by Kendall, Muenchberger and Matalano (2009) showed that CBR caregivers has faced ongoing barriers to implementation, including lack of resources, and limited opportunities.

According to the CBR Guidelines (WHO, 2010) as cited by Chappell and Lorenzo (2015), access to assistive devices are an important part of any development strategy in the CBRs. Without assistive devices, many persons with disabilities would not be able to function independently and gain education. However, in the Western Cape, some persons with disabilities are still struggling in terms of receive devices due to poor human resource management.

2.2.2 Caregiver's poor health

Some caregivers in the study conducted by Geere et al (2012) linked their physical dysfunction they were experiencing with the caregiving activities. Physical and emotional health of caregivers is negatively impacted by the demands of caregiving. Long-term caregiving for persons with disability may lead to chronic physical ailments effects. Caregivers commonly suffer back and shoulder pain, which is associated with the need to regularly lifting those persons with severe disability and could not be able to walk. Caregivers for persons with disability may also experience 'burnout' due to pressure and stress for caring (Murphy, Christian, Caplin, and Young, 2006). The study conducted by Kilonzo (2004) reveals that caregivers of persons with disabilities and chronic illness suffer from psychological and physical stress.

2.2.3 Lack of training and education

Lack of training of CBR caregivers is a challenge which seems to be affecting most of the CBRs globally. This lack of training reduces caregiver's effectiveness when working in complex domains such as health and leads to low recognition by other professionals (Iemmi, Kuper, Blanchet, Gibson, Kumar, Rath, Hartley, Murthy, Patel, and Weber, 2016). According to Cornielje, Majisi, and Locoro (2013), there is no sufficient training for CBR field workers and volunteers as they are offered short training programmes. It has been assumed that the shorter the training, the better the programme would be. The study on "*CBR stories from Africa*" reveal that in Mpumalanga CBR-DSP caregivers receives training which is needs-based. The main focus of this training is on counseling and sharing of information and not therapy. Trainees receive at least three days training

in facilitation skills and basic counseling and human rights workshops (Ferreira, Sibeko, and Mhlabane, 2010).

According to Cornielje, Majisi, and Locoro (2013), in most CBRs, training for both theoretical and practical to take on the task to become CBR staff and clearly defined function and with roles that focus on establishing and developing CBR at local levels, is lacking. Some people believe that CBR is an approach that needs to be adopted across sectors and eventually generate categories of all sorts of practitioners who as part of their professions will contribute and run CBR. As CBR is not having an established identity, it runs the risk of being forgotten or ignored. A research paper by Kendall, Muenchberger and Matalano (2009) showed that CBR caregivers has faced ongoing barriers to implementation, including inadequate training and limited opportunities.

2.2.4 Lack of funding

According to Bruce (2016), in Ghana there is no government funding available for Community Based Rehabilitation or care, and if persons with disabilities and their families cannot afford to pay for it, they will not receive it. CBR programs in Ghana shut down due to a lack of government support and remaining ones are funded private sectors such as churches and international donors. Hartley et al. (2009) as cited by Lemmi et al (2016) reveals that lack of funding for the support of CBR projects is still a challenge in most areas. Although if funding is available, it is often not sufficiently stable to plan for the long term, and once the non-governmental organisation removes the funding the CBR programme is usually not sustainable. The study conducted by Musoke (2010) revealed that Tororo CBR in Uganda has been donor-driven and

therefore faces the challenge of sustainability. The steady funding they used to receive has been phased out, and the Government has not yet indicated how activities are to be handled in future without funding. It has a low local revenue base, too to meet any co-funding obligations.

According to Philpott and McLaren (2011), under the Children's Act (2007), government is responsible for ensuring that comprehensive funded social services are provided for children in poor communities and to ensure that these services are accessible to persons with disabilities. However, although CBRs are rendering services mandated by the Children's Act, funds paid to them do not cover the full cost of providing all the services in the CBRs. The Department of Social Development has acknowledged difficulties with the funding of services provided by CBRs at the national level. This clearly means that the issue of funding is a challenge to DSD. The well-being of many persons with disabilities is not well-protected because of the lack of funding of CBRs. As a result, it is not easy for CBRs working in the disability sector to access government funding. Some organizations are faced with a challenge that even when a service level agreement is in place, funding does not always come through, as agreed. Most donors for CBRs prefer a charitable approach, which is more visible and easy to evaluate and they are satisfied with pictures and numbers of persons with disabilities who have received rehabilitation services. However, it is not easy to evaluate a CBR project that is involved in community development. This makes it difficult for CBRs to get funded.

2.2.5 Poor relationship with government and families

Relationships and partnerships operated at several levels in the CBR programme to enhance its effectiveness. It is important that partnerships between NGOs and government are based on criteria of mutuality and respect. However the study conducted by Dawad and Jobson (2011) that revealed that the partnerships with government is inadequate as the government used their position as providers of funding to dictate how programmes should be run, and did not consult with the NGO around changes made to programmes. It was also noted that the government is not interested in consultation and dictatorial and there is no relationship and partnership between the government and NGOs which includes CBRs.

Most CBR caregivers face challenges in establishing collaboration with persons with disabilities and their family, as well as the community. The reasons for the challenges in finding support and recognition from the family were different expectations and a negative attitude. CBR caregivers are struggling to get support sometimes due to poverty and illiteracy from where they are operating. (Rozing, 2015)

2.3 COPING STRATEGIES OF CBR CAREGIVERS

The term coping refers to the things caregivers do to increase a sense of well-being in their lives/workplace and to avoid being harmed by challenges they are facing. Caregivers use a broad range of coping strategies of which some strategies are more successful in some situations than in others. However, other caregivers tend to be avoidance in a way of dealing with the challenge they are facing (Savage and Bailey,

2004). Coping strategy differ from one individual to another depending on internal strengths and resources available. Coping is complex and it may include a variety of behavioural efforts in which an individual manages challenges and stressful situations. Failure to adopt a coping mechanism may lead to deterioration of health of both the caregiver and care-recipient (Kilonzo, 2004).

Acknowledge that, despite of all the burden and stress caregivers may have, you have made a conscious choice to provide care. Therefore, some caregivers focus on the positive reasons behind that choice of caring. Speaking up is also one of the coping strategies used by caregivers of persons with disabilities. If ever there a challenge, is best to talk to someone for guidance and advice as a caregiver rather than stressing with a burden alone (Melinda Smith and Gina Kemp, 2016). Informal sources of support such as friends and religious groups and the use of respite care services reduces stress in caregivers of persons with disabilities. Building relationships with other caregivers who are in a similar situation also helps reduce stress Solomon et al (2001) as cited by (Gona, Mung'ala-Odera, Newton and Hartley, 2010)

2.4 SUMMARY

The aim of chapter two (literature review) was to explain and describe what other authors and researcher are saying about the challenges faced by CBR caregivers. The government is failing to provide what is needed for the CBRs to run properly. This implies that without government and from non-governmental organization support towards CBRs, the programmes will never meet the needs of persons with disabilities even though caregivers are willing to do so.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The discussion in this chapter was about the choices of research design and methods. This chapter includes the research approach, research design, study setting, population, sampling procedures, research instrument, pre-testing, trustworthiness, and data collection methods, method of data analysis, ethical considerations and dissemination and implementation of results. It also contains a clear explanation of how the study was conducted.

3.2 RESEARCH APPROACH

A qualitative approach was used to explore and describe the challenges faced by caregivers caring for persons with disabilities in the CBRs, Vhembe District. The researcher used this approach in order to analyze information obtained from caregivers in the form of words than numbers, and to obtain first-hand in-depth information from caregivers rather than the views of other people who are not CBR caregivers.

3.3 RESEARCH DESIGN

A qualitative phenomenological design was used to explore and develop an in-depth understanding of the caregivers' challenges. This design was best for this study as the researcher was aiming at understanding the lived experiences of caregivers. This

design has philosophical underpinnings and typically involves conducting interviews (Creswell, 2014).

3.4 STUDY SETTING

The study was conducted in Vhembe District. Vhembe District consists of four local municipalities: Thulamela, Makhado, Mutale and Musina Municipality. The District is located in the Northern part of Limpopo Province and shares borders with Capricorn, Mopani District municipalities in the eastern and western directions respectively. The District covers 21 407 square km of land with a total population of 1 294 722 people, according to Stats SA, 2011. The district had a total of 335 276 households, mostly rural (Vhembe IDP, 2013/2014).

There were three (3) CBRs for persons with disabilities within Vhembe District which consisted of appropriately 200 persons with disabilities and nine (09) caregivers. The CBRs were established by community members who started as volunteers and therefore apply for funding from different stakeholders in order to provide for the needs of persons with disabilities. However, CBRs are Department of Social Development infrastructures. The Vhembe District CBRs consist of caregivers, gardeners, coordinators and managers. There are persons with different types of disabilities, including sight, hearing, communication, physical and mental disabilities and those with difficulty in self-care.

3.5 STUDY POPULATION

Barbie (2010) defines the study population as the aggregation of elements from which the sample is actually selected. The total study population consisted of 9 caregivers working in three CBRs for persons with disabilities within Vhembe District. Table 3.1 shows the total population per CBR.

3.1 Number of CBR Caregivers in Vhembe District per Municipality

CBR	No. of caregivers
Makhado	02
Mutale	02
Musina	05
Total	09

3.6 SAMPLING PROCEDURES

Since there were only three (3) CBRs for persons with disabilities located within Vhembe District, all CBRs were included in the study. The study was supposed to have been conducted with the entire population of nine (9) caregivers who were purposively selected. They were purposively selected in the sense that only caregivers were interviewed not all CBR workers. However, it was conducted with a sample size of six (6) caregivers because the other three were absent during the interviews. CBR caregivers were interviewed until data saturation and then interviews were stopped. Data saturation is when the researcher finds that there is no additional data needed to

develop new properties of categories and the categories are disentangled (Creswell, 2014).

Table 3.2 shows the number of caregivers who were part of the study per CBR.

Table 3.2
No. of caregivers who participated in the study

CBR area	No. of caregivers
Musina	03
Mutale (Thengwe)	02
Makhado (Elim)	01

Inclusion criteria

The criteria of inclusion for sampling will be:

- ❖ Being a caregiver in a CBR for persons with disabilities in Vhembe District.

3.7 RESEARCH INSTRUMENT

A semi-structured interview guide was developed by the researcher for data collection. The questions were opened-ended to allow caregivers to share their challenges openly. One central question to stimulate the discussion during the interviews was, “*What are the challenges that you face when caring for persons with disabilities?*”. However, additional questions not anticipated in the instrument were asked as follow-up questions, to allow for more thoughtful responses from the caregivers and rephrasing

was considered for clarity. The questions in the instrument were drafted in English, but interviews were conducted in Tshivenda as not all caregivers were comfortable with English. Demographic information for each caregiver was also included as the first section on the interview guide.

3.8 PRE-TESTING

The instrument was pre-tested with one CBR caregiver who have similar characteristics to the study participants, to determine whether the questions were appropriate and accurate. The responses obtained during pre-test were used when analyzing data as the pre-test was done just to validate the instrument. Through pre-testing, the researcher then found out if questions in the interview guide elicited relevant responses to the discussed topic.

3.9 TRUSTWORTHINESS

Four strategies for establishing trustworthiness were used; namely, credibility, transferability, dependability and conformability (Shenton, 2004).

3.9.1 Credibility

To ensure credibility, the researcher provided a brief description of her qualifications and background and encourage caregivers to be open from the beginning of the sessions, with the aim of establishing a rapport in the opening moments and indicating that there is no right or wrong answers to the questions. Thereafter, the researcher was engaged in prolonged phenomenological interviews for about 30 to 40 minutes with

caregivers. Observation and in-depth individual interviews were used as different methods of data collection with different caregivers and different CBRs. After the data has been collected, the researcher played back the tape and read field notes to confirm if the responses were in line with the study objectives and follow-up interviews were conducted to validate responses which the researcher did not understand very well. The researcher then undertook an examination of previous research findings to assess the degree to which the study's results were congruent with those of past studies to ensure credibility.

3.9.2 Transferability

Transferability was ensured through the provision of background data to establish context of the study. The researcher ensured that the findings and conclusions were useful to other settings and populations, not only Vhembe District. This study was conducted in different environments with different people but using the same methods to ensure transferability. In addition, description of the challenges faced by CBR caregivers were detailed in each CBR. Research design and methodology ensured possible application of the study in other settings.

3.9.3 Dependability

Field notes were recorded during data collection to ensure dependability. The processes within the study, which include research design and its implementation, describing what was planned and what will be executed on a strategic level; the operational detail of data collection, and addressing the trivial details of what was done

in the field, and reported in detail. This was done in such a way that even future researchers gain the same results. The researcher had an assistance of an independent coder in analyzing data and discussing findings. The effectiveness of the process was also be evaluated.

3.9.4 Conformability

The researcher used the written field notes and a tape recorder to confirm if the collected data meets the objectives. Substantial literature review was done to verify whether existing literature supports the findings or not. Follow-up interviews were conducted for validation of data. The researcher ensured that the study findings were the result of the challenges faced by CBR caregiver in Vhembe District and their ideas rather than the preferences of the researcher. All methods adopted in this study were acknowledged within the research report. The findings and report were peer reviewed and evaluated by supervisors.

3.10 DATA COLLECTION METHODS

Data was collected through in-depth individual interviews and the use of a tape recorder.

Procedure

All CBRs for persons with disabilities in Vhembe District were visited by the researcher in different days to request for permission to conduct the study. Therefore, on the very same day of requesting for permission, appointments were made with the managers for

each CBR to facilitate meeting with the caregivers. Then the researcher suggested that the caregivers be the ones to suggest a convenient day and time for the meeting. The researcher used 10 days to visit all the CBRs within Vhembe District.

Before the interviews, caregivers were distributed with information sheets and consent forms to sign. The purpose of the study was explained to them. However, it was made clear to caregivers that they have the right to withdraw from the study at any point, and they will not be required to disclose a reason to the researcher. Caregivers were also encouraged to be open from the beginning of sessions, with the aim of establishing a rapport in the opening moments. Thereof, caregivers were told that there is no right or wrong answer to the questions.

During interviews with caregivers in each CBR, biographic information for each caregiver were asked first. Therefore, one central open-ended question was asked, followed by probing questions. The interviews in each CBR lasted for about 20 minutes and more, but it was not the same in every CBR depending on the fact that not all caregivers had a lot of information to give for 1 day. Follow-up interviews were conducted for validation of data. The interviews took place in CBR centres in Vhembe District and it was suggested by caregivers themselves. A voice recorder was used with the permission of the caregivers to capture the interview but not with all caregivers. Field notes were also written during the interview to record non-verbal gestures. The caregivers were told their rights and shown the stop button so that they can stop recording if they do not want information that they are giving to be recorded. Caregivers were allowed to express their challenges freely. Although, the researcher ensured that

caregivers provide information which is aligned with the objectives of the study. However, the interviews were being stopped when caregivers give no new information and when they have said that they have no other information.

3.11 METHOD OF DATA ANALYSIS

Data was analyzed using thematic analysis as suggested by Braun and Clarke (2006)

3.11.1 Phase 1: Familiarizing yourself with your data

The researcher played the audio for interviews several times to be familiar with the findings and also transcribe. After that the entire data set was read repeatedly in an active way to search for meanings, ideas and identify possible patterns. After being familiar with data, researcher started marking ideas for coding. The researcher then checked the transcripts back against the original audio recordings for accuracy.

3.11.2 Phase 2: Generating initial codes

This phase involves the production of initial codes from the data. The researcher coded the content of the entire data set. The coding was done manually. However, the researcher was working systematically through the entire data set, giving full and equal attention to each data item, and identify interesting aspects in the data items that may form themes across the data set. During the process of coding, the researcher wrote notes on the texts which were analyzed using highlighters to indicate potential patterns and identify codes and then match them up with data extracts that demonstrate that code.

3.11.3 Phase 3: Searching for themes

Data had been initially coded and collated. The researcher then sorted the different codes into potential themes, and collate all the relevant coded data extracts within the identified themes. The researcher started to analyze codes, and consider how different codes may combine to form an overarching theme. Table was used to organize codes into theme-piles.

3.11.4 Phase 4: Reviewing themes

The researcher read all the collated extracts for each theme, and consider whether they appear to form a coherent pattern. The candidate themes appeared to form a coherent pattern, then researcher focused on re-reading the entire data set to ascertain whether the themes work in relation to the data set.

3.11.5 Phase 5: Defining and naming themes

The researcher defined and further refined the themes which were presented for analysis, and analyze the data within them. The researcher went back to collated data extracts for each theme, and organize them into a coherent and internally consistent account, with accompanying narrative. The themes were named and they contained sub-themes. Then the researcher gave the analyzed data to peer to review, independent coder, supervisors for evaluation and proof reader for language editing before producing report.

3.11.6 Phase 6: Producing the report

The researcher had a set of fully-worked-out themes and sub-themes, and involves the final analysis and write-up of the report. The report will be in a form of dissertation and might as well be published.

3.12 ETHICAL CONSIDERATIONS

3.12.1 Permission to conduct the study

Research proposal was presented to the Department of Public Health, School of Health Sciences Higher Degrees Committee for quality check. The research proposal was further submitted to the University of Venda Higher Degree Committee for approval. After the approval of the proposal by the University of Venda Higher Degree Committee, the researcher applied for ethical clearance certificate from the University of Venda, Research Ethics Committee. The Ethical clearance request was also submitted to the Provincial Department of Social Development for permission to conduct the research in the Community-Based Rehabilitation in Vhembe District. The Ethical clearance request was also submitted to each CBR manager. The researcher also requested permission in writing from each CBR manager.

3.12.2 Voluntary participation

Caregivers were not forced to be part of the study by the researcher. Rather, they were encouraged to participate freely without any fear. It was also made clear to caregivers

that they have the right to withdraw from the study at any point, and they will not be required to provide a reason to the researcher.

3.12.3 Informed consent form

The researcher gave a brief about the purpose, objectives and significance of the study for informed decision-making to caregivers. The informed consent forms and information sheets were administered to willing caregivers to sign.

3.12.4 Protection of participants

Researcher ensured protection of participants by avoiding asking sensitive questions which might expose caregivers to mental distress, whether intentional or unintentional. If during the interview the caregiver showed emotional distress, the researcher was going to stop the interview. The researcher also applied this ethical consideration of preventing harm to caregivers by not discussing issues that might have made them feel uncomfortable. The researcher used language which was acceptable to the caregivers.

3.12.5 Confidentiality and Anonymity

As caregivers were signing the information sheet and informed consent, they used their real names, and they were assured that those forms will be kept in a safe place where no one can see them except of the supervisors. Caregivers were also assured that any information they were giving will not be disclosed to anyone and their names will not be published or mentioned in the dissertation or anywhere else.

3.12.6 Rejection of any form of plagiarism

One of the key ethical principles of scientific publication is the acknowledgment of others' sources. In this way, the researcher referenced all sources consulted, either directly or indirectly, which had made a significant contribution to this study. The researcher adhered to this ethical issue throughout the study, by ensuring that all journals, books, articles and other sources of information were acknowledged, both in text and in full references.

3.13 DISSEMINATION AND IMPLEMENTATION OF RESULTS

The report of the study in the form of a dissertation will be submitted to the University of Venda Library. The findings might be presented to the Department of Social Development in Vhembe District and at the Provincial Research Day, workshops, national and international conferences. Furthermore, the findings might as well be published.

3.14 SUMMARY

The aim of this chapter was to discuss the research methodologies that the researcher used in collecting data of the study. The chapter outlined more on the methodology procedures and requirements in order to gather information. The researcher explained the research methods, data collection instrument, sampling, analysis and ethical considerations.

CHAPTER 4

STUDY FINDINGS AND DISCUSSION

4.1 INTRODUCTION

This chapter focuses on the discussion of the qualitative study findings obtained from CBR caregivers for persons with disabilities in Vhembe District, South Africa. The study findings are discussed in accordance with the study purpose and research questions. It also presented the analysis of the raw data according to the themes and sub-themes to reflect CBR caregivers' challenges. Literature control was done to support the study findings by comparing them in order to find out whether there is a difference, similarities and changes with what the previous researchers found. The purpose of this study was to explore and describe the challenges faced by CBR caregivers for persons with disabilities in Vhembe District, South Africa. The objectives of the study were to:

- To explore the challenges faced by CBR caregivers for persons with disabilities in Vhembe District.
- To explain the coping strategies for CBR caregivers for persons with disabilities in Vhembe District

4.2 STUDY FINDINGS

A total of 6 Community Based Rehabilitation caregiver for persons with disabilities in Vhembe District were interviewed. One central question to stimulate the discussion during the interviews was, *“What are the challenges that you face when caring for*

persons with disabilities?”. However, additional questions not anticipated in the instrument were asked as follow-up questions, to allow for more thoughtful responses from the caregivers and rephrasing was considered for clarity. The data presented was collected using in-depth individual interview as a data collection method and an interview guide (**APPENDIX 3**) as an instrument. Table 4.1 outlines profile of CBR caregivers and table 4.2 outlines the summary of the findings of the qualitative interviews with the Community Based Rehabilitation caregivers.

4.2.1 Profile of CBR caregivers

This section was about presenting the biographical information of CBR caregivers in Vhembe District who were involved in the study. The presentation addresses information about caregivers which include: name, gender, age, occupation, qualification, CBR name, CBR area and years of experience. The biographical information of the caregivers is presented in Table 4.1.

Table 4.1
Biographical information

Participants	Gender	Age	Occupation	Qualifications	CBR name	CBR area	Years of Experience
1	Female	43	Caregiver	Grade 10 and Auxiliary health care NQF level 3	Thandululo CBR	Thengwe	11
2	Female	42	Assistance Caregiver	Grade 10	Thandululo CBR	Thengwe	07
3	Female	33	Finance officer, caregiver	Abet level 4, computer literacy and Auxiliary health care	Musina SANABP	Musina	03
4	Male	53	Caregivers	Diploma in teaching	Musina SANABP	Musina	04
5	Male	39	Project officer , caregiver	Computer	Musina SANABP	Musina	04
6	Female	51	Caregiver	Diploma in agriculture	Rivoni society for the blind	Elim	14

Table 4.1 shows the profile of the CBR caregivers who participated in the study. It shows caregivers' age range from 33 to 53 years. This implies that most caregivers are in the middle adulthood. It is also shown that caregivers had experience not less than 2 years and not more than 15 years. In addition, most caregivers seem to be having grade 12 as a low educational level. There were four female who participated in the study and only two males.

4.2.2 Summary of findings from CBR caregivers.

Table 4.2 shows the themes and sub-themes that emerged from the analysis of raw data of the caregivers. These are the findings from Community Based Rehabilitations caregivers for persons with disabilities in Vhembe District, South Africa. Caregivers mentioned the different changes they are facing in their organisations. Six (6) major themes emerged from the data with sub-themes.

Table 4.2

Themes and sub-themes emerged from the findings

Theme	Sub-theme
1. Poor relationships between caregivers, government department and families	1.1. Lack of co-operation from families of persons with disabilities. 1.2 lack of intervention by government.
2. Unavailability of material and human resources.	2.1 shortage of assistive devices and other materials. 2.2 shortage of staff
3. Poor funding system	3.1 inappropriate funding. 3.2 lack of donors
4. Caregivers' well-being	4.1 Emotional challenge of caregivers
5. Education and training	
6. Coping strategies of CBR caregivers	

4.2.2.1 Theme 1: Poor relationships between caregivers, government departments and families.

The study findings showed that caregivers are experiencing challenges within their organisations. CBR caregivers indicated that they are experiencing difficulties to have good relationships with families where persons with disabilities are coming from. Challenges faced by caregivers are said to be a lot and involves different aspect as described by themselves caregivers. The following sub-themes emerged from the main theme

- Lack of co-operation from families of persons with disabilities and;
- Lack of intervention by government departments.

a)Sub-theme 1: Lack of co-operation from families of persons with disabilities.

CBR caregivers expressed their challenges that they do not receive support from the beneficiaries' families. It was revealed that families of persons with disabilities thinks that if their family members receives services form the CBR it may mean that their disability grant will be taken away or disability grant beneficiary maybe changed. Some of persons with disabilities are being locked up by their guardians for that matter. Other members of the families have given up on their members with disabilities and they are switching all the burden to CBR caregivers as they are tired of caring for their family member who has disability. According to Bruce (2016) that CBR workers must first find persons with disabilities for them to provide some services to them but it often difficult

because many families hide their members with disabilities. A caregiver in one of the discussion sessions said:

“In this organisation we operate by going out to the community after person with disability has been identified, but most of these persons with disabilities are still locked up by their guardians. Hhmm, they think that when we are with them, working with them, registering them in our organisation, conducting home visits to assess the situation and what are their difficulties, they think that “Neh, hai” it seems like is a plan that the disability grant for this child or relative will be taken away, you see.” A 51 years old female caregiver with 14 years working experience.

Another caregiver added that:

“Eish, guardians or family members thinks that when we get to their families maybe we are trying to make a way of taking away disability grant of their person.”

Another caregiver also commented that:

“emmh, the challenge that we have is that eeh, as we are working with people from rural and some from villages, some people don’t have knowledge about this things of organisations, and it is difficult for us to work with those communities and families because they think that maybe the disability grant for their person will be suspended, ehh, and they end up not accepting us.”

Caregivers also indicted that families of these persons with disabilities don't feel for them as they maltreat persons with disability to the extent to which it ends up affecting caregivers emotionally. When caregivers try to reach out to the guardian or parent to find out what the problem is they do not receive good answers. This findings was supported by the paper written by Wickenden, Mulligan, Fefoame and Katende (2012) which stated that caregivers are encountering difficulties in implementing CBR programmes because of lack of cooperation from the community members, persons with disabilities and their families. A study conducted in Musina reported that families of persons with disabilities does not co-operate with caregivers (Mbedzi, 2014). It was further revealed by Kangethe (2009) that caregivers are not receiving adequate support from friends, relatives, private individuals, and other service delivery networks. One caregiver commented this:

"We are facing a lot of challenges a lot. There are times where a child with disability comes to the organisation without bathing for 3 to 4 days, not bathing at all not bathing and when we try to call the parents or guardians they are so rude and tell us that they have allergies and if it was possible that the organisation does not close, they were just going to bring all the stuff of the persons with disability including grant and be left free."

Another caregiver commented that:

"When we talk about their grants, their rights are also violated, Eehh, because you find that a person with disability comes to the organisation without proper clothing, but receiving their own R1 500.00. They don't care about them, they

only bath them, when? On payment day. After the SASSA payment day.....it is done.”

Other families of person with disabilities to try to show some little support and appreciate what caregivers are doing, but due to the fact that most members of the families are unemployed, they lose co-operation and leave all the responsibility of caring to caregivers alone.

“They leave us responsible alone. And most of the time you find that no one is working in those families hmmm. Even though they may want to co-operate and show support, how are they going to do it?”

CBR caregivers regarded working with family members of persons with disabilities as not an easy task to do. The findings showed that the relationship between families where a person with disability comes from and caregivers is not that good as caregivers are not receiving social support from the families. The findings also showed that caregivers are facing challenges when families where a person with disability comes from are not co-operating. It was also revealed that family members of persons with disabilities see CBR caregivers as threats to disability grant of their relative as they care for it than the life of that person with disability.

b.Sub-theme 2: Lack of intervention by government departments.

Discussions with CBR caregivers in this study revealed that government departments do not care about the challenges that caregivers face as they don't even bother to show

any form of interventions to the challenges that are being raised. One of caregivers said:

“When we mention our problems a person will just say “we will intervene” and they never intervene. We also raise our concerns in the Department of Social Development that this issue of persons with disabilities not being cared for at their homes and the violation of their rights in many places is affecting us, you as government as department what are you saying about it? You find that they will say, NO, don’t worry we will get into it but they never intervene.” A 43 years old female caregiver.

Another caregiver said:

“SASSA department or let’s say worker they don’t understand at all, you can take a blind person there and they see that this person cannot see, but they will tell you that No, we need this papers and this papers and you end up getting tired. We sometimes go to the social work offices for help, but you find that other social workers are just social workers by profession...they don’t have that heart to feel for someone, eeehhh. You go there and talk to the social workers they will say NO, we will assist you and they do nothing, you will go to their offices until you get tired.”

Another caregiver commented:

“We are tired, the government does not take us serious at all. They are failing us by always saying that they will help us but they don’t.”

The findings showed that government departments don't get involved in trying to solve challenges that are faced by CBR caregivers neither to show a little support or intervention to the challenges. A study conducted by Dawad and Jobson (2011) support this findings as it has revealed that the partnerships with government is inadequate as the government used their position as providers of funding to dictate how programmes should be run, and did not consult with the NGO around changes made to programmes. It was also noted that the government is not interested in consultation and dictatorial and there is no relationship and partnership between the government and NGOs which includes CBRs.

4.2.2.2 Theme 2: Unavailability of material and human resources.

Findings from this study revealed that all CBR caregivers have a serious challenge of material and human resources to run the CBR according to its aim. CBR caregivers cited financial problem as the reason for not having resources that are expected to be available when implementing CBR services. The following sub-themes emerged from the main theme:

- Shortage of assistive devices and other materials and;
- Shortage of staff

a) Sub-theme 1: shortage of assistive devices and other materials.

The findings from this study revealed that all CBRs caregivers in Vhembe District are faced with a challenge of assistive devices which are the most important tools/equipment to be used in order to rehabilitate persons with disabilities. It was

revealed that the resources needed in the CBRs are human resources, material resources, and financial resources and they may not be always available (Khasnabis et al 2010). A research paper by Kendall, Muenchberger and Matalano (2009) showed that CBR caregivers has faced ongoing barriers to implementation, including lack of resources, and limited opportunities. This is how a caregiver expressed it:

“There is an issue of walking sticks for people who cannot see and for one to buy them is when you do what, eehhh, we should have received money from DSD, and sometimes you find that, eeh, the money comes in late and those people who cannot see are really in need of those sticks because they use them in their basis in their lives. That’s our challenge.”

Another caregiver said:

“We only have 4 specialised computers, the one which speaks when the person who cannot see is working with it, shortage of assistive devices to count money and walking sticks.”

A 51 years old caregiver with 14 years working in the CBR added that:

“Assistive devices we don’t have, truly speaking, training devices of people who are blind are a lot, but we have nothing even one cane here in this organisation we don’t have because we don’t have donor funding to buy those canes and canes are expensive is about R450.00 each. And if we have to buy them for so many people, what are we going to use to buy them. Training devices for these people are so many and they not cheap.”

“We don’t have enough brailed machines. Come January or December, they will go around, the government will walk be busy delivering books even here at our organisation, even though they know very well that this is an organisation for the blind those books which are not brailed and they know that this CBR is for people who cannot see, how do they learn.”

Caregivers mentioned that their CBR fall under the same category with Early Childhood Development (ECDs) but there are material resources that are needed in their CBR but there are not available to them.

“We have a challenge that we don’t have beds for maybe, there is resting time, we are just trying to walk around asking for donations, the blankets and other staffs we got them from SABC 2, Muvhango actors and Phalaphala FM. But the challenges is what...?, is that we do have beds for resting during rest time or when it sick bay maybe other child is not feeling well can get a place to rest, we have a challenge on that.”

“How many wheelchairs do we have??mmh, we have three wheelchairs, two (2) we got them from SABC 2 and one (1) from the Department of Social Development, is only those three. This other one is for a certain child who comes with it from her home is not for the organisation. They are not that much in a way that we can say they are enough because we carry one child drop her and they go take another one using the same wheelchair just like that.”

Another caregiver said:

“We don’t have recreational equipment for these children to have life skills and be active, but when they fund us they told us that we are like ECDs but ECDs are receiving money for miswinki but us we don’t.”

Some CBR caregivers in this study explained they lack other important material resources needed in their organisations. It was revealed in this study that all CBR caregivers in Vhembe District are facing challenge on shortage of assistive and training devices to render quality services to person with disabilities. Contradictorily, a chapter on a book on stories of Africa by Musoke (2010) revealed that in Uganda CBRs assistive devices are produced and supplied to the district, meaning that assistive devices is not a challenge to them. A study conducted by Luruli, Netshandama, and Francis (2016) also revealed that assistive devices provided to the CBRs are of poor quality which means that material resources is a challenge to CBRs. Wickenden, Mulligan, Fefoame and Katende (2012) supported the findings of this study as their study revealed that in both countries, it was felt that both human and financial resources are lacking to support CBR. According to Chappell and Lorenzo (2015), in the Western Cape some persons with disabilities do not receive devices due to poor human resource management in within the CBR.

a) Sub-theme 2: shortage of staff

The discussions with CBR caregivers in this study revealed that all of them are facing shortage of staff challenge. CBR workers are resigning and it was cited by the caregivers that they are resigning due to financial problems that they are facing. Other caregivers leave the CBRs here in Vhembe and go to other provinces because there, they get paid in time. On the other hand people don't volunteer in the CBRs for persons with disabilities. This is how a caregiver expressed it:

“As you can see we are only two (2), that other one is just an assistance caregiver because I cannot give care to more than 35 persons with disabilities alone, her duty is to cook but because there is no other way, she then assist me.”

Another caregiver said:

As you can see we are understaffed, we are only two (2) left caregivers in this CBR, the reason why we are only two is money. Five (5) rehabilitators dropped out and now I heard they are working in Mpumalanga province where NGOs are funded and taken serious.

Findings in this study revealed that there is a high rate of caregivers dropping out of the CBRs due to financial problems and a feeling of not being taken serious by the departments. It also shows that the ratio of caregivers to beneficiaries has a huge different meaning that the number of caregivers per CBR is so small. Shortage of staff in Vhembe Districts' CBR seem to be affecting most of CBR caregivers. A study conducted by (Roziing 2015) in Ghana revealed that shortage in human resources is a challenge in CBRs and these leads to high workload of caregivers. A study conducted in

rural India revealed that female individuals with disabilities do not access rehabilitation services due to lack of female caregivers to assist them. Female caregivers were available but they are just dropping out and this leads to lack of human resources (Mannan, MacLachlan, and McAuliffeH, 2012a). According to the results from the study conducted by Akinsola, Mamabolo, Ramakuella, and Tshitangano (2013), it showed that there is a shortage of manpower and resources which seems to be affecting CBRs in Vhembe District for people with disabilities. Similarly, the findings of this study was also revealed by Mannan, et al. (2012b) that human resources for rehabilitation is inadequate in many countries. In Uganda, there is a shortage of health personnel, particularly orthopaedic surgeons, physiotherapists and psychiatric nurses. This leads to corrective surgery having to be undertaken outside the district, which affects the access and increasing the cost and human and material resources are also limited (Musoke, 2010).

4.2.2.3 Theme 3: Poor funding system

The study findings showed that there are some caregivers who are not receiving funds as per agreement with the departments. Hence others do receive according to agreement but not at the agreed time and this leads to poor services within the organisations and the caregivers to suffer financially. The following sub-themes emerged from the main theme:

- Inappropriate funding
- Lack of donors

a.Sub-theme 1: Inappropriate funding.

The discussions with CBR caregivers in this study revealed that all of them are experiencing financial problem. CBR Caregivers explained that this issue of not being funded on time and sometimes funded the amount they did not agree on is affecting them as they have to be consistently changing their plan. A story from Niger by Pate (2010) revealed that there are no sufficient funds for CBR programme activities, especially any expansion because the country is so large. Hartley et al. (2009) as cited by Lemmi et al (2016) reveals that lack of funding for the support of CBR projects is still a challenge in most areas. One of the caregivers said:

“Mmhhh, we get our funding from Department of Social Development. Eemmh it, I might say most of the times funding is available but you may find that, when it comes to what...?, sometimes we tell ourselves that we want to render this type of service to our beneficiaries, when we want to build ramps for those who are using wheelchairs and Musina is too large because we are merged with other part of Mutale municipality. Hmm, it is too large now, and we cannot reach our target of service as the money that we get sometimes is not enough.”

Another caregiver commented that:

“As you can see this organisation was established so many years ago, but there are no funds. That’s why you can see it like this, even though you look at it carefully you can see that the buildings are so old but we cannot even renovate because we don’t have money. The government might say that they will give you

some money, but it is not enough and it ends up not covering all the expenses that we have like petrol, stationary and other things.”

Another one said:

“Sometimes you find that we have made a proposal or they promise that they will fund us with R300 000.00, then when the time of agreement comes for them to pay that money, they pay less amount from what we agreed on, maybe they will just fund us with R200 000.00 meaning they have cut other amount. Same applies to Department of Social Development, they are doing the same thing. They will say here is the contract, per quarter we will give you R20 for example, then come that quarter you submit all the reports for that quarter and they give you R5 instead of that R20 we agreed on, and is tough to do follow up they will call it... is mmmhhhh I forgot what they call it, they say is their audit. We don't understand how they audit the money they we have already had agreement on and they gave us the contract from the beginning and we sign for the amount.”

Some caregivers raised an issue showing that every year they sign the forms from the department of health under Expanded Public Works Programme (EPWP) stipulating that they will receive stipends and they never received even a cent, so their issue of concern is they don't know where their money is pending for several years. Some are experiencing a challenge where they work for several months without receiving any stipends or rather receive a small amount but not from EPWP. Thus these caregivers are having their own families to support financially. One caregiver said:

“As we are working, we are supposed to get our rewards/stipend as we are health practitioners. They said that those who are under EPWP will receive some stipends, but from all the disability organisations/centres here in Vhembe District we are just requested to fill forms and wasting the little money and no one is being paid. But the disability district coordinator has been informed about our concern. No one has being paid but we are requested to sign. The Department of Health is giving away our money but it is not reaching us, we don’t know what is going on and where our money is pending.”

Another one added:

“There is somewhere where they are taking our money to, but we are only being used to sign every year, but we don’t get that money. Our duty is just to append our signatures that there is so much for us but I never received even a cent.”

Another one commented:

“There is nothing I can do, I work here, I can even work for six month without getting salary.”

Some CBR caregivers mentioned that lack of funds in the organisations leads them to failure to fulfil their duties and they feel it was going to be helpful if they give them something so that the services in the CBRs could be run accordingly. Mannan and Turnbull (2007) mentioned some duties which needs to be performed by CBR caregivers which is to train people with disabilities and their family members at the community level. However, this service is not mostly rendered in CBRs around Vhembe

District due to financial challenges. According to Philpott and McLaren (2011), government is responsible for ensuring that comprehensive funded social services are provided for children in poor communities and to ensure that these services are accessible to persons with disabilities. However, although CBRs are rendering services mandated by the Children's Act, funds paid to them do not cover the full cost of providing all the services in the CBRs.

“Once we have a beneficiary in this centre it means the whole family was supposed to be trained, but we are failing to train them because there is no money for us to do that. There were supposed to be trained all of them, if like for example, it means when we go out to train them, we have to blind fold them the entire family for them to feel the pain that that person is feeling, and then we tell them to go and fetch water, cook, do this and that, go to the shop, clean your room, and wash clothes for them to feel pain inside that person. But we end up failing to reach out to those people. Even though we know that this kind of service should be rendered to family members should be trained on certain things so that when the person is at home, they are being accepted even the community to accept the person, but there no money, nothing to render such service.”

Another caregivers said:

“Another challenge is that you may find that the beneficiary, beneficiary I mean a person with disability. Not all beneficiaries are suffering from the same disability, you may find that maybe the person just gone blind maybe last week, is a serious

challenge because for that person to cope with the situation that really he/she cannot see is our problem actually our responsibility to counsel, speak to that person until he or admit that really I will no longer see, and this services need to be rendered in their home but money is the problem.”

Another one commented that:

“After the beneficiaries are being trained the daily living skills then they qualify, they were supposed to be grouped and groomed so that they can start projects but is one and the same thing because it needs money to buy things to start the project but if there is no donation or even one donor who gave money, that means that it can even take three to four years failing to help those people with disabilities. The skills are there but there is no money for implementation.”

The findings of this study revealed that all CBR caregivers are faced with financial challenges. Some challenges are affecting service delivery to person with disabilities. It shown by the findings that financial problem is not only affecting them on the service delivery but also affecting caregivers personally because they have families to provide for. Although if funding is available, it is often not sufficiently stable to plan for the long term, and once the non-governmental organisation removes the funding the CBR programme is usually not sustainable. The results from the study conducted by Mbedzi (2014) showed that some caregivers receive stipends from the Department of Social Development but is not enough as they receive it in a quarterly basis and they have families to support. It was also supported by (DSD, DWCPD and UNICEF, 2012) that, CBR caregivers are faced with challenges for category of personnel as the level of

training and skills are inadequate; stipends are low; and CBR is still a contested concept.

The Department of Social Development has acknowledged difficulties with the funding of services provided by CBRs at the national level. The well-being of many persons with disabilities is not well-protected because of the lack of funding of CBRs. As a result, it is not easy for CBRs working in the disability sector to access government funding. Some organizations are faced with a challenge that even when a service level agreement is in place, funding does not always come through, as agreed. According to Bruce (2016), in Ghana there is no government funding available for Community Based Rehabilitation or care, and if persons with disabilities and their families cannot afford to pay for it, they will not receive it. CBR programs in Ghana shut down due to a lack of government support and remaining ones are funded by private sectors such as churches and international donors.

a.Sub-theme 2: Lack of donors

The discussion with CBR caregiver showed that most of them are struggling in terms of finding donors. It was cited by one of the caregivers that the reasons for them to be struggling is that donors are no longer interested in funding NGOs. A caregiver from the discussion sessions said:

“In this organisation, we have a serious financial problem and when we are thinking of going to the donors, most donors has withdrawn from funding NGOs. You may find that you apply for funds from donors, they tell you everything fine

and it seem to be promising, but at the final stage once everything is been done they will tell you it has been disapproved.”

Another caregiver added that:

“We are trying to engage ourselves with donors but up to so far we there is no progress.”

A 39 years old male caregiver also commented that:

“Eeehhh, we are struggling to get funds from business man, and something lottery and other funders. We are only funded by the Department of Social Development.”

The study findings revealed that most CBR caregivers showed that it is not an easy thing to find donors to fund their organisations. This results was supported by findings from a study conducted by Mbedzi (2014) on the challenges faced by caregivers in the drop-in-centers which revealed that it is difficult for caregivers to get donors. According to Philpott and McLaren (2011) most donors for CBRs prefer a charitable approach, which is more visible and easy to evaluate and they are satisfied with pictures and numbers of persons with disabilities who have received rehabilitation services. However, it is not easy to evaluate a CBR project that is involved in community development. This makes it difficult for CBRs to get funded. The study conducted by Musoke (2010) in Tororo CBR, Uganda revealed that it has been donor-driven and therefore faces the challenge of sustainability. The steady funding they used to receive

has been phased out, and the Government has not yet indicated how activities are to be handled in future without funding.

4.2.2.4. Theme 4: Caregiver's well-being

It was noted during interview sessions with CBR caregivers that being a caregiver for persons with disabilities have a negative impact on their emotional health. CBR caregivers expressed their feelings that when persons with disabilities are not treated well in a way that it came to their attention, it really hurts them a lot as their duty is to ensure that these people are being treated like everyone in the community. One theme emerged from this main theme:

- Emotional challenges of caregiving

a) Sub-theme 1: Emotional challenges of caregiving

Some CBR caregivers mentioned that they are affected negatively by seeing those persons with disabilities every day and knowing that there is nothing they can do change the situation, more especially those from poor families. It was evident even from the narratives of one of the caregivers that their roles had a negative impact on their emotional health. The following responses were elicited from a caregiver:

“Outside is very tough, sometimes when you go out for home visits you may come back crying, and think how I can assist this person. And you think that if I receive money at the end of the month, I was going give even R200 for them to buy maize meal, but you find that I am failing and there is nothing I can do to help them.”

Some caregivers indicated that they are affected emotionally due to discrimination they see towards these people that they are caring for. A caregiver expressed that:

“Discrimination towards these persons with disabilities is a serious challenge to us, our beneficiaries are being discriminated. Our duty as caregivers is to fight for the rights of the disabled, in my activity class if you go there now, you will find that the rights of people with disabilities are being displayed. There is a right which says person with disability has the right to privacy even when they are at hospitals they should be treated like everyone else not that because they have disability they should be attended to even in an open space, he/she has the right to privacy just like everyone else, but the way they are treated even by community members, their rights are being violated. And this affects us emotionally”

“Starting from transport that they are using, you may find that is very cold but because there are those with disabilities inside you find that the tent is opened, but the moment they get off the tent will then cover those who are left. eeh or maybe they are smelling.”

The findings of this study revealed that caregiving for persons with disabilities has an impact on the well-being of most CBR caregivers. Discrimination towards persons with disabilities by the community also contributed a lot on the emotional challenges of caregivers. A study conducted by Geere et al (2012) revealed that caregiver’s physical and emotional dysfunction were experiences linked with the caregiving activities. Physical and emotional health of caregivers is negatively impacted by the demands of

caregiving. Long-term caregiving for persons with disability may lead to chronic physical ailments effects. Caregivers for persons with disability may also experience 'burnout' due to pressure and stress for caring (Murphy, Christian, Caplin, and Young, 2006). The study conducted by Kilonzo (2004) reveals that most caregivers of persons with disabilities and chronic illness suffer from psychological and physical stress and their caregiving roles have a negative impact on their physical and psychological health.

4.2.2.5 Theme 5: Training and education

It was expressed by CBR caregivers during discussion that they are happy with the training they received from the Department of Social Development even though they are other challenges. It was cited by another CBR caregiver that they received a lot of training and they are equipped with a lot of skills. One of the CBR caregivers said:

"We have been trained a lot at Polokwane but for now they have stopped. They trained us a lot, we went to Watervall, even oases hotel, and we used to go there for training, jaah."

Findings of this study showed that most CBR caregivers were receiving proper and adequate training. They were being trained a lot. The study findings was supported by findings from Dawad and Jobson (2011) which revealed that training provided for community-based caregivers in CBRs are very important in ensuring that the services that caregivers provide are relevant and useful. Most CBR caregivers underwent a 2-year training course provided by a local NGO. The training course that caregivers had undergone had a broad scope and covered a wide range of aspects of rehabilitation.

This enabled the CBR caregivers to provide a broader level of assistance to persons with disabilities. However, there are some evident which are in contradiction with the study findings, Lemmi et al (2016) revealed that lack of training of CBR caregivers is a challenge which seems to be affecting most of the CBRs globally. This lack of training reduces caregiver's effectiveness when working in complex domains such as health and leads to low recognition by other professionals. According to Cornielje, Majisi, and Locoro (2013), there is no sufficient training for CBR field workers and volunteers as they are offered short training programmes. It has been assumed that the shorter the training, the better the programme would be. The book on "*CBR stories from Africa*" reveal that in Mpumalanga CBR-DSP caregivers receives training which is needs-based. The main focus of this training is on counselling and sharing of information and not therapy. Trainees receive at least three days training in facilitation skills and basic counselling and human rights workshops (Ferreira, Sibeko and Mhlabane 2010). The literature of these studies by Lemme et al 2016; Cornieljie, Majisi and Locoro 2013; and Ferreira, Sibeko and Mhlabane (2010) are not in line with this study findings. A research paper by Kendall, Muenchberger and Matalano (2009) showed that CBR caregivers has faced ongoing barriers to implementation, including inadequate training and limited opportunities.

4.2.2.6 Theme 6: Coping strategies

It was noted during discussions with CBR caregivers that some caregivers are trying what they think can help them from the challenges they are facing whereas others has

just given up and tend to be ignoring. CBR caregivers had the following responses respectively:

“Ok, yeah, we are trying our best to engage ourselves with relevant people, like eehhm, for those of education, we are trying to engage with the department of education to see how they can assist us because is a worrying factor. And for this one for being sponsored by what eeh, DSD, we are busy negotiating that, neh, their money should sometimes no longer be late because this lead to suffering services. And then we are also trying to engage with Venetia mine for donation in order for sustainability.”

Another caregiver said:

“How can you cope? I work with these persons with disabilities every day, it is so painful to face a person knowing that this person is not 100percent like me, at least me even if I sleep with an empty stomach sometimes I understand, but what has this person done wrong, others don’t even receive disability grant.”

Other caregivers are being motivated by the choice they took to help persons with disabilities.

“Eeehhmm, you can see I’m a person with disability. I’m motivated every time to see to it that the needs of persons with disabilities are being met.”

This study findings showed that some CBR caregivers had some strategies which are assisting them to cope with their challenges rather than to quit jobs. However, other

caregivers tend to be avoidance in a way of dealing with the challenge they are facing (Savage and Bailey, 2004). Lack of support may affect the ability to cope with challenges. It was revealed by Kilonzo (2004) that most caregivers were not coping with their caregiving roles. Acknowledge that, despite of all the burden and stress caregivers may have, you have made a conscious choice to provide care. Therefore, some caregivers focus on the positive reasons behind that choice of caring. Speaking up is also one of the coping strategies used by caregivers of persons with disabilities. If ever there a challenge, is best to talk to someone for guidance and advice as a caregiver rather than stressing with a burden alone (Melinda Smith and Gina Kemp, 2016). Informal sources of support such as friends and religious groups and the use of respite care services reduces stress in caregivers of persons with disabilities. Building relationships with other caregivers who are in a similar situation also helps reduce stress Solomon et al (2001) as cited by (Gona, Mung'ala-Odera, Newton and Hartley, 2010)

4.3 SUMMARY

This chapter presented the study findings about the challenges faced by CBR caregivers. The presentation of study data entails data obtained from six (6) CBR caregivers as respondents in the study.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter consist of conclusions drawn from the results and the recommendations of the study of the challenges faced by CBR caregivers for persons with disabilities in Vhembe district, South Africa. The recommendations include recommendations for the CBR caregivers, community, policy, government, as well as recommendations for future researchers.

5.2 Summary of the study

- **Purpose of the study**

The purpose of this study was to explore and describe the challenges faced by CBR caregivers for persons with disabilities in Vhembe District, South Africa.

- **Study objectives**

To explore the challenges faced by CBR caregivers for persons with disabilities in Vhembe District.

To explain the coping strategies for CBR caregivers for persons with disabilities in Vhembe District

- **Methodology**

A qualitative phenomenological design was used to explore and develop an in-depth understanding of the CBR caregiver's challenges. The study was conducted in three Community-Based Rehabilitation centres located within Vhembe District. The study was conducted with a sample size of six caregivers who were purposively selected from the three Community-Based Rehabilitations centers. An interview guide was developed by the researcher as an instrument for data collection. Data was collected through in-depth individual interviews in order to allow Community-Based Rehabilitation caregivers to express the challenges they face when caring for persons with disabilities freely, without restrictions. Data was analyzed using thematic analysis. Credibility, transferability, dependability and conformability were the measures which were used to ensure trustworthiness in the study. Permission to conduct the study, rejection of any form of plagiarism, confidentiality and anonymity, protection of participants, informed consent form and voluntary participation were included as ethical considerations.

5.3 LIMITATIONS OF THE STUDY

If the target group of the study was CBR staff/workers including managers instead of only caregivers, the study would have yielded more results. The number of CBR caregivers was so small than what the researcher had known. The study was also limited due to dropping out of caregivers.

5.4 CONCLUSIONS

This study pointed out that CBR caregivers are faced with multiple challenges and still some of them are continuing with caring for persons with disabilities even though there

are challenges. It was further concluded that caregivers who participated in the study does not have mechanisms for resolving their challenges. Therefore, there is a need for intervention from different stakeholders such as government departments, family members of persons with disability, and the community members as well for CBR caregiver's challenges to be resolved or minimized.

5.5 Recommendations

5.5.1 Recommendations for CBR caregivers

- The researcher recommends that CBR caregivers form support groups for the entire Vhembe District so that they could share ideas on the challenges and maybe they could come up with strategies to such challenges.
- This might help them come up with strategies which might help them and also the lives of persons with disabilities.
- It is also recommended that caregivers starts some income generating projects in their centers for sustainability of the CBRs.

5.5.2 Recommendations for community and families

- The researcher recommends that members of communities and families should play a role in ensuring that the needs of persons with disabilities are being met by showing support to CBR caregivers and also participate in the implementation.
- It is also recommended that community members should engage themselves in numbers in the community based programmes to fill the gap of shortage of staff.

- Community members including family members of the persons with disability should recognize the burden associated with caregiving responsibilities and be aware of the factors that impact both negatively and positively on the lives of CBR caregivers.
- Where a person with disability receives grant support from the government, guardians or parents of such person with disability should buy affordable assistive devices themselves like canes, crutches and even wheelchairs to reduce government expenditure and making life easier for CBR caregivers.

5.5.3 Recommendations for policy

- Policy makers should work out on a compensation plan for CBR caregivers for persons with disabilities as a way of showing appreciation for their contributions to the health care system.
- There should be also a policy framework or Act drafted with the aim of protecting CBR caregivers as there is an Act about the protection of persons with disabilities.
- It is therefore important to also have policies which protects those who are caring for them in the CBRs.

5.5.4 Recommendations for government departments

- Governments departments should recognize CBR caregivers as partners in the delivery of primary health care to persons with disabilities in community level.

- Therefore there is a need for more support from the government which includes financial support, emotional support and also material resources support that should be commensurate with the needs of the CBR caregivers.
- Provision of counselling sessions to CBR caregivers on coping skills is essential to enable them find solutions to the problems that they encounter in daily basis. This will successively assist them to cope better with their work.
- Since most CBR caregivers had relevant qualifications and were being trained, it is better for the government to see to it that they secure their jobs by making them permanent employees and they are being registered by the department of labour like every employee.
- There should be coordination across different government agencies and service providers in ensuring that CBRs are being provided with the assistive devices, material resources etc, and not the responsibility of only one department.
- The department of education should provide educational training devices to CBRs.
- All government departments should see to it that funding is being provided in CBRs.
- The government should also ensure that CBR caregivers receive appropriate proper payments and in time.
- There should be establishment of complaints mechanisms in every nearby agencies and such complaints should be taken into account without any delay.

5.5.5 Recommendations for future researchers

- Future researchers to investigate why donors pull out or rather not interested in funding CBRs
- Finding out why CBR caregivers drop out.
- Including the entire CBR staff for persons with disabilities as target group if interested in studying the same topic in other setting.

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APPENDIX 1: INTERVIEW GUIDE

A SEMI-STRUCTURED INTERVIEW GUIDE USED FOR THE STUDY.

The interview schedule and questioning

Duration of interview: 40 minutes

The researcher started by introducing herself and extending her gratitude to the caregivers for agreeing to take part in the study and then discuss ethical considerations.

Section A: Biographical information of caregivers

Name:

Gender:

Age:

Occupation:

Qualifications:

Years of experience:

Section B: challenges of CBR caregivers

The researcher's central question was: "What are the challenges that you face when caring for persons with disabilities?" During the interview, the following probing questions were asked:

Where do you get your funding from?

How often do you get paid?

What are your coping strategies?

APPENDIX 2: LETTER FOR PERMISSION TO DEPARTMENT

University Of Venda

P. Bag X5050

Thohoyandou 0950

Head of Department

Department of Social Development

Polokwane

0700

Dear Sir/Madam

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH ON THE CHALLENGES FACED BY CBR CAREGIVERS FOR PERSONS WITH DISABILITIES IN VHEMBE DISTRICT, SOUTH AFRICA.

I'm Murendeni Maphutha, currently studying for a Master of Public Health at University of Venda. As part of the qualification, I am expected to conduct a research project of my choice.

My study is aimed at exploring and describing the challenges faced by CBR caregivers for persons with disabilities in Vhembe District, South Africa. An interview guide will be developed as a tool for data collection. The information obtained will be made available to the University of Venda in the form of a research report and also in your office if needed.

I hope this will help Rehabilitation workers and managers of CBR to be more aware of factors that might have negative effects on the caregivers' participation in CBR.

I remain optimistic and thank you in advance for your support.

Yours faithfully

----- **Date**-----

APPENDIX 3: Letter for permission to Rivoni Society for the blind

University Of Venda
School of Health Sciences
Department of Public Health
P. Bag X5050
Thohoyandou 0950

The manager
Rivoni Society for the blind
P.Bag X344
Elim hospital
0960

Dear Sir/Madam

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH.

I'm Murendeni Maphutha, currently studying for a Master of Public Health at University of Venda. As part of the qualification, I am expected to conduct a research project of my choice.

My study is aimed at exploring and describing the challenges faced by CBR caregivers for persons with disabilities in Vhembe District, South Africa. An interview guide will be developed as a tool for data collection. The information obtained will be made available to the University of Venda in the form of a research report.

I remain optimistic and thank you in advance for your support.

Yours faithfully

----- **Date**-----

Maphutha M

APPENDIX 4: INFORMATION SHEET

Department of Public Health, University of Venda.

I am a post-graduate student pursuing a master's degree in Public Health at the University of Venda. I'm conducting a study to explore and describe challenges faced by Community-Based Rehabilitation caregivers for persons with disabilities in Vhembe District, South Africa. I'm inviting you to become part of the study. Your positive response will enable the researcher to draw some conclusions from the findings and provide recommendations that can be helpful to CBRs. As a participant in the research, you will be entitled to your own privacy about your thoughts, beliefs and personal understanding. After the collection of data, the researcher will take responsibility of maintaining confidentiality and anonymity of the information given by participants.

Statement of agreement to participate in the research study

I have read and understood the contents of the informed consent and I'm freely, voluntarily and willingly, choosing to take part in the study.

Respondents' signature----- Date-----

Witness' signature----- Date-----

APPENDIX 5: INFORMED CONSENT FORM

CHALLENGES FACED BY COMMUNITY-BASED REHABILITATION CAREGIVERS FOR PERSONS WITH DISABILITIES IN VHEMBE DISTRICT, SOUTH AFRICA.

I,.....hereby confirm that the purpose, the procedure, the possible risks and potential benefits associated with participation in this research project have been explained to me by the researcher, Mrs. Murendeni Maphutha and that I am under no coercion to participate in the study. I also confirm that Mrs. Maphutha has informed me that my participation is voluntary and that I will not receive any remuneration of any kind and that I can withdraw my participation at any time.

I certify that the study has been explained to the above individual by me, including the procedure, the possible risks and potential benefits associated with participation in this research project. All questions have been answered to the respondent's satisfaction.

Name of the participant (Print)

Signature

Date

**RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR**

NAME OF RESEARCHER/INVESTIGATOR:

Mrs M Maphutha

Student No:

11610194

PROJECT TITLE: Challenges faced by community-based rehabilitation caregivers for persons with disabilities in Vhembe District, South Africa.

PROJECT NO: SHS/16/PH/21/1909

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Prof T Mashamba	University of Venda	Supervisor
Dr NS Mashau	University of Venda	Co-Supervisor
Mrs M Maphutha	University of Venda	Investigator - Student

ISSUED BY:

UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: September 2016

Decision by Ethical Clearance Committee Granted

Signature of Chairperson of the Committee:

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

UNIVERSITY OF VENDA
DIRECTOR RESEARCH AND INNOVATION
2016 -09- 2 1
Private Bag X5050 Thohoyandou 0950



University of Venda

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