CHALLENGES EXPERIENCED BY PRIMARY CAREGIVERS IN RAISING CHILDREN WITH PHYSICAL DISABILITIES IN MVUNYANE AREA, VRYHEID, KWAZULU-NATAL

By

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DECLARATION

I, the undersigned, **Ntombizodwa Zungu (19981335)** hereby declare that the work contained in this Masters Dissertation is my own work, except where due acknowledgement is in the references. This dissertation has not been previously submitted to any university or institution of higher learning for any qualification or certificate.

Signed ……..

Date ……

DEDICATION

This study is dedicated to my Husband Revd. Thokozani Zungu

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ABSTRACT

The aim of the study was to investigate the challenges experienced by primary caregivers in raising children with physical disabilities who were undergoing rehabilitation in Mvunyane area, Vryheid KwaZulu-Natal using a qualitative approach. Data was gathered using semi-structured interviews from a sample of twenty primary caregivers who were selected using the purposive sampling method. The findings of the study showed that primary caregivers faced a number of social and economic challenges which included inadequacy of the care dependency grant, social isolation, immobility, emotional stress and stigmatisation and discrimination in the community. However, it was noted that primary caregivers used faith-based organisations, support from social workers, families, support groups in their community as their coping strategies.

It was concluded that many primary caregivers who are raising children with physical disabilities have to deal with problem and challenges related with the care that is required. Though the primary caregivers showed commitment to their responsibilities, they also faced challenges resulting in their having emotional difficulties. It was also concluded that a family who has a physical disabled child is likely to fall into poverty. This is because the effects of financial constraints not only affect the primary caregivers of children with physical disabilities but they affect the whole family. It was concluded that there are inadequate intervention care programmes and services designed to assist the primary caregivers and physically disabled children.

It was recommended that healthcare workers should educate all family members on how they can assist the primary caregivers of children with physical disabilities. Social workers should educate primary caregivers about acceptance of disability so that primary caregivers do not feel isolated. Non-governmental organisations and the Government can enter partnerships in developing projects that will financially empower primary caregivers to be self-employed. The Department of Social Development can employ more development workers who will train the primary caregivers on poverty alleviation programmes. Healthcare workers should do awareness campaigns in the communities on disabilities so that people can be familiar with disabilities and that can decrease stigmatisation of people living with disabilities.

Government can provide respite care such as day care centres that will cater for children living with disabilities in the community.

Key words: anxiety, coping strategies, depression, interventions, poverty, social isolation, stigmatisation, discrimination, rehabilitation

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ACRONYMS AND ABBREVIATIONS

ACPF	African Child Policy Forum
CBR	Community Base Rehabilitation
CDG	Care Dependency Grant
CLD	Children Living with Disabilities
DICAG	Disabled Children's Action Group
DPSA	Disabled People South Africa
DSD	Department of Social Development
ECD	Early Childhood Development
HBR	Hospital based rehabilitation
IDDC	International Disability and Development Consortium
KZN	KwaZulu-Natal
NGO	Non-Governmental Organisation
OSDP	Office on the Status of Disabled Person
PCM	Primary Caregivers
PH	Physical Disability
RSA	Republic of South Africa
SAINDS	South Africa's Integrated National Disability Strategy
SASSA	South African Social Security Agency
TBI	Traumatic brain injury
UN	United Nations
UNCRCD	United Nations Convention on the Right of a Child
UNCRPD	United Nations Convention on the Rights of Persons with a Disability
WHO	World Health Organisation
WROD	World Report on Disability

CHAPTER 1:
GENERAL OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This chapter provides the background of the study, the definition of key concepts, problem statement, research aims and objectives, research questions, and the significance of the study. The chapter ends with the chapter outlines.

1.2 BACKGROUND OF THE STUDY

According to the World Health Organization (WHO) (2011), the number of children with disabilities is estimated to be 95 million globally of whom 13 million are said to have severe disabilities. The United Nations (UN) (2012) estimated that about 80% of people with disabilities are living in rural areas and isolated areas. In South Africa, according to Statistics South Africa (Stats SA) (2011), over 2.8 million people are living with disabilities of which half are children under the age of 18 years.

South African society still regards children with disabilities as incapable, ill and a burden on society. In other words, they represent a problem to be dealt with separately from other children's issues. Children with disabilities need primary caregivers in their everyday lives. These primary caregivers encounter different experiences in raising and caring for their children with disabilities. Raising and caring for a child with a disability should not differ from caring for a child without disabilities but raising and caring for a child with a disability has specific challenges. Although the primary caregivers of children living with disabilities have a special and specific role to play in the development of their children, mothers, especially, often face ostracism from their partners, their families and their communities (Office of the President, 1997). Caring for children living with disabilities can be a challenging experience as it sometimes drains the primary caregiver, socially, psychologically, financially as well as health-wise.

In relieving the financial burden of caring for children with disabilities, the South African government provides assistance to disabled children in the form of a Care Dependency Grant (CDG). To be eligible to apply for the CDG, one needs to be a primary caregiver or foster parent of a disabled child. The amount of the grant is R1 690 a month. According to South African Social Security Agency (SASSA) (2018),

the number of children in South Africa who are receiving the CDG is 145 000 but it was mentioned that it is not possible to calculate accurately the take-up rate for CDG because there are no reliable data on the numbers of children living with disabilities in South Africa. The province which was reported to have largest number of children receiving CDG is Kwa-Zulu Natal province with 39 374 followed by Eastern Cape Province with total number of 22 434 in 28 February 2018.

In the South African context, there is limited research on challenges faced by primary caregivers of children with physical disabilities. Nevertheless, some authors like Resch, Mireles, Benz, Grenwelge, Peterson & Zhang (2010: 139) have conducted studies focusing on the challenges and the benefits of caring for a disabled child. According to Resch et al. (2010:139), caring for a child with a disability can be challenging, but many of these challenges are likely due to a lack of necessary environmental supports. Brown (2015:247) and Chimhenga and Musarurwa (2011:99) noted increased stress among caregivers. Raising a child with a physical disability is a major challenge for the primary caregivers, especially those who live in poor resource communities of the developing countries. This includes bearing the additional financial burden for treatment of the child's condition and dealing with stigmatisation associated with disability (Ceylan & Aral, 2010:746).

The WHO (2011: 123) states that disability and health policies place great emphasis on the environment, and its role in limiting the children with physical disability activities and restricting their full participation in society. The social model of disability argues against the previous dominant view that disability is a problem of a person, directly cause by health conditions, which require medical care provided in the form of individual treatment by professionals (Friedman, 1992). It rather views disability as a social construct which requires active steps to combat stigmatisation and to fully integrate children into society. As observed by the researcher, stigmatisation of people with disabilities is quite prevalent in the community and consequently, most of the time, children with disabilities do not have the confidence to play with other children who are not disabled.

McNelly and Mannan (2013:96) argue that children living with disabilities require greater physical care and supervision than average children. Both children and their families need greater emotional and social support. This increased need results in

increased financial, physical, and social demands on their primary caregivers. The study also found that most of the primary caregivers do not have the basic knowledge of how to deal with caregiving of children living with physical disabilities. The unavailability of basic education on the caring role for children with disabilities has had a severe impact on the primary caregivers as this has left them with little knowledge of what to do when it comes to caregiving (Resch et al., 2010:139).

In order to cope effectively with the increased demands associated with children living with disabilities, their primary caregivers have to develop additional resources and coping skills. Altiere and Von Kluge (2009:142) indicate that families have tremendous resilience and could have resources to cope with their particular challenges. Consequently, understanding the experiences of primary caregivers, including what factors influence their wellbeing, is essential for the development of meaningful and effective interventions, services and supports, and this is an area of inquiry that merits further investigation (Sigongo, Meshi & Rhoda, 2015:274-279). The majority of research in that area focuses on the wellbeing of individual family members, especially primary caregivers. However, there is growing interest in the conceptualisation and measurement of family quality life (Resch et al., 2010:139).

McNally and Mannan (2013:96) argue that most research identifies the strong interaction between the types of disability, primary caregiver's behaviour and practices with children living with disabilities, at home and in the community. Several factors are associated with caring for the child with a physical disability. These include the support system at home, cultural values and beliefs and financial resources for seeking treatment and rehabilitation services for the child concerned.

From the literature reviewed above, it was noticed that there is limited literature in South Africa on challenges faced by primary caregivers in raising children living with physical disabilities. Therefore, this study explores and describes the challenges faced by the primary caregivers using in-depth interviews to produce rich, detailed information. This will increase the understanding of challenges and coping strategies of primary caregivers in the rural area of Mvunyane, Kwa-Zulu Natal.

1.3 DEFINITION OF KEY CONCEPTS

The following key concepts of the study are defined below:

1.3.1 Disability

The UN (2012:13) defines disability as any restriction or lack of ability to perform any activity in the manner or within the range considered normal for a human, such as children with physical disability being restricted to participate in a sport event owing to physical limitations.

1.3.2 Physical disability

The term physical disability is a bodily impairment that hinders the movement capacity of one or more limbs, or impacts gross or fine motor ability. A physical disability can also include impairments that make activities of daily living difficult (WHO, 2011:11).

1.3.3 Primary caregiver

According to the Children's Act 38 (Office of the President, 2005:21), a primary caregiver is a person who has the responsibility of taking care of the child. It can be a biological parent, foster parent, relatives, friend or a paid worker.

1.3.4 Child

According to the Children's Act 38 (Office of the President, 2005:22), a child is any person under the age of 18 years.

1.3.5 Rehabilitation

Rehabilitation is a means of a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and social functioning level, thus providing him or her with the skills to change his or her own life (UN, 2006:44).

1.4 PROBLEM STATEMENT

Millions of children with disabilities in all parts of the world are often excluded from the mainstream of society and experience difficulties in accessing education, social grants and health care as their fundamental rights (United Nation International Children's Fund [UNICEF], 2006:45). McNelly and Mannan (2013:96) perceived that because of the increasing number of disabled persons, the field of disability has become important to researchers and policy developers. Policy developers need to be aware of the

increasing number of people with disabilities in order to plan for their integration into the mainstream society. While in the developed countries, the trends of segregation and exclusion of children with disabilities from the mainstream of the society seem to have changed to greater inclusion over the last two decades, the situation in the developing countries has either remained the same or is worsening (Sitienei & Mulambula, 2012:79).

The impact of physical disability in the developing countries has become a problem in health, welfare and social issue. The developing countries present many challenges in the lives of disabled people. Greef and Nolting (2013:396) identified the contribution of the environment to disability in developing countries. They noted that poor sanitation, infectious diseases, malnutrition and war are the few of the factors contributing to disability. One of the burdens of physical disability is that there is no cure for this type of disability. The primary caregivers of the children living with disabilities are therefore faced with a life-time caring role and commitment to ensuring that the children undergo rehabilitation that improve functional abilities. These interventions require primary caregivers to be active participants in the caring role for these children (Miller, 2010:131). Marther (2010:58) notes that there are no respite care facilities in rural areas where many children with disabilities reside; therefore, the care for these children is the responsibility of their primary caregivers.

The number of children living with physical disabilities has increased globally over the past three decades. The increase in numbers of children with disabilities means that primary caregivers and the community are faced with the challenge of providing rehabilitation programmes at home as well as in hospitals. Caring for a physically disabled child at home may mean a primary caregivers need to make some home modification to ensure they provide the best possible care. The day to day caring of a physically disabled child may, however also involve dealing with challenges and changing behaviours and so the predictable routine may help the primary caregivers. Developing a routine can also help the primary caregivers balance their role as caregivers with other aspects of their lives, such as working or parenting other children. Caring for a child living with physically disability increases responsibilities because the primary caregiver has to meet the child's personal needs and that of the immediate family members. The rehabilitation services are available at the hospitals and the healthcare professionals have a great focus on assessment, evaluation and

wellbeing of a disabled child. However, they do not focus on how the caregiver is coping in raising the child and what are the challenges they faced (Sitienel & Mulambula, 2013:79).

The researcher observed that at Vryheid Hospital there are rehabilitation systems provided for children with physical disabilities. The discharge system in the hospital works on the basis that children with physical disabilities, before discharge the disabled child is supposed to be seen by multi-disciplinary team which consist of physiotherapists, occupational therapists, medical practitioners, social workers, dieticians, speech therapists, psychologist as well as audiologists for assessment. Physiotherapist and occupational therapist train their primary caregivers on how to continue with rehabilitation services at home, after that they are sent home and given return dates. The primary caregivers are expected to carry on with the rehabilitation programmes until the children return back to hospital for assessment. It was observed by the researcher that when the children's return dates were due some children did not come back for rehabilitation. Others came back but sometimes with worsened conditions than the time when they were discharged from the hospital.

Despite the difficulties associated with caring for a child with disabilities, many families have successfully adapted to their new styles of caregiving role (Greef & Nolting, 2013:396). The major problem that prompted this research was the failure of some primary caregivers to take care of their children living with physical disabilities on their own at home. Therefore, the aim of the study was to explore and describe the challenges faced by primary caregivers in raising children living with physical disabilities.

1.5 RESEARCH AIMS AND OBJECTIVES

The main aim of the study was to investigate the challenges experienced by primary caregivers in raising children with physical disabilities in Mvunyane area, Vryheid. The specific objectives for the study were as follows:

- To explore and describe the social challenges faced by primary caregivers in caring for the physically disabled child.
- To explore and describe the economic challenges faced by primary caregivers in caring for the physically disabled child.

- To explore and describe the coping strategies of primary caregivers in raising children with physical disabilities.

1.6 RESEARCH QUESTIONS

The main research question for the study was:

- What are the challenges experienced by primary caregivers in raising children with physical disabilities in Mvunyane area, Vryheid.

The study was guided by the following sub-questions:

- What are the social challenges faced by caregivers in caring for the physically disabled child after the rehabilitation?
- What are the economic challenges faced by caregivers in caring for the physically disabled child after the rehabilitation?
- How do primary caregivers cope in raising their children with physical disability?

1.7 SIGNIFICANCE OF THE STUDY

The study is intended not only to contribute to the knowledge capacity of the researcher, but it would seek to play a fundamental role in adding new information to the body of existing knowledge on children living with physical disabilities. The study is also of significance in that it is going to unveil the challenges faced by primary caregivers. Unveiling of those challenges will help the community to be aware of those challenges. It will also contribute to the caring of the children living with physical disabilities.

The results of the study could be used to formulate recommendations for improving caregiver's conditions that interfere with their participation in rehabilitation programme at home. Such support could enhance the quality of their lives and that of their children living with disabilities. The health professionals need to be aware of the challenges that might have positive or negative effects on the caregiver's participation in rehabilitation programme. Health professionals tend to focus more on the child concerned but there is no one who focuses on the caregivers coping mechanisms. This may help the health team in the understanding of the demands placed on caregivers in caring for children with physical disabilities.

1.8 KNOWLEDGE DISSEMINATION

The researcher shall present the result of the study at the local academic conference and publish article the research will also be presented at a social work conference. The dissertation will be available at the University of Zululand library. The data collected will also be safely stored in a secure environment at the Department of Social Work at University of Zululand for a minimum of fifteen years.

1.9 CHAPTER OUTLINES

The dissertation is composed of the following chapters:

Chapter 1: Introduction to the study

This chapter gives the overview of the study. The significance of the study and the problem statement is explained in this chapter. Research questions and objectives are presented. Definitions of key concepts, significance of the study and knowledge dissemination are found in this chapter.

Chapter 2: Literature Review

This chapter reviewed various literatures on physical disability, the challenges experienced by primary caregivers who are raising children living with physically disabilities and their coping strategies. Theoretical framework is also discussed in this chapter.

Chapter 3: Research Methodology

The chapter contains information on research methods that were employed in the study and the reasons why they were particularly chosen to give the best results. Qualitative research methodology was adopted and data was collected using purposive sampling and analysed using thematic analysis.

Chapter 4: Presentation of findings and discussion

This chapter contains the presentation of findings. It also contains the analysis of those findings and the discussion thereof.

Chapter 5: Summary of findings, Conclusions and Recommendations

This chapter encompasses the summary of the study's findings, conclusions and recommendations.

1.10 CHAPTER SUMMARY

This chapter has provided the back ground to the study on the challenges experienced by primary caregivers who are raising children living with disabilities. Aims and objectives of the study were also included in this chapter as well the significance of the study, knowledge dissemination and the chapter outline. The following chapter will review literature on children with disabilities and the challenges experienced by the primary caregivers who are raising those children.

CHAPTER 2:
LITERATURE REVIEW

2.1 INTRODUCTION

This chapter reviews literature on disability. It gives information on the local and international prevalence of disability. It also includes a description of home based rehabilitation programme. The concept of caregiving and its impact will be discussed in this chapter as well as the coping strategies of primary caregivers. A conceptual model of caregiver's adaptation will be discussed and explained. The chapter concludes by summarising the main facts that emerges from the context of the reviewed literature.

2.2 PREVALENCE OF DISABILITY

UN (2012:14) estimated that 500 million of people worldwide have various disabilities such as mental, physical, or sensory impairment. On the other side the World Health Organisation (WHO, 2011) estimated that almost 10% of the world's population at any given time is physically or mentally impaired. Studies conducted in China, Canada, Mali and Great Britain show that disabilities range from 0.2% to 21% of the population.

According to Stats SA (2011) the index of disability shows that disability is more prevalent among females than males (female 8.3% and males 6.5%). Disability types show noticeable differences across the four population groups (Black African 7.8%, Coloured 6.2%, Indians 6.2%, Whites 6.5% and other 5.6%). Among the Indian and Asian population, 12.3% reported mild disability in seeing compared to 10.3% of Whites. The results show that hearing and walking disabilities were more prevalent in the white population. The results also show disability according to ages which are as follows: age 05-09 years is 10.8%, age 10-14 years is 4.1% and age 15-19 years is 2.6% results further shows slightly high rate of disability and ages between 05-09 years.

However, there are no common definitions and classifications of disability, which is uniformly applied to all countries. This lack of uniformity therefore makes international comparisons of disability data not meaningful. Two thirds of disabled individuals reside in developing counties (UN, 2006:16). In the developed countries, less than 3% of disabled people receive community based or hospital based rehabilitation. Millions of

children with disabilities in all parts of the world are often excluded from mainstream of society and experience difficulties in accessing education and healthcare services.

2.2.1 Prevalence of childhood disability in South Africa

According to African Child Policy Forum (ACPF, 2011:11) statistical data on the prevalence of age and gender-specific childhood disability in South Africa is inadequate, unreliable and at times conflicting. The reason for the above statement is that:

- The lack of recent population based childhood disability prevalence studies using a two phase methodology.
- The lack of comparable survey methodologies used in childhood disability prevalence studies.
- The fact that almost all existing childhood disability studies were undertaken before year 2000, so data does not reflect the most recent situation.
- The lack of age specific, population based childhood disability prevalence studies only two studies specifically focused on children using the 10-question screen (Christianson, 2000; Cooper, 2002). The lack of consistency and consensus regarding the definition of disability particularly produced and socially constructed.
- The different definition of disability and confusion with impairment which can lead to a lack of clarity about what is being measured.
- The fact that chronic illness and disease often go undiagnosed and resultant impairments unrecognised, particularly in areas with poor health and rehabilitation coverage.
- The different approaches used to record multiple disability or impairment and proxy versus self-reporting, which have all had an impact on prevalence rates.
- The lack of disaggregated data in terms of age and gender makes it impossible to estimate the number of disabled children in South Africa, because some impairments are age-specific rates in relation to impairment types.

The lack of reliable, comparable prevalence rates for children with disabilities is a major challenge to the development of targeted and appropriate services, and thus negatively impact on the rights of disabled children.

2.3 CONCEPTUALISATION OF PHYSICAL DISABILITY

Physical disability is a physical condition that affects a person's mobility, physical capacity, stamina or dexterity. It could be any one of a number of physical conditions that significantly inhibits a person ability to undertake routine daily activities (Office of the President, 1997). These conditions include but are not limited to brain or spinal cord injuries, multiple sclerosis, cerebral palsy, respiratory disorders, epilepsy and hearing or visual impairment (ACPF, 2011:44). The causes of physical disability vary as the conditions themselves. They usually fall into one or two categories; hereditary or congenital. This is where a person has been born with a physical or developed one due to inherited genetic problems, has suffered an injury at birth, or has issued with their muscles. An acquired physical disability could be due to a road traffic accident, workplace incident, via an infection or disease or as side effects of a medical condition such as stroke or cancer (UN, 2006: 61).

2.3.1 Types of physical disabilities

People with physical disabilities have a physical impairment which has a substantial and long-term effect on their ability to carry day to day activities (ACPF, 2011:45). Some physical disabilities which are discussed in this section include impairments which limit other facets of daily living such as cerebral palsy, traumatic brain injury (TBI), spina bifida, respiratory disorder and blindness.

- **Cerebral palsy**

Cerebral palsy is a group of chronic condition that affect the brain's ability to coordinate muscles and body movement, damages to one or more parts of the brain during foetal development, birth process or infancy period. It is first identifiable when a child fails to reach motor skills milestones and displays qualitative differences in motor function development (Croot, Grand, Mathers & Cooper, 2012: 1540).

- **Traumatic brain injury (TBI)**

TBI is a physical disability which has occurred through accidents, strokes, tumours, infections, generative neurological disease or lack of oxygen. Brain injury can result in

specific impairments primarily manifested in the physical or medical condition of the child. TBI can affect mobility of the child coordination, communication and learning (Anderson & Yeates, 2010:8).

- **Spina bifida**

Spina bifida is the term that describes a number of different birth defects that contribute to problem with the development of the nervous system and spinal column. Spina bifida results from problems in the first month of pregnancy, when the neural tube is developing in the foetus. People with spina bifida often develop learning difficulties, mobility symptoms and paralysis, muscle wastage scoliosis and bowel and bladder symptoms. Many theories have been developed to explain the causes of physical disabilities (Office of the President, 1997).

2.4 LEGISLATIVE FRAMEWORK ON DISABILITIES

According to the White Paper on Integrated National Disability Strategy (INDS) (Office of the President, 1997:99) the debate as to whether the interest of children with disabilities would be better served by disability –specific legislation or within mainstream (i.e. children's) legislative is important. Some argue that disability specific legislation undermines the goal of inclusion, while others feel that disability rights will not be realised within mainstream systems of provision alone. Whatever the final position, consideration needs to be given not only to the outcome, but to what it represents as a means of promoting the goal of inclusion and equal rights for children with disabilities.

2.4.1 The UN Convention on the Rights of the Child (UNCRC)

In 1996, South Africa signed the UNCRC thereby signalling its rights of children in the country in line with the principle of:

- Non-discrimination
- Giving primary consideration to the best interest of the child.
- The rights of children to survival, protection and development.
- The right of children to participate fully in family, cultural and societal life (ACPF, 2011:20).

On the other side the United Nations Convention on the Rights of Children with Disabilities (UNCRCD, 2011: 99) mentioned that there is currently disability specific legislation in South Africa. The country's first democratic government developed the integrated national disability strategy with the aim of ensuring that disability would be incorporated into all relevant legal and other provisions in the country. Within the children's sector the Children's Act 38 (Office of the President, 2005) has extensive provisions for children with disabilities. However, the strategic plan of the Department of Social Development (2011:419) includes a long-term goal to develop legislation on the provision of social services to people with disabilities that is aligned to the UN Convention on the Rights of person with disability (UNCRPD). This will begin with review of the policy on the provision of social services to people with disabilities, followed by draft legislation on the same. The UN Convention on the right of a child is a universally agreed upon set of non-negotiable standard and obligations to protect the full range of human rights for all children i.e. civil, cultural, economic, political and social rights. The UNCRC acknowledges children as subjects of rights and participants in all matters affecting them. Although all the rights contained in the UNCRC apply to all children, the Convention also introduced specific rights for children with disabilities for the first time in the international human rights law (UNICEF, 2006:49).

2.4.2 The South African Constitution

The South African constitution (RSA, 1996a:18) as a supreme law of the country embodies the government's commitment to protect the rights of all citizens. Its intention is to heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human's rights as well as to improve the quality of life of all citizens and free the potential of each person. While each of the rights itemised in the Bill of Rights contained in the constitution applied to every citizen of South Africa, the following three are especially pertinent to children with disabilities.

- The right to equality 'everyone is equal before the law and has equal protection and benefit of the law. The state may not unfairly discriminate against anyone or more grounds including disability.
- The right to basic nutrition, shelter, basic health care and social services, protection from maltreatment, neglect abuse or degradation.
- The right to basic education

The rights of people with disabilities are protected by the constitution. Government departments and state bodies have a responsibility to ensure that, in each line function, concrete steps are taken to ensure that people with disabilities are able to access the same fundamental rights and responsibilities as any other South Africa (ACPF, 2011:18).

2.4.3 Social Assistance Act

The government recognises that children with severe disabilities need substantial care and attention, and that parent may need to stay at home or employ a carer to attend to the child. Children with disabilities may need medication, assistive devices or frequent treatment such as physiotherapy. These extra costs can put strain on families that are already struggling to make ends meet (ACPF, 2011:25). The Social Assistance Act provides for the CDG, a non-contributory monthly cash transfer for parents, primary caregivers or foster parents of a disabled child who requires and receives permanent care or support services due to his/her physical or mental disability (SASSA, 2018). To qualify a child is required to undergo medical assessment and the parent or carer must pass an income or mean test. In April 2018, the value of CDG increased to R1 620. Any carer of a disabled child is eligible for the grant including members of the extended family (SASSA, 2018).

2.4.4 UNCRPD

In 2007, South Africa ratified the UNCRPD, thereby indicating the government commitment to protect the rights of disabled people. The government also signed the optional protocol, allowing individuals whose rights have been violated to bring them to the attention of the committee on the rights of persons with disabilities and giving this committee authority to undertake inquires of these violations. The UNCRPD replace the standard rules for the equalisation of opportunities for persons with disabilities (ACPF, 2011:20). In its preamble, it recognises the family as the natural and fundamental group unit of society, which needs to be protected by both society and the state and given assistance where necessary. The UNCRPD also emphasise the importance of mainstream disability issues, with signatories undertaking to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes (UN, 2006:44).

Although the UNCRPD applies to both adults and children but it refers to specifically children with disabilities, assuring them that:

- They have the same rights as the other children.
- The principle of the best interest of the child will be upheld in all decisions concerning them.
- They have the right to participate in decisions which affect their lives.

The UNCRPD (2011:99) also include the right to education and obliges signatories to ensure that educational systems are appropriate for disabled children, enabling them to develop their potential and become involved in society. It stresses the importance removing barriers that exclude children with disabilities from free compulsory education. The following paragraph will focus on the education for disabled children in South Africa. The Department of Social Development has begun the process of aligning policies to the UNCRPD as well as developing a department specific disability mainstreaming strategy, training manual and implementation plan. This is recognised as essential to ensuring that people with disabilities enjoy full and equal human rights and freedom, and there is respect for their inherent dignity (DSD, 2011:5). While there has been increasing recognition of disability as a human issue, stakeholders in the disability sector emphasise that the link between disability and the rights needs to be supported by personnel and services so that rights can become realities for adults and children with disabilities.

2.4.5 The South African Schools Act

Children with disabilities are often denied an education because they are the most vulnerable and excluded people in their communities. Section 29 of the South African constitution (RSA, 1996a) indicates that all children are guaranteed the right to basic and further education and the state must take reasonable measures to make these progressively available and accessible. The South African Schools Act (RSA, 1996b) provides for compulsory basic education for all children from seven to fifteen years of age and bans unfair admission policies and discriminatory education practices. The guidelines for implementing the national disability framework indicate that persons with disabilities should have equal access to education opportunities, irrespective of the severity of their disabilities (Office on the Status of Disabled Persons [OSDP], 2008:31).

The education white paper (Department of Education, 2011) provide framework for the government's goal of an inclusive education and training system. Its intention is to investigate and address barriers to learning and to develop a system with which to recognise and accommodate the diversity of learners and their needs. The long-term goal is to build an open, lifelong and high-quality education and training system for all citizens, including children with disabilities (OSDP, 2008:33). The short- and medium-term goals are to address the weakness and deficiencies of the current system and to expand access for children of compulsory age who are not accommodated in the present education system. The white paper embodies the following premises:

- All children, youth and adult have the potential to learn, given the necessary support.
- Many people experience barriers to learning primary because of the system's inability to recognise and accommodate the diverse range of learning needs this is the major shift from assumption that barriers to learning resides within the individual learner.
- The establishment of an inclusive education and training system will require changes to mainstream education, so that those experiencing barriers to learning can be identified early and given the support they need.

The white paper does not abolish special schools, but instead seeks to strengthen them and enhance their expertise to ensure that children with severe disabilities are accommodated appropriately. It is envisaged that special schools will be converted into resources centres, which cater for learners who need high level of support. Resource centres will also provide support for teachers and schools in the surrounding community/district to help them cater for learners with diverse needs. Taking into account the fact nearly 40% of young children in South Africa grow up in conditions of severe poverty and neglect, it attempts to break the cycle of poverty by increasing access to ECD, particularly for poor children and children with disabilities and to ensure good quality programmes (ACPF, 2011:28). According to the report on children with disabilities in South Africa, the Department of Basic Education (2012:45) has made progress towards ensuring that children with disabilities can access basic education, based on the policy of inclusive education. Currently some 110 300 learners with disabilities are attending ordinary public schools. In addition, 423 special

needs schools nationwide are catering for approximately 105 000 learners. The number of full service school, schools that are equipped to support a range of disabilities has grown from 30 in 2008/2009 to 513 in 2010/2011 (Sitienel & Mulambula 2013: 79). Nonetheless, evidence from surveys suggests that children with disabilities are substantially less likely to attend school than their non-disabled peers.

Looking at the above-mentioned information it is evident that children with disabilities are ten times less likely to attend school than those without any disabilities. Even if they attend school they are more likely to drop out early while the level schooling they receive is frequently below that of their peers. Children with disabilities especially physical disabilities are often unable to go to school because of infrastructure. In addition, there is limited understanding within their communities and among teachers about their learning needs, which is often filled by prejudice around disabilities.

2.4.6 The White Paper on the Rights of Persons with Disabilities

Special schools are still viewed as extension of separation and stigmatisation, which attributed persons with disabilities as different in the way they learn, perceived and think as compared to non-physically disabled children. According to the White Paper on the Rights of Persons with Disabilities (DoE, 2009), children who are placed in special school due to physically disabilities, which are not server, may end up developing negative self –concept as they continue interacting with their peers who are severe disabled. This can reduce their opportunity to relate with other non-physically disabled peers diminishing their competence and self-esteem, alienate them from others, nurture a meanness of spirit and make them fewer people than they could became. By that reason the department of education comes out with the programme of inclusive education.

2.4.7 The Children's Act

The Children's Act (Office of the President, 2005:369) outlines the government's obligation to protect the right of children as embodies in the UNCRC. It identifies the role of provincial Department of Social Development around key areas of service provision for:

- Partial care
- Early childhood development

- Prevention and early intervention
- Child protection services
- Child and youth care centres.

Early childhood development is critical for children with disabilities as well as means of access to early identification and referral where necessary; it also provides opportunities for social, physical and emotional development. Indeed the guidelines for the implementation of the national disability policy framework hold that early child hood development (ECD) and stipulation within an inclusive environment is the cornerstone for the development of an integrated and equitable society, Office on the status of disabled persons (OSDP, 2008:36). The Children's Act (2005) indicates that funding must be prioritised to make appropriate ECD programme available to disabled children that cater for their needs.

The guidelines for ECD services (DSD, 2011:13) recognise that children with disabilities need to have access to services, and thus stipulate that premises and equipment must be disability friendly. It also emphasises the fact that the parent of children with disabilities should receive information on local services and treatment from which the child will benefit. Practitioners must be trained in ECD and management of programmes and facilitates for young children, including skills to accommodate children with disabilities. If children with disabilities are admitted to ECD centres they must be helped to participate in or enjoy the activities provided. Support needs to be given to families to bring children with disabilities to ECD centres. They need to be informed that these centres have admission policies that welcome and accommodate their children (DSD, 2011:15). Having explained the legislation framework in the understanding of disability, it is important to discuss the two types of rehabilitation available for people with disabilities, namely, home based rehabilitation and hospital based rehabilitation.

2.5 REHABILITATION OF CHILDREN WITH DISABILITIES

The World Report on Disability (WHO, 2014: 96) defines rehabilitation as a set of measures that assist individuals who experience disability to achieve and maintain optimal functioning in interaction with their environments. Rehabilitation has long lacked a unifying conceptual framework. Historically, the term has described a range of responses to disability, from interventions to improve body function to more

comprehensive measures designed to promote inclusion. Rehabilitation is always voluntary and some individuals may require support like children with disabilities they need support of their primary caregivers to attend rehabilitation. In all the cases rehabilitation should help to empower people with a disability and their families. The following paragraphs will focus on two types of rehabilitation programmes that occur in our society.

2.5.1 Community Based Rehabilitation

According to the World Report on Disability (WHO, 2014:96) community-based rehabilitation (CBR) is both a philosophy and a strategy of providing more equitable, sustainable and appropriate rehabilitation services to the majority in a community. In home based rehabilitation, the disabled person, the family, primary caregiver, community and health professionals collaborate to provide needed services at home and in the environment or community where services for disabled person are seriously needed or totally absent. On the other hand, the International Disability and Development Consortium (IDDC, 2012: 4) defines CBR as a strategy within general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities and the relevant government and non-governmental organisations.

2.5.1.1 Providing community-based support to the primary caregivers

It is important that community members and extended family members provide the primary caregivers with any support they have in order for them to cope with the caregiving role. The UNCRPD (2011: 101) states that changing attitudes towards children with disabilities is an ongoing challenge. An important part of this challenge is to provide the necessary support to parents, caregivers and community members who play a critical role in the lives of their children with disabilities. Such support should include tracking developmental milestones, teaching independence and caring for children. However, in order for them to care for and support their children, parents need to know their rights and responsibilities and what resources are available to them (ACPF, 2011:57). Parents need to be given information if they are to make informed decisions about the development and education of their children and where possible,

children need to be empowered to make informed decisions as well. Information must be disseminated in different formats and in ways that take cognisance of parents and children's level of education. UNCRPD (2011:101) further indicates that disability and diversity awareness programmes need to be recognised as a critical component of social cohesion and as a means of reducing the vulnerability of children with disabilities to abuse and neglect.

2.5.1.2 The linkages between CBR and the convention rights of people with disabilities

While the convention provides the philosophy and policy, CBR is practical strategy for implementation (IDDC, 2012: 5). CBR activities are designed to meet that basic needs of people with disabilities, reduce poverty and enable access to health, education, livelihood and social opportunities all these activities fulfil the aims of the convention. IDDC (2012:5) further explains that people with disabilities should be able to access an inclusive, quality and free primary education on an equal basis with others in the community in which they live. Due to the infrastructure in the schools in our society inclusive education is not possible as many schools have two storeys which make it impossible for children using wheel chairs to access classes on the second floor.

2.5.1.3 Partnership to promote CBR

According to the KwaZulu-Natal (KZN) Department of Health (2014: 64), CBR has been advocated as one approach to meeting the needs of persons with disabilities including children; that is, it complements accessible and inclusive services at the community level, particularly access to primary health care. In KZN, 22 CBR workers are employed through a service level agreement between the Department of Health and Disabled People South Africa (DPSA) to work in the province's 11 districts. These workers are linked with a district rehabilitation co-ordinator, and are responsible for the identification and referral of adults and children with disabilities. However, there are challenges around the training and employment status of these mid-level workers with the provincial health system.

2.5.1.4 The role of CBR in poverty reduction

According to Mousavi (2015:125), CBR is considered as a tool for social change and to fight the war on poverty. There is a dynamic relationship between disability and

poverty. In the international development literature, poverty and disability have been identified as part of a vicious circle: disability increases the risk of poverty and circumstances of poverty raise the risk of disability (UN, 2011: 99). On one hand, people with disabilities are much less to find employment, women with disabilities are more vulnerable to physical violence and sexual abuse, and children with disabilities are much less likely to be literate and more vulnerable to malnourishment and early death. Consequently, CBR has not only been recognised as a community development model for empowering people with disabilities and their communities, but is also considered to be a strategy for reducing poverty as well (WHO, 2011:33).

The consequence of this cycle is that people with disabilities and their families are usually among the poorest of the poor. According to the UN (2014:25), approximately 15–20% of the world's poorest citizens have a disability of one form or another. It is very difficult to break out of the vicious cycle of poverty and disability. Thus, poverty and disability reinforce each other: each is both a cause and consequence of the other, contributing to increasing vulnerability and exclusion (UN, 2014:26). CBR is intended to change attitudes in the community towards the acceptance of disability, to promote the social integration of people with disabilities, to provide opportunities in education and employment, to provide opportunities in education and employment, to protect the rights of people with disabilities and empower them (WHO, 2011). CBR also aspires to fight poverty by providing a range of vocational skills development and income generating activities.

2.5.2 Hospital-Based Rehabilitation

Rogers (2013:123) mentions that hospital-based rehabilitation is provided in a health or educational institutions such as hospitals and rehabilitation centres. Such services usually cater for a small number of people with disabilities. Hospital rehabilitation is therefore a limited approach and could deny people with disabilities their right to access rehabilitation services. In many instances, where these hospital-based rehabilitation services are available, they may be expensive as the majority of disabled person live in rural areas away from urban areas where most of the rehabilitation facilities are located. However, the hospital model of rehabilitation is essential for home based rehabilitation to work effectively.

Lee (2009:93) argues that the two models of rehabilitation are not separate but are interdependent. In addition, Marther (2010:51) comments that home-based rehabilitation needs hospital-based rehabilitation services for referrals and assistance with problems that cannot be solved by home-based programmes, while hospital-based rehabilitation needs home-based rehabilitation because that is where most referrals come from. The objective of home-based rehabilitation is integration of the following components: prevention, promotion, curative and rehabilitative services through participation of community members and groups at all levels of societal spectrum.

UNICEF (2011:49) argues that home-based rehabilitation has been advocated as one approach to meet the needs of persons with disabilities, including children, and complements accessible and inclusive services at the community level, particularly access to primary health care. UNICEF (2011:51) further states that there is no comprehensive national strategy on CBR in South Africa. With decentralisation to communities in the development of strategies and its implementation, certain provincial departments such as Mpumalanga Province, Limpopo and Kwa-Zulu Natal Province have been entered into public-private partnerships with non-governmental organisations (NGOs) to implement home-based rehabilitation projects for children with disabilities. However, a cohesive, strategic national position on home-based rehabilitation is still lacking. Although caregivers can use one or both of the types of rehabilitation programmes mentioned above, there are some challenges that the primary caregivers experience in raising those children with physical disabilities.

2.6 CHALLENGES FACED BY CHILDREN WITH PHYSICAL DISABILITIES

Most of the physical disabilities result from the damage of motor system, which interferes with the movement of legs and arms. Physically disabled children may not be able to walk, run, jump, write or hold utensils (Sigongo, Mweshi & Rhoda, 2015:274). It may result in a partial or complete paralysis of the affected body parts, which in turn reduces sensation and causes retards development of the muscles (Sitienei & Mulambula, 2012:79). Most physically disabled children use crutches, braces and wheelchairs all their lives. Looking at their situation, they require a lot of emotional support from their parents, teachers at school, their peers as well as the whole community in order to adjust to their status in life. It should be noted that the

intelligence of these children is not affected and so they can attend regular schools and be taught by regular teachers.

Abuse of children with disabilities in South Africa is a growing problem. A study on the rights for disabled children in South Africa found that NGOs reported widespread family violence, abuse and rape of children. The study also reported high profile press reports of disabled children in special schools which never reached the courts (UNICEF, 2011:53). The South African Children's Act (Office of the President, 2005) is the primary legislation giving effect to the rights of children to protection from abuse and neglect, and to family care or appropriate alternative care when removed from the family environment. The Act obliges the state to provide programmes which focus on developing appropriate parenting skills and capacity of parents and primary caregivers to safeguard the best interest of the children with disabilities. At times, parents have been reluctant to take action against the schools in cases of abuse for fear of the child losing their place at school. Research suggests that children with disabilities are two to five times more likely to be abused than their non-disabled peers (UNICEF, 2011:55). Children with certain disabilities are prone to particular types of abuse. Mentally and physically disabled children are at increased risk of sexual abuse, while those with learning disabilities are especially vulnerable to neglect (NMF, 2005).

Disabled children's vulnerability to sexual assault also appears high in institutions; however, studies show that 80-85% of criminal abuse of residents in institution is not reported to authorities. This is compounded by the lack of general information about, and understanding of, sexuality, particularly on the part of young people with intellectual disabilities. A study conducted by the Disabled Children's Action Group (DICAG, 2013:69) found that in a sample of 36 cases of abuse of children with disabilities that came to trial, 14 were withdrawn, and there were eight acquittals and 14 convictions. The prime reason given for this was that witnesses were seen as being incompetent when the level of language used in court proceedings was too complex and not understandable to many of the victims.

The few studies on the unmet rehabilitation needs of children with disabilities in South Africa were conducted almost a decade ago. According to a study of 156 disabled children in a peri-urban township in Orange Farm, Gauteng, only a quarter of the children in need of rehabilitation received such services, and, of the 233 assistive

devices required, only 64 were issued (UNICEF, 2010:97). Children with motor impairments were found to be significantly more likely to receive rehabilitation than those with intellectual disabilities. According to the results of a study that was conducted in Manguzi in Kwa-Zulu Natal, the rehabilitation staff at the local hospital interacted with only 35% of the children requiring rehabilitation services. Research done by Department of Social Development in Mpumalanga in deep rural areas in Ehlanzeni, Nkangala and Gert Sibande District found that only 42% of the children with disabilities identified were receiving rehabilitation and only 33% had the assistive devices they required. Some 59% reported that the primary caregivers did not know how to apply for assistive devices (WROD, 2014:96. A recent study evaluating the management and implementation of rehabilitation services at a district level, within the context of the National Rehabilitation Policy of the Department of Health, found that, despite the call for CBR and the application of the social model of disability to improve access and quality, rehabilitation services are still rooted within the medical model, resulting in poor outcomes for people with disabilities, including children (UN, 2014:54). Policies, norms and standards aim to guide rehabilitation professionals working in the public health sector where the majority of the children with disabilities access services, are not coherent which influences performance negatively and highlights the lack of service integration at an institutional level (WROD,2014).

2.7 CHALLENGES FACED BY PRIMARY CAREGIVERS IN RAISING CHILDREN WITH PHYSICAL DISABILITIES

Raising a child with disabilities can sometimes be challenging and the primary caregivers can face many physical, emotional and psychological challenges. According to Resch et al. (2010: 139), primary caregivers encounter different experiences in raising and caring for children. Raising and caring for a child with a disability does not differ from caring for a child without a disability, but there are some challenges faced by primary caregivers in raising children with physical disability. McNally (2013:96) indicates that families have tremendous resiliency and are able to mobilise resources to cope with their particular challenges. In his study, it was found that emotional and subjective challenges that emerged included rejection, stigmatisation, discrimination, isolation, worry and pity. Stigmatisation, isolation and pity were identified as the worst experiences in raising and caring for the child living with disability. Rejection and discrimination in the community are manifestations of

stigmatisation which are often shown by gestures such as pointing, laughing and staring. Many caregivers are worried about the future of their disabled children because of lack of support. Many feel alone and they are the only ones who know that their children have special needs and need special attention (McNally, 2013:96). Among these challenges that primary caregivers face, the following sections discuss the effects of disability in the family, stress and burden of caring for a disabled child, inadequacy of infrastructure for health and education, perceived barriers, and facilitation of participation in physical activities for children with physical disabilities.

2.7.1 The Effects of Disability in the Family

Having a child with a disability in the family can have negative or positive effects. Living with a disabled child can have profound effects on the family, parents, siblings and extended family members. It is a unique shared experience for the family and can affect all aspects of the family functioning (Meyer, Ingersoll & Hambrick, 2011:1413). According to WHO (2011:99), disabling conditions have effects that extend beyond the child with disability to the family at large, the caregiver, the neighbourhood and the community in general. The birth of a child with a physical disability can be traumatising to the family. When the siblings who first establish the relationship with their new-born siblings realise that the child has a disability, this impacts dimensions of the relationship; in particular, the siblinghood attachment can be negatively affected. This adjustment process may require a large portion of family time, attention and psychological support depending on the degree of disability, modifications in the home and in parental activities. Meyer et al. (2011:1413) concur that living with a disabled child can have profound effects on the entire family, parents, siblings as well as extended family members.

On the other hand, Resch et al. (2010: 139) found that living with a sibling that is physically disabled can be rewarding despite being confusing and stressful. Siblings may express various emotions and responses to the disabled sibling such as fear and anger. Emerson, Yasamy and Saxena (2012) argues that the non-disabled siblings may experience jealousy on the basis that they may be often required to do house chores, whereas the sibling with disability is not required to do anything. Emerson et al. (2012) further revealed that the positive or negative nature of a relationship between siblings and among family members may be influenced by factors such as

family's resources, their lifestyle, the child-rearing practices, the kind and severity of disability, the number of children in the family and the age difference between children (Emerson et al., 2012:96).

Under most circumstances, being a parent comes with many challenges. As noted by Resch et al. (2010: 139), accessing information and services to meet the needs of children with disabilities, financial barriers to obtain needed services, and ongoing efforts to ensure meaningful inclusion in schools and communities are additional challenges associated with parenting children with disabilities. These challenges can place families under stress. The findings of the study conducted by Resch et al. (2010:139) showed the additional stressors that caregivers may experience associated with the raising children with disabilities and the lack of support for family members as they attempt to cope with those stressors. Resch et al. (2010:139) further revealed that the primary caregivers felt overwhelmed, stressed or depressed when they first learn about their children disabilities. Primary caregivers revealed that extra time and occasionally unpredictability of raising a child with a physical disability can affect the entire family, including siblings, and extended family members; for example, some caregivers reported that they often had difficulties balancing the needs of the entire family due to the unpredictable nature of their children's disability. The interpersonal impact of having a child with physical disability, also affects parents' relationships with each other (Kresak, Gallagher & Kelly, 2014:3). A child with physical disability can have a negative impact on the marital relationship (Lee, 2009:93) as well as on a parent's social life (Altiere & Von Kluge, 2009:142).

The mother, often the primary caregiver, has to restrict time that was previously used for her spouse and friends because of the additional time demands for caring for the disabled child. Parental stress and the demands placed on them also have the potential to negative impact on the family system as a whole (Kresak et al., 2014:3). Meyer et al. (2011:1413) point out that the siblings of children with physical disabilities displayed higher rates of adjustment problems than those without children with disabilities. However, this relationship was found to be mediated by maternal depressive symptoms. A primary caregiver who is experiencing high levels of depression may find it difficult to balance the needs of several children with different developmental demands and may be unable to provide the required emotional support and discipline for all the children (Nadon, Feldman, Dunn & Gisel, and 2011:98).

Although the previous research explores and describes the experiences of caregivers raising children with physical disabilities, most of the studies reviewed do not differentiate the experiences of mothers and fathers. Experiences are accounted for separately, based on the assumption that as primary caregivers, mothers are likely to experience substantially higher level of psychological and emotional distress than fathers (Kresak et al., 2014:3).

Consequently, understanding the experiences of primary caregivers including what factors influence their wellbeing, is essential for the development of meaningful and effective interventions, services and support, and this is an area of inquiry that merits further investigation (Rosenbaum, 2011:68). Several studies in this area have focused on the wellbeing of individual family members, especially caregivers. Nevertheless, there has been growing interest in the conceptualisation and measurement of family quality life (Rosenbaum, 2011:68). According to the study conducted by McNally et al. (2013:96) in Tanzania, negative experiences that are experienced by primary caregivers can lead to stress and caring becoming a burden.

2.7.2 Stress and Burden of Caring for a Disabled Child

Raising a child living with physical disability is stressful for the primary caregivers because it requires intensive physical engagement and may occasion emotional reactions to the child's condition. Having a disabled child may increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable child care and affect decisions about work, education or having another child, and relying on public support may reduce self-esteem (Nadon et al., 2011:98). Stress and burden have been the main background for many studies on caregiving as reflected in extensive literature on these subjects (Kahana & Young, 2009; Nolan, Grant & Keady, 2010). Opie (2011:31) recognises that although stress is an inevitable part of caring, and indeed life in general, it can also be a positive experience providing opportunities for growth and challenges. Despite the challenges in gender norms, females remain more personally involved in caregiving than males. Hartley, Ojwang, Baguwebu and Chavuka (2014:167) are of the opinion that the burden of caring for a physically disabled child and attending to the child's bodily needs falls primarily on the mother in the family and, in the absence of the mother, the grandmother usually takes care of the child with a disability. Primary caregivers have different modes of

adaptation to stress and demands caused by caring for the child (Croot et al., 2012:1540).

There are numerous studies mostly by international researchers which examine the burden of care, stressors and needs of caregivers of children with physical disabilities; for example, the British Survey (2014) posits that 47% of 1 500 parents were battling with anxiety, unresolved frustrations and exhaustion associated with the burden of responsibilities. Adjacent to these findings, a South African study by the Uhambo foundation in Soweto found that 82% of parents of children with disability were living in a state of anxiety and displayed symptoms of depression which induced physical health complications (Nelson Mandela Foundation [NMF], 2005:102).

The British Survey found that a child living with disability leaves the caregiver with antagonistic feelings. Moreover, the continuous day-to-day care and support induces psychological strain due to lack of resources and economic circumstances. Opie (2011:31) explored the stressors and need for South African families of children with disabilities in disadvantaged communities and also found that families of children with disabilities have a number of stressors emanating from the battle of meeting needs of the ordinary family and the specific needs of the child living with disability. This therefore confirms the notion that caregivers of children living with physical disability suffer from the psychological and physical illnesses. Emerson et al. (2012:96) highlighted that there is a need for information on physical disability, their children's financial needs, counselling and day-care centres. Opie (2011:31) concurred with other studies like those done by Oruche, Gerknmeyer, Stephan, Wheeler and Hanna (2012:382) as well as Nolan, Grant and Keady (2010:822) which found that primary caregivers of children with physical disabilities are more stressed than those with other disabilities.

McNally and Mannan (2013:96) argue that most research identifies a strong interrelationship between the types of disability and primary caregiver's behaviour and practices with children with special needs, at home and in the community. On the other hand, raising a child with a physical disability is a major challenge for the primary caregivers, especially those who live in poorly resourced communities. This includes bearing the additional financial burden for treatment of the child's condition and dealing with the stigmatisation associated with disability (Hughes, 2013:47). In view of these

findings, there are several factors that are associated with caring for the child with physical disability. These factors include the support system at home, cultural values and beliefs, financial resources and stability for seeking treatment and rehabilitation services for the child concerned (McNally & Mannan, 2013:96).

2.7.3 Inadequate Infrastructure for Health and Education

According to Qayyum, Zainulabdin, Ghazal and Rafique (2013:50), healthcare facilities and services are also recognised as key issues. Lack of rehabilitation professionals, healthcare centres and hospitals, are problems caregivers experience when seeking treatment and rehabilitation services for their children with physical disabilities. Information and awareness about the available health facilities within their communities was also found to be lacking among caregivers. Even if some of the facilities such as rural health centres, basic health units, and some private clinics were available nearby, most of the caregivers did not utilise them as they were perceived as dysfunctional most of the time (Qayyum et al., 2013:50). Qayyum et al. (2013:50) further revealed that lack of information from the healthcare professionals regarding management and treatment of the child with physical disabilities at home was perceived as a problem for primary caregivers.

A study conducted by the NMF (2005:67) on the educational status of children in rural communities points out that children with disabilities are a large group whose needs often go unnoticed. Widespread biases and exclusionary practices affect the educational possibilities of boys and girls who have disabilities (NMF, 2005:67). A large number of children with severe and profound disabilities stay at home, placing an additional burden on the family because of their need for full-time care, and preventing the mother from going to work. Many families are forced to pay for day care and even school hostels out of the social grants received by their children. Globally and also in South Africa, the group of disabled children who are most vulnerable live in extreme poverty, and are those with intellectual disability and those in rural areas, (ACPF, 2011:76). Children with disability who are hidden are also not recorded by the system and consequently do not have access to any services. The link between poverty and disability has also been systematically examined. Information relies heavily on anecdotal evidence and case studies (Eskay, Onu, Igbo, & Ugwuanyi, 2012:473). As a result of limited infrastructure, children with physical disabilities do not

go to school because mainstream schools cannot cater for their needs. As a result, children with physical disabilities stay at home, placing a burden on the caregivers. This leads to unemployment because caregivers would have to stay at home and take care of their children.

2.7.4 Perceived Barriers and Facilitation to Participate in Physical Activities for Children with Physical Disabilities

Most of the time children with physical disabilities are unable to participate in the activities in school as a result of the nature of the activity or the infrastructure on the sports field. Shields, Synnot and Barr (2013:989) argue that children with physical disabilities engage less in physical activities than their typically developing peers. Regular participation in physical activities by children including those with disabilities enhances body composition, bone health, psychological health and promotes social engagement. There are additional therapeutic benefits to participating in regular activities for children with physical disabilities.

Children with physical disabilities often have delayed gross motor development, less proficiency in balance and coordination and poor cardiovascular fitness compared to their peers with typical development, all of which could potentially be improved by participation in physical activities. The conceptual model helps to illustrate the relationship between physical activity behaviour, its determinants, and health, including the role of contextual factors for people with disability (Shields et al., 2013:989). Any restriction or lack of ability to perform an activity in the manner within the range considered normal will obviously have a direct negative impact on the child involved. The direct impact includes the disabled child's exclusion from mainstream society, stigmatisation and loss of self -esteem. The emotional effects of the child's disability can interfere with his socialising with other children through play, sports, schooling and other leisure activities for both the disabled and non-disabled child (Nocon, Müller-Riemenschneider, Nitzschke & Willich, 2010:458).

2.7.5 Cultural Influences on the Care of Children Living with Disabilities

The cultural surroundings have an effect on how people with physical disabilities identify themselves, or are identified by others and this can influence their social wellbeing, economic and health status. Eskay et al. (2012: 473) mention that, in every

culture, disability is perceived differently and such perceptions shape the kind of services that are rendered. Wilson (2011:45) concurs with this view by stating that a mother's culture will determine the way she respond to the situation that she has given birth to a disabled child. Further, Wilson (2011:45) found that culture may influence attitudes and reactions to the level of caregiving given to children with disabilities. He also found that, in some cultures, children are perceived as the extensions of the parents' bodies and the impairment to the children's bodies may seem like impairment to their parents' bodies, which they are unable to accept. The Chinese culture holds with this idea of reciprocity. According to Eskay et al. (2012: 473), parents give to children when they are young and these children, when they become adults, must return the gifts and services to their parents. Children will therefore be nurtured with the expectations that they will in turn nurture their parents. Therefore, a child born with disability in China causes a disruption to the exchange as giving good things to a disabled child will be perceived as pointless in the usual cultural sense.

Marini (2012:4) supports the statement by Hall (2017:24), saying that people with disabilities are devalued and perceived as less than human in some cultures as there is a belief that disabled people consume resources without providing anything in return. However, in some cultures, where disability is perceived as a temporary condition, primary caregivers of disabled children may see themselves as the chosen ones for this important role (Wilson, 2011:48). The WHO (2011:79) mentions that cultural beliefs and stereotyping of people with disabilities is still a pervasive problem that threatens the physical, psychological and emotional health and wellbeing of people with disabilities. It is believed that culture could prevent some individuals from coming forward for diagnosis and treatment.

2.8 FACTORS AFFECTING CAREGIVING

There are some factors that can affect caregiving of physical disabled children. These factors can include the physical condition of the primary caregivers, level of knowledge and nature of disability, age and financial cost of the caregiving. These factors are discussed below.

2.8.1 The Physical Condition of Caregivers

The health of the caregivers is a critical element in the caregiving continuum as it has a bearing on the wellbeing of the child with physical disabilities who is being cared for. Primary caregivers who have to lift and carry care recipients with disabilities have been found to have reduced physical functioning and back pain in comparison with those who are caregiving but do not need to give such assistance (Mweshi & Mpofu, 2010:39). The primary caregivers in low-income countries face a huge task in the caregiving continuum because of the high load of physical work required as a result of lack of special equipment which assists them to reduce the workload.

2.8.2 Level of Knowledge

Caring for a physically disabled child needs a person who has knowledge of how to do it. It has been observed that the primary caregivers often do not have the right skills and knowledge to give adequate care and will need assistance from the formal social and healthcare services providers (Mweshi & Mpofu, 2010:39). According to Peshawaria, Menon, Roy, Rajam and Gupta (2014:1), primary caregivers mentioned that they faced challenges with the lack of knowledge of the problems with the children they were raising, the stress of the child's condition and their inability to care in the best way for the child. Mwesh and Mpofu (2010:39) highlighted that primary caregivers often do not possess the right skills and knowledge to give adequate care and hence will need assistance from the formal social and healthcare service providers. Primary caregivers of the physically disabled children reported spending substantial periods discussing their needs with health and education officials in an effort to help them to meet the needs of their children (Resch et al., 2010:139). Peshawaria et al. (2014;1) identified some barriers to compliance such as lack of knowledge from primary caregivers, financial problems, stigmatisation by community and lack of time to do the exercises with the child, difficulties in primary caregivers' tasks like feeding, bathing, diminished sleep, social isolation and lack of recreation as well as the age of a primary caregiver.

2.8.3 Financial Problems

Caring for a child living with a disability results in financial challenges among primary caregivers. Some of these challenges include high costs of medication and even

transportation to hospital every month (Resch et al., 2010:139). Lack of transportation may also present a barrier to compliance to the primary caregivers who may want to participate in leisure activities or become involved in activities that enhance their ability to cope, such as primary caregivers' support groups (Williams, Forbes, Mitchell, Essar & Corbett, 2012:280). A study by Kresak et al. (2014:17) further identified poor physical health of the children living with disability, lack of information regarding the condition, unavailability of services and government benefits, and lack of facilities as the most pressing areas of concern.

Physical disabilities in children can impose considerable cost on families caring for them. Vecchio, Cybinski and Stevens (2008:782) state that the increased financial burden may be attributed to the special medical care, education, therapeutic and special needs. According to a study conducted by Anderson and Phohole (2007:99) in the USA, 40% of families of children living with disabilities faced financial burdens as a result of disability of the child. Irrespective of the nature of the disability, the cost of care for a child living with disabilities is three times more than that of a child without disabilities (Singongo, Mweshi & Rhoda, 2015:274). In addition, the study found that these costs were often long-term, even lifelong costs. Looking at the above-mentioned situation, the South African government provides the primary caregivers with some financial assistance in the form of a CDG in order to help them meet the needs of the children. The following section focuses on the impact of the grant in enhancing the lives of disabled children.

2.8.4 The Impact of CDG in Enhancing the Lives of Children Living with Disabilities

CDG is a social grant intended to provide financially support to parents, primary caregivers or foster parents of any child with severe mental or physical disabilities up to 18 years, requiring full-time home care. Even though the child may make use of professional support services, the child should not be cared for in an institution but at home in order to qualify. The child's disability must be assessed by a medical doctor (SASSA, 2018). The amount of grant is R1 620 per month. According to SASSA (2018), the 145 000 children in South Africa receive the CDG. KwaZulu-Natal is the province with high numbers of children who receive CDG; in February 2018, the number was 39 374.

Vecchio et al. (2008:782) argue that children with physical disabilities require greater physical care and supervision than average children. These increased needs results in the increased financial, physical, and social demands on their primary caregivers. The study conducted by McNally and Mannan (2013:96) discovered that the financial costs of amenities were among the leading challenges faced by primary caregivers of children with physical disabilities. The basic amenities such as food, nappies and housing were found difficult to meet using the CDG. Most primary caregivers are unemployed; as a result, they are compelled to care for the physically disabled child at home since they struggle with hospital fees and transport fees. According to the study conducted by the Nelson Mandela Foundation (NMF, 2005:68), children with disabilities face barriers in accessing welfare services due to difficulties in obtaining a birth certificate and identity document. It also found that a high number of children with disabilities do not receive CDGs. In Mpumalanga Province, 43% and in Gauteng more than half of children with disabilities do not receive CDG (NMF, 2005:68). Even for those who receive it, it is not enough to meet their daily needs because rehabilitation services are not integral to primary care programmes and remain largely a specialised service at tertiary level. The current service provision highlights deficiencies and gaps; for instance, although there health services are free to children under the age of 6 years and people living with disabilities, this does not include assistive devices. In Mpumalanga Province, 67% of children with disabilities did not have any assistive devices, which makes them less functional and more dependent on caregivers (UNICEF, 2012: 96).

The recognition of disability as a developmental issue, i.e. as both a cause and a consequence of poverty, has facilitated a broadened understanding of disability, contributing towards social transformation. Disability increases vulnerability to poverty, while poverty creates the conditions for increased risk of disability. Furthermore, disability increases vulnerability to poverty because of the costs associated with living with a disability, discrimination in the labour market, and difficulties related to access to education and assistive devices (Emmett, 2012). On the other hand, UNICEF (2012:98) found that CDG has a significant and positive impact on children and households of those are recipient. The study that was done into the profile of social security grant recipients found that 98% of households in which a disabled child was a recipient of CDG indicated that the grant had improved the general wellbeing of the

household. Significantly, 78% of CDG recipients also reported that improvement in the household's wellbeing was as a result of being able to purchase better quality food. For some, 8% was used to cover the cost of attending a medical facility, 7% to purchase medicine and 6% for improved housing. The above sections have shown the challenges that the primary caregivers face (NMF, 2005:68). It is, therefore, important to discuss how the primary caregivers cope in raising the children despite the challenges they face.

2.9 COPING STRATEGIES OF PRIMARY CAREGIVERS

Coping is complex and includes a variety of behavioural efforts in which an individual manages a stressful situation (Nolan et al., 2010:822). Failure to adopt a coping strategy may result in deterioration of health of both the primary caregiver and the child with disabilities. The resilience model of family stress, adjustment and adaptation postulates that the utilisation of certain coping strategies facilitates successful family adaptation to the child's condition (Krstic & Oros, 2012:373). Nolan et al. (2010:822) categorised coping strategies into two broad categories, namely, problem-focused coping strategies which include efforts to manage the stressful situation, and emotion-focused coping strategy which focuses on the efforts to alleviate the emotional distress caused by stressful conditions. Emotion-focused coping strategy tends to be associated with negative psychological states such as depression and anxiety. Resch et al. (2010: 139) divided emotion-focused coping strategy into three coping styles, i.e. intrapsychic, wistfulness and acceptance.

Intrapsychic styles are said to be related to poor mental health of the caregivers while emotion-focused strategy of acceptance is related to better mental health. Nolan et al. (2010:822) found that problem-focused coping had positive mental and physical outcomes in primary caregivers. Nolan et al. (2010:822) further suggest that all strategies are potentially useful but they must be matched with the nature of the stressor. Coping may be liberating, but at the same time, it may also prove to be a stressful experience itself. Therefore, supporting and boosting caregivers' coping efforts should be a major objective when planning for professional support. Coping resources are part of an individual's internal or external environment that are not under their direct control and lie dormant until called upon in a stressful encounter. Within a person's internal resources are factors such as personal skills, relevant life

experiences and psychological and reasoning abilities (Nolan et al., 2010:822). To cope effectively with the increased demands associated with children with special needs, their primary caregivers must develop additional resources and coping skills. It was also found that primary caregivers from the low-income group felt more isolated and lonely. They were physically unable to access other service providers like physiotherapists, psychologists and social workers (William et al., 2012:280). In addition, Croot et al. (2012:1540) postulated that there is a wide variation in coping strategies that are utilised by primary caregivers of physically disabled children in response to different circumstances. This is consistent with a study conducted by Trute, Benzies, Worthington, Reddon and Moore (2010:37) suggesting that primary caregivers have different individual coping strategies such as acceptance of a child and faith. Social support includes the utilisation of external support such as family members and relatives and is considered helpful by caregivers in managing challenges of raising a disabled child.

Researchers have determined that primary caregivers of children living with physical disabilities who have a range of stress-coping resources are in better shape to avoid emotional difficulties, sustain good health and represent fewer signs of depression than those with few or no coping resources facing the same problem (Kiruma & Yamazaki, 2013:118). Furthermore, acceptance of the child with physical disabilities can act as a coping strategy of the primary caregiver. The study conducted by Bayat (2014:702) argues that the negative ideas about disability arise from caregivers' previously-held ideas about disability and those of close associates like family and society. Reframing the disability as a blessing empowers parents to challenge this view and in doing so facilitate acceptance of the child. Trute et al., (2010: 37) also emphasise that following the birth of a child with disability, parents' ideas about disabilities change over time and this transition influences their experience and management of their situation. Greeff and Nolting (2013:396) also postulated that following the birth of a child with disability, parents adapt to the situation and accept that there is nothing they can do to change the situation and therefore they have to live with it. This view was considered to be aligned with one of the assumptions of the family resilience framework of stress, adjustment and adaptation which places emphasis on viewing a crisis as manageable. Peshawaria et al. (2014) identified better marital satisfaction or support from the husband as effective for compliance while less

satisfactory marriages and less support could be inhibitors to compliance with rehabilitation at home.

2.10 THE ROLE OF THE SOCIAL WORKERS IN FAMILIES OF CHILDREN LIVING WITH PHYSICAL DISABILITIES

Social workers as change agents can make a difference in the lives of children living with disabilities. By using the social model of disability, social workers can address socio-political constructs that cause challenges such as negative perceptions and attitudes towards disability. The social workers' role is to identify community resources and make referrals for children with disabilities for early childhood development. Another role of the social workers is to educate the primary caregivers on the condition of their children with disabilities. Algood and Harris (2013:126) mentioned that at times the parent or a primary caregiver of children with disabilities report that they do not understand the medical terms used by healthcare providers, which often creates a barrier that results in primary caregivers being unable to access information on available resources that will help them manage the child's condition. This creates the opportunity for social work interventions to ensure that the primary caregivers understand their children's diagnosis.

A social worker can also introduce primary caregivers to assistance and community resources available which could include housing, health, recreation and educational services (Hall, 2017:24). Other than the social work intervention previously discussed, social workers play a significant role in preventative interventions to address the needs of people living with disabilities and that of their families. Al-Good and Harris (2013:126) are of the opinion that social workers have a professional obligation to provide services to people and children with disabilities and their families by creating a supportive environment. This supportive environment should make it possible for children with disabilities and their families to define their own needs and challenge service provision constraints. Social workers should implement interventions that are appropriate to the circumstances of the children with disabilities.

According to the study done in Namibia by Hall (2017:24), social workers should do community awareness campaigns and educate communities in terms of disabilities, policies regarding disabilities as well as special inclusive education. Social workers may do this by working with community health forums, health extension workers or

other established forums. Most importantly, social workers in their role as educators and advocates can help educate communities on the rights of person with disabilities. Areas of focus as stipulated in the UNCRCD are that persons with disabilities deserve to be respected as individuals with inherent dignity, they should not be discriminated against on the basis of their impairments, and they deserve equality of opportunities (UN, 2008:66).

2.11 THEORETICAL FRAMEWORK

The phenomenological exploration of challenges experienced by primary caregivers in raising children living with physical disabilities is insufficient without the theoretical lens. Therefore, the researcher has chosen three theoretical aspects underpinning the broad discourse: the medical model, the social empowerment model, and the cultural model of disability.

2.11.2 Medical Model

The medical model of disability means that the organisations for people with disabilities are usually controlled by non-disabled who provide services to people with disabilities (Office of the President, 1997). The medical model of disability is included here since the research is more focused on the medical rehabilitation programmes of children with physical disability. According to UNICEF (2011:20), the medical model perceives disability as an individual pathology or malfunction, or as a specialised health problem at the heart of which is an emphasis on clinical diagnosis. Using this approach, the problems of people with disabilities are viewed as their own personal inadequacies. It is also viewed as defects and difficulties they experience and is attributed to individual functional limitations. UNICEF (2011:40) state that medical professionals such as therapists are regarded as the experts who know best the needs of children with disabilities, and therefore have the power to make decisions on their behalf. The medical model of disability viewed individuals with disabilities as tragic victims or helpless individuals who are dependent on the charity of others. It also underlies the delivery of service. Service for people living with disabilities are channelled through welfare institutions, and much of the responsibility of caring for children living with disabilities is placed on civil society organisations (Office of the President, 1997:91).

The perception of disability as a medical model issue leads to the isolation of disabled children and their families and they are separated from their communities and excluded from participation in society (UNICEF, 2011:41). This entrenches the cycle of dependency and helplessness. In South Africa, this approach has been compounded by the legacy of the inequities of the apartheid system, as well as persisting stereotypes of disability which continue to exclude children with disabilities from mainstream society. As a result of a badly designed built environment, inaccessible public transport, discriminatory attitude and practice and other barriers, people with disabilities are usually excluded from participating in mainstream society (Office of the President, 1997:90).

According to the medical model, poor parental care, malnutrition and poor hygiene living conditions are the causes of disabilities (WHO, 2011:99). WHO (2011:101) further states that other causes of disabilities include accidents, transmissible and non-transmissible diseases, injuries due to violence old age and disasters. However, it can be noted that there are preventative activities that could be done which include awareness campaigns among the communities, rehabilitation of people with physical disabilities and medical intervention as soon as possible.

2.11.2 Social Empowerment Model

Friedman's (1992) social empowerment model was introduced as an alternative to the medical model. The social model of disability recognises that the barriers that excluded children with disabilities from participating in society are not created or caused primarily by their impairments, but arise from the way that society is organised to meet the needs of the non-disabled. Adopting of this model is aimed at shedding light on the experiences of the primary caregivers in raising children with physical disabilities in the Mvunyane area in Vryheid, KwaZulu-Natal. Friedman's social empowerment model has eight bases, namely, financial capacity, formal and informal social network, surplus time, social organisation, appropriate information, knowledge and skills, of specific skills.

- Financial capacity means that the household must have enough resources in order to buy the goods and services they require.
- Having strong formal and informal social networks is also important. These help a household to engage in reciprocal actions that benefit both parties. Families,

friends, neighbours and colleagues tend to make up the bulk of one's social network.

- Surplus time means the amount of time available after the requirements of subsistence living have been met. The greater one's surplus time the more time the caregiver has for leisure, pursuing sources of additional income, and for creating strong social network.
- Social organisation is both the formal and informal organisation that the caregivers belong to such as churches, support groups, community sports clubs.
- Appropriate information is needed by caregivers of family members of the disabled child about various aspects of their lives in order to make them better and to move beyond subsistence living; for example, knowing about the special schools around the area, the best child-rearing practices, and healthcare information.
- Knowledge and skills refers to both the education and ability of family members to manage living with a child with disabilities.
- Mastery of specific skills needed to make the household as prosperous as possible. Each member recognises the need that they must be as educated and skilled as possible (Wilson, 2011:45).

This model is relevant because a brief exploration of the topic revealed that, in the developed countries, primary caregivers of the children with physical disabilities do benefit from the application of this theory. In many low-income countries, however, this is not the case, not only because of financial problems due to loss of income and the high cost of treatment, but because of negative societal attitudes and stigmatisation that still surround disability. This leads to social isolation for the primary caregivers and the children concerned. With the social model, intervention is focused not on the individual person with disability, but on removing the barriers that prevent them from exercising their right to participate in society (UNICEF, 2011:33). It is a collective responsibility of society to remove barriers to the equal participation of children with disabilities. The social model of disability reflects a human rights approach to development. Difficulties face by children with disabilities as well as their caregivers are regarded as a human rights issue and those with disabilities are seen as group that experiences discrimination. Their rights are not respected and fulfilled; for example, refusal of main stream schools to accept children with disabilities constitutes a violation of the right to education.

2.11.3 Cultural Model

According to Groce (2009:13), the cultural theory of disability states that culture might view disability in both negative and positive ways. People from different cultures may have the same cultural beliefs as well as biological beliefs on disability. Groce (2009:13) is of the view that culture that perceives disability in a positive light are more open to modern approaches to disability than those that hold negative ideologies concerning disability. It can be viewed that in some cultures, like Uganda, physical disability is viewed as a curse or punishment from the ancestors that is brought about because the family of the person with a physical disability did not behave according to the set norms and values (Abosi & Koay, 2008:196). According to Haihambo and Lighfoot (2010:76), some African communities perceive disability as a punishment for the wrong actions from God or their fore fathers and disability is, therefore, always difficult to deal with. Through the attitude of the community towards the acceptance and accommodation of people with physical disabilities, it is evident that the people with physical disabilities are still being stigmatised and viewed as incompetent, because of negative perceptions (Haihambo & Lighfoot, 2010:76). In light of the views of community members, people with physical disabilities struggle to get assistance in the community even from the extended family members.

2.12 CHAPTER SUMMARY

Several points of interest in the literature reviewed revealed that there are challenges faced by families and parents in raising children living with physical disabilities. However, the literature reviewed purely indicates the lack of research on the concept of children's disabilities, particularly on experiences of caregivers caring for children living with physical disabilities. In view of the above findings, the researcher saw a need for ascertaining what could be the challenges encountered by primary caregivers in caring for children with physical disabilities in rural areas. The next chapter will describe the research methodology of this study.

CHAPTER 3:
RESEARCH METHODOLOGY

3.1 INTRODUCTION

Research methodology in social science research refers to the framework associated with particular set of paradigmatic assumptions that researchers use to conduct their research, such as scientific method and action research (Babbie, 2016:79). On the other hand, Neumann (2013) describes the primary aims of research methodology as a series of precise explanations that are aimed at clear amplification the approach utilised during the process of conducting the study. It is a sequential detailed description of methods adopted during the course of the study without deviating from its purposes and objectives. This chapter explains how the research was conducted. It includes the research approach, type of research, research design, and the research methods which includes a description of the area where the study was conducted, study population and sampling methods. Also included in the chapter is the data collection method that was used, the data analysis process and how the data quality was ensured. It also entails a description of the ethical issues associated with the study and steps taken to maintain high ethical standards.

3.2 RESEARCH APPROACH

The research approach entails the qualitative, quantitative or mixed methods nature of the study (De Vos, Strydom, Fouche and Delport, 2011:90). Qualitative research is described as research that attempts to collect rich descriptive data in respect of a particular phenomenon or context with the intention of developing an understanding of what is being observed or studied. It therefore focuses on how individuals and groups view and understand the world and construct meaning out of their experiences (Creswell, Ebersohn, Eloff, Ferreira, Ivankova, Jansen, Nieuwenhuis, Pietersen, Plano Clark & Van der Westhuizen, 2013). The quantitative research designs are intended to collect primarily quantitative data such as numeric scores and metrics. Examples of quantitative designs include survey research and laboratory experiments. The mixed method research design combines both the qualitative as well as quantitative designs.

The research approach that the researcher used in this study was the qualitative approach because qualitative research takes place in a natural setting where human

behaviour and events take place. According to Creswell et al. (2013), qualitative research focuses on participants' perceptions and experiences as well as their ways of making sense of their lives. Furthermore, Pickle (2013) describes the presentations of qualitative findings as being critical determinants of their usefulness. Qualitative findings are typically detailed and to the point. Qualitative methodology systematically documents, classifies and interprets informants' cognitions and experiences, so that it accurately reflects their lifestyle and acknowledges (Sawatzky & Fowley-Kelly, 2013). One of the unique features of the qualitative research methodology is a small number of participants in a study (Hennink, Hutter & Bailey, 2011).

The advantage of qualitative approach is that the reality is interpreted from the participants' frame of reference; therefore, a phenomenon is understood in its natural context (Bless, Higson-Smith & Sithole, 2013). The other advantage of qualitative research approach is that the emphasis is on the quality and depth of information and not on the scope or breath of the information provided as in quantitative research (Creswell et al., 2013). However, due to the small sample size, the findings from a qualitative study cannot be generalised to a whole population.

3.3 RESEARCH DESIGN

De Vos et al. (2011:307) describe a research design as a plan, recipe or blueprint for the investigation and provide a guideline according to which a selection can be made of data collection methods which are most appropriate for the researcher's goal and selected design. Qualitative researchers are interested in the meaning that subjects bring to their life experiences (Fouche & Schurick, 2011:308).

On the other hand, Babbie (2016:89) defines research design as a process where a researcher clearly describes the plan for conducting the scientific inquiry by designing a strategy for finding answers to the problem that is being investigated. In order to address the research problem logically and unambiguously, the researcher chose to make use of a case study design because the researcher sought to enter the field with knowledge of relevant literature before conducting the field research. According to De Vos et al. (2011:320), case study design is more of choice of what to study than how to study it. Although the case study method is sometimes regarded as an inadequate or inappropriate strategy of inquiry, the case study is versatile because of its ability to be applied to a wide life history, phenomenology, grounded theory and ethnographic

research. Case study research is noted as a strong methodology that seeks to bring an understanding of a complex issue which is then used to add knowledge to other research already completed. According to Creswell (2013:73), a case study involves an exploration of a bounded system or a single case or multiple cases over a period of time through detailed, in-depth data collection involving multiple sources of information. There are various types of case study designs such as a descriptive, collective or explanatory case study.

For the purpose of this study the researcher used an explanatory case study design because the aim of the study was to explore the challenges faced by primary caregivers in raising children living with physical disabilities. It was also aimed at exploring the coping strategies of the primary caregiver.

Explanatory case study design is also called instrumental design. The purpose of explanatory case study is both theory building and testing. Case studies can be particularly useful for producing theory and new knowledge, which may inform policy development (De Vos et al., 2011:321). This type of case study would be used if you were seeking to answer a question that sought to explain the presumed causal links in real life interventions that are too complex for the survey or experimental strategies. According to Babbie (2016:92), explanatory research answers the questions of why.

During the process of designing the case study, several primary caregivers of children with physical disabilities qualified as participants of the study. Certain characteristics that are detailed in the sampling method discussed in the next section were utilised as selection criteria to define the unit of analysis. The research was thus able to convey accurately the events of the study and also validated the experiences of primary caregivers and meanings they attached to their caregiving role. The study was based on a case study of Mvunyane area.

3.5 AREA OF THE STUDY

In this section, the researcher provides a detailed explanation on the study population and sampling method that was applied in the study. In addition, the data collection, pilot study and data analysis for this particular study are also discussed.

The study was conducted at Mvunyane area in Vryheid, in Northern Kwa-Zulu Natal under Abaqulusi Municipality. It is a deep rural area with ten villages, approximately

100 kilometres away from Vryheid. The area has high rate of persons living with disabilities, unemployment and child-headed households (Stats SA, 2011:6). Although the area is extremely rural, basic health amenities are found, for example, the area has two clinics (Siyakhathala and Ntababomvu clinics) which fall under the Vryheid District Hospital. There are 13 public schools – six secondary schools and seven primary schools. There is only one registered crèche and one community hall. The unemployment rate in Mvunyane area is very high because there are no industrial areas for development. Somalians immigrants are the only ones that seem to benefit from Mvunyane area in terms of income because they are own tuck shops. The residents of Mvunyane spend their money at these tuck shops because Vryheid town is very far for them to do their required shopping. There are no running water supplies or electricity in some of the villages which makes life difficult. According to Stats SA (2011:6), Mvunyane community has an approximate total population of 25 490 with 10 070 children under the age of 18 years, while the total percentage of people living with physical disability is 7.4%, including the children. Teenage pregnancy is very high in Mvunyane. Most girl teenagers are uneducated because they drop out of school due to teenage pregnancy.

3.5.1 Study Population

Population can be defined as a target population; it is a set of elements that the researcher focuses upon and to which the results obtained by testing the sample should be generalised (De Vos et al., 2011: 389). According to Babbie (2016:116), the population is the group usually of people about whom the researchers want to withdraw conclusions. The population encompasses all the elements that make up our units of analysis. Babbie (2016:193) also defines population as the aggregation of elements from which the sample is actually selected. The target population for this study was the primary caregivers who were raising children

- with physical disabilities;
- who were undergoing rehabilitation; and
- who resided at Mvunyane area in Vryheid, Northern Kwa-Zulu Natal province.

3.5.2 Sample and Sampling Method

A sample comprises elements or subset of the population considered for actual inclusion in the study, or it can be viewed as a subset of measurement drawn from a population in which we are interested (De Vos et al., 2011:390). A sample refers to the sum of those individuals within a specific territory or a small portion of a population, a small representation of a large whole, intended to reflect and represent the character, style, content of the population from which it is drawn (Babbie 2016:187). The size of the sample is largely informed by the types of research methods or approach applied in the study.

In this study, a purposive sampling approach was adopted. Babbie (2016:187) defines purposive sampling as the type of nonprobability sampling in which the units to be observed are selected on the basis of the researcher's judgments about which ones will be the most useful or representative. The advantage of the purposive method is that the researcher is able to control the eligibility of the participants as they had to meet specific requirements (Strydom, 2011:232). A total of 20 participants were selected from the Vryheid Hospital database who were primary caregivers of children with physical disabilities.

The sample was drawn from the population that met the following sampling criteria:

- The participant must be the primary caregiver who is caring for a child with physical disability who is between the age of 7 and 18 years of age;
- The participant must reside in Mvunyane area; and
- The participant must attend rehabilitation services at Vryheid District Hospital.

3.6 DATA COLLECTION AND ADMINISTRATION

The applied research methods and the research designs were the primary determinants which culminated in the data collection strategy in this study. In-depth interviews guided by a semi-structured interview schedule were used to gather data from all 20 participants. An in-depth interview is a one-on-one mode of gathering information which involves the researcher as a primary interviewer and the participant as an interviewee discussing the subject of the research more deeply. Furthermore, an in-depth interview is described as a conversation with purpose because the

researcher's main purpose was to elicit insights on specific issues and concerns using a well-tested, semi-structured interview guide (Hennink et al., 2011).

The interviews with each participant lasted between 20-30 minutes. Open-ended questions were used. This provided the researcher with rich information because it enabled her to the adapt the research instrument to the level of understanding and articulacy of the participants (Fielding & Thomas, 2011). The semi-structured interview guide consisted of a variety of constructs that were to be covered namely, social challenges, economic challenges and coping strategies. The researcher worked with an assistant and each of us used notebooks which were compared and discussed after each interview to ensure trustworthiness of the responses.

A recording instrument was used to record the interviews after seeking written consent from the participants. A recording instrument was used during the collection of data to ensure that the data collected was accurate and credible. It also enabled the researcher to participate fully in the research process. The participants were informed that the recording instrument would be used and the purpose was explained. They were all comfortable with the use of the recording instrument.

3.7 DATA ANALYSIS

The data gathered from the interviews were analysed using thematic analysis. Thematic analysis is a way of summarising information which is done by reading through a body of material and identifying the themes or categories. The data were analysed thematically according to Creswell's analytical spiral process as described by Schurik, Fouche and De Vos (2011: 403). Creswell (2013: 182) mentioned that, to analyse qualitative data, the researcher should engage in the process called an analytic circle: one enters the circle with raw data consisting of text or images and exits with an account or a narrative. During this cycle, the researcher would touch on several facets of analysis and, therefore, circle around and around (Creswell, 2013: 182). The researcher, while processing and analysing the data, utilised the data analysis spiral as suggested by Creswell (2013:182). The following paragraphs focus on discussing the different steps of data analysis as described by Schurink et al. (2011:403).

3.7.1 Planning for the Recording of Data

According to Schurick et al. (2011: 405), the researcher should plan for the recording of data in a systematic manner that is appropriate to the setting, participants or both, and that will facilitate analysis before data collection commences. A digital recorder to ensure quality was used. After the participants gave their permission, an appropriate space was sought where the interviews were conducted and recorded. The interviews took place at two clinics of Mvunyane area, Vryheid, that is Siyakhathala and Ntababomvu clinics, but for some participants who did not manage to come to the clinics, interviews took place at their homes. During the recording process, only the researcher, assistant and the participant were in the room. The recorded interviews were later transcribed and translated into English.

3.7.2 Data collection and preliminary analyses

Schurink et al. (2011:405) state that data analysis in a qualitative inquiry consists of a twofold approach. The first stage involves data analysis at the research site, following the period of data collection. The second stage was conducted between site visits prior to and after completion of the data collection. In this study, the researcher used this twofold approach to make meaning of some of the data while still in the field. Notes were taken during the interviews and these notes were later compared with the transcribed scripts and recordings.

3.7.3 Managing (organising) data

De Vos et al. (2011:408) state that during this stage the researcher organises the data into files, folders, index cards or computer files. Besides organising files, researchers convert their files to appropriate text units, for instance words, sentences, or an entire story, for analysis either by hand or by computer. The researcher listened to the recording of the participants, transcribed the interviews verbatim and coded the participants to maintain confidentiality and anonymity.

3.7.3.1 Reading and writing memos

After the organisation and conversion of the data, the researcher continues analysis by getting a feeling for the whole data set (De Vos et al, 2011:409). The transcriptions of the interviews were read and compared to each other before dividing them into

sections for analysis. The researcher made notes in the margins of the transcripts to gain a sense of interviews as a whole. During the reading and writing of memos, the researcher repeatedly read the collected material and developed some ideas on how to categorise the data that had emerged (Bless et al., 2013:342).

3.7.3.2 Generating categories, themes and patterns

De Vos et al. (2011: 410) mentioned that identifying silent themes, recurring ideas, or language and patterns of belief that link people and settings together is the most intellectually challenging phase of data analysis and one that integrates the entire endeavor .On the other hand Creswell (2013:186) state that themes in a qualitative research are broad unit of information that consist of several categories that need to be reduced to small and manageable sets of data. The themes and sub-themes that were identified from the data which were obtained from the participants were based on direct quotes from the participants. The researcher developed these categories by focusing on the elements that occurred most in the data that was collected from the participants.

3.7.3.3 Coding the data

Coding data is the formal representation of analytic thinking (De Vos et al., 2011: 410). The tough intellectual work of analysis is generating categories and themes. The researcher applied a coding scheme to categories and themes, and diligently and thoroughly marked passages in the data using codes. The researcher considered similarities and patterns as well as the topics addressed in the data. The researcher wrote down words and phrases that were coded into categories. This process of coding involved the identification of themes and sub-themes.

3.7.3.4 Testing emergent understandings

A researcher, in this phase, begins the process of evaluating the credibility of this developing understanding and exploring it through the data. This entails a search through the data during which the researcher challenges the understanding, searches for contradictory instances within the patterns and incorporates these into large constructs, as necessary. Part of this phase is evaluating the data for its usefulness and centrality. The researcher should determine how useful the data are in illuminating

the questions being explored and how central they are to the story that is unfolding about the social phenomenon being studied (De Vos et al., 2011: 415).

The data was evaluated for its usefulness and centrality by analysing the transcribed interviews and considering their meanings and relevance to the study. This is supported by Creswell (2013: 182) who highlighted that not all information is utilised in a qualitative study and some may be discarded.

3.7.3.5 Searching for alternative explanation

As the researcher discovers categories and patterns in the data, the researcher should critically engage in challenging the patterns that seems very apparent (Schurink et al., 2011: 417). The researcher searched for other possible explanations for the data and the links between the participants' responses and did not solely rely on the literature that had been reviewed for possible explanations to address the issues in question. This approach is supported by Creswell (2011:187) who points out that interpreting metaphors as a rich source of multiple meanings is of paramount importance.

3.7.3.6 Presenting / interpreting the data

In the final phase of the spiral, the researcher presents the data, which entails packaging what was found in the text (De Vos et al., 2011:418). The interpretation of data is based on the discussion and analysis of the actual phrases stated by the participants and then compared the literature review. The interpreted data are presented in the text in Chapter 4.

3.8 DATA QUALITY

De Vos et al. (2011:419) state that an understanding of the literature enables the researcher to establish the quality of data gathered. It supports the line of enquiry that is pursued and is used to compare established findings and ideas with emergent information.

Trustworthiness was used to ensure the validity of the study as well as providing accuracy in the research process. Guba's model of trustworthiness was utilised to ensure trustworthiness. Trustworthiness refers to four criteria which must be applied.

3.8.1 Credibility

Trust value using the strategy of credibility was used. Credibility, in qualitative research, refers to the degree to which the information and data investigation are authentic and constant. Credibility is equivalent to internal validity as it looks at the research findings and compares it to the reality in the environment (De Vos et al., 2011:419). Credibility was met in this study by ensuring that the research was driven by ethical considerations and conducted in a professional manner. The researcher thus summarised the key points of the interaction during the interviews and this helped to ensure credibility. The reader of the findings will also be able to judge the credibility of the results. Trust value determines whether the research has established confidence in the credibility of the findings of the research. Factors taken into consideration are the truth of the findings, based on the research design, informants and context.

3.8.2 Transferability

Transferability refers to the extent to which the findings could be applied in other contexts or with other respondents (Babbie & Mouton, 2015:227). Research findings are considered to be transferable if they are found to be applicable in a new context. When the findings are published, the reader will thus be capable of identifying with the specific details of the research situations. The degree to which the research findings are generalised is termed transferability, the equivalence of external validity in quantitative research. Generalisability denotes the degree to which one can relate the settings of a specific situation directly to other people, periods or environments than those that are under study. A thorough description of processes and data is given to allow judgments about transferability to be made by the reader. Transferability allows the readers the option to apply results to other contexts (De Vos et al., 2011:420).

3.8.3 Dependability

Dependability is similar to reliability. In dependability, the researcher asks whether the research process is logical and well documented with an easily detectable audit trail. It is the alternative to reliability in quantitative studies, in which the researcher attempts to account for changing conditions in the phenomenon chosen for the study as well as changes in the design, created by an increasingly refined understanding of the setting

(De Vos et al., 2011:420). To ensure dependability the researcher was able to report in a great detail on each process of the study, thus ensuring that an external researcher would able to repeat the inquiry and achieve the same results.

3.8.4 Conformability

Conformability refers to how research findings are reinforced by the data collected. This establishes whether the researcher has been biased during the study because the assumption is that qualitative research allows the research to bring a distinctive viewpoint to the study (De Vos et al., 2011:421). The quality of research was enhanced by reference to findings by other authors.

3.9 PILOT STUDY

De Vos et al. (2011: 236) define a pilot study as one way in which researchers can orientate themselves to the project they envision. They further define a pilot study as a procedure for testing and validating an instrument by administering it to small group of participants from the intended test population. In this study, the pilot study was conducted with two participants who were selected on the grounds that they were all primary caregivers of children with physical disabilities. The same sampling methods and techniques were utilised to select these participants. During the pilot study, it was found that all the questions, bar one, were correctly expressed and easy to understand and followed logically. The last question was ambiguous and difficult to answer. The ambiguous question was then simplified and made clear in the main study. Another thing that was observed during the pilot study was that probing encouraged the participants to provide more detailed information in their responses. The probing strategy was therefore used in the main study.

3.10 ETHICAL CONSIDERATIONS

All social research involves ethical issues. This is because the research involves collecting data from people and it is about people. Throughout this study, ethical principles were adhered to, participants were informed about the purpose of the study and their consent to participate was obtained. Babbie (2016:62) states that anyone involved in social science research needs to be aware of the general agreements shared by researchers about what is proper and improper in the conduct of scientific inquiry. De Vos et al. (2011:113) mention that recognition and handling of ethical

aspects are imperative if successful practice and research are the goals. The ethical considerations that were observed are discussed in the following paragraphs.

3.10.1 Privacy and Confidentiality

The clearest concern in the protection of the subjects' interest and wellbeing is the protection of their identity (Babbie, 2016:65). Privacy and confidentiality were ensured since participants' names were not used in the analysis of the data, and they were advised that any information obtained from them was solely for the purpose of the study. The study respected the right and dignity of participants. Both the researcher and participants had a clear understanding regarding the confidentiality of the results and the findings of the study. All participants' information and responses shared during the study were kept private and the results were presented in an anonymous manner in order to protect the identities of the participants.

The researcher used pseudonyms to maintain confidentiality. No discussion on the participants or issues that arose from the interviews were done outside the interview. The data collected will be safely stored in a secure environment at the University of Zululand for five years before being destroyed.

3.10.2 Informed Consent

According to Babbie (2016:64), informed consent allows participants to choose their voluntary participation in a research project with a full understanding of the possible risks involved. All the participants signed the consent form that they agreed to participate in research study and they had a right to decide not to continue if they felt it was too emotional or they had any problems. According to Strydom (2011: 117), obtaining informed consent implies that all the information regarding the aim of the investigation, the expected duration of the participants' involvement, the procedures which will be followed during the investigation, the advantages and disadvantages that may occur during the process and the dangers that the participant might be exposed to should be clearly defined and provided to the participants. An important aspect that the researcher considered was that participants had to be psychologically competent to give their consent (Braun & Clarke, 2013: 63). Participants were informed that letters of consent must be signed and that an audio recorder would be used during the interview.

3.10.3 Permission to conduct the study

The study was conducted after obtaining ethical clearance from the University of Zululand ethics committee and permission to conduct the research from the hospital management as well as operational managers of the Ntababomvu and Siyakhathala clinics.

3.10.4 Protection from harm

According to De Vos et al. (2011: 115), subjects should not be harmed in a physical or psychological manner during the course of the study. It is therefore the responsibility of the researcher to minimise the risks and to protect the participants from physical and psychological harm (Babbie & Mouton, 2015: 523). In this study, the welfare of the participants was the major concern. The study protected the participants from unwarranted physical or psychological harm, danger and deprivation.

The participants were also informed that they might not receive direct benefit from participation in the study, but that their participation may help others in the future. According to Babbie (2016:63), social research should never injure the people being studied regardless of whether they volunteer to be part of the study or not. This signifies that the participants should be informed of the risks and the research purpose should be explained. The potential risk related to the study was psychological, and counselling was offered to those participants who showed any signs of emotional stress. During the interviews, the researcher was cognisant of emotions shown by the participants and would give breaks in between and asked permission to continue with the interview.

3.10.5 Debriefing process of participants

Babbie (2016:68) defines debriefing as the interviewing of participants in order for one to learn of their experiences of the research process and to update them of any unrevealed purpose. This is exceptionally critical where there is a likelihood of damage through participation. The debriefing process of the participants was done by the researcher after data collection. This process of debriefing assisted participants in dealing with the emotions that might have been triggered by their participation in the study (De Vos et al., 2011: 122). The researcher referred the participants who seemed

to be affected emotionally for counselling to discuss their feelings and emotions with the counsellor in an effort to prevent potential harm.

3.10.6 Actions and Competence of the Researcher

According to De Vos et al. (2011:124), researchers have an ethical obligation to ensure that they are competent and have adequate skills to undertake the investigation they propose. Before undertaking this study, the researcher was equipped with research theory from the research methodology modules and supervision by an experienced researcher who gave her guidance on practical research. The researcher, as a social worker by profession, has interviewing skills that were utilised during the process of data collection, when interviewing the primary caregivers of children living with physical disabilities. The counselling skills that the researcher possessed were used to provide counselling to the primary caregivers who became emotional during the data collection process.

3.10.7 Publication of Findings

Publication of findings of this study will add to the existing literature on the challenges experienced by primary caregivers in raising children with physical disabilities and the article will be published in a recognised academic journal. Publication of the findings of the study will also help the healthcare workers at Vryheid Hospital to know the challenges that the primary caregivers encounter while raising children with physical disabilities.

3.11 CHAPTER SUMMARY

This chapter has described the research process in depth, including the research design and methodology that was followed in the study. The following chapter presents and discusses the findings.

CHAPTER 4:
PRESENTATION OF FINDINGS AND DISCUSSION

4.1 INTRODUCTION

This chapter presents the research findings and provides discussion of these findings. The chapter starts by presenting the demographic information of the twenty participants who were interviewed. This is followed by a presentation and discussion of the themes and sub-themes which emerged from the interviews conducted.

4.2 BIOGRAPHICAL INFORMATION OF PARTICIPANTS

The researcher interviewed 20 primary caregivers of children with disabilities from Mvunyane area in Vryheid. Table 4.1 below illustrates the biographical information of these participants.

Table 4.1: Biographical information of participants

Pseudo names	Age	Gender	Race	Marital status	Employment history	Kinship with child
Zamile	31	F	African	Single	Unemployed	Biological parent
Betty	26	F	African	Single	Unemployed	Biological parent
Jane	44	F	African	Married	Unemployed	Biological parent
Juliet	25	F	Indian	Single	Unemployed	Foster parent
Petronella	43	F	African	Married	Unemployed	Biological parent
Pamela	38	F	African	Married	Unemployed	Biological parent
Pummy	31	F	African	Married	Unemployed	Biological parent
Rose	39	F	African	Married	Employed	Biological parent
Nana	28	F	African	Single	Unemployed	Biological parent
Nelile	25	F	African	Single	Unemployed	Biological parent
Herriet	39	F	African	Married	Employed	Biological parent
Promise	43	F	African	Married	Unemployed	Biological parent
Joyce	42	F	African	Married	Unemployed	Biological parent
Winnie	44	F	African	Married	Unemployed	Biological parent
Hlengiwe	31	F	African	Single	Unemployed	Biological parent
Nozipho	40	F	African	Married	Unemployed	Biological parent
Ntombi	29	F	African	Single	Unemployed	Biological parent
Pride	41	F	African	Married	Unemployed	Biological parent
John	45	M	African	Widower	Employed	Biological parent
Mirriam	62	F	African	Married	Unemployed	Foster parent

As indicated in the table above, out of 20 participants who were interviewed, 19 participants were females and only one participant was a male who was also a widower. The fact that the majority of the participants were female is consistent with the study conducted by Hartley et al. (2014: 172) which suggested that women are more likely than males to take responsibility of their families and take care of the

children including children with disabilities. The study done by Hartley et al. (2014: 172) found that women shoulder the responsibility of everyday caregiving despite the change in gender norms.

In terms of age, the ages of participants ranged between 25 and 62 years old. Furthermore, out of 20 primary caregivers who participated in the study, 19 participants were black African, Zulu-speaking while only one participant was an Indian and English-speaking. Mvunyane is a predominantly black African area that is why most of the participants were Zulu-speaking and black Africans. The findings further revealed that 12 primary caregivers who participated in the study were married, one was a widower and seven were single.

Regarding the employment status of the caregivers, 17 participants were unemployed. Although there is high unemployment rate in South Africa, most of the participants who participated during the study reported that they were unemployed because it was difficult for them to leave their children with disabilities with other family members because they perceived their children as a burden. Only three participants reported to have full-time jobs. Among the participants who reported to be employed two were educators and one was a paramedic. Promise said:

> *I resigned last year from my work because the person who was looking after my physically disabled child passed away. I tried to get another person but they said they can't cope in taking care of my child. This was because of her health condition made them to perceive that she is a burden.*

Nana said that:

> *Before my mother passed away, I was able to do something that was an income generating within the family. I went to Johannesburg, Durban and Pietermaritzburg to buy clothes, bags and some cosmetics to sell to people at SASSA pay points. But now I can't because no one in the family can take care of my younger sister who is physically disabled.*

In terms of the relationship of the primary caregivers to the children, 18 participants were the biological parents of the children and only two were foster parents. That confirmed findings by Resch et al. (2010:139) which highlighted that most of the children with disabilities are cared for by their biological parents. Furthermore, foster

parents are not willing to take care of these children because they see them as a burden (Resch et al., 2010:139). During data analysis, there were further themes and sub-themes that were identified. The following discussion presents the themes and sub-themes which emanated from the data collected.

4.3 AN OVERVIEW OF THE THEMES AND SUBTHEMES OF THE STUDY

The analysis of the results led to various themes and subthemes which emerged. Table 4.2 below shows these themes and subthemes which emerged.

Table 4.2: Themes and sub-themes

Themes	**Subthemes**
Social challenges faced by primary caregivers raising children living with physical disabilities	Social isolation
	Immobility
	Stigmatisation and discrimination
	Emotional stress
Financial challenges of caring for children with physical disabilities	Inadequacy of CDG
	Lack of money for necessities
The coping strategies of primary caregivers in raising children with physical disabilities	Emotional support
	Financial support
	Professional support
	Use of FBOs
	Positive experiences

The themes and sub-themes are presented and discussed in detail in the following sections.

4.3.1 Theme 1: Social challenges faced by primary caregivers in raising children living with physical disabilities

The first objective of the study aimed at exploring the experiences of primary caregivers. The results of the study gave a better understanding of both positive experiences and negative experiences. The responses were thematically analysed and the following sub-themes were identified: social isolation, social relationships, immobility, lack of friends, stigmatisation and discrimination. Each subtheme is discussed and supported by direct quotes, literature and reference to the theoretical framework.

4.3.1.1 Sub-theme 1: Social isolation

All the participants who participated in the study mentioned that they felt like they were isolated from social gatherings. This is because whenever there were family functions away from home, they could not attend because they had to take care of their children. All the primary caregivers who participated in the study reported that spending time with friends was valued before they had children living with disabilities. After having children living with disabilities, they actually found themselves spending time indoors and visiting their friends less often as their children needed constant supervision. Some of the participants mentioned that:

> *I can't even attend funerals because I have to take care of my child and now that she has gained weight it is very difficult to travel with her* (Nozipho).
>
> *Ever since my wife passed away, I feel so isolated from my friends because during the weekends I have to stay at home and take care of my boy* (John).
>
> *All my friends ran away after my mother passed away because I had to take care of my younger sister who is disabled. I am always at home with her, I feel isolated and neglected even by my other family members* (Juliet).

Wilson (2011) concurs with the findings of the study that the mothers of children with disabilities participate less in social activities compared to mothers who have children without disabilities. The researcher is of the opinion that because of their caregiving role the primary caregivers spends a lot of time in taking care of their children who need supervision all the time, so they do not have time to attend social gatherings.

The participants were asked about how having a child living with disabilities affected their social life. Social life was important for primary caregivers to function optimally. All primary caregivers noted that social life helps them to lessen the burden of caring and also to ensure that they have respite time. During data collection, it was discovered that the majority of the primary caregivers have disconnected their social life with friends and concentrated on their caregiving role. In this regard, 15 participants reported to be disconnected from friends. They highlighted their experiences in regard to the kind of relationships that they had and their effect on their social lives and caregiving.

Harriet mentioned that:

> *I don't have friends anymore because of my role of caregiving; I cannot go and see people. The only time I go out is when I go to church and when I have hospital appointment. I lost all my friendships when I found out that my girl is physically disabled and I had to spend all my time looking for her.*

Promise pointed out that:

> *I don't have friends anymore and it's not a big deal for me. The bottom line is my child and I have to look after him. I can't even move anywhere if my family go out, I have to stay at home and take care of him.*

It is evident from the participants' responses that their social lives have been negatively affected because of their role of caregiving. Most of the primary caregivers mentioned that before taking on the caregiving role, their social life was normal. Most of them pointed out that they cannot go out with their friends and family because they have to spend their time with their children. The participants stated that they lost their friends because of the time they spend with their children. The participants' level of interaction has thus been minimised and they can only spend time at church with their children. However, not all the participants have disconnected their social life with friends and family members. Some participants have maintained their friendships. Five participants mentioned that they still have time to hang out with their friends especially those caregivers who were single and living with their parents.

Previous research indicates that primary caregivers have difficulties in maintaining social relationships (Davis, Shelly, Waters, Boyd, Cook & Davern, 2009:63). Another study conducted by Oruche et al. (2012:382) states that the nature of the disability which might require special care can lead to grave disruption in the family relationships, thereby impacting heavily on the primary caregiver's social life. In most cases, the primary caregivers who are affected are those whose children have severe physical disabilities. A study conducted by Rosenbaum (2011:68) also states that the functionality of the family is the key factor in the psychological and physical health of the primary caregivers. This assertion is also confirmed by the evidence that suggests that there is a significant association between the functionality of poor families and the

heavy burden placed on the primary caregivers of children with physical disabilities (Temont, Davis, Bishop & Fortisky, 2008:203).

4.3.1.2 Sub-theme 2: Immobility

One of the subthemes that emerged was immobility when participants were asked about the accessibility of public transport for those children who are using wheelchairs. Eighteen participants said that they could not take their children with disabilities along with them whenever they went somewhere, especially those who were using wheelchairs because public transport was not easily accessible for people with disabilities in Mvunyane area. This caused feelings of frustration among the primary caregivers and the children. In addition, some participants reported that because public transport was not user-friendly, they ended up not taking their children to hospital regularly for check-ups. As a result, participants missed their appointment dates because it was expensive to hire private transport from Mvunyane to Vryheid Hospital. Not attending the appointment may results in defaulting treatment, thus reducing the life expectancy of their children living with physical disabilities and increasing mortality rates. Pride said:

> *I go to hospital once a quarter as a result of transport. This is because I cannot afford going every time I have an appointment because it is expensive for me. I have to hire a private car every time I go to hospital*.

Only two participants reported that they did not have any problems as far as immobility was concerned because they had their own private cars, and used them when they took their children living with disabilities to the hospital. Harriet said:

> *I do not have any problem because I have my car. Even if I am working that day, I ask my brother to take my child to hospital using my car.*

The majority of the participants showed that they had a problem in using public transport to go to the hospital every month because it was not user-friendly for people living with disabilities, as there was no space to put their wheelchairs. In addition, the participants highlighted that there were some needs that were not met that contributed to the challenges they experienced. Fifteen participants mentioned that some services that were meant to help them in caring their children were not met and were also delayed. They mentioned the shortage and delayed process of getting wheelchairs

from the government. Other participants pointed out that it had been five years since they applied for wheelchairs. Mirriam also mentioned that:

> *If they were having wheelchairs, we wouldn't have that backache we have now because I have to put her on my back every time we are going to hospital or clinic, even if we go to church.*

Winnie said that:

> *If she had a wheelchair, I could go and visit my friends and relatives. Now, I am always at home because she is now fifteen years and too heavy to carry around.*

The following section focuses on the stigmatisation and discrimination among primary caregivers of children living with disabilities.

4.3.1.3 Sub-theme 3: Stigmatisation and discrimination

When the participants were asked about how stigmatisation and discrimination affected them in their caregiving role, all the participants pointed out that their children were discriminated against at social gatherings because of their disabilities. The participants highlighted that various stigmas emanated from their communities. Joyce mentioned that stigmatisation and discrimination were shown in gestures such as pointing, staring and laughing. She said:

> *They just see the way she is disabled and they just laugh at her.*

Nellie mentioned that:

> *On his father's side, they point at him and they just avoid him when we visit his father. He feels so uncomfortable around his father's family and that's why we decided to stay with my family and the father is the one that comes to visit us.*

Winnie mentioned that:

> *Other children at church, they always discriminate my child, other children push her and mock her, they see her as not normal child and they don't want to play with her and that is very sad to me as a parent because at church it's where I expect to find love and warmth. Even their parents they don't discipline them when they discriminate my child*.

The participants were able to relate their experiences of stigmatisation from the community members. It was evident that the community had negative attitudes towards disability. The primary caregivers stated that the child living with disabilities was not the burden to them but the burden came from community members who were having negative attitude towards disability. That was the evidence that the communities were rejecting people living with disabilities as well as their family members especially their primary caregivers. Haihambo and Lightfoot (2010:76) also concur with the results of the study by highlighting that primary caregivers of children with disabilities in the western countries have noted the presence of discrimination, stigmatisation and exclusion among community members for them and their children with disabilities.

The primary caregivers stated that they were no longer comfortable to take their children to public places due to the level of stigmatisation against the children living with disabilities. It was noted by most of the primary caregivers that community members used derogatory terms for people with physical disabilities. The data from the research indicated that primary caregivers experienced stigmatisation even at church. The participants stated that this had a negative effect on their wellbeing as caregivers to the extent that at times they left the children at home because of the fear of stigmatisation and discrimination.

According to the study done by Hartley et al. (2014:167) in Uganda, the primary caregivers caring for children with disabilities faced stressors in the caregiving process and this lead them to have less time for doing other tasks for the house. Exclusion from mainstream activities can thus lead the primary caregivers to have challenges in the care offered to the child who is living with disability. In the current study, some of the participants indicated that their family were leaving them out of family events or programmes because of the disabilities and the role that they played. The participants

indicated that the families gave reasons which included that the primary caregivers were always busy and that they did not have anyone to leave the child with and hence could not participate fully in the family programmes. Many African communities still lack programmes and amenities, and do not cater for the full inclusion of people with disabilities.

In contrast to the medical approach, the social model of disability recognises that the barriers that exclude children with disabilities from participating in society are not created or caused primarily by their impairments, but arise from the way that society is organised to meet the needs of the non-disabled. As a result of a badly designed built environment, inaccessible public transport, discriminatory attitudes and practices and other barriers, people with disabilities are usually excluded from participating in mainstream society.

Stigmatisation and discrimination is rampant in most of the communities as evidenced in the interviews. If community members were supportive and accepted disability, most of the caregivers would likely increase social interaction, thus reducing psychological effects of stigmatisation on the primary caregivers as well as children living with disabilities. Stigmatisation and discrimination have been noted to have adverse effects on caregiving and there is, therefore, a need to address it holistically. The following section examines the emotional stress experienced by primary caregivers.

4.3.1.4 Sub-theme 4: Emotional stress

The participants highlighted that it was difficult for them to accept and adjust to the new role that they faced of being the primary caregiver of a physically disabled child. The emotional states ranged from depression to stress and worry. The participants stated that many children took time to manifest their conditions clinically; for example, delayed milestones like crawling, sitting and walking. This was confusing to the caregivers because most of them confirmed that the children were looking healthy when they were born. Even when a diagnosis was made at birth, recognising the long-term implications was difficult and confusing. Caregivers expressed their difficulty with initial acceptance of disability at first. The responses of the primary caregivers indicated that, in most cases, the mothers had difficulties with not knowing the implications of the diagnosis for themselves and their families.

All the participants stated that they were not sure whether they would be able to handle a child with physical disability. They also mentioned that they were worried about the future of their children which is why it took a long time to accept their children's disabilities. This agrees with the findings of the research done by Kiruma and Yamazaki (2013:118) who stated that it took time for mothers of newly diagnosed children to accept the conditions and they also worried about the future of the child. Most caregivers faced difficulties in accepting the diagnosis of their children. This is quite evident in the study as most of the participants indicated that it was very difficult for them at the beginning to accept and deal with the fact that the child had disability.

John said that:

> *It is difficult for me to deal with the role of being a father as well as the mother at the same time. This is just too much for me since my wife passed away I am stressed and depressed because of my roles. At the same time I am working and I am a breadwinner at home. I sometimes have a severe headache [and] when I go to see the medical doctors, they said I am having stress.*

Nana mentioned that:

> *If you have a child with physical disability as mine you worry a lot, every time you go out you wonder how he is doing at home. Can't event trust anybody that she/he can take care of him, since my child cannot talk, walk or sit on his own.*

The participants highlighted that the role of the primary caregiver of a physically disabled child is normally a source of stress. The feelings of what will happen to their children when they die are also stressful to them. The participants of the study expressed their emotional experiences with regard to the care they offer to their children with physical disabilities. Caring for a physically disabled child involved concern over the child's health, daily attention and caregiving to the physically disabled child as well as of the other normal children requiring attention, as well as dealing with the child's severe mobility limitations and communication difficulties (Mbugua, Kuria & Ndetei, 2011:513).

The following section addresses the second theme on financial challenges experienced by primary caregivers.

4.3.2 Theme 2: Financial challenges faced by primary caregivers in caring for children living with disabilities

Another objective of the study was to explore the financial challenges faced by primary caregivers. Indeed, the primary caregivers of children living with physical disabilities mentioned various financial challenges they were facing. The cost of caring was high because of the special needs of children who are having disabilities. Thus, this increases the cost of care because of the needs of the children and the fact that most of the primary caregivers were unemployed. The majority of the primary caregivers who participated in the study did not have any source of income for themselves and depended only on the CDG. The participants indicated that having inadequate funds to care for their children had caused negative effects on the care offered as they needed the money to buy basic care goods. Thus, the sub-themes which emerged from the objective were lack of money for necessities and inadequacy of CDG. Resch et al. (2010: 139) argue that, in general, families of children with disabilities regardless of the type of disability experience higher expenditure than other families.

4.3.2.1 Sub-theme 1: Lack of money for necessities

Lack of money for necessities such as food, clothes, nappies and shelter was a major financial challenge encountered by several primary caregivers. As a result of inadequate financial resources, several primary caregivers reported that they could not afford hospital fees. Pamela expressed her inability to afford food:

> *My economic situation is very hard because I do not even have enough food to feed my child.*

Nana also said that:

> *When my child gets sick and I don't have money for treatment, I feel like I have a very big burden because I can't afford to take her to a private doctor because it is very expensive.*

A mixture of low income and lack of time resulted in unemployment issues. The dominant challenge was the lack of time to work. Only three managed to use the time

their children were cared for to do some work. As a result, one of the challenges faced by primary caregivers who were raising children living with disabilities was poverty. Based on the responses, food insecurity leads to poverty as most participants mentioned that they did not have enough food for their children. Seventeen participants mentioned that having a physical disabled child caused poverty within the family because they required more caring time than normal children. The participants mentioned that they could not even establish a vegetable garden at home or join the poverty alleviation projects within the community. Hartley et al. (2014:167) also noted that exacerbating these financial challenges was the finding that children with disabilities are significantly more likely to live in families considered to be poor.

Juliet highlighted that:

> *Before my mother passed away, I was involved in community projects that were meant to alleviate poverty and we were not struggling with food. My mom was the biological mother of the child and when she passed away I had to take care of the child and put my life on hold*.

The participants' responses reflected food insecurity as an indication of poverty for their households. This was attributed to lack of money in the households and failure of the Department of Social Development to provide food security. According to SASSA (2018:13), if a child is receiving CDG, the caregiver does not qualify to get social relief of distress in a form of food voucher. The literature highlights that failure to access social welfare services has perpetuated the low socioeconomic status of caregivers of children with disabilities (Stienel & Mulambula, 2012:79).

When participants were asked about the effects of caring for the disabled children, as far as finances were concerned, some indicated that they were experiencing challenges to ensure that the family budget stayed manageable. The household funds did not meet the needs of the family and this increased because of the special needs of most of the children with physical disabilities. The result of the study revealed that people raising children with physical disabilities are likely to be poor especially when they come from low socioeconomic status families.

The unemployment status of most primary caregivers of children with disabilities had led them into the poverty trap. Murphy, Christian, Caplin and Young (2010) concur

with the participants by saying that the financial strain incurred by families of the children with disabilities is due to increased expenses related to the child's needs as well as loss of employment or ability to work because of parenting responsibilities. The financial status of the participants correlated with the literature in that some of primary caregivers of the disabled children reported that their financial status often prevented them from obtaining services for their children with disabilities (Resch et al., 2010:139).

4.3.2.2 Sub-theme 2: Inadequacy of the CDG

CDG is a social grant intended to provide financial support to parents, primary caregivers or foster parents of any child with severe mental or physical disabilities from 0-18 years of age. All 20 primary caregivers mentioned that their children living with disabilities were receiving CDG from SASSA. All the primary caregivers started by appreciating what the government of South Africa was doing for them by giving them social assistance in a form of CDG which is R1 620 per month (SASSA, 2018:3). Although they appreciated the help, they mentioned that the grant was not enough to meet the basic needs of their children living with disabilities since they had more demanding needs than normal children. Nelile argued that:

> *My son is attending Inkanyiso Special School. I am unemployed and I have to use the grant money to pay for his school fees, transport every day from Mvunyane to Vryheid where Inkanyiso Special School is situated. He is supposed to go to school with a lunch box every day. The grant is just not enough since I am a single parent and I am unemployed. The father of my child and his family they do nothing for my child; the father doesn't even send pocket money for his child.*

When Nelile started talking about the father of her child and his family, she was so emotional that she started to cry. That shows that some fathers of children living with disabilities do not provide for the needs of their children, and they neglect them emotionally and financially. There are implications of having insufficient resources for children living with disabilities. The psychological impact of insufficient money can be depression, and, when the primary caregivers are depressed, they will struggle to take care of their disabled children. Some children may drop out from school due to lack of transport money, thus they might not finish schooling. Due to inadequate finances, some children may have malnutrition.

Five participants mentioned that, because of their health conditions, their children with disabilities were using disposable nappies which were very expensive. They spent all CDG money on disposable nappies and at the end of the day, they were left with no money to buy food and to hire private transport to take the child to hospital.

4.3.3 Theme 3: Coping strategies of primary caregivers

One of the objectives of the study was to explore the coping strategies of the primary caregivers. When participants were asked about how they were coping with caring for their children living with disabilities, the themes which emerged were centred on support. These included financial support, emotional support, professional support as well as the use of FBOs. The theme of support was found to be common in responses that were given by the majority of caregivers who described it as the key factor in participants coping strategies. Fifteen participants highlighted the supportive role that was played by their family members in raising their children with disabilities.

4.3.3.1 Sub-theme 1: Emotional support

Five of the participants highlighted that they were receiving emotional support from their family members. Below are some of the responses from the participants:

> *My family give me emotional support which enables me to cope and accept the disability of my child* (Betty).

> *My parents help me a lot, they encourage me to focus in the future, they always help me to take care of the child so that I can go out and relax a little bit* (Pummy).

The responses of the primary caregivers identified family unity as an important factor in the adaptation process of raising a child with a physical disability. The findings correlate with the literature which revealed that the support they get from family members or relatives is very helpful to primary caregivers and it assists them with navigating the challenges of raising a child living with a physical disability (Bayat, 2014:702). Cohesion among family members during difficult times has been noted as a factor for successful adoption of the resilience model (Weber, 2011:177).

Participants mentioned that the support they got from their family members had helped them deal with emotional difficulties of caring for a disabled child. Therefore, they

experienced less stress. The findings of this study correlate with the literature which has shown that social support may serve as a coping strategy, in primary caregivers' wellbeing and better health outcomes among parents of the children with disabilities (Bayat, 2014:702). The results of the study showed that primary caregivers who had support systems at home did not experience difficulties in raising children living with physical disabilities and those who had a relatively high level of support managed better than those with no family support system.

4.3.3.2 Sub-theme 2: Financial support

Five participants mentioned that they received financial support from families and relatives. Zamile highlighted that:

> *When I have financial difficulties as a result of my child's condition, my parents and my siblings who are working always help me with the money. For example, when my child was using pampers at this age, they bought me pampers as well as the food for my child since she only eat soft diet.*

Financial assistance was a need identified by all unemployed primary caregivers. They mentioned that it is difficult for them to look for employment because of the children being fully dependent on them. Rose mentioned that:

> *We need to be assisted with allowance not only for the child's needs but also for us as caregivers because we can't leave the children with this condition to go and look for work, yet we have personal needs. We have other children to take care of.*

According to the literature, caregivers assume full-time caregiving roles and this may require them to stop working which may have financial implications that extend to the entire family, and this in turn could lead to poverty (Hughes, 2013:47). Financial support is therefore of paramount importance as it creates a barrier between the primary caregivers of children with physical disabilities and the effects of poverty. Families that are financially stable cope better during times of adversity than families who struggle financially.

4.3.3.3 Sub-theme 3: Professional support

The participants also mentioned receiving emotional support in terms of counselling they received from hospital social workers and psychologists following the diagnosis of the child. Some participants stated that the medical procedures that had been done to reduce the effects of disability gave them hope which had helped them adjust to the child's condition. Some of the participants mentioned that:

> *It was difficult for me to accept the condition of my child but through counselling I received from the social workers, I ended up accepting the situation and the diagnosis (*Ntombi).

> *I was so stressed after the birth of the child's because I didn't know how to feed my child, but through attending session of occupational therapy at the hospital, my child now is able to cooperate when feeding him* (Pride).

The findings of the study show how professional intervention had assisted primary caregivers in addressing challenges they experienced in raising their children with disabilities. Carona, Pereira, Moreira, Silver and Canavarro (2012:971) mention that primary caregivers of children with disabilities present with poor psychological wellbeing which is associated with the caregiving role, and thus professional intervention is of paramount importance. The literature on resilience shows that a key to successful parental adaptation lies in the capacity of the families to access appropriate resources and services that both support them in coping with their child's needs and reduce disability-related problems (Hughes, 2013:47).

Five participants mentioned physical support, in the form of professional intervention and the availability of devices, as an important resource that had helped them to adapt to the life of raising a disabled child. As a result, the primary caregivers identified the need for a rehabilitation centre that would provide holistic care in terms of intensive rehabilitation care and respite care. Ntombi said that:

> *It will be better if the government can provide rehabilitation centre like day care centre, but special for disabled children, so that we can leave our disabled children when we go work and fetch them in the afternoon, because at normal day care, they don't admit children with disabilities*.

Hlengiwe said:

> *It will be very helpful if in that day care there will be occupational therapist and physiotherapist who will visit the centre at least twice a week. Because it is difficult to go to hospital every month for the rehabilitation service, government must bring service to the people especially disabled people because they need special treatment.*

The participants believed that the development of such service would benefit them and their disabled children. The respite care that was suggested by the primary caregivers is an important service to support the families of the disabled children as the level of care required for those children with disabilities. The need identified by the primary caregivers reflects the gaps in support services that are currently being provided to children with disabilities and their families, despite a firm and comprehensive national policy on care for the disabled people. Although the suggested strategies are very important in addressing the needs of the participants, temporary relief was singled out as the most effective support strategy that would be beneficial to primary caregivers.

4.3.3.4 Sub-theme 4: Physical support

Most of the participants indicated the need for help in physically turning the children. The participants who indicated that were those whose children had not received wheelchair yet. Ntombi said that:

> *Since she doesn't have a wheel chair I have to lift her up every time even to go to the toilet since we are using outside toilets and are far from the house, it is difficult to take her out just to sit outside the house because I have nobody to assist me to take her outside since she gained a lot of weight. She is having bed sores as we speak right now because I can't handle to change her sides now and again, and I am also suffering from back pain now*.

Pride said:

> *I am the one who take care of him every day but now he has grown up, I can't take him or bath him on my own properly because of his condition and the body weight and all the family members are not willing to help me. The only person who come once a week to help me is the community care worker, we bathe him properly once a week when I have the support from the community worker and we take him outside once a week. If he is having a wheelchair, it will be better to move him around*.

Most of the participants giving physical support highlighted that they need help in various aspects of their lives. The primary caregiver's role is ensuring that the children's needs are met every time. Maintaining good hygiene and health life of the children is important to the primary caregivers. It appeared that most of the primary caregivers had to bathe, feed and move their children especially those with mobility problems. While some primary caregivers indicated that their children could bath themselves, their role was to supervise them to ensure that hygiene was maintained.

Pamela mentioned that:

> *Bathing is a little bit problem to her. She is not becoming clean when she bathes on her own without my help but I try every time to teach her on how to bathe herself proper, because I am just worried that, if I die, who is going to bathe her twice a day, it's important for me to teach her while I am still alive*.

Most of the primary caregivers of the children with mobility problems faced a number of challenges when bathing the children; this is because of the weight of their children as well as the age and health of the primary caregivers. The participants also mentioned that the big challenge they faced is that the toilets were far from the houses since they stayed in deep rural areas where they used outside toilets and they did not have bathrooms which could accommodate people with disabilities. These results were in line with the results of the study done by McNally and Mannan (2013:139) that mentioned that to ease the responsibility of caring for disabled children, the primary caregivers needed proper bathrooms to allow the disabled children to access to bathe themselves. This, however, also applied to the primary caregivers of those children

who cannot bathe themselves because it would be easy for them to bathe their children without requesting assistance from family members. Due to lack of physical support from family members, most of the caregivers whose children were unable to walk complained about physical pain in their body which was caused by carrying the children around. Participants believed that the physical pain they experienced as aggravated by the non-provision of physical support from family members who should be assisting them in carrying the children. Some statements of the participants were as follows:

> *Every day I have to put her in the bath, and now I have developed pains all over my body but it is worse in my shoulders I can't sleep without painkillers. Painkillers are like a drug now to my body* (Hlengiwe).

Betty mentioned that:

> *When the child is supposed to go to hospital for medical check-ups, I have to carry her on my back alone, and from Vryheid town to Hospital there is no transport. I have to pass the bridge with a steep slope with her on my back without any assistance. I am experiencing chronic back pain and I am also on chronic medication as a result of caring the child.*

These experiences that were shared by participants are supported by literature that states that an increased amount of assistance is needed by children who are physically more dependent on others to carry out their daily duties which lead to body pain among primary caregivers (Byrne, Hurley, Daly & Cunningham, 2009: 696). The findings of the current study confirmed the view of the study done by Al-Gamal and Long (2013:624) as well as study conducted by Mol, Van Brakel and Schreurs (2014:20) which found that primary caregivers of children with disabilities were more likely to experience poorer physical and mental health than the general primary caregivers. McNally and Mannan (2013:139) suggest that this poor health could be attributed to the extra daily tasks that do not allow caregivers to take care of themselves. The resilience model states that when families are dealing with chronic stressors such as caring for a child with disability, there is an accumulation of pre- and post-stressors which may include poor health and this has an impact on the family's level of vulnerability in a crisis (McConnell, Savage & Breitkreuz, 2014:833).

4.3.3.5 Sub-theme 5: Use of faith-based organisations

FBOs were noted to play a role in the coping of primary caregivers caring for the children with physical disabilities. The participants mentioned that a religious group was the best source of strength when raising a child with physical disabilities. Participants also mentioned that religious and personal faith played a major role in helping caregivers to accept and deal with their children's disabilities. They also highlighted that their pastors usually visited them for prayers at home if they were unable to go to church as a result of transport difficulties. The following are some responses from participants:

> *My faith and attending the church group has played a greater role in my way, because every time I attend the church service, I come back with new strength to cope and faces the challenges they come on the way* (Petronella).

Similar statements were also expressed by Pamela:

> *Let us say that this situation leads us to coming closer to God. We pray every day for God to help us with more coping mechanism and accepting the situation as it is.*

Betty also acknowledged the great role of FBOs by saying that:

> *I always go to church; I even go to crusades where they are powerful Pastors who pray for the sick and disabled people. These prayers have helped me to get strength to go on.*

The primary caregivers agreed that they derived great satisfaction from their churches. The results showed that the most of the primary caregivers used their religion as a coping mechanism in order to accept the condition of their children. The participants held the belief that having a child who was disabled or being a primary caregiver of a disabled child was God's will. Many caregivers felt that spirituality was a great support during difficult time. The participants reflected that religion played a greater role in providing a psychological and emotional support to them as primary caregivers.

The findings of this study showed that the most important element that led to primary caregivers' acceptance of their children's condition was their faith and joining FBOs in

their areas. The findings of the study are consistent with previous research which suggests that for the primary caregivers' role to be more positive, spiritual support is essential (McNally & Mannan, 2013:96). The participants noted that the church played a critical role for them to cope with the burden of caregiving. The results of the study emphasised that faith brought caregivers the reality of hope that allowed them to express themselves as being closer to their Maker. It was also discovered that most of the participants found their own coping strategies in the positive experiences they had with their children.

4.3.3.6 Sub-theme 6: Positive experiences

The children's progress, respect and happiness were positive experiences identified by primary caregivers. All 20 participants talked about seeing their children's progress in terms of independence and ability to do tasks.

> *I can tell her to go to the toilet if she can be able to walk, but I believe one day she will be walking because I can see an improvement since she started rehabilitation services* (Zamile).

> *I can imagine telling him to go and buy bread for me at the nearest tuckshop and him coming back with it; I just can't wait for that day* (Betty).

Half of the primary caregivers felt respected and were shown respect by members of the community compared to others.

> *We like you because you love your disabled child, you don't hide her like other parents who have disabled children. Parents with disabled children normally lock their children up in their houses and they don't give them food* (Ntombi).

> *Most of the community members say I have a good heart because I take care of my child. They say if it was another man, they would have thrown him away or sent him to a disabled centre after his mother passed away* (John).

Most of the primary caregivers felt happy when they were respected by other community members. Some primary caregivers indicated that the positive experiences

made them enjoy being with their children all the time. Five participants stated that simply seeing their children alive was a positive experience in their lives. Winnie said:

> *My son is alive; I can see him going around the house in his wheelchair. That is a positive thing for me as a parent.*

The study done by McNally and Mannan (2013:96) on the perceptions of caring for disabled children also revealed that there are some positive experiences that can make the caregiver happy.

4.4 CHAPTER SUMMARY

This chapter provided the analysis and interpretation of the research findings according to several themes and sub-themes which emerged. The findings of the study presented included the different challenges faced the primary caregivers in raising children living with physical disabilities and their coping strategies. The findings have suggested that caring for child with physical disabilities exposes caregivers to many challenges such as social isolation, emotional burden of caring, financial problems, poverty and stigmatisation and discrimination. Some of these challenges are directly attributed to the nature of disability of a child while some are due to insufficient services provided to the primary caregivers. There were some coping strategies identified which include religious belief, support system from family members and acceptance of a child's disability. The next chapter of the study provides an overall conclusion, bringing together the research objectives and an analysis of whether they have been met. The chapter also discusses the limitations of the study, recommendations based upon the research findings as well as areas for future research.

CHAPTER 5:
SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter, a summary of the findings, conclusions that have been drawn from the study as well as recommendations which have been based on the conclusions are presented. The study had certain limitations and these will also be discussed. The chapter also discusses the implications of the findings for social work practice and offer suggestions for further studies.

5.2 LIMITATIONS OF THE STUDY

The study was limited to primary caregivers of physically disabled children who were undergoing rehabilitation programs at Vryheid Hospital only, aged 7 to 18, those who were less than seven years were not included in the study. At Mvunyane, there were many children with physical disabilities who were left out of the study because they were not undergoing rehabilitation programmes at Vryheid Hospital. Some of the physically disabled children who reside at Mvunyane area undergo their rehabilitation programmes at Charles Johnson Memorial Hospital which is under Nqutu area.

5.3 SUMMARY OF THE FINDINGS

The study interviewed 20 primary caregivers who were raising children living with physical disabilities In Mvuyane area in Vryheid. The majority of the participants were female constituting 19 participants while only one participant was a male. The majority of the participants were unemployed; only three participants reported to have full-time jobs. Nineteen participants who participated in the study were Zulu-speaking and only one participant was an English-speaking Indian. In terms of their ages, they ranged between 25 and 62 years of age.

The findings are summarised with respect to the three objectives which were formulated to guide the study concerning the challenges experienced by primary caregivers in raising children with physical disabilities who undergo rehabilitation in Mvunyane area, Vryheid, KwaZulu-Natal province.

5.4 ACHIEVEMENT OF THE AIM AND OBJECTIVES OF THE STUDY

The main aim of the study was to investigate the challenges experienced by primary caregivers in raising children living with physical disabilities who undergo rehabilitation in Mvunyane area, Vryheid, KwaZulu-Natal. The aim was achieved through the appropriate use of the qualitative research methodology. The aim of the study was attained by achieving the following objectives:

5.4.1 Objective 1

- **To explore the social challenges faced by caregivers in caring for the physically disabled children who undergo rehabilitation**

This objective was achieved in a discussion in Chapter 2 and in Chapter 4 (Section 4.4). The research findings show that the experiences of caregivers can be divided into positive and negative experiences. In terms of negative experiences, the findings confirm that primary caregivers of physically disabled children experienced some difficulties in their caregiving roles. Regardless, the problems they encountered in their caring role, they were actively participating in caring for their disabled children.

Participants revealed that they felt like they were isolated from social gatherings as a result of their caregiving role. They also mentioned that even their old friends had deserted them since they had taken on the role of caregivers to their children with disabilities. Participants further revealed that it was difficult for them to travel with a disabled child using public transport especially those who were using wheelchairs because the public transport was not easily accessible. This had caused most of the participants to miss appointment dates for rehabilitation because it was expensive for them to hire private cars.

The study also revealed that even participants with private cars did not feel comfortable to travel to relatives with their children with disabilities. Participants highlighted that they experienced difficulties in accepting their new roles as primary caregivers of children with physical disabilities. It was indicated by the participants when asked about stigmatisation and discrimination that this prevented them from attending social gatherings which increased their stress levels as they could not socialise with the community members. They even pointed out that other children used derogatory terms for their children who were living with disabilities.

The findings of the study further indicated that the primary caregivers were worried about the future of their disabled children and it took them a long time to accept the condition of their children. The findings of the current study were similar to the results of the previous study done by Kiruma and Yamazaki (2013:118) which stated that it took time for the mothers of newly diagnosed children to accept the condition of their children and they worried about the future of their children.

On the other hand, the findings of the study showed that the caregivers had some positive experiences in caring for their children with disabilities. One of these was that the participants had noticed progress in terms of independence and ability to do tasks since they had started the rehabilitation programmes. The participants also revealed that seeing their disabled children alive was a positive experience in their lives.

5.4.2 Objective 2

- **To explore economic challenges of caring for children with physical disabilities**

The second objective of the study was to explore the economic challenges of caring for children with physical disabilities. This objective was achieved in the discussion in Chapter 2 and in Chapter 4 (Section 4.5). One of the findings under this objective was that the care activities increased the household budget making it difficult for households to meet their basic needs. Some of the participants also mentioned that they needed money to buy disposable nappies. The findings also revealed that, it was difficult for the primary caregivers to send their children to special schools because special schools were expensive and they could not afford it which was why most of the disabled children of caregivers who participated in the study were kept at home.

Participants further explained that children living with physical disabilities had special needs such as assistive devices, diapers, special food and transportation to go to hospital for medical reviews and also transport to special schools. All these things cost a lot of money and required a steady income. Nevertheless, the participants revealed that they were receiving financial assistance in a form of CDG which amounted to R1 690. The findings also showed that the primary caregivers used the grant money to hire vehicles to go to the hospital very month for their appointments. However, the

CDG was reported to be insufficient to meet the needs of their children due to their special needs which were costly.

The results of the study also indicated that the financial needs of the primary caregivers were not met as they sacrificed their personal needs in order to meet the needs of their children. Other participants mentioned that they even resigned from their full-time employment since there was no one who was willing to help them in the caregiving role. Therefore, findings of the study highlighted that having a child with special needs in a family affected the family's financial status.

5.4.3 Objective 3

- **To explore the coping strategies of primary caregivers in caring for children with physical disabilities**

This objective was achieved in a discussion in Chapter 2 and in Chapter 4 (Section 4.6). The findings of the study revealed that religion played a critical role in motivating the primary caregivers to continue in the provision of care to children living with disabilities. Other participants mentioned that their pastors and church leaders helped them in coping with their role as primary caregivers. The findings also indicated that the formation and presence of support groups helped the caregivers mitigate the stressors. The support groups strengthened the primary caregivers' coping capacity as they were able to relate to the needs of caregiving. The presence of the professionals or healthcare workers in the support groups helped considerably in growth and coping capacities of group members or primary caregivers. The participants stated that they needed their family members to help them with alternative care if they wanted to go and attend social gatherings. The findings of the research also indicated the need for families to play enabling roles in the care continuum.

5.5 CONCLUSIONS

Based on literature reviewed and the empirical findings of the study, it can be concluded that many parents who are raising children with physical disabilities have to deal with problems and challenges related with the care that is required. Though the primary caregivers showed commitment to their responsibilities, they faced challenges that resulted in their having emotional difficulties. This includes difficulties of accepting their new role as a primary caregiver, financial stress as well as the

burden of caring. The support they received from the healthcare workers such as counselling and respite care lessened the burden of caring.

It can also be concluded that the family who has a child with physical disabilities are likely to fall into poverty. This is so because the effects of financial constraints do not only affect the primary caregivers of children with disabilities but it affects the whole family.

It can be concluded that most of the community members discriminated against people living with disabilities. This caused them to isolate themselves from social gatherings. As a result of the stigmatisation and discrimination, the primary caregivers of the disabled children had emotional and psychological difficulties.

The researcher has also concluded that there were inadequate intervention care programmes and services available to assist the primary caregivers and disabled children with wheelchairs and other assertive devices.

Furthermore, although the findings of the study cannot be generalised to the whole population of caregivers raising children with physical disabilities, the study concludes that there are certain resilience factors that appear to have facilitated adaptation to caring for a physically disabled child. The factors include acceptance of the child, understanding the disability as well as the role played by family members and community members in supporting the caregivers.

5.5 IMPLICATIONS FOR SOCIAL WORK PRACTICE

In order for the primary caregivers to care for their children living with disabilities, they need to know their rights and responsibilities, and what resources are available to them. Social work professionals must make sure that the primary caregivers know all the above by giving educational talks. Social workers need to give the primary caregivers information if they are to make informed decisions about the development and education of their children, and, where possible, social workers need to empower children to allow them to make informed decisions as well. Information must be disseminated in different formats and in ways that take cognisance of primary caregivers and children’s level of understanding.

Social workers should organise awareness campaigns on disability to community at large or educational talks that will focus on engaging the extended family members as well as community members in the improvement process. Social workers must create campaigns that will fight against stigmatisation of people living with disabilities. Social workers must be aware that disability is a problem affecting parents and family as a whole and has implications for broader societal issues. It is also crucial that social workers should be knowledgeable to assist so that their needs can be met but blaming them for their situation will not foster engagement. Social workers could also advocate for the support of disability forums such as committees for people with disabilities, support groups and societies aimed at empowering and strengthening the functionality of people with disabilities. Social workers should integrate an intervention into the lives of children with disabilities and their families. Social workers should advocate for the right of persons with disabilities and their primary caregivers to access information and assistive devices that will help them to meet their needs. Accessibility to information can be enhanced by utilising CBR as well as establishing child welfare forums to disseminate information regarding disabilities. This is an appropriate role for a social worker to ensure that the core values of the social work profession include service delivery and the enhancement of social justice, dignity and worth of individuals, groups and communities.

Furthermore, disability and diversity awareness programmes need to be recognised as a critical component of social cohesion, and as a means of reducing the vulnerability of children with disabilities to abuse and neglect.

5.6 RECOMMENDATIONS

The healthcare worker should educate all family members on how they can assist the primary caregivers of children living with disabilities. Those include bathing, feeding, doing rehabilitation exercises at home as well as caring for the children with disabilities to allow caregivers to rest and to perform other duties. The social workers should educate the primary caregivers about acceptance of disability so that primary caregivers do not feel isolated.

NGOs and the government can develop partnerships on projects that will financially empower primary caregivers to be self-employed, like small businesses funded by government. The Department of Social Development should also employ more

development workers who will train the primary caregivers on poverty alleviation programmes. Healthcare workers should do awareness campaigns in the communities on disabilities so that people can be familiar with disabilities that can decrease stigmatisation of people living with disabilities.

Government can provide respite care such as day care centres that will cater for children living with physical disabilities in the community. That will help the primary caregivers to keep their children safe during the day and they will be able to go to work. That will also allow the primary caregivers to earn an income, and to have rest and time to have social activities. This will reduce the amount of stress that overwhelms them and they will be able to maintain health for a long care provision. Social workers, the medical profession, FBOs as well as Department of Social Development should establish and promote more support groups for primary caregivers who are raising children living with disabilities. The government should provide the primary caregivers of disabled children with a grant-in-aid on top of the CDG in order to assist them in meeting the needs of their children.

5.7 CONTRIBUTION OF THE STUDY

The current study discovered some of the challenges that are faced by primary caregivers in caring for the children living with disabilities. Various recommendations that would help in modifying the effects of the challenges were discussed.

5.8 SUGGESTIONS FOR FUTURE STUDIES

The study was limited to the primary caregivers of children with disabilities who only undergo rehabilitation at Vryheid Hospital between the ages 7-18 years. The experiences of these families may not be applicable to others. For future research, the researcher recommends that studies should also include those children who are not attending rehabilitation. Future research might address the coping strategies and challenges faced by other family members such as siblings and extended family members.

Subsequent research should also explore potential techniques and strategies to empower families and communities of persons caring for children with disabilities. Such research inputs would play a valuable role in the enhancing of social functioning of caregivers in a broader context and children in particular.

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ANNEXURES

ANNEXURE A: INTERVIEW GUIDE

FOR PRIMARY CAREGIVERS WHO ARE RAISING CHILDREN WITH PHYSICAL DISABILITIES WHO HAVE UNDERGONE REHABILITATION PROGRAMME

1. Introduction

My name is Ntombizodwa Zungu. I am doing my Master's degree in Social Work with University of Zululand. I am doing my research on the 'Challenges experienced by primary caregivers in raising children with physical disabilities who undergo rehabilitation programmes in Mvunyane area, Vryheid KwaZulu-Natal Province'. This is a requirement of my studies.

I would like you to participate in my research since you are raising a physically disabled child. Your input and opinions will play a major role for this study to be successful. The target population for this study are the primary caregivers who are raising physically children between ages 07-18yrs who undergo rehabilitation programme.

The information you will be giving me here will be kept confidential, it will only be used for academic purposes only.

During the interview, I will use a recorder to record the interview for later transcription.

SECTION 1: BIOGRAPHICAL DATA

1.1. How old are you?
1.2. Are you employed?
1.3. If employed what type of job you are doing?
1.4. If not employed what is your source of income?
1.5. How many children do you have?
1.6. What is the relationship between you and the child?
1.7. How many children you are raising who are living with physical disabilities?
1.8. Who do you live with at home?
1.9. In the household how many family members you live with?
1.10. How long have you been raising that child?

SECTION 2: Data related to the experiences of caregivers in caring for the disabled child after rehabilitation

2.1. What are the challenges you experience in raising a child with physical disabilities?
2.2. Tell me after you started attending rehabilitation programme with your child what are some difficulties you come across during the programme?
2.3. What are some difficulties you encounter at home when there are no professional if you do the programme on your own?
2.4. Do you think it's difficult to raise a child who is living with physical disabilities compared to raising a normal child?

SECTION 3: Data related to the financial challenges of caring for the physically disabled children.

3.1. Are you employed?
3.2. If answer to 1 is no, what is your source of income?
3.3. Did the child receive care dependency grant?
3.4. If answer to the above question is yes, is the grant enough to raise a child living with disabilities?
3.5. If the child attends special school how much you pay a month at school?

SECTION 4: Data related to the coping strategies of primary caregivers in raising those children

4.1. Do you need more support system in raising your child living with disabilities?
4.2. If yes, what nature of support do you need in raising the child?
4.3. What role will the above support play in raising the child?
4.4. How have you been coping from the day you discovered that your child is living with disabilities up to now?

SECTION 5: To identify the enabling factors that contributes to caregiver's compliance with rehabilitation at home

5.1. Since your child is attending rehabilitation programme at hospital, are you complying with schedule appointment?
5.2. Do you able to carry on with the exercises at home alone?
5.3. If no what prevented you to continue with rehabilitation exercises at home.

ANNEXURE B: INFORMED CONSENT FORM (ENGLISH)

Participants consent declaration

Title: Challenges experienced by primary caregivers in raising children with physical disabilities who undergo rehabilitation.(Ntombizodwa Zungu, researcher) Masters student at University of Zululand, Social Work Department has requested my permission to participate in the above mentioned research project.

I am aware that:

1. The purpose of the research project is to explore the challenges experienced by primary caregivers who are raising children living with physical disabilities.

2. The University of Zululand has given ethical clearance certificate to this research project and you may request to see the certificate if like.

3. The Department of Health has also given the permission to conduct the research project. You may request a copy if you wish to see it.

4. I will participate in the project by doing in-depth interviews conducted by the researcher and her assistant.

5. My participation in the research is voluntary and should I feel at any stage that I want to withdraw from participation, I may do so without any negative consequences.

6. I will not get any compensation for my participation in the study but I will only get transport money. The researcher will provide a basic light meal during the interviews.

7. I am aware that there may be risk associated with my participation in the project.

7.1. The following risks are with my participation: emotional reaction

7.2. The following steps have been taken to prevent the risk: participants will be referred for counselling by a social worker or psychologist.

8. I will not receive feedback regarding the results obtained during the study.

9. All the information I provided during the interview will be kept confidential and the report will use pseudo names.

10. By signing this informed consent declaration I am not waiving any legal claims, right or remedies.

11. A copy of this informed consent declaration will be given to me, and the original will be kept on record.

I …… have read the above information /confirm that the above informed has been explained to me in a language that I understand and I am aware of this documents contents. I have a right to ask all the questions that I wished to ask and these have been answered to my satisfaction. I fully understand what is expected of me during the research.

Participant signature Date

ANNEXURE B: IFOMU LOKUZIBOPHEZELA

Isihloko sogcwaningo: **Izigqinamba ezihlangabezana nababheki abakhulisa izingane eziphila nokukhubazeka ngokumzimba**

U (Ntombizodwa Zungu, umgcwaningi) ovela e Nyuvesi yakwa zulu ongoye emunyangweni wezenhlalakahle, ube nesicelo sokuzibandakanya kulolugcwaningo olulothwe ngenhla.

Imvelaphi kanye nenhloso yalolugcwaningo nalolu lwazi nophawu lokwamukela ukuzibophezela ngichazeliwe ngalo ngolimi enilizwayo.

1. Inhloso yalolucwaningo ukuthola ukuthi yiziphi izinqginamba ababheki abahlangabezana nazo ekukhuliseni abantwana abaphila nokukhubazeka ngokomzimba.
2. Inyuvesi yakwazulu inikele ngemvume kubenzi balolu cwaningo ukuba banze loluhlelo futhi ngiyibonile leyomvume.
3. Ngokubamba iqhaza kulolugcwaningo ngizonikezela ngokutholakala kwezingqinamba ababheki babantwana abaphila ngokukhubazeka abahlangabezana nazo ekukhuliseni abantwana.
4. Ngizobamba iqhaza kulolucwaningo ngokunikezela ngolwazi oluyiolo noluyiqiniso ngesikhathi ocwaningayo ebuza inhlolomibuzo okuhloswe ngayo ukuthola umnyombo ojulile ngaloludaba okucwaningwa ngalo.
5. Ekuzinikeleni kwami kubamba iqhaza kulolucwaningo angizukubheka nzuzo engizoyithola emva kocwaningo.
6. Angizukuxhephezelwa ngokuzibandakanya kulolucwaningo, kodwa kodwa izindleko zokugibela zozikhokhelwa.Umcwaning uzolekelela ngezindleko zokudla kanye nemali yokugibela.
7. Kuzoba nesimo esibucayi ekuzimbandakanyeni kwami kulolucwaningo ngiyaqonda ukuthi:

7.1. Lobu bungozi obulandelayo kuxhumene nokuzibandakanya kwami isimo esingalindelekile somphefumulo esibangelwa imibuzo ejulileyo ezobe ibuzwa ngogcwaningayo ngesikhathi senhlolomibuzo.

7.2. Lezi zinsiza ezilandelayo zozosisa ukubhekana nobungozi obungabakhona,ukuthola usizo lokwelulekwa ngokomqondo.

8. Angeke ngifune ngenkani imiphumela ephume ngesikhathi sogcwaningo.

9. Eminye imibuzo ephathelene nalolucwaningo ingaphendulwa umcwaningi uqobo.
10. Ikhophi enolwazi oluphelele nophawu lokwamukela ukuzibophezela kwami ngizokunikezwa, bese okungungqo wakhona ngikusayine kusale kumcwaningi.
11. Mina ……ngikufundile konke lokhu okubhalwe ngenhla nomcwaningi wangichazela ngakho lana bengingaqondi kahle khona.Ngiyaqonda kahle kuba kulindelekeni kulolucwaningo.Angiphoqwanga kuzibandakanya kulolucwaningo kodwa ngizithandele mina.

…… ……..

Isishicilelo kobambe iqhaza usuku

ANNEXURE C: ETHICAL CLEARANCE

UNIVERSITY OF ZULULAND
RESEARCH ETHICS COMMITTEE
(Reg No: UZREC 171110-030)

RESEARCH & INNOVATION
Website: http://www.unizulu.ac.za
Private Bag X1001
KwaDlangezwa 3886
Tel: 035 902 6887
Fax: 035 902 6222
Email: MangeleS@unizulu.ac.za

ETHICAL CLEARANCE CERTIFICATE

Certificate Number	**UZREC 171110-030 PGM 2016/356**							
Project Title	**The challenges experienced by primary care givers in raising children with physical disabilities after rehabilitation in Mvunyane area, Vryhead in KwaZulu Natal**							
Principal Researcher/ Investigator	IN Zungu							
Supervisor and Co-supervisor	Dr P Gutura							
Department	Social Work							
Nature of Project	Honours/4th Year		Master's	x	Doctoral		Departmental	

The University of Zululand's Research Ethics Committee (UZREC) hereby gives ethical approval in respect of the undertakings contained in the above-mentioned project proposal and the documents listed on page 2 of this Certificate.

Special conditions:
(1) This certificate is valid for 2 years from the date of issue.
(2) Principal researcher must provide an annual report to the UZREC in the prescribed format [due date-31 October 2017]
(3) Principal researcher must submit a report at the end of project in respect of ethical compliance.

The Researcher may therefore commence with the research as from the date of this Certificate, using the reference number indicated above, but may not conduct any data collection using research instruments that are yet to be approved.

Please note that the UZREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the documents that were presented to the UZREC
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

Classification:

Data collection	Animals	Human Health	Children	Vulnerable pp.	Other
×					
Low Risk		Medium Risk		High Risk	
		×			

The table below indicates which documents the UZREC considered in granting this Certificate and which documents, if any, still require ethical clearance. (Please note that this is not a closed list and should new instruments be developed, these would require approval.)

Documents	Considered	To be submitted	Not required
Faculty Research Ethics Committee recommendation	×		
Animal Research Ethics Committee recommendation			×
Health Research Ethics Committee recommendation			×
Ethical clearance application form	×		
Project registration proposal	×		
Informed consent from participants	×		
Informed consent from parent/guardian			×
Permission for access to sites/information/participants	×		
Permission to use documents/copyright clearance			×
Data collection/survey instrument/questionnaire	×		
Data collection instrument in appropriate language		Only if necessary	
Other data collection instruments		Only if used	

The UZREC retains the right to

- Withdraw or amend this Certificate if
  - Any unethical principles or practices are revealed or suspected
  - Relevant information has been withheld or misrepresented
  - Regulatory changes of whatsoever nature so require
  - The conditions contained in this Certificate have not been adhered to

- Request access to any information or data at any time during the course or after completion of the project

The UZREC wishes the researcher well in conducting the research

Professor Gideon De Wet
Chairperson: University Research Ethics Committee
Deputy Vice-Chancellor: Research & Innovation
24 February 2017

IN Zungu - PGM 2016/356

CHAIRPERSON
UNIVERSITY OF ZULULAND RESEARCH ETHICS COMMITTEE (UZREC)
REC NO: UZREC 171110-80
24 -02- 2017
RESEARCH & INNOVATION OFFICE

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address Coswald Brown Street, Vryheid 3100
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www.kznhealth.gov.za

VRYHEID DISTRICT HOSPITAL

To: Mrs. I.N.Zungu

Social work Department

Vryheid Hospital

Re: Granting of authority to conduct research on challenges experienced by primary care givers in raising children with physical disabilities after rehabilitation in Mvunyane area at Vryheid in Kwa Zulu Natal Province.

Your letter requesting authority to conduct research based in the above mentioned topic refers:

The Department of Health, particular Vryheid Hospital sees a need in the study on the basis that we are the only Health Facility rendering rehabilitation services to children with physical disability conditions in the area where you choose to conduct the study (Mvunyane area).

Vryheid Hospital assumes that your chosen study will be conducted for the first time at Mvunyane area, we would therefore like to be furnished with the outcomes of the study. Kindly note that the Department cannot commit to the involvement of primary care givers as this will be based on their individual decision and personal free will in serving as respondents participants in the study.

You are further reminded of the substantial importance of ethical considerations in this regard.

We wish you all the best in your research study.

MS N.F. NGEMA
ACTING HOSPITAL CEO

CHIEF EXECUTIVE OFFICER
VRYHEID DISTRICT HOSPITAL
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Fighting Disease, Fighting Poverty, Giving Hope