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**2016-07-28**
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# THE EXPERIENCES OF PRIMARY CAREGIVERS CARING FOR CHILDREN WITH PHYSICAL DISABILITIES IN HARDAP REGION OF NAMIBIA

**A dissertation presented to**

**The Department of Social Work**

**School of Human and Community Development**

**Faculty of Humanities**

**University of Witwatersrand**

**In fulfilment of the requirements for the degree**

**Masters of Arts in Social Work**

**By**

**ALLAN NDADZUNGIRA**

**March 2016**



**DECLARATION**

I solemnly declare that this work is my own and no plagiarism whatsoever was done. Every source used has been acknowledged and authors of such work have been referenced in this research report.

Signature……
Date……

## ACKNOWLEDGEMENTS

I would like to thank God for being the source of strength throughout the process of working on this research project. I also give gratitude to my supervisor Professor Edwell Kaseke for all the assistance he rendered to help me complete this project. Your patience with me cannot be matched. I would also like to thank the community of Hardap Region for their participation in the research. I would also like to extend my gratitude to the research assistant who helped me in this research as well as to translate the interviews. To my peers who assisted me in the research from Hardap region, Fadzai, Mutakani and Tafadzwa no words can express my gratefulness. You made this a reality. To Mr Chihobvu and Nakwezi thank you for the transport to travel around the region. To my family, Mrs Ndadzungira, thank you so much for the love and support. God bless you so much.

## ABSTRACT

Child disability has not been addressed holistically in Namibia. The absence of policies and programmes has exacerbated the challenges faced by primary caregivers and children with physical disabilities. There is paucity of literature on the experiences faced by the caregivers of children with physical disabilities. The aim of this study was to explore the experiences of primary caregivers of children with physical disabilities in Hardap region, Namibia. The study population consisted of primary caregivers of children with physical disabilities from Hardap region and purposive sampling was used to select 20 participants. A qualitative research approach was used to collect data using a semi-structured interview schedule. The study was descriptive and exploratory in nature. The study was based on a case study of Hardap region, Namibia where it sought to bring an understanding of complex issues to add strength to what is already known through previous researches. Thematic content analysis was used to analyse the data. The study revealed that participants played important roles in providing care as they were involved in feeding, carrying, turning and lifting of the children as well as taking the children for medical check-ups. The study also revealed that participants experienced challenges in the care continuum which included carrying the children around due to lack of special equipment, financial challenges and lack of psychosocial support from the family. The study also noted that the participants used religion as a means of coping for their wellbeing. The Government of Namibia needs to set policies on disability issues to ensure the wellbeing of the primary caregivers. The caregivers need training that will help them to improve the quality of care offered to children with physical disabilities as well as improve the psychosocial functioning of the primary caregivers. It is thus anticipated that the results of the study will help in designing interventions that will help the primary caregivers and reduce their burdens. The study will also contribute to knowledge on disability and caregiving.



**Keywords**: primary caregiver, caregiving, children with disability, physical disability

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# CHAPTER 1

## 1.1 INTRODUCTION

This chapter highlights the background of the study, statement of the problem and the study theoretical framework. It further illuminates the research question, research aim and objectives of the study. The limitations faced on carrying out the study are outlined while the definition of key terms is also given as a guide for the study.

## 1.2 BACKGROUND OF STUDY

The care for children with physical disabilities can be an over-whelming experience as it constantly drains the primary care giver financially, psychologically, socially and health-wise. Disability is defined as the limitation or nonexistence of capability to make a movement in a way that is viewed as normal for people according to the World Health Organisation (WHO), (2011). According to the WHO (2011) the number of children with disabilities is estimated to be 95 million (5.1%) globally of whom 13 million (0.7%) is said to have severe disability, that is 10% of a country's population is having a disability. United Nations estimates indicate that about 80% of people with disabilities are living in third world countries mostly in rural and isolated areas (Priestly, 2001). From the estimates it can be noted that sensory and mental health impairments constitute about two hundred million. The estimates provides a yardstick of 2.5% of children who are between the ages of 0-14 years with undisputable or mild to severe levels of physical, sensory and intellectual impairment and a further 8% have behavioural or learning difficulties or a combination of both.

WHO (2011) state that the situation has remained bad in Africa when it comes to available data and countries like Namibia, Malawi, Zimbabwe and Zambia recording statistics of between 24%-29% of children living with disabilities who never attended school. According to the UNICEF annual report (2013) Namibia has 33 614 learners with disabilities, of whom 15 408 are girls and 18 206 boys. The report further estimates that over 50% of the children with disabilities have never attended primary school especially those in the rural areas. The Namibian Population and Housing census report (2011) stated that 4.7% of the Namibian population is living with disabilities. Sintef (2008) states that the general disability prevalence rate is around 1,62%, and

this figure is significantly lower if compared with the estimates from the national census of 2011 of 4,7%.

The plight of children with disabilities has gone unnoticed in many situations as evidenced by the limited number of schools and facilities for children with disabilities in Namibia. Children with disabilities in Namibia face multiple challenges including reduced quality care by the primary caregivers, limited access to health professionals and education. Lots of children who have physical disabilities have mobility challenges and hence their ability to interact with their peers is greatly affected. In most instances they are left to play alone and hardly attend school. Many times they are locked up in the houses as the caregivers do their daily activities leaving them to spend the day at home without any activity. Adnams (2010) summarises that there is paucity of literature on the delivery of services to people living with disabilities as well as their caregivers in most communities.

It can also be noted that stigma is quite prevalent in the community against disabilities and hence most of the times children with disabilities do not have the courage or confidence to play with other non-disabled children. Primary caregivers also face a number of challenges in regards to offering care to the children with physical disabilities (Parnes et al, 2009). Most of the primary caregivers do not have the basic knowledge on how to deal with caregiving of children with disabilities (Nelson, 2002). Unavailability of basic educational services for children with severe physical disabilities has compounded severely on the caregivers as this has left them with little to do when it comes to education for the children.

## 1.3 STATEMENT OF THE PROBLEM AND RATIONALE OF STUDY

Child disability has not been addressed holistically in Namibia. Fragmented services are being offered by various institutions and hence they have failed to deliver and address the key issues in child disability (Lang, 2008). Lang (2008) noted that coordination by the disability unit in the Prime Minister's office, line ministries and the National disability council is lacking. The study by Lang (2008) stated that the absence of statistics on disability makes it difficult implementing and evaluating disability services. The disability grants given out by the Ministry of Gender Equality and Child Welfare were 1821 in 2010 though there were about 33614 children living with disabilities attending formal schools in Namibia (MGCW, 2010).

Children with disability fail to meet most of their needs. Disabilities World (2011) gave an outline of physical disabilities which include mobility, hearing and visual impairments. Problems of care for children with physical disabilities is not only unique to Namibia, but to most countries. Coomer (2013) and Chirwa (2012) have carried out studies to assess the experiences of care and the impact faced by caregivers in Namibia. Caregivers in most cases experience the same challenges which include burnout and high cost of caring. The problems associated with burden of caregiving globally are also prevalent in Namibia. Not much has been researched about the caregiving burden of children with physical disabilities in Namibia. From observations made by the researcher, caregivers face huge problems emanating from non-existent policies of caregiving, unavailability of resources and infrastructure for children with physical disabilities. The dearth of literature on the subject matter thus motivated the researcher to study the area. The monitoring and evaluation systems present do not capture data of the experiences of the caregivers and hence the need for the study. The study is expected to contribute to knowledge on disability and specifically on the burdens of care provided to children with physical disabilities. The findings are also expected to inform policy on caregiving of children with disabilities. Finally, the findings might help social workers to develop efficient and real intervention programmes that take into cognisance the desires of both care givers and the care recipients who are the children with physical disabilities. The identified unique needs of the target population will thus be presented to relevant authorities to ensure that appropriate steps are taken to address them. The results will be sent to the division of rehabilitation within the Ministry of Health and Social Services through the regional office where the researcher conducted the study.

## 1.4 THEORETICAL FRAMEWORK

The social model of disability will form the theoretical framework of the study. The model was chosen because of its ability to bring to the surface most of the underpinnings of disability and caregiving. The social model of disability as put forward by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 as alluded to by (Oliver,2004), looks at disability in relation to the family environment, the community and societal relationships. WHO, (2001, p.17) states that “disability is the outcome of a complex relationship between the individual’s health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives”. The social model identifies three major societal problems that bring

forth the problem of disability as environmental, attitudinal and institutional. In relation to environmental factors, the model argues that infrastructure discrimination occurs where public services, buildings and transport are deliberately not designed to factor in people with disabilities. The model further postulates that people with disabilities may be socially excluded due to attitudinal characteristics emanating from perceptions on what the disabled can do or not. The attitudinal factors thus see impairments as emanating from the perceptions of the community as they see the disabled people as not being able to do certain activities. Institutional barriers occur when the progression of persons with disabilities or their carers is hindered through laws or institutions that do not fully advocate for their rights. The laws that are put in place do not provide for the needs of the carers and the care recipients and hence a need to relook at the factors influencing such.

The social model of disability views disability as an attribute shaped by the settings in which the individual lives in (McNair & Sanchez, 2008). Action is thus the need for social change which is fundamentally the intervention needed. The social model of disability hypothesises that if societal barriers are addressed, the problem of disability will not be evident even though the impairment exists. The social model focuses on eliminating societal barriers through advocating for the rights of persons with disabilities in education, jobs, access to health facilities and services (Kayama & Haight, 2014). These barriers have been noted to hinder the progress of caregivers and care recipients in their attempt to access services. This thus helps the primary caregivers to be able to cope and manage the caregiving process as most of the societal barriers would have been addressed. Oliver (2004) further argues that unlike the charitable model of disability, which promotes dependency by viewing a person with disability as one who needs charity, sympathy and special services, the social model of disability promotes independency, a positive self-image and stimulates potential in persons with disabilities. Once the potential of the child with a physical disability is realised, the caregiver can thus have a reduced workload as the individual can function in accordance with his or her inherent capacity.

The social model of disability uses an empowerment construct as one of the underlying principles. The social model of disability will be the basis of looking into the experiences of the primary caregivers of children with physical disabilities. The social model of disability is relevant in the Namibian context where as indicated by (Chilwalo, 2010). Children with

disabilities can be neglected by their parents due to myths and misconceptions about disability. This model seeks to address societal perceptions which hinder progression by focusing on attitudinal, environmental and institutional barriers that characterise most communities (Disability and Development, 2010). With its focus of empowering and capacitating people with disabilities and their immediate families, the social model of disability uses a developmental approach to disability. Midgley (1995) stated that the focus on individuals and families within a developmental approach includes a capacity-building, and promoting structural changes in the community. The capacity building will thus be viewed in relation to caregivers and the community. Capacity building for the primary caregivers and the children with physical disabilities becomes a core focus in an attempt to ensure that there is visible growth. The capacity building can be done through a number of activities which include training and enabling of appropriate family systems. Therefore, the developmental face of the social model of disability makes it the most appropriate model in this study.

The social model of disability considers disability as a human rights issue. Disability becomes a human rights issue especially when interest groups challenge the status quo and call for recognition, equal rights and elimination of barriers to participation. The various groups of carers of children with physical disabilities can thus call for the removal of the barriers that affect caregiving. The primary caregivers will be empowered to advocate for policy review that pertains to the areas that are of concern to them. Advocacy thus becomes an approach that can be used to guarantee that the rights of the caregivers and the care recipients are met. The social model suggests the existence of a complex form of institutional discrimination, which leads to a collective disadvantage of the disabled manifested through, for instance, the built environment, institutional arrangements and education systems which do not cater for diversity (Mitra, 2005). The model suggests that a complex form of institutional discrimination abides which leads to a collective disadvantage to the disabled. The model thus provides a relevant theoretical framework for the study, as it will enable the researcher to contextualize the burden of care and come with recommendations on how the needs of carers and the children with physical disabilities can be realised.

## 1.5 RESEARCH QUESTION

The research question for the study is as follows:

What are the experiences of caregivers in providing care to children with physical disabilities?

## 1.6 AIM AND OBJECTIVES OF STUDY

### AIM

- To explore the experiences of caregivers of children with physical disabilities

### OBJECTIVES

1. To establish the nature of care provided to children with physical disabilities by caregivers
2. To explore the financial implications of caring for children with physical disabilities
3. To explore the psychological experiences of primary caregivers of children with physical disabilities
4. To consider the options needed in order to support caregivers of children with physical disabilities.

## 1.7 LIMITATIONS OF THE STUDY

1. Some participants lived in remote areas and are seasonal workers thereby making contact and access a bit challenging.
2. Some participants anticipated immediate benefits arising from the study and hence some participants provided socially desirable answers.
3. Language barriers. All the participants spoke Afrikaans and Nama and the interview schedule was in English

To address the limitations to the study a number of approaches were made use of. To address the language barrier, a reliable transcriber was used during the interviews. The medical rehabilitation worker from the district hospital who spoke the same local language as most of the participants

and had already been working with some of the participants conducted some of the interviews. The researcher ensured that the transcriber was knowledgeable of the questionnaire and thus a brief training was conducted.

## 1.8 DEFINITION OF KEY TERMS

**Primary caregiver**- Any individual who has complete day to day responsibility for the child with a physical disability for more than 6 months

**Physical disability**- WHO (2011) views physical disability as weakness of the body which limits the full functioning of limbs. If there are other impairments that limit the person from other activities of daily living it can be viewed as physical disability. For the study, the following types will be considered under physical disability: arthritis, cerebral palsy, multiple sclerosis, epilepsy and muscular dystrophy.

**Caregiving -** Caring refers to the act of nurturing, providing or attending to someone who is need of such services. Caregiving can best be described as the service of providing informal unpaid services to the family members or friends who have physical, psychological, or developmental needs.

**Children with disability-**Any child under 18 years of age who is living with a medically diagnosed physical or mental impairment and is thus called a child living with a disability. The child is thus regarded as having a disability because the impairments result in functional limitations.

## 1.9 CONCLUSION

This chapter provided the background to the lived experiences of caregiving. The dearth of data was the key aspect in regards to caregiving in Namibia. The theoretical framework was also presented in the chapter. The chapter introduced various aspects to be explored and used in the subsequent chapters. These include research objectives and questions. The next chapter will look into the literature on disability and the needs of primary caregivers.

# CHAPTER 2

# DISABILITY AND THE NEEDS OF PRIMARY CAREGIVERS OF CHILDREN WITH PHYSICAL DISABILITIES

## 2.1 INTRODUCTION

This chapter reviews the literature on disability, models of disability and experiences of the caregivers in regards to the care they give to children living with physical disabilities. The chapter conceptualises the terms 'disability' and 'caregiver', and explores the experiences of families supporting children with physical disabilities, copying mechanisms of the families and the support systems available to the children. The issue of social safety nets and how they play a critical role in supporting children living with physical disabilities will be explored in this chapter. The chapter also looks at the legal and policy framework that regulates the care and support of children with physical disabilities in Namibia.

## 2.2 DEFINITION OF DISABILITY

The term 'disability' is defined in the 2006 Namibia Inter-Census Survey as "a limitation in carrying out everyday activities at home, at work, or at school because of long-term (lasting more than six months) physical or mental condition" (National Planning Commission, 2010, p. 16). Disability is viewed as the covering term which include limitation of activities, restriction to participation and impairments denoting the undesirable aspects of the connection between a person living with the disability and that person` s environmental and personal factors (WHO, 2011). The term disability is used to refer to individual functioning relating to, sensory, cognitive impairment, physical and intellectual impairment and various types of chronic diseases (Disabled World, 2010). Disability is viewed as a long lasting physical, mental, or emotional condition which usually results in difficulty in conducting normal activities such as bathing, eating, remembering and walking (Census Data Organisation, 2011). Disability thus has extensive effect on the life on one diminishing the ability to carry out the normal activities. (The American Heritage Dictionary, 2000). There are different theoretical explanations of the causes of disabilities. In this section, the theoretical explanations of the causes of physical disabilities are discussed in relation to the medical, social and cultural models.

### 2.2.1 Theoretical explanations of disability: Classification of disabilities

The International Classification of Functioning, Disability and Health (ICF), developed and adopted by the WHO in 2001, provide a framework for structuring intervention services for children with disabilities (WHO, 2001). It uses a bio-psychosocial model which merges together components of social and medical models of disability. The ICF provides a proper instrument which helps in the enactment of mandates of international human rights and the Namibian national legislation. In light of its alignment to the UN statutes, the ICF has been noted to provide a robust framework that helps to monitor varying facets of the UN Convention on the Rights of Persons with Disabilities, as well as aiding in the crafting of national and international policy (UN, 2006).

### 2.2.2 Medical model

The medical model considers disability to be an illness (Seligman & Darling, 2007). It views disability as an undesirable medical condition that needs treatment and rehabilitation. The medical model infers an obligation to treat people with disabilities (Shuttleworth and Kasnitz, 2004). In Namibia, the dominant approach for understanding the causes of physical disability is the medical model of disability (Lang, 2008). This emanated from the understanding that is inherent amongst the people on the causes of disabilities.

According to the medical model, poor parental care, malnutrition and unhygienic living conditions results in disabilities occurring (Edmonds, 2005). Edmonds (2005) also states that there are causes of disabilities which include conflicts and 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 utilised which include raising awareness through community campaigns, rehabilitation of people with physical disabilities and medical interventions. From the study on disabilities, Edmonds (2005) noted that about 50 percent of disabilities in Africa and Asia can be avoided through early interventions of primary health care. The study by Edmonds (2005) indicate that the bulk of the people living with disabilities in Africa and Asia were noted to have minor to moderate disability (children constituting a larger percentage) and those ones with complex disabilities having a shorter lifespan. Edmonds (2005) expounds that two thirds of disabilities on children have been a result of conflicts and landmines, accidents and injuries, congenital causes and malnutrition and micronutrient deficiencies

Borzutzky (2000) stated that the medical theory of disability considers disability to be long-term issue covering different spectrums of health including mental health issues, physical, vision and hearing disabilities. Mobility disabilities oftenly are as a result of conditions present at birth or as a result of injury of the person. Once the spine is affected as a result of injuries, mobility impairments can occur depending with the area of the spine that is affected. Disability can also be as a result of polio, deficiencies of iodine and vitamin A, Hanson's disease and complications at child birth (Power, 2001).

The ICF 2011 argues that disability is associated with a health condition which is one of the core components in its development and is linked to one or more related impairments. The health condition is expressed at three different equally important levels:

- Body function and structure level
- Person or activity level
- Participation or societal level.

According to the WHO (2001) there is a dynamic interaction between these three levels and the context of the individual which includes personal and environmental factors. The health condition may be diagnosable but frequently it may not be clearly identifiable. Examples of a diagnosable condition include epilepsy, brain damage (resulting in conditions such as cerebral palsy and intellectual impairments), physical abnormalities such as underdeveloped or missing limbs, malformations of various body organs and genetic syndromes like Down syndrome (Rosenbaum, 2004).

The person level is concerned with activities such as walking, learning and playing. When a child is doing a task or activity, he or she is using his or her whole being in a complex set of actions that make up that activity. If a child has difficulty in doing one or more activities, as determined by an assessment process, by observation or by report from the caregiver, this is called an activity limitation. This is what is usually referred to when using the term persons with disabilities. A child with one or more activity limitations is at risk of being excluded from participating in a range of activities because of the impact of environmental and other contextual factors. The degree to which a child with a physical disability does not partake in recreation,

socialization, and learning suited for the child's age is affected by their mobility and communication abilities. This is considered to be the societal or participation level of the ICF.

### 2.2.3 Cultural model

The cultural theory on disability states that culture might view disability in both negative and positive ways (Groce, 2005). People might have the same cultural beliefs as well as biological beliefs on disability but might be coming from different cultural. Groce (2005) is of the view that cultures that perceive disability in a positive manner are likely to show a progression in regards to positive attitude more positive attitudes to worldwide ideologies of disability than those that hold negative ideologies concerning disability. However, it should be noted that socially created notions and views on disability are continuously changing (Groce, 2005).

It can be noted that in some cultures in 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 behaved not according to the set norms and values (Abosi and Koay, 2008). Van Dyck, Kogan, McPherson and Weissman (2004) indicated that some African communities perceive disability as a punishment for the wrong doings from God or the fore fathers and hence disability will always be difficult to deal with. Though the attitudes of people in the communities are changing in an attempt to accommodate and accept physically disabled persons, it's evident that the people with physical disabilities are still being stigmatised as a small subgroup and viewed as incompetent, because of the negative association that people have with disability. Characteristic of communities in Namibia, families oftenly accuse each other of using witchcraft and casting wicked curses upon resulting in disability (Haihambo and Lightfoot, 2010). In light of the views of community members, people with physical disabilities struggle to get assistance even from their families as well. Disability is viewed as being caused by not eating adequate and healthy food by the mother as well as not being able to take good care of herself during the time she was pregnant (Haihambo and Lightfoot, 2010). In a study conducted in Namibia, it is believed that when a woman is pregnant she should not eat food with a lot of chillies as they may cause disability (Haihambo and Lightfoot, 2010).

### 2.2.4 The social model

WHO (2001) states that the social or contextual component which reflects the social construct of disability comprises two factors, namely, environmental and personal factors. At the societal

level of functioning, the effect of environment factors is critical. Environmental factors that can be considered include goods and technology, support and relationships, systems, policies, the natural and constructed setting, approaches and services. In a facilitative environment, the child may have significant movement restrictions but might still be able to partake in everyday living activities and endeavours such as learning and attending school. Where there are a lot of barriers in the environment, the child could encounter multiple difficulties like accessing the toilet and not being accepted by community members because of an unreachable physical environment or a demanding and non-supportive social grouping.

The second contextual component, personal factors includes aspects such as gender, age, education, preferences and lifestyle. The contextual components of the ICF influence and modify all the other components and need to be taken into account in view of the dimensions of body role or structure, activity and participation (WHO, 2001). An understanding of the societal constructs concerning disability in a given culture contributes to developing strategies to sustain identified needs of children living with physical disabilities and as well as their immediate family unit (WHO, 2001). The disability context is helpful in understanding the interactive nature of the relationship between a child's health condition, activities, participation and a child's context which includes personal and environmental factors.

### 2.2.5 Societal view of disabilities

Friends, neighbours, and the general populace may act in a negative way through various ways which include avoiding the people with physical disabilities, remarks that are paining or efforts of exclusion which might extend even to the family (Haihambo and Lightfoot, 2010). In most African states, disability is still viewed in a negative way. This assertion is supported by an article in The Namibian newspaper of (2014) which talks about the prevalence of negative traditional perceptions in Namibian communities. The full and satisfying involvement of people with physical disabilities and their families is still lacking in many African states (Hartley, Murira, Mwangoma and Carter, 2005). Caregivers who are also from the family unit of the individual with a disability state that the attitude of community members who stigmatise them and reject their families because of the care they offer, has become a major burden for them (Hartley, Murira, Mwangoma and Carter, 2005). The same observation was made in some Western states such as USA and Greece as they have constantly reported of the stigma and

discrimination they face as well as being excluded from the community activities (Huffstutter, Bradley, Brennan, Penn, & Rosenzweig, 2007). It can be noted that in one study from Uganda the primary caregivers of children with disabilities, who mostly are often stressed and suffer psychologically, normally results in them having little time to do other household chores and feel (Hartley, Murira, Mwangoma and Carter, 2005). Exclusion from mainstream activities can thus lead the primary caregiver to have challenges in care provision.

The caregivers` load might increase as a result of social stigma. The stigma from the community if perceived as emanating from curses or evil spirits will only worsen the stress level of the caregiver. Families who are offering care to children with physical disabilities view society held beliefs and negative attitudes as problem issues. Families found difficulties in meeting the needs of the children with physical disabilities due to cultural superstitions within their communities (Bunning, Gona, Odera-Mung'ala, Newton, Geere, Hong and Hartley, 2014). Having a child with disabilities in the Japanese community was considered to be offensive and a taboo and the blame was mainly pointed towards the mothers by other family members (Kimura and Yamazaki, 2013). This normally results in an increased burden on the primary caregiver caring for a child with physical disabilities as they will be psychologically affected by the cultural perceptions.

### 2.2.6 Disability, culture and coping

Whilst disability is a universal trait of human beings, the cultural surroundings have effects on how people with physical disabilities identify themselves, or are identified by others and this can influence their social wellbeing, economic and health status. The concept of health and wellbeing is related to the way in which people construct reality and is influenced by culturally defined belief systems and anticipations Brookins (as cited by Salojee, 2007). Hence cultural sensitivity and affirmation are critical to providing effective health and rehabilitation care.

Groce and Zola (as cited by Salojee, 2007) stated that the influence of the cultural environment in solving problems and managing family life primarily has influence on adaptation to disability. Family life processes govern the how families relate to bearing a child with a physical disability and thus play an essential role in determining how the family react to medical needs of the child, which comprises rehabilitation therapy, McCubbin et al. (as cited in Itzhaky and Schwartz,

2010). Therefore it is vital for health care workers to comprehend the traditional beliefs, attitudes and practices relating to disability, Groce (as cited in Salojee, 2007).

Culture and ethnicity are defined within the confines of customary beliefs, integrated patterns of human behaviour, social norms and traits of a group (McCubbin et al. as cited in Itzhaky and Schwartz, 2010). They are nurtured, cultivated and transferred across generations and among family members through traditions and celebrations, as well as through problem solving efforts. Individuals thus depend on familiar cultural cues, such as communication patterns and customs, as they grow and mature, but may not be consciously aware of these cues.

The concept of disability itself cannot be taken for granted. Cultures differ and hence one cannot be disabled for the guileless reason that disability as an acknowledged grouping is not found amongst people, Ingstad (as cited by Salojee, 2007). There are visually impaired people and those who cannot walk, but as evident amongst most communities, the term disabled is difficult to translate into many languages. The concepts of handicap, disability and rehabilitation emerged in from a historical perspective in Europe. Thus they suggest that the social identity of being disabled is historically a European concept which does not easily translate into all African cultures, Ingstad (as cited by Salojee, 2007).

Hartley, Ojwang, Baguwemu, Ddamulira & Chavuta, (2005) point out that baseline information is lacking about how families with a child with a disability in resource-constrained settings cope. One consequence of this is that rehabilitation in these areas is often based on myths regarding attitudes towards, and care of, children with disabilities together with implementing simplified rehabilitation practice from income-rich countries. This may be at odds with local reality (Hartley et al., 2005).

Actual life situations need to be analysed in order to identify the constraints, possibilities, beliefs and values that generate patterns of coping with disability. Saloojee (2007) states that adopting this approach may help in avoiding the risk of creating stereotypes within communities. Groce (as cited in Salojee, 2007) observed that understanding socio-cultural models of disability will culminate in better understanding of disability and culture. Salojee (2007) states that rehabilitation workers are trained to focus more on clinical aims which help to restore the purpose in specific muscles or train the person on daily living skills, without considering the

social and cultural matrix that the person with disability lives in. Awareness of the weaknesses and strengths of the community which encircles the disability community is critical in the disability care continuum and hence the need for rehabilitation workers to be more efficient in their work and also advocate for sound working partnerships with their clientele.

In some communities, the potential for miscommunication and misunderstanding increases when the family and therapist are coming from different cultural backgrounds (Black and Purnell, 2002). This has consequences for rendering effective care, for example, a caregiver may not respond to a therapist's advice and intervention if they do not agree with or understand the principal reason for the treatment (Black and Purnell, 2002). McCubbin et al. (as cited in Itzhaky and Schwartz, 2010) suggest that there are several factors which determine the ease with which health care professionals incorporate cultural or ethnic factors into their practice when dealing with caregivers and families of children with disabilities. These include the cultural or ethnic background of the professional health care as well as their sensitivity and competence to deal with cultural and ethnic factors.

The social and cultural challenges for caregivers can be wide ranging. Cichon (2004) notes that culture and social environment might differ in societies leading to different definitions of disability between the professionals and them, and this may create problems in accessing suitable support services. Furthermore, the primary caregivers, who in most cases are the mothers, may reject or fail to accept the actual definition of the disability of the child as they may feel that they are being labelled or may blame themselves for their child's disability (Littlewood, 2006). Nevertheless, accepting unrealistic definitions of the child's disability may result in negative effects upon the caregivers or the mothers.

Reid-Cunningham (2009) stated that difficulties with perceptions of disabilities are often closely related to cultural stigma in some communities. Literature indicates that caregivers who are caring for children with disabilities encounter different degree of rejection in the social settings and the family (Schall, 2000; Cichon, 2004; Simeonsson, 2008). Some mothers experience subtle and sometimes overt judgement by family members, friends and strangers about their competence as parents (Schall, 2000). Schall, (2000) is of the view that such experiences may lead to the mothers' refusal of the actual definition of the child's disability. Haihambo and Lightfoot (2010) state that children with disabilities are often viewed as crazy in African

communities, especially in low-income communities. Such perceptions can be due to low levels of education or lack of knowledge with regard to the disabilities. Families that have children living disabilities have higher chances of being isolated and excluded in such communities (Office, 2011). Haihambo and Lightfoot (2010), state that in African communities like Uganda and Namibia, disability is often viewed as a punishment from the ancestors. Subsequently, the caregiver (usually the mother) may hide the child with the disability from the public in order to avoid being judged, stigmatised or discriminated against by people in the community. In some cases, families are also accused of causing the child's disability through witchcraft. Cichon (2004) is of the view that mothers of children with disabilities may face many obstacles when seeking health interventions and services for children with mental health problems. They are usually discouraged by the stigma and prejudice, and discrimination associated with mental health problems. A study on attitudes of mothers of children with disabilities noted that a significant number of mothers were not happy with their neighbours' and communities' reactions towards them for having a disabled child as they feel it's discriminatory in nature (Simeonsson, 2008).

## 2.3 CAREGIVING

The concept of caregiving can be described as a physically and emotionally strenuous task, though at times can be viewed as a special, rewarding experience whether it is for a child family member or client. (Mintz, 2008) states that caregiving varies from situation to situation and can last for a few months, three to five years and at times it can be a lifetime commitment. To overcome the limitation, researchers in this area tend to use traditional approach on analysis to assess the cause and result association after altering other variables. Raina et al. (2005) proposed a single multidimensional model which examined the effects of comprehensive traditional variables on the health and well-being of caregivers. These variables included socio-economic factors, child characteristics (that is, child behaviour and functional status), care-giving demands and caregiver perceptions about formal care, caregiver intra-psychic factors, community support, functionality of families, control of stress and caregivers' physical and psychological. Results from a study on caregiving revealed that behaviour of the child, functionality of families as well as the demands of caregiving are significant in forecasting the well-being of the primary caregivers (Raina et al., 2005).

The well-being of a child living with physical disabilities can be greatly affected by the ill health or psychosocial state of the primary caregiver (Brehaut et al., 2004; Raina et al., 2005). Brehaut et al. (2004) state that a care giver of a child living with disabilities is tasked with conducting the daily care requirements of the child is done and also the decisions that are made in regards to the care offered. WHO (2001) noted that caregiving involves a number of activities which include the provision of assistance to an individual who is not able to care for himself or herself, to ensure that activities which are critical for human living or functioning are done. The concept of caregiving might involve a wide range of physical activities depending on the disability nature and extent and resources that are available. Activities of daily living that the primary caregivers assist with include but not limited to positioning or transferring a child who is not mobile, dressing, eating, drinking, carrying the child to the toilet as well as bathing.

### 2.3.1 Roles of a caregiver

Caregivers can be family members, neighbours or friends and thus constitute informal caregivers. Considerable stress is placed onto care givers creating a position whereby their health, both physical and psychological may be compromised (Rowe, 2003). Mintz (2008), describe caregiving as both extremely taxing and exhausting, with a multitude of contributing factors affecting the caregiver's well-being, such as coping, burden, stress, burnout, and compassion fatigue. Having effective coping strategies is paramount given the elevated number of contributing factors to the expectations on caregiving (Rowe, 2003). These unrealistic expectations then get placed on the individual and can create situations whereby the caregiver has a substantial amount of stress and burden relating to the caregiving process. These negative experiences are not isolated from the other responsibilities each caregiver carries on a daily basis and consequently, have a continuous and cumulative effect.

According to Rowe (2003) a primary caregiver, needs to understand what their roles and responsibilities are in caring for children with disabilities. This affects their emotional and physical capability to do their job well. The individual caregiver identifies with the role of a caregiver, which creates a certain image of the caregiver and implicitly that of a patient. Most informal caregivers end up in the role of being caregivers thus adding strain to the themselves (Harding and Leam, 2005). Clarke (2001) noted that the role of caregiving is embodied with conflicts at various levels which require caregivers to develop effective coping strategies that

will help them to cope. The manner in which caregivers themselves perceive their role will influence the nature of support offered to them (Payne, Smith and Dean, 1999).

Duxbury, Higgins and Schroeder, (2009) considers the connection between caregiving and work to be related to the need for the kind of gratification gained from the involvement with others. Many times such work is considered as labour because the caregiver engages in strenuous tasks often within the confines of some form of attachment (Semiatin & O'Conner, 2012). The most difficult aspect of understanding work and caring is the unpredictable and changing nature of caregiving itself. Slade (2010) notes that caregivers are frequently graced with fundamental responsibility of emotional management, regarding any emotional responses they may have in relation to the patient and the circumstances that surround the patient's well-being. Thus eventually by assuming the role of the caregiver, the individual locates themselves in a role in which their needs are secondary to those of their patients. Semiatin & O'Conner, (2012) however noted that the role of a caregiver also needs to be located within the greater context of the caregiving concept. This is particularly vital in consideration of the interaction between different factors within the environment and the mutual effects they have on each other.

### 2.3.2 Role of the family in caregiving

Larson and Miller-Bishoff (2014) noted that family life will be changed, and often in major ways because of the presence of one living with a disability in the family. Caregiving responsibilities may lead some of the primary caregivers to change their career paths or totally leave their jobs. Larson and Miller-Bishoff (2014) in their study on caregiving experiences saw that female family members highly give up their jobs or change their job roles because of the new roles of caregiving that they will assume. Larson and Miller-Bishoff (2014) deduced that the taking up of caregiving roles is high amongst females because males are likely to be paid more money for their work. He further added that for the families to fully function when it comes to division of roles, the families take into cognisance the financial implications involved. The study furthermore showed that alternatively, some carers have got side jobs part-time to augment the income of the family and depend on family members to help with care for the child though some fulltime employment was a preference by some primary caregivers. The nature of care demanded that the carers offer round the clock care to the care recipients and this limited those caregivers who wanted to return back to work (Larson and Miller-Bishoff, 2014). The caregivers managed

the challenges that they faced in different ways and these challenges came because of pressure from the nature of care, need of employment and income of the family.

Cuzzocrea, Larcan and Westh, (2013) state that some family members felt left out while others were being excessively closer to the care recipient as a result of family allegiances which oftenly emerge like the primary caregiver getting so close to the child with a physical disability. The act has been found commonly amongst mothers who have children with disabilities (Cuzzocrea et al., 2013). Characteristic of such families is the low levels of participation in the care continuum by the fathers as they are either busy at work or engaged in other recreational activities and might lead to marital problems. Hartley et al. (2005) state that divorce rates are not so common among parents who have a child living with a disability though there might be marital strains. It has thus been noted that when there is disability within the family, it can lead to an increase in divorce rates (Godwin, Kreutzer, Arango-Lasprilla and Lehan, 2011). Some caregivers became more attached to their partners due to the disability present in the family. For instance, one parent stated that their son had brought them closer and thus had bonded as a couple (De Pape and Lindsay, 2014). Although some parents reported becoming closer, it was also shown that some of the couples grew apart because of the caring role of the other partner for the child with a physical disability (De Pape and Lindsay, 2014). The cultural environment has been noted to have influenced the separate roles both parents play in the upbringing of the child living with disability. In a study conducted in Turkey it was stated that the mothers were frequently blamed for the misfortune and thus were supposed to care for the child Aylaz et al. (as cited in De Pape and Lindsay, 2014). Some studies conducted in Australia and in the United States of America observed anger in some of the mothers caring for children living with disabilities which were because of their husbands not helping them enough in the caregiving process. It is evident that problems in marriages might occur and lead to high divorce rates among couples who have children with disabilities and the findings agree with researches done earlier, Hartley et al. (as cited in De Pape and Lindsay, 2014).

### 2.3.3 Factors affecting caregiving

There are a variety of factors that affect caregivers of children living with disabilities. These include physical condition of the primary caregiver, level of knowledge, and nature of disability, age and financial cost of caregiving. These will be discussed below;

#### 2.3.3.1 Physical condition of caregivers

The health of a caregiver is a critical element in the caregiving continuum as it has got bearings on the wellbeing of the child with physical disabilities who is being cared for. According to Geere, Gona, Omondi, Kifalu, Newton, and Hartley (2011) many carers of children living with disabilities in low income countries cope with poverty, inadequate public services and special equipment for children living with physical disabilities. For the child with a physical disability to be comfortable the primary caregiver has to be healthy (Brehaut et al., 2004). Tong, Haig, Geisser, Yamakawa and Miner, (2007) state that primary caregivers who are normally carrying and transferring care recipients with disabilities have been found to have reduced physical functioning and back pain in comparative to those who are caregiving but do not need assistance. The primary caregivers in low income countries face a mammoth task in the caregiving continuum because of the high loads of physical work required as a result of lack of special equipment which aids them to reduce the workload. This might result in physical health disorders and injuries. Elliott, Shewchuk, and Richards (2001) state that primary caregivers who face challenges to address their coping capacities might have increased levels of depression, and health problems when they begin caregiving roles. Older caregivers are associated with more health problems (Rivera, Elliott, Berry, Shewchuk, Oswald and Grant, 2006). It was noted that the older caregivers have high frequencies of chronic health conditions (Vitaliano, Zhang and Scanlan, 2003), and that if they have ill health, they are highly susceptible to the burden of caregiving. Rivera et al., (2006) noted that caregivers of persons with disabilities who are in their old age are associated with higher depression.

A study by Kimura and Yamazaki (2013) states when a primary caregiver takes care of a number of children that have disabilities, the workload is high and might contribute to exhaustion both physically and exhaustion of the mothers. The primary caregivers who are normally the mothers face a number of care needs for the various types of physical disabilities. The primary caregivers stated inadequate support from the family as being the major cause of fatigue hence contributing to the burden of care for them (Kimura and Yamazaki, 2013).

The caregivers of children living with physical disabilities have been noted to succumb to poor mental health, depression and limited daily living activities (Smith and Grzywacz, 2014). Smith and Grzywacz (2014) in a study on the wellbeing of guardians and parents of children with

disabilities who have special health needs saw that the carers of children who have special health care needs showed a drop in their capability to do daily living activities as well as depression compared. Akerlof and Kranton (2000) states that the identity is central to how people feel they should behave, leading in some cases to behaviour that might be viewed as self-destructive. In a study conducted in Canada, it was found that 63.6 per cent of Canadian women believed that it was a parent's responsibility to sacrifice his or her own wellbeing for the benefit of the disabled children (Burton, Lethbridge and Phipps, 2008). This may include sacrificing leisure time, resting and socialising, which may negatively impact their health, especially over a long period of time. The primary caregivers stress levels might increase over time because of caregiving for a child living with physical disabilities emanating from the high cost of medical care, time strains and the fear for the future of the child (Brehaut et al. as cited in Smith and Grzywacz, 2014). Witt, Gottlieb, Hampton and Litzelman (2009) reported that the frequency of activity limitations was two times among the parents of children with disabilities (23.1%). Smith and Grzywacz (2014) observed from new studies that caregiving of a child with severe disabilities and high special dietary needs may create health problems in the long run for the primary caregivers. Psychological distress namely anxiety, depression and insomnia has been reported to be twice as high for parental caregivers of children with disabilities (Girard, 2010). The mental burden is related to caregiving responsibilities and is the result of dealing with disruptive behaviours and providing emotional assistance (Girard, 2010). Smith and Grzywacz (2014) reported a surge in the number of children with disabilities who have special health care needs, which led to a rise in the number of care givers who will then have health deteriorations because of the care they are offering to the child with physical disabilities.

Care giving of a child living with disability can be an exceedingly stressful and time-consuming. Sleep deprivation and stress are common experiences for the caregiver (Girard, 2010). The health of the carer can also be directly negatively affected if they feel guilty about not living up to idealised norms about being a worthy carer who is able to provide for the care recipient with normal childhood. The social health of the carer can be affected as a result of the carer's (normally the mothers) guilt feeling, blaming themselves for the care recipient's disability (Burton, Lethbridge and Phipps, 2008). This can result in the carer having anxiety about the child's current condition and future prospects (Burton, Lethbridge and Phipps, 2008). Moreover, the provision of the required care may result in compassion fatigue in the caregivers. Figley

(1995) states that compassion fatigue is characterised by exhaustion and dysfunction within biological, psychological and social domains due to intense distress and empathy for other persons in anguish over a certain matter and hence accompanied by a strong desire to alleviate the pain and remove its cause. One can also note that compassion fatigue can emanate from lengthy exposure to compassion stress due to absence of reprieve from responsibility encumbrances and inability to decrease the compassion stress, and hence creates a disruption or change in a person's functioning or lifestyle (Figley, 1995). The results of compassion fatigue can be detrimental as it leads to various experiences like a sense of helplessness, confusion, isolation from family and friends, hyper-arousal, sleep disturbances, concentration difficulties, agitation, irritability, hyper-vigilance, distress, a decrease in pleasurable activities and contagion (Figley, 1995).

#### 2.3.3.2 Level of knowledge

Caregivers of children living with physical disabilities suffer substantial psychosomatic and physical challenges due to the burdens associated with caregiving, Parminder et al. (as cited in Oruche et al., 2012). These primary caregivers mentioned that they faced challenges of lack of knowledge of the problems with the children they are caring for, the stress of having to seek diagnoses and their inability to possess the right skills and knowledge on how to care in the best way for the child, Nuutila and Salantera (as cited in Oruche et al., 2012). Hayles, Harvey, Plummer and Jones, (2015) stated that the needs of a child with disability increase as they develop in age. The family has to respond to the changing demands in the caregiving continuum emanating from the community's changing attitude and possibly going to school by the child.

It can also be observed that the caregivers oftenly do not have the right skills and knowledge to give adequate care and hence will need assistance from the formal social and health care service providers (Nuutila and Salantera, 2006). In regards to provision of caregiver services, the provision of services by the local providers is not visible and hence the caregivers will always feel neglected. Caregivers of children with disabilities reported spending substantial periods discussing with the health and education systems in an effort that will help them to meet the needs of the child (Murphy, Christian, Caplin and Young, 2006). Nuutila and Salantera, (2006); Yantzi, Rosenberg, and McKeever, (2006) reported facing challenges in difficulty in getting satisfactory respite care because of the nature of care which requires one to be knowledgeable in

the care of children with disabilities. Experience gained from earlier caregiver interventions has helped the caregivers to deal with emerging caregiving issues as they can use it to cope and adjust (Hayles et al., 2015).

What is common in most communities in Africa is the design of the environment, services, leisure activities and most aspects of everyday life which do not cater and accommodate the majority of the children with physical disabilities in relation to their conditions and hence primary caregivers find themselves with a difficulty on how to relax outdoors with them. This leaves them out from the mainstream community and hence caregivers are left with a lot to tackle to ensure that they find alternatives for the children. Primary caregivers of children with physical disabilities have been known to encounter challenges in ensuring that the resources that they need as well as for the child are met (Nelson, 2002; Smith and Smith, 2000).

Caring for a child with disability often requires expert understanding, widespread partnership with health professionals, and the attainment of special skills by caregivers or parents that are frequently connected with professional health care work (Leiter, Krauss, Anderson and Wells, 2004). Caregivers feel that they have to perform complicated tasks, such as administering complex medical treatments and attending numerous medical appointments with their care recipients. The caregivers are involved with a wide variety of professionals in social, educational and health service as a result of the child's disability which creates the need for specific knowledge (Shearn and Todd, 2000).

#### 2.3.3.3 Nature of disability in the family

The implications of bringing up children with physical disabilities on the relationships between family members and their psychological and social well-being are often strained and grave in nature. Study done on nature of disability and its effects have obtained evidence that the mental health of mothers caring for disabled children was found to be much poorer than those of mothers of children without disabilities (Byrne, Hurley and Cunningham, 2009). Many parents caring for mentally and physically disabled children succumb to enhanced stress compared to those without children with disabilities. The stress can emanate from the inconsistency between the child's physical size and developmental capacity and that of other children, the visibility and nature of the disability, and stigmatisation from the people in the community (Girard, 2010). While these children develop and the disability becomes more visible, parents are often

confronted with an increase in child management that leads to further psychological and emotional draining (Girard, 2010). This stress can be both physical and psychological (Girard, 2010).

Oruche, Gerkensmeyer, Stephan, Wheeler and Hanna, (2012), state that the nature of the disability which might require special care can lead to grave disruptions on the family relationships and functioning thereby impacting heavily on the primary caregiver. These demands persist throughout childhood and into the adult years, and thus require continual adaptation by care providers. In a survey conducted in the United Kingdom on caring for school children with mental or physical disabilities, caregivers indicated that having to care for a mentally or physically disabled child had resulted in straining of their relationships (Paediatric Nursing News, 2004). The study found that one in ten study participants felt that it had led to couple's separation and one in six indicated that they were raising the disabled child alone (Paediatric Nursing News, 2004). Ferguson (2012) mentions that the day to day stress of providing care might result in extreme tiredness and weakness, wearing the physical and emotional energy of the primary caregiver. Mothers of children with physical disabilities risk emotional problems especially those who supposed they are have a part in causing the disability of their child (Ferguson, 2012). The primary caregivers have to face a number of social and psychological challenges which result in emotional strain for them.

The nature of disability can be linked to the way caregivers of children living with physical disabilities access medical expertise and care. Upon diagnosis, a new child could be severely disabled and this could often be extremely stressful and can instil strong feelings of being overwhelmed and powerless regarding the care that might be offered in the future by the parents. Graungaard and Skov (2006) state that the initial contact between the parents and the health professionals may determine how the parents are going to manage with the kind of disability that the child has. Once the disability is classified, finding suitable and appropriate care for the child can be a struggle because of the nature of the disability (Shearn and Todd, 2000).

#### 2.3.3.4 Age

The age of the parents when a child's disability is diagnosed contributes significantly in determining the family response to disability, Bigby and Ozanne (as cited in Savage and Bailey, 2004). Savage and Bailey (2004) state that because of the age of a teen parent who is yet to

mature and do not have enough resources to meet the demands of caregiving adaptation is likely to be poor. When a couple decides to have a baby, the risks are very high that the child will be born with disabilities. Rivera et al. (2006) state that the older caregivers may have less energy to cater for the extra burden that is faced in the care process and may also be fearful of death leading to worries about who will take care of the child when they die. The type of the disability that the child has is also noted as a contributing factor to the challenges encountered by the parents and the way they cope and deal with it (Mori, Ujie, Smith et al., 2009). Culture can thus influence care and in the case of death of the caregiver who might be the parent, the child might end up living on the street and hence the fear amongst some caregivers about their own death.

#### 2.3.3.5 Financial cost of care

Care giving of a child living with a disability results in several challenges to the caregivers, such as high cost of medication for treating the child's condition, finding ways to deal with a dealing with the child's difficult behaviour, and stigma from the community against people with disabilities (Lecavalier, Leone and Wiltz, 2006). In the SADC region, most countries do not have grants to give to children with disability with the exception of South Africa and Namibia. In Namibia, children with disabilities are given an amount equivalent to 250 rand. There is no grant for the caregiver in Namibia, unlike in the UK where the caregiver is given a grant. This poses a great threat to the economic life of the primary caregiver.

Inherent within caregiving is the cost of care which increases with time. This is supported by Emerson, Hatton and Blacher, (2006) who state that families find that their expenditure increases and simultaneously their capacity to earn and eke out a proper living is reduced. High costs are incurred with respect to the special diets for some disabilities in children, fuel, transport, relocation to more suitable and conducive homes, and all place extra financial strain on the families (Michalak, 2013). It can also be noted that women and low earning primary caregivers may have enhanced challenges. This appreciably reduces the income of the family while the child's care expenditures increases, although the costs are varied (Olsson and Hwang, 2006; Anderson, Dumont, Jacobs and Azzaria, 2007).

Physical disabilities in children can impose considerable costs on families caring for them. Vecchio, Cybinski and Stevens, (2008) stated that the increased financial burden may be attributed to the special medical care, education, therapeutic and other special needs. Anderson et

al. (2007) carried out a study in the USA and derived that 40 percent of families of children living with exceptional health care needs face financial burdens as a result of the disability of the child. Irrespective of the nature of the disability, the cost of care for a severely disabled child is three times that of a child that is not disabled. In addition, these costs are often long term, even lifelong costs (Kagan, Lewis, Heaton and Cranshaw, 2008)

The cost of care giving for a child with physical disability can strain financial resources of the family. Lukemeyer, Meyer and Smeeding, (2000) used the Human Capital Approach to expound the economic effect of caring for children with chronic disabilities and ailments which majors its focus on the direct and indirect cost of medical care. Direct costs include rehabilitative or curative services, medical services and the cost of hospitalisation, home health care and special equipment. These direct costs can strongly increase the risk of families gliding into poverty. Lukemeyer et al. (2000) state that medical care which includes tests, hospital stays or therapies, as well as unique equipment, such as wheelchairs, crutches or braces, are at the forefront of major expenditures for the families of a child with physical disability. The effect these costs have on families with disabled children is also strongly dependent on the availability of health insurance and similar state measures, for example, social grants. Lukemeyer et al. (2000) in his study indicated that less than 10 percent of the parents and guardians of children with disabilities in the United States have no form of health insurance coverage. Thus, out of pocket expenditure becomes higher. Lukemeyer et al. (2000) thus suggest that most families who have low income face difficulties to meet the total cost of the requirements of the children with physical disabilities.

It is vital to note that caring for a child with physical disabilities can result in indirect costs. Lukemeyer et al. (2000) state that indirect cost can result from the foregoing other beneficial activities, such as loss of income, associated with the degree and intensity of caregiving activities. Lukemeyer et al. (2000) observe that 32 per cent of the mothers were hindered from working other jobs because of the special care that they are providing. The increase of single parent households, as well as the economic need for two incomes in two parent families, exacerbates the impact of these costs. The employment situation can further exacerbate the risk of sliding into poverty. Yantzi et al. (2006), in a research on mothers with children living with disabilities, noted that their engagement in activities that bring income were limited to only small

portion of the day and mostly in low income and unskilled jobs that do not require professional skills. The study revealed that the mothers preferred such jobs since it gave them more time with their children if they are not at school. Caregivers of children with physical disabilities stated that their employers understood their situation and hence would give them time off to collect their children when they fell sick, got injured or had a medical appointment. In other words, mothers selected jobs that suited their demands at home and their caring role (Shearn and Todd, 2000). According to Ceglowski, Logue, Ullrich and Gilbert (2009), the existence and severity of a child's physical disability plays an important role in making work related decisions for about one third of the families, especially the mothers. Ceglowski et al. (2009) state that the fear of being isolated at work has resulted in the mother care giver not to bring the issues they need help with to the other professionals they might be working with. This is because of the fear of the professionals' judgement of their parenting or questioning their motivation for supporting for their children and hence they continue being quiet.

A study on employment noted that mothers whose children are not having disabilities are having a higher employment level compared to the mothers of children with disabilities (Olsson and Hwang, 2006). Primary caregivers who are not earning an income cannot gain from the likely cushioning effects of many roles that are, being involved in both work that gives an income and childcare. Olsson and Hwang (2006) fear that the primary caregivers might develop negative feelings about the other role and hence might not be more effective at work which might result in them negative stress reactions. Children with physical disabilities whose caregivers are employed have been noted to show little undesirable effects related with care they offer for a child with disabilities. The involvement of the father in the upbringing of the child with a disability can lead to the positivity of the parental well-being. The nature of the marital relationship can affect the conduct of mothers of children with disabilities who are employed and might result in unsatisfactory employment. For most of the caregivers, this state is unwanted and discordant with their individual goals. All these issues, including the inability to work so that they can provide full time care for their disabled child, as well as resulting issues, are strongly exacerbated by an already precarious economic situation of the family, or mother, in, for example, low income communities.

Absence of data on the financial costs incurred by primary caregivers in Namibia makes it difficult to know the cost of caring for children living with disabilities. The nature of care for a child with a physical disability has been noted to an overwhelming task for caregivers and hence costs of care might be high.

### 2.3.4 Coping strategies of caregivers

Primary caregivers of children living with physical disabilities employ different coping mechanisms to use. Social support which is readily available as well as the financial position of the primary caregiver are critical in managing situations that the primary caregivers might use as coping resources Nolan et al. (as cited in Savage and Bailey, 2004). The effects of caregiving on caregivers' psychological health, self-esteem and the coping strategies they employ have been cause of concern. Nolan et al. (as cited in Savage and Bailey, 2004) categorises the coping responses as coping strategies or coping resources. However, the creation of social platforms for the carers of children with physical disabilities to share experiences has proved to be an influential method for information sharing and problem solving in developed countries (Hayles et al., 2015).

Parminder et al. (2004) state that there are other considerations that are important in deriving the psychological well-being of the primary caregiver and these include the level of care recipient to communicate, age and gender and the presence of other cognitive or sensory impairments. White and Hastings (2004) note that high levels of unity within a family and closeness are vital coping resources. Glidden et al. (2009) in a research involving parents of children with disabilities established that coping mechanisms influenced the stressors of the primary caregivers. Parnes, Cameron and Christie (2009) state that women and girls significantly bear the duty for caring for the family and face stress, have reduced employment chances and often end up taking the caregiving roles even in the event of themselves getting old. McKenzie and Swartz (2011) noted that women are always daunted with economic burdens as a result of them failing to seek work because of the caregiving demands for the child with physical disabilities. As a result of insufficient support from the family, community and health professionals, the primary caregivers of children with physical disabilities often feel unhappy and neglected (Butcher, Wind and Bouma, 2008). The impact of financial burden and stress might affect the primary caregiver's health and well-being in a negative way. Mothers who are offering care for children living with

disabilities experience increased stress related to daily activities compared to mothers without care giving responsibilities (O'Brien, 2004).

Of late, researchers have gradually paid detail to the caregiver' s stress-coping resources, which include positive perceptions, being hopeful, optimistic, having self-efficacy, self-esteem and a sense of coherence, Baker, Blacher, and Olsson (as cited in Kimura and Yamazaki, 2013). Scholars have determined that carers of children with physical disabilities who have a number of stress-coping resources are in better shape to avoid stress and sustain good health and display lesser signs of depression than those with lesser stress coping resources facing the same problems, Olsson and Hwang (as cited in Kimura and Yamazaki, 2013).

### 2.4 Current situation of disability in Namibia

Visual, hearing and speech impairment, physical disability and mental conditions are all limitations found in the Namibian Society (Haihambo and Lightfoot, 2010). Haihambo and Lightfoot, (2010) adds that these limitations compromise the ability and opportunities of the affected people as well as complete participation in the society and these people tend to be victims of rejections, isolation and negative attitudes from the community. Lang, (2008) adds weight to this view explaining that developmental opportunities such as conventional education, training and employment have been the main areas not fully embracing the person living with disabilities. This is in spite the presence of clear government commitment through legislative frameworks (Lang, 2008).

This lack of opportunity realisation is attributed according to Ntinda, (2013) to the lack of rehabilitation centres and vocational training centres for people living with disabilities. He further adds that this is one of the reasons why unemployment rate of persons with disabilities lies at 90% in Namibia out of the 102 100 people living with disabilities. Statistics indicating the child disability rate in relation to the child population are not available. It is however noted that Research and Information Services of Namibia (RAISON) (2014, p.61) states that 28% of children living with disabilities to be physically challenged. The paucity of data on the disability of children thus remains a challenge to Namibian researchers.

The lack of opportunity in education by children with disabilities are noted by RAISON (2014) as 83.4% children without disability are enrolled in schools while only 69.2% of the disabled are

enrolled. Moreover 15.2% of the disabled had never attended school against a mere 4.7% of non-disabled children.

The realisation of total education for children living with disabilities is a commitment made by the Ministry of Education in Namibia but barriers such as school structural settings and negative attitudes by teachers, school heads, family and the rest of the society still limit access to the necessary opportunities. A 2003 study assessed the living conditions of persons with disabilities in Namibia. It noted that 72.9% access rate to health services was recorded while other services where noted to be less than 30% for vocational training, assistive devices, counselling services, educational and welfare services. The comparison of children who are older than 5 years who never attended school shows that 38, 6% is for children with disabilities and 2% for children without disabilities. Only 23% of the disabled were noted to have completed grade 8-12 compared to 31% of their counterparts. Unemployment rate amongst the disabled lies at 90.9% compared to 77.6% of the non-disabled.

There are a number of structures that have been put in place to address disability issues and these include the disability unity in the Prime Minister's office, the Division of Disability Prevention and Rehabilitation within the Directorate of Primary Health Care Services in the Ministry of Health and Social Services and the National Council on Disability. These units as noted by Lang (2008), are supposed to collaborate their activities to guarantee that services are delivered to people with disabilities. The signing of various conventions by the Namibian Government is vital in ensuring that disability issues are discussed at government level where policies are made. Civil society organisations can lobby for people with disabilities rights through the National Federation of People with Disabilities in Namibia.

However the functionality of the National Disability Council also appears to be challenging and needs to be addressed to ensure that people with disabilities have got an organ they can rely on. The National Disability Council functions include an obligation to oversee the execution of the National Policy on Disability, to recognise areas for law and policy reform and remark on recommended legislation from the viewpoint of people with disabilities and to implement all essential steps to improve the state of persons with disabilities in Namibia (Lang, 2008). However, since the council was established not a single report is available or documented actions conducted by the Council are not available. The disability policy was observed to have not been

properly implemented as evidenced by the lack of reports submitted by various government ministries (Lang, 2008) and the same was said about the Disability Council which has also not presented annual reports to the Minister of Health and Social Services and then to the National Assembly as required by the National Disability Council Act.

### 2.4.1 Legal and policy framework for disabilities in Namibia

The Namibian Government signed the United Nations Convention on the Rights of Persons with Disabilities of 2007. By being a signatory the Government of Namibia committed itself in protecting the disabled people` s rights (Lang, 2008). Despite the Namibia government ratifying the UN Conventions, many people in Namibia still suffer from discrimination, social marginalisation and exclusion from the mainstream activities of life (Lang, 2008).

MGECW, (2010) states that the government of Namibia has ratified a number of international agreements and these include the African Charter on the Rights and Welfare of the Child (1990), the United Nations Convention on the Rights of the Child (1990), the ILO Convention on the Prohibition and Immediate Elimination of the Worst Forms of Child Labour (1999) and the Convention on the Rights of Persons with Disabilities (2006). The Namibian government in 1990 signed and ratified the Convention on the Rights of the Child. The rights of the child ensured that the child with disabilities has the right to education, health care, abuse and neglect protection as well as not being discriminated. Other facets of the ratified rights include the right social security and acceptable living standards. In acknowledgment of the fact that there are sets of children who are more susceptible than others and frequently find themselves in need of further safety, the convention states that children living with disabilities are more vulnerable and hence forbids discrimination and exclusion against children with disabilities (MGECW, 2010). The Convention recognises the need for the state to have a closer working relationship with the guardians of children with disabilities to ensure that legal statutes that protect the vulnerable group are enacted and uphold. This provision gives the state responsibility in providing assistance to parents and care givers of children living with disabilities (MGECW, 2010).

Children living with disabilities are given distinctive attention in the 1990 Rights of the Child Convention. The Convention states that there is need to avail resources to children living with disabilities and the caregivers to ensure that they optimally function. The resources that are to be given to the children with disabilities and their carers should be provided free of charge as a

result of the financial difficulties the group faces. MGECW (2010) state that the assistance to be rendered to a child with disability and the carer should ensure that there is access to education, training, rehabilitation, health care services, recreation and employment within the confines of Namibia. The equalisation of chances for child development should be visible in the community as it helps the child to be able to socially integrate and develop as an individual. However, it can be noted that most people with disabilities or those caring for people with disabilities are highly exposed to poverty and poor living conditions as a result of not having equal opportunities for education, training and employment within Namibia. It is thus evident that people living with disabilities need financial help as well as a steady stream of income to help them with daily needs because of the disability. The streams of income and related services should be of significant value to the person with a disability as well as the carer as it helps to mitigate the burdens and improve opportunities for education, training and health care.

### 2.4.2 The National Council Disability Act (2004)

The National Disability Council Act (2004) gives a platform for the creation of a consultative organ to assist with expertise and strategic guidance on disability matters to the Namibian government. The government of Namibia put in place the National Disability Council Act (2004) which has got the ability to help in safeguarding the disabled person` s rights and ensuring that the government effectively meets its mandate of service delivery to the people with disabilities. Though the legislation was put in place, justice has not been done to ensure that it functions as expected as the National Disability Council has never been established and no meetings have taken place to date (Lang, 2008).

### 2.4.3 National Disability Policy in Namibia (1997)

The Ministry of Lands, Resettlement and Rehabilitation published the National Policy on Disability in 1997 and the policy was approved by the National Assembly in July of that year. The National Policy on Disability of 1997 adopted the social model of disability to conceptualise and implement the policies in the document. The policy document identified 14 priority areas for the Namibian Government to prioritise and to ensure that disability issues are addressed holistically. The key proponents on which the National Policy on Disability hinges on include social inclusion and integration as well as ensuring equal opportunities for all thus helping to protect the rights of children with physical disabilities. The National Policy on Disability states

that human development is critical for the growth of the society and hence the need to make sure the Namibian government plays a vital role in advocating for people with disabilities rights.

### 2.4.4. Employment, vocational rehabilitation and social protection

People with disabilities should have access to employment opportunities just like those without and should not be discriminated against by employers or other employees as enshrined in the National Disability Policy of Namibia. The Government of Namibia has got the Affirmative Action (Employment) Act 1998 which specifies that every company with over 25 employees should make an intensive effort to give work to vulnerable sectors like people with disabilities. Nevertheless, as is synonymous with third world countries the policies are poorly implemented because of inadequate regulatory systems. The Namibian Government established vocational training centres to ensure that people with disabilities can be trained and hence compete equally with those who are not disabled on the labour market thus giving hope to children with disabilities that they an equal opportunity is availed to them. The institutions are supported by the National Vocational Training Act of (1994) which aims at getting people with disabilities to have full access the training institutions. The National Policy on Disability also states that people with disabilities should be employed in settings or environments that are disability friendly and work learning and training centres as this helps them to obtain securing long term sustainable work.

People with disabilities receive grants which were put in place to cushion people with disabilities and only a few countries in Africa have such a social protection system in place. The Ministry of Labour and Social Welfare administers the grant and it gives N$1000 (approximately ZAR1000) per month for adults and N$250 rand (approximately ZAR 250) for children. With the increase in the price of goods and services, the amounts continue to have less buying power and hence the need to continuously relook at the amounts given to sustain the basic needs of people living with disabilities living in the country.

### 2.4.*5* National Policy on Special Needs and Inclusive Education (2008)

The Ministry of Education published the National Policy report on Inclusive Education in 2008 which sought to address the needs of the marginalised people or group's emphasis on children with disabilities was of significance to organs that deal with disabilities. The National Policy on Inclusive Education was based on the situational analysis done in 2004 which aimed at looking

into the special requirements of education for children living with disabilities. The findings of the situational analysis made suggestions to the Ministry to come up with a framework for special needs education for the country. The analysis report also recommended that teachers be trained in special education at tertiary institutions as well as decentralising special needs education systems to all regions of Namibia (Lang, 2008). Inherent within the policy is the reference to the CRC Article 24 which encourages signatory states to fully accept and instigate the principles of inclusive education.

## 2.5 SUPPORT STRUCTURES FOR PRIMARY CAREGIVERS AND CHILDREN WITH DISABILITIES IN NAMIBIA

### 2.5.1 Community programmes

The primary caregivers and the children with disabilities should fully and equally participate in the community through the enhancement of social security systems as noted by the United Nations Committee on Economic and Social Rights (Guthrie and Sait, 2001). Social safety nets and social protection spring from the apprehension that there is continually a degree of inequality and limit to opportunities for some households in any economy. Thus it is within the human realm to be able to give a helping hand to the less fortunate members of the community (Chiripanhura and Niño-Zarazúa, 2015). Social security entails safeguarding the individuals within the community who are at most risk against social threats through the provision of welfare services to those individuals that are within households fail to meet some of their own basic needs. The theory of social security is interpreted differently in various countries with some of them directing their focus on social risks or possibilities, others focus on the protective aspects, and therefore the meaning of safety nets would depend on the goal of the systems. Gentilini and Omamo (2009) state that there is an increase in the consensus on the meaning of social protection, although there is no agreed global definition of social protection. The various social protection schemes include safety nets and social services. Broader preventative actions would include ensuring safety at work, health care and capacity building initiatives. Social security contributes immensely to the country's social stability where the negative implications of social risk are a threat to the whole nation. The establishment of social security is thus viewed as a means of protecting individuals and communities from these contingencies.

In a study by Raina et al. (2004), they observed that mothers who were primary caregivers of children living with disabilities were in poorer mental and physical health, received less emotional support from family and friends and had greater demands placed on their time and finances. Raina et al. (2004) thus concluded that the absence of formal and informal sources of social support, was significantly related to the deterioration of the emotional wellbeing in children` s parents. From social support studies it was noted that the social support quality was more important than the quantity of social support (Mugno, Ruta, Valentina, Genitori, D'Arrigo and Mazzone, 2007). Research noted that when primary caregivers received support, their capability to manage and cope with the burden of care giving is enhanced, Totsika et al. (as cited in Oruche et al., 2012). Kagan et al. (2008) noted that the psychological wellbeing of the parents is enhanced by increased involvement in community related peer support networks.

According to Matengu, (as cited in The Namibian, 2014), absence of support groups in Namibia which help in catering for the psycho-social needs of children with physical disabilities and their carers has worsened the challenges faced by the primary caregivers. The support groups can be conduits for capacity building, advocacy and sustainable livelihoods. Matengu (as cited in The Namibian, 2014) states that the support groups should aim to lobby and advocate for the rights on education and restoration of children with disabilities so that they will be integrated, included in mainstream programmes and effectively participate in their communities. Community based rehabilitation (CBR) programmes are noted to play a crucial role in ensuring that family and community resources are used accordingly by the primary caregivers and children with disabilities (Hartley, Ojwang, Baguwemu , et al., 2005).

UNICEF (2014) singles out Namibia for commendable progress in developing policies for inclusive education, since independence. The New Era (2013) states that the report by UNICEF (2013) on the State of the World's Children says very little information is available on Namibian children with disabilities, their actual participation in education, and coverage of disability grants. It has been observed that the absence of data might be resulting from the lack of systematic methods to collect relevant data (UNICEF, 2013). This might explain the paucity of data in the country. Parents who live in poor rural areas experienced lower partnerships than those in urban areas because of inadequate resources for them (Hayles et al., 2015). The lack of sound partnerships had a great negative impact of the primary caregiver as they had to endure

challenges in the health cycle of care giving to a child with physical disabilities. As a result of discrimination and different perceptions of communities, the primary caregiver's needs or those of the child with a physical disability are not being met (Hayles et al., 2015). Parents described their relations to be involving fights and battles.

Various studies have indicated that care for children living with disabilities that impacts upon the primary caregiver in a negative way (Biesinger and Arikawa, 2008). Magliano et al., (2013) in a study conducted in Italy, noted that caregiving was significantly a greater psychological burden to families especially those who had poorer social support. Characteristic of most parents who are mostly the primary caregivers varies and include self-blame, guilt, denial, withdrawal, grief, rejection, and acceptance are the usual parental reactions (Hartley et al., 2005). Acceptance has been noted to affect parents which result in them experiencing helplessness, feeling inadequacy, shock, anger and guilt whereas others go through moments of denial, self-blame and depression (Gupta and Singhal, 2004). This can thus impact the care in a negative way as the children suffer. The absence or lack of programmes to help the parents cope with disability exacerbates the challenges amongst the children with disabilities.

## 2.6 COPING STRATEGIES

As noted in the previous discussions, mothers or caregivers caring for school going children with physical disabilities may experience stress and challenges as they have to change and adapt to new roles, different prospects about their child, and cope with noteworthy emotional, physical, social and financial stresses because of their child's disability. Accordingly, it results in the necessity of the carers being informed and educated on the coping strategies they can employ in order to address the challenges that arise from their caring role and hence provide effective care for their disabled child.

Lazarus and Folkman (as cited by Feelay, Turner-Henson, Christian, Avis, Heaton, Lozano, and Su, 2014) define coping as "constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person". Coping may include any effort to deal with stress, irrespective of how sound it works. Coping strategies also include attempts to change the origin of stress and attempts to regulate emotional answers to the stressors (emotional focused coping).

Feelay et al. (2014) state that parents with children with disabilities can use different coping strategies to meet their needs. Parents who use problem focused coping strategies that put emphasis social support, actively deal with the problem, and remain optimistic about life and tend to cope better than those who do not. Those parents who use emotionally focused coping strategies when confronting problems by blaming themselves, believing the problem will go away, engaging in activities that prevent confronting an issue, and trying to keep their feelings from others are all evidence of passive appraisal (Glidden, Billings and Jobe, 2006). It can be noted that although passively reacting to a problem may delay a family's active or immediate response, the use of these coping strategies may negatively impact on a family's sense of competence in providing care for a disabled child (Glidden et al., 2006). The use of escape as a coping strategy has been linked with increased stress and depression, whereas confrontation coping skills have been associated with reduced depression (Glidden et al., 2006). Caregivers of children living with severe physical disabilities with greater distress and lower self-esteem may focus on using emotion focused coping strategies more often, which may increase their stress levels. On the other hand, those with greater self-esteem may use more task focused coping methods, and this may have positive results such as reduced stress and finding the caring role more fulfilling. Savage and Bailey (2004) state that one of the main coping resources for mothers caring for school going children with disabilities is general or specific beliefs and include a sense of mastery or self-efficacy and religious beliefs. They report that low levels of self-esteem and mastery were associated with increased depression. Therefore, enhancing a sense of growth or self-efficacy empowers mothers and is therefore mainly sustainable kind of support (Savage and Bailey, 2004).

### 2.6.1 Coping mechanism for stress

Caregivers of children living with physical disabilities face a lot of stress and their stressors can be examined in a number of ways. Glidden et al. (2006) states that stress suffered by carers of school going children living with disabilities is affected by numerous aspects which comprise the child's level of disability and the availability of social support resource. One of the support service programmes that could be provided for these mothers to alleviate their stress is the stress relief programme. The programme allows the carers to explore the diverse stress management strategies and relaxation systems that may meet their own need. The programme aims at ensuring that carers remain at ease and improve their self-confidence thus adapting and coping to the

caregiving demands of children living with a disability (Hu, Lin, Yen, Loh, Hsu, Lin and Wu, 2010). Envisaged within the programme is a booklet that helps the carers with impeccable and valuable information on how to deal with stress. Hu et al., (2010) states that the programme includes health information on stress management tips, information on difficulties connected to the behaviour of the children living with disabilities, respite care and social support services. Hu et al., (2010) in one study found that the majority of their participants in Taiwan benefited from the face to face workshops with professionals and thus are able to speak to social workers, teachers and psychiatrists. Of paramount importance is the observation in the decrease in the stress and depression levels after attending these workshops with professionals (Hu et al., 2010).

To relieve stress experienced by carers caring for their disabled children it is vital to contemplate optimal use of respite care and psychosocial intervention to inspire constructive appraisal and problem solving for the carers (Feelay et al., 2014). Hu et al. (2010) also report that in one study carried out in Saudi Arabia it was noted that the more the informal support resources are available to the mothers, the lower the level of stress and the higher the sense of well-being they experienced. Positive thinking tips and techniques, visualisation, and scheduling activities for time management are also useful as they reduce emotional exhaustion and burnout.

### 2.6.2 Respite care

Respite care is defined as 'alternative care arrangements for persons with disabilities that allow their carers a short break from care commitments' Damiani et al. p.77 (as cited in Yantzi, Rosenberg, & McKeever, 2006). The encumbrance of offering care for a child with disabilities may result from lack of family cohesion, conflict and problem solving skills. It is imperative to provide relevant and adequate support in order to ease the caregiving strains on the function of the (Shelton, Duerden and Witt, 2010). Research studies regarding the issue of relieving stress on the care giving families for disabled children have observed that respite care (where the child is under the care of someone who is not the parent for some time providing short-term respite for primary caregivers from the on-going duty of caring for an child with disabilities), has proved to be helpful in creating an opportunity for the mothers to renew their energy, and have time spent with their other children with no disabilities, or do other necessary things such as work or socialise with friends (Shelton, Duerden and Witt, 2010). This is also supported by literature from Jeon, Brodaty and Chesterson (2005) where they found that respite care provided several

benefits to the caregivers who included relaxation time, freedom to endeavour in other activities, improved self-esteem, family relationships, and sleep patterns. Yantzi et al. (2006) state that caregivers receive respite when another care provider, such as another family member or paid worker, offers care to the child with disability for short defined period. Respite services are crucial for primary caregivers to do other activities they hardly do because of the care, devote precious time to the other children, have time to relax and recreate or even going on short holidays (Yantzi et al., 2006). Many primary caregivers depend on government funded or voluntary services to get an opportunity to be away from caregiving but however, these services are less realistic. Other studies have also found that mothers who were provided with respite care for their disabled children reported less caregiving stress after their child had returned from the respite care facilities, such as camps. Mothers' level of psychological distress also decreased while their child attended respite care camps and feelings of well-being were greater and they experienced fewer depressed moods (Jeon et al., 2005).

Respite services for mothers or carers of severely disabled children or life-threatening disabilities can be also complex, problematic and confusing as these services often detract them from being capable carers rather, Redmond and Richardson (as cited in Yantzi et al., 2006). The significance of these respite services for primary caregiver's physical, emotional and psychological well-being cannot be overstated. Gardner and Harmon (2002) identified themes which showed that respite services were of paramount importance to the carers and these include use of support and everyone has got a vital role to play. Respite care enhances coping skills of caregivers and reduces their stress levels. In order to realise the needs of these mothers a strength-focused orientation would have been applied. The availability of respite care in Namibia is however limited as most of the caregivers do not access it and in most cases it is hardly available. According to Girard (2010) the strengths focused orientation has been effective in decreasing the symptoms of mental illness and refining interpersonal relationships. This is an intervention that helps one to focus on one's strengths during emotional distress rather than focusing on the emotional distress (Gold and Hartnett, 2004). This is supported by Sharman and Kitter's (2015) report which found that depressed participants benefited from a psychotherapy approach that raised awareness of their strengths.

Reid et al. (2005) impressed on the value of caregivers' experience in the creation of family interventions. According to Dyson (1993) professional support that utilises family strengths can assist mothers or carers in handling stress, negativity and family problems that may arise from providing care to a child with physical disabilities. Savage and Bailey (2004) observed that bringing up a child with disabilities can negatively affect the functioning of the family and relations. This could result in the stifling of the social development of disabled children. Families that are able to cope positively with the burden of caring for a child living with disabilities can help the child to increase his or her social and cognitive alteration. Girard (2010) noted that the child's coping mechanism could help to decrease the distress and disruption within the family.

## 2.7 INFORMAL SUPPORT

Informal support is the support that is usually provided by families, friends, associates and co-workers and it is usually provided free of charge. Informal support takes the following forms:

### 2.7.1 Emotional support

Emotional burnout can happen to the carers of children with physical disabilities. Hung, Liu, Hung, and Kuo (2003) stated that emotional support can be effective to address the issue of emotional burnout. Within the community, the carers can join support groups or they can use the professionals within the setup to help them to develop their own particular support directory that comprises names of people who are able render emotional and informational support. Professionals can also assist the carers to recognise available informal and formal sources of care and unexploited possible avenues of aid and help that equate the necessary needs of the family. Often many existing and potential sources of support are overlooked by professionals because they fail to consider the full range of social support options available to carers. The process of identifying both existing and untapped potential sources of resources and assistance can be accomplished either in an interview format or by mapping a family's social support network (Hung et al., 2003). In a study on emotional burnout levels, it was noted that carers of children with disabilities had decreased emotional burnout level after they attended an informative course that provided facts on the nature of care for a child living with physical disability, educating the disabled children, as well as equipping the caregivers with ways of dealing with stress (Hung et al. as cited in Bilgin, 2009). Yildirim and Conk (2005) found that when nurses head the programmes of educating the parents of disabled children, depressive symptoms decreased

drastically in the parents, proposing that education may serve to reduce the burdens that the families felt. Mothers of children with disabilities at times feel that they are not capable of enhancing their own livelihood and that of their children, Hung et al. (as cited in Bilgin, 2009). However, it can be stated that different types and forms of support that match family identified needs, enhances parent and family well-being and increases positive parental perceptions of child functioning (Yildirim and Conk, 2005).

### 2.7.2 Social support

Social support may be provided both informally (by friends, family, social groups) and formally (by professionals and agencies). Savage and Bailey (2004) stated that the amount and social support quality available to caregivers is an important factor in regulating the effect of offering care to a child with physical disability. Data from the Victorian Carers Program states that the primary caregivers who have higher levels of informal support links experience greater life satisfaction and also receive ample support from family and close friends Schofield et al. (cited in Savage and Bailey, 2004). The Victorian Carers Program research notes that because of the less resentment and anger the primary caregivers who had higher levels of informal support receive, they were happier than those carers who reported smaller informal support systems as noted by Schofield et al. (cited in Savage and Bailey, 2004). The primary caregivers explained that they were being empowered or disempowered because of the level of trust and self-assurance that they have with the health care workers of the child and their services, which develop from their involvement with them. For example, in the presence of support and guidance the parents were empowered and gained confidence in helping and seeking help for their child living with a disability. In a study on forms of services, one parent gave a description of her level of confidence in the health care workers for her child and the services they offered when an intervention was provided (Hayles et al., 2015).

Social support which is vital in the care continuum can be rendered both informally, by social groups, friends, family and neighbours, and formally, by professionals and agencies. Nonetheless informal support sources such as families, religious groups, friends and the availability of respite care services have led to less stress for the primary caregivers of children living with physical disabilities (Hartley, Ojwang, Baguwemu, et al., 2005). Contrary to the above assertion, the primary caregivers have stated that there is a decline in the availability of informal sources of

support especially in cases where the disability is severe (Shin and McDonaugh, 2008). Data from the Victorian Carers Program in Australia states that the primary caregivers who have higher levels of informal support links experience greater life satisfaction and also receive ample support from family and close friends Schofield et al. (cited in Savage and Bailey, 2004). The Victorian Carers Program research notes that because of the less resentment and anger the primary caregivers who had higher levels of informal support receive, they were happier than those carers who reported smaller informal support systems as noted by Schofield et al. (cited in Savage and Bailey, 2004).

The effect of social support suggests that we should mobilise funds and other material needs that are needed to meet family needs. Yantzi et al. (2006) state that within the caregiver's circle, there are people (friends, neighbours and family) who can offer respite for no fee and hence reduce the costs of care. The availability of alternative carers is subject to the carers meeting the requirements needed like having the required knowledge, skills and expertise and hence the carers might struggle to get one (Yantzi et al., 2006). Close family members, particularly spouses, play important roles in providing respite for mothers, although the family might not possess the right knowledge and skills on how to realise that the child's needs are met (Yantzi et al., 2006). The primary caregivers of children with physical disabilities cannot afford to be away for longer periods though the immediate family may do it for a short time. From the findings of the study on respite care, it was noted that the carers cannot leave the child for more than 24 hours because the other family members may not have the required skills and knowledge (Yantzi et al., 2006). Nevertheless, the informal support networks of caregivers of children who are having physical disabilities are likely to be small and confined to close family members, which leads to less availability of informal support and may predispose parents to higher levels of distress.

### 2.7.3 Non-governmental organisations (NGOS) and churches

The role of NGOs in Namibia has been obscure as most of the intervention is done by the state. Although there is limited visibility of NGOs, the scope of work can be noted in some communities where they are playing a vital role in dealing with disability issues. In South African low-income communities, the NGOs and churches often provide a great deal of support to children with disabilities, such as providing food parcels. However, even though these NGOs

provide support, most of them do not focus on helping the mothers who are offering care for their children with disabilities (Children's Disability Center, 2010). Cheshire and Lebensschule provide relief to families with disabled children. They do this by supporting schools and homes for disabled children through funding and training from Germany. Therapeutic services are being offered by specialists (physiotherapist and occupational therapist) to the children who are having disabilities at Lebensschule in Namibia.

Churches also play a vital part in providing emotional and social support and most importantly meeting the spiritual needs of their members, which is very helpful in assisting them to manage the experiences of caring for their physically disabled child. However, there is evidence that churches still do not provide enough support for families with disabled members (McNair and Sanchez, 2008). Borchard (2011) reports that families with children with disabilities need more support from the church as well as congregation members. However, literature suggests that religious groupings have not been able to sufficiently engage the families because have limited knowledge and understanding on how they can help them (Garland, 2011). McNair and Sanchez (2008) in their study noted that there is a potential and willingness from churches to assist people with disabilities.

McNair and Sanchez (2008) state that disability is not only dominant in church groups, but is associated with substantial distress that regularly goes overlooked as a result of social construct amongst members. To raise awareness in a church, the health care providers and church members have to team up and assist struggling families so that they might be able to cope. Conversely, many churches are not aware of how they can reach out to the carers of children with physical disabilities, as they lack knowledge of these disabilities and even have other beliefs with regard to disabilities. Borchard (2011) is of the view that education will remove misconstructions, fear, and bias which can result in better conduct of the church members. Churches can also conduct sermons covering topics on disabilities and how the congregation can support members who care for family members with disabilities, as well as educating the congregation about the disabilities and the support they can render to those who provide care (McNair and Sanchez, 2008). Borchard (2011) states that a church is a normal area or place for the support groups for those who have disabilities or care for the disabled to conduct their

meetings. Churches should provide literature on different disabilities and how the carers can be supported in order to help them provide effective care.

## 2.8 CONCLUSION

This chapter has reviewed literature on disability and the experiences of primary caregivers caring for children with physical disabilities in Namibia. This chapter analysed the definition of disability, the models of disability, role of the caregivers, factors affecting caregivers, legal and policy framework and the support systems for the caregivers. The various policies in place do not address the plight of primary caregivers holistically. The literature reviewed has strongly highlighted that quality of care and support for the children with physical disabilities is affected by the coping strategies of caregivers and the motivation they receive in the care continuum.

# CHAPTER 3

# RESEARCH METHODOLOGY

## 3.1 INTRODUCTION

The chapter discusses the research methodology used in the study and specifically discusses the research approach and design study population and sampling, instrumentation, including pre-testing, data collection techniques, data analysis, trustworthiness, ethical considerations and the conclusion of the chapter.

## 3.2 RESEARCH APPROACH AND DESIGN

Qualitative research methodology was employed in this study. According to Babbie (2008, p.117), qualitative research involves the "construction of social reality and cultural meaning, focus on interactive processes and events, dealing with few subjects, involving thematic analysis and the researcher is fully involved". De Vos et al. (2005, p.74) observed that a "qualitative approach is a method that elicits participant's account of meaning, experience or perceptions and it also produces descriptive data in a participant's own written or spoken words and involves identifying the participant's beliefs and values that underlie the phenomena". Creswell (2003) asserts that qualitative study offers a rich source of information that leads to the formation of theories, patterns and or policies which assists in informing the phenomenon of the study. This study sought to understand the experiences of primary caregivers of children with physical disabilities in regards to the care they offer. Qualitative research seeks to understand the natural setting under study and exploring the reality thereof. The use of the qualitative approach thus helped to derive the experiences of the primary caregivers who are offering care for children with physical disabilities in their natural settings.

The research was exploratory and descriptive in nature. Saunders et al. (2007, p.134) depicts exploratory research as a means of "gaining new insights, establish what is happening, ask questions and assess a phenomenon in new light". Babbie (2008, p.95) states that "exploratory studies are most typically done on three purposes; to satisfy the researcher's curiosity and desire for better understanding, to test the feasibility of undertaking a more extensive study and to develop the methods to be employed in any subsequent study". Exploratory research is more useful in settings where available information is limited information and the researcher wishes to

have the elasticity to explore in the future research areas (Cooper and Schindler, 2006). In the study, it is evident that there was paucity of data availed to the researcher on the experiences of primary caregivers in Namibia and hence the exploratory nature of the study. The study sought to understand and explore the experiences of the care givers as well as the meaning of the actions in the caring process of children with physical disabilities. The aim was to understand the nature of their experience, the elements of their lives, what they experienced, what their experiences meant and what their world looked like within their respective communities of Hardap region.

The study was also descriptive in nature as it allowed the researcher describe the experiences of primary care givers in caring for children with disability. Reaves (1992, p.8) points out that "descriptive research does not explain or predict the future of the study but rather simply describes". The objective of much descriptive research is to map the terrain of a specific phenomenon and always depend on the observations, preferences, sensitivities, and sensibilities of the describer (Emerson, Fretz, & Shaw, 1995). The research thus was able to convey accurately the events of the study in a proper manner and also validated the experiences of care givers and meanings they attached to care giving

This study adopted a case study research design. The study was based on a case study of Hardap region, Namibia. A 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 researches already completed (Soy, 1997). The aim in a case study design is to comprehend the confines of the case under study and the complexity of the behaviour forms of the confined system (Cohen and Crabtree, 2006). Yin (2003) states that a case study design is used when the emphasis of the study is to respond to where and how one cannot influence the behaviour of those involved in the study. In this study, the case study design was used to ensure that the contextual conditions that are relevant to the phenomenon under study were covered. De Vos et al. (2011, p.171) describes a research design as a "plan, recipe, or blueprint for the investigation, and they provide a guideline according to which a selection can be made of data collection methods which are most appropriate for the researcher's goals and the selected design". It can thus be noted that qualitative research stresses the value of the natural social context for insight in the social world. The social creation of the domain where the carers live in gives a better understanding of their behaviour and actions in the caregiving process.

## 3.3 STUDY POPULATION AND SAMPLING

### 3.3.1 Study population

The study population consisted of primary caregivers (parents and guardians who are legally appointed) of children with physical disabilities living in Hardap region. Children in the study range from 1-year-old to 18 years old. Four percent of the Hardap region's population of 79 507 people have disabilities (Namibia population and housing; Census indicators, 2011). This percentage of the population with disabilities includes both adults and children.

### 3.3.2 Sampling

20 participants were selected by use of non-probability purposive sampling method. This type of sampling revolves around the researcher` s judgement. Elements of a sample comprise of most of the characteristics and typical traits of the total population (Babbie, Mouton, Vorster and Prozesky, 2007). Purposive sampling is appropriate in instances where a researcher desires to discover specific types of cases that suit the researcher's outline of study for in-depth examination (Trochim, 2006). Purposive sampling does not generalise findings to a large population but rather obtains a deep-seated understanding of the phenomenon under study. The researcher chose participants with an unambiguous rationale in mind as depicted in figure 3.1 below:

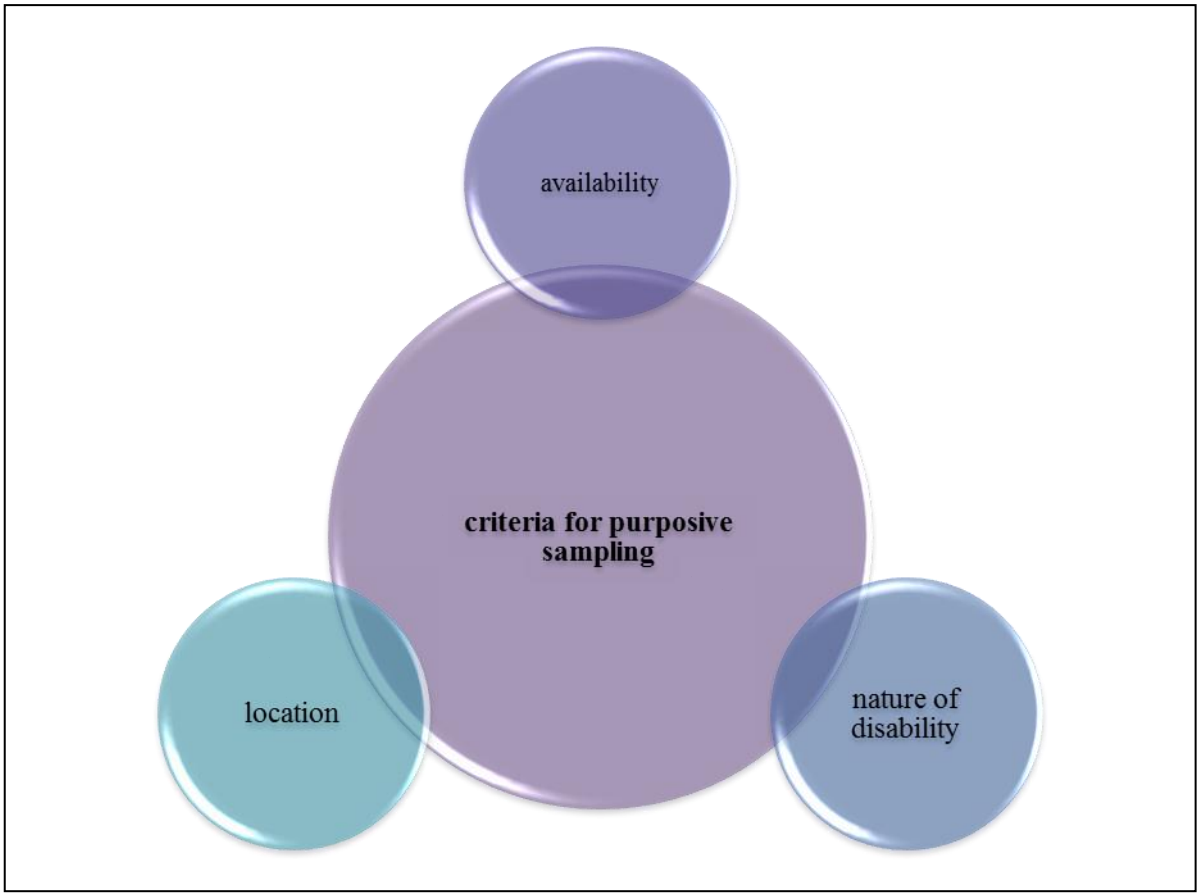



**Figure 3.1: Criteria for purposive sampling** **Source: Author (2016)**

The following types of disability were considered under physical disability: arthritis, cerebral palsy, multiple sclerosis, epilepsy and muscular dystrophy. There was no equal representation of the disorders of the children with disabilities and hence the researcher chose the participants based upon the criteria stated in figure 3.1. The participants were chosen based upon their location within the region under study. The researcher also chose the participants based upon the nature of disability which was physical disability and those who were available for the study. The participants were drawn from eight different constituencies in the region. The researcher chose the participants whose constituencies were accessible. The researcher worked with nurses and medical rehabilitation workers who are the gate keepers for people with physical disabilities in the region to identify and inform the participants for the research.

## 3.4 INSTRUMENTATION

Data was collected using semi-structured interview schedules with open and closed questions. Semi-structured interview schedules are used to gather information on past or present behaviors or experiences. These allow participants time and scope to think about their views on a particular subject matter (Cresswell, 2003). Semi-structured interview collects detailed information in a style that is somewhat conversational and thus enabled the researcher to probe further.

However, there are some shortcomings associated with semi-structured interview schedules. The interviewer may provide unconscious cues that might influence the participant to give responses that are anticipated by the interviewer. However, the researcher was concise during interviewing thus minimising giving out unconscious cues. The use of semi-structured interview schedules is time consuming and expensive.

## 3.5 PRE-TESTING

Rubin and Babbie (2011, p. 226) argue that "no matter how carefully researchers design a data collection instrument such as a questionnaire, there is always the possibility indeed the certainty of error. They will always make some mistake: an ambiguous question, a question that people cannot answer". The research instrument was pre-tested at Mariental Hospital using two primary caregivers who were not part of the study. The pre-test was done to determine whether the instrument would enable the researcher to collect relevant data. The pre-test allowed the researcher an opportunity to make adjustments to the research instrument in order to make it more effective in gathering the required data. In addition, pre-testing provided an indication of how long it would take to go through the interview schedule. The researcher thus got the opportunity to adjust the semi-structured interview schedule. After noting the challenges in the interview schedule, the researcher thus adjusted the semi-structured interview schedule accordingly.

## 3.6 DATA COLLECTION

Face to face interviews with individuals were used to collect the research data. In this type of interview, the interviewer personally attends and is physically present to conduct the interview and thereby ensures that the questions are answered (Muise and Olsen, 2013).

It can be stated that face to face interviews were used in the study to enhance the quality of the data. Face to face interviews allow researchers eminent control of the data collection process as well as the environment (Zohrabi, 2013). Each interview took approximately 40 minutes. The interviews took place at the place of care for the children. Only two of the interviews took place at a day care centre for the children with disabilities. This was as a result of the sampling that the researcher used.

With the permission of the participants, the researcher also used a tape recorder to record the interviews. This made it possible to capture accurately the information gathered. Thus use of the tape recorder ensured that a detailed account of the interview was captured and allowed the researcher to concentrate on the research proceedings. In instances where the participants were not comfortable to be interviewed in English, the research assistant conducted the interviews in the local languages, Afrikaans or Nama. The research assistant conducted 12 interviews in the local languages. The data was collected over a period of four weeks. The researcher also helped with the transcribing of data collected in the field. Field notes were part of the data collection process used in the research. Field notes thus assisted the researcher to bring to memory the elements of the interview and explore the processes of the interview (Babbie, 2007).

### 3.7 DATA ANALYSIS

Thematic content analysis was employed to analyse data. According to Braun and Clarke (2006, p.79) thematic content analysis entails "identifying, analysing and reporting patterns (themes) within data and minimally organises it and frequently it goes further than this, and interprets various aspects of the research topic". This allows for the data to be interpreted and for trends to be identified in the findings (De Vos et al., 2005). This method emphasizes organization and rich description of the data set. Thematic analysis goes beyond simply counting phrases or words in a text and moves on to identifying implicit and explicit ideas within the data. In addition, Marks and Yardley (2004) denote that thematic analysis allows the researcher to derive an association between the frequent themes and the theme of the whole content. The researcher made recordings and notes of the interviews conducted. The recorded tapes were encoded and interpreted using the tones and contrast in the voices of the participants. This data was then transcribed. The researcher repeatedly read the transcribed data as well as listening to recording

to pin point key words, trends, and themes. The key themes were identified and transformed into codes.

## 3.8 TRUSTWORTHINESS

The researcher strove to achieve trustworthiness by conducting the following measures:

### 3.8.1 Credibility

Credibility in a 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 (Shenton, 2004). Credibility was met in this study by ensuring that the research was driven by ethical considerations and conducted in professional manner. The researcher thus in most cases summarised the key points of the interviews to the participants and was also interactive during the interviews and this helped to ensure credibility. The readers of the findings will also be able to judge the credibility of the results.

### 3.8.2 Transferability

Research findings are considered to be transferable or generalizable if they can be acceptable in new contexts besides the real research context. When the findings are published, the reader will thus be capable of noting the specific details of the research situation and methods, and hence be able to compare them with familiar situations. The degree to which research findings are generalised is termed transferability that is equivalent to external validity. Generalizability denotes the degree to which one can relate and lengthen the settings of a specific situation or populace to other people, periods or environment than those who are under study directly (Maxwell, 2012). To ensure transferability, the researcher gave a highly detailed description of the research method and the situation under which the research was done and how the data was gathered. A thorough description of processes and data is given to allow judgements about transferability to be made by the reader. Transferability allows readers the option of applying results to outside contexts.

### 3.8.3 Dependability

Dependability is similar to reliability, that is, the reliability of noting the similar findings under familiar settings. According to Merriam (1998), dependability refers to "the extent to which research findings can be replicated" (p. 205) with like disciplines in a like context.

The excellence of interpretations is subject to personal interpretation of meanings centred on distinct experiences of the researcher and the researcher` s data collection and interpretation skills (Merriam, 1998). The traditional meaning of reliability therefore is foregone in qualitative study as it is impractical. Merriam (1998) suggests that reliability in qualitative research have to be defined in relation to the unison of the results with collected data. To ensure dependability the researcher did not go into the study with predetermined answers or ideas. The research findings and content were based on set theories and explorations of other studies already undertaken. The researcher was able to report in greater detail each process of the study thus ensuring that an external researcher is able to repeat the inquiry and achieve identical results.

### 3.8.4 Confirmability

Confirmability refers to how the research findings are reinforced by the data collected. This is a method to establish 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. The quality of results was enhanced through continued enquiry and engagement with the participants. The interpretation of the results was done through reference to literature confirming findings by other authors. When the study is published, an external researcher should be able to make a confirmability audit.

## 3.9 ETHICAL CONSIDERATIONS

Research ethics deal primarily with the interaction between researchers and the people they study. The following ethical considerations were taken into account:

### 3.9.1 Voluntary participation

It should be a participant's choice s to take part in the research (Babbie et al., 2007,). The researcher did not use any force, deception or coerced the participants to be part of the study. The researcher notified the participants that at any time they had the right to abandon the study.

The researcher informed the participants that the research was about the experiences of caregivers of children with physical disabilities

### 3.9.2 Informed consent

To obtain informed consent the participants or their representative are to be made aware of any potential dangers, disadvantage, advantage, the study procedure and goal of it. The credibility of the researcher should also be made known to the participants. (De Vos et al., 2005). The researcher provided the participants with detailed information on the research methods, possible outcomes, possible associated discomforts and the fact the study was for academic purposes. The researcher ensured that participants consented based on the facts provided by the researcher in regards to the research. The researcher enlightened the participants of the estimated time that the interviews would take. The participants were invited to put their signature in agreement to participation against a consent form

### 3.9.3 Ensuring no harm

According to Babbie et al. (2007, p.522) 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 participant should be informed of the risks and the research purpose should be explained. The potential risk related to the study was psychological therefore the researcher made counselling arrangements n participants who showed signs of emotional breakdown during the interview. During the interview the researcher was cognisant of emotions shown by the participants and would give breaks in between and asked for consent to continue with the interview. When a participant would cry or have an emotional breakdown, the researcher would create an environment where the client would recover and continue with the session.

### 3.9.4 Confidentiality and anonymity

Anonymity and confidentiality were observed in the study. Babbie (2008, p.71) states that a research "guarantees confidentiality when the researcher can identify a given person's responses but promises not to do so publicly". The researcher explained to the participants how the information will be stored and that the data would be accessed only by the researcher the supervisor and the translator involved in the research. Strydom, 2002 in De Vos et al. (2005) says confidentiality requirements in research probes the researcher to take responsibility and

extra guard of the information that he is furnished with. The researcher ensured that he did not disclose identifiable information about participants and protected the identity of research participants on data collection and write up of the study. Instead of using names the researcher used participant codes to maintain confidentiality. The research assistant was also required to maintain confidentiality. No discussions on the participants or issues arising from the interview were done outside the interviews

### 3.9.5 Debriefing

According to Babbie (2008) debriefing is the interviewing of participants in order for one to learn of their experiences in the area under study and to update them of any unrevealed purpose. This is exceptionally crucial where there is a likelihood of damage through participation. Strydom cited in De Vos et al., (2005) states that debriefing is conducted after the study, the subjects find the chance to relate the experiences of the data collection process and it's after effects. This is a way that the researcher can use to assist in minimising possible harm on the participants, in spite of precautionary steps employed. The researcher thus took time to relook at the experiences of the caregivers and revisit all the issues and thus explored to see whether any harm took place during the phase of the research or after.

## 3.10 CONCLUSION

This chapter highlighted the study methodology, the study population and sampling as well as instrumentation. The chapter discussed pre-testing, data collection and data analysis methods employed. It also examined the trustworthiness of the study focusing on credibility, transferability, dependability and confirmability. The chapter also discussed the ethical considerations taken during the research.

# CHAPTER 4

# DATA PRESENTATION, ANALYSIS AND INTERPRETATION

## 4.1 INTRODUCTION

This chapter presents the results of the research on the experiences of primary caregivers who are caring for children with physical disabilities in the Hardap Region of Namibia. The thematic content data analysis is aligned to the study objectives while the findings bring out the emerging themes out of the research questions dealt with. The researcher draws from existing literature in the interpretation of results. The profile of the participants is given below.

## 4.2 PROFILE OF PARTICIPANTS

### 4.2.1 Age distribution of participants

Table 4.1: Age of the participants

| **Age range** | **Number of participants** |
|---|---|
| 18-25 | 3 |
| 26-35 | 6 |
| 36-45 | 2 |
| 46-55 | 5 |
| 56-65 | 3 |
| 66+ | 1 |
| **Total** | **20** |

### 4.2.2 Marital status of participants

The majority of the participants were single (11) whilst only one participant was a widow. The data also revealed that 8 of the participants were married.

### 4.2.3 Educational level of participants

Table 4.2 Educational level

| Formal education level | Number of respondents |
|---|---|
| Tertiary | 1 |
| High school | 3 |
| Junior secondary school | 12 |
| Primary | 2 |
| Never attended | 2 |
| **Total** | **20** |

The table above shows that the majority of the participants had only junior secondary school qualification whilst only primary caregiver had tertiary qualification. The low level of education of most of participants suggests that participants have a minimal chance of getting well-paid jobs and thus may be able to support their households. This supports the observation Nuutila and Salantera, (2006) that many caregivers looking after children with disabilities tended to have low levels of education and training, limiting them to very poorly paid jobs, resulting in a greater burden of care.

## 4.3 DATA ANALYSIS AND DISCUSSION

### 4.3.1 Objective 1: The nature of care provided to children with physical disabilities

The first objective of the study was to establish the nature of care provided to children with physical disabilities by caregivers. The activities conducted by care givers encompass necessary responses to the psychological, social and physical needs of the person living with a disability. These are referred to as the activities of daily living (ADLs) which include feeding, bathing, dressing and personal grooming which eventually translate to instrumental activities of daily living (IADLs) namely; preparing meals, housework, and managing budgets. The participants in the study were requested to indicate the nature of care they provide to children with disabilities and the following themes emerged.

#### 4.3.1.1 Provision of special equipment for children with disabilities

One theme that emerged with respect to the nature of care was the issue of assistive devices for the children with physical disabilities. Participants indicated that they provided assistive devices such as wheelchairs, walking frames and crutches. The special equipment thus was vital in ensuring that caregiving does not become burdensome to the carers. The caregiver's role was thus to ensure that the children with disabilities acquire or get the special equipment. The participants had this to share in regards to assisting the children to acquire the special equipment for use by the children with physical disabilities.

**Participant 10** responded by saying:

*"I managed to get the wheelchairs from the local medical rehabilitation officer. We received one new wheelchair and a broken one which I fixed to perfection for the use of the boy. I'm planning to get for the girl a special toilet seat as she is struggling more than the boy to use the toilet and considering that she is growing and may need a bit of privacy away from the smaller children who at times helps her in the toilet. Such a seat with support beams will enable her more independence"*

**Participant 7** said that;

*"One of my children has a problem in the brain, the doctor said it is cerebral palsy, he can neither speak nor walk so he just lies in bed. I had to seek help and I applied for a wheelchair in Windhoek but Naomi the physiotherapist helped me to get it in time. The wheel chair helps me a lot to move him around or even just let him seat outside. His other brother walks on his toes also had to get special shoes for him from Windhoek. These were made for him and I go back to collect when they have to be changed."*

**Participant 18** had this to say;

*"She has a problem with her spinal code so she cannot walk. The authorities said that they will provide a wheelchair for her. I tried to follow up in May and they promise to provide some time in July but nothing has happened".*

The participants caring for children with physical disabilities played a great role in ensuring that the children in their care have the appropriate equipment. Such views highlight the need to have special equipment for the care recipients. The caregivers pointed out that it's their responsibility to ensure that the children they are caring for had the right equipment. Caring for a disabled child can include the need to aid mobility of the child. The primary caregivers of children with physical disabilities noted that it was within their mandate to take the child for measurement at the hospital or the health centre so that the care recipient would receive the right special equipment. Primary data from the research indicate that the primary caregivers have to make a number of visits to the hospitals to get the special equipment for the children with physical disabilities.

There were however indications by some participants that it was difficult and the process was long for one to get the assistive devices. The caregivers seemed to be finding the process of getting the equipment from the government cumbersome. This thus affects the care they offer as they are not able to care holistically for the children with physical disabilities. The care giver however did show the commitment and take responsibility in following up with the government officials on her applications. It is of note that one of the participants actually had not taken initiative to apply for the assistive device though she was aware of the need. The researcher derived with concern that this could be an issue of ignorance or rather lack of knowledge of programmes offered through the government. The researcher also linked this issue to the fact that the care giver made minimal visit to the medical centres thereby increasing the chances of not being knowledgeable of the programmes.

In the absence of assistive devices, the care giver has the burden of carrying the child where any movement or travels are required (Girard, 2010). The lack of assistive devices for children with disabilities is usually noted in low income countries (Elliott, Shewchuk, and Richards, 2001). The study showed that the participants did not have the aiding equipment and also that they are actually seeking assistance to get the equipment. The researcher noted that participants could not afford to purchase the special equipment which would help to ensure the mobility of the child. McCabe, Roberts, and Firth (2008) state that it is essential for the caregivers to help their care recipients who have disabilities to get special equipment that could aid them to be mobile.

#### 4.3.1.2 Feeding the children

The study showed that some of the care givers took the responsibility of feeding children with disabilities. This was noted in children who cannot feed themselves due to missing limbs or incapacitation. The participants highlighted that most of the children are not able to feed themselves and hence they are supposed to feed the care recipients on a daily basis. The nature of the disabilities was noted as the one that necessitated the role of feeding for the primary caregivers. The participants had this to say;

**Participant 1** explained that:

*"When he was growing up I was informed that he is supposed to have a certain spoon he had to use but I never got one. This is supposed to be connected to his limbs so that he can learn to feed himself. Since I do not have it I therefore have to feed him every meal even though at his age he should be able to feed himself like normal children…. My child` s disability has made him fail to do the normal things expected of children".*

**Participant 17** also mentioned that;

*"The child basically does nothing at the house. He is just lying in bed all day as he does not have any wheelchair. So I have to feed him every day so that at least he is healthy".*

**Participant 2** shared the same sentiments noting that;

*"My child cannot do anything, I just keep him lying on the bed he cannot even sit up, move around, speak or eat alone. I have a burden of feeding him, not only that but now I have learnt to know when he is hungry or when he is full as I am feeding him. It was difficult to learn but with time now I am used to the work."*

Inherent within caregiving is the fact that most the children under care will always rely on the primary caregivers for most of their day to day survival. In the study most of the children had cerebral palsy as a form of disability. This thus limited their motor ability. The caregivers thus had a huge role to play in ensuring that they feed the children under their care. The caregivers spend time also feeding the children in their care because of lack of special equipment like the spoon for children without limbs especially if they are young children. The equipment is necessary to aid functions of the missing limbs. The primary caregivers indicated that their role

includes even determining that the child wants water to drink as they have to make him or her drink the water at regular times. The primary caregivers noted that they have to feed the child with physical disabilities at regular intervals during the course of the day. Some of the participants stated that they have to prepare the special diets for the children and then feed the child with physical disability. The primary data indicate that the child oftenly eats on regular intervals and the primary caregiver has to be there to feed the child.

#### 4.3.1.3 Carrying the children with physical disabilities

The study indicated that the participants` caring activities included carrying the child. Most of the participants indicated the need for help in turning the kids at night or lifting them up to change their positions during the day or night. Explaining this nature of care, the participants indicated that this was because the child was incapacitated or they did not have wheel chairs or other mobility aiding equipment. The following were sentiments from some of the participants.

**Participant 20** noted that;

*"She does not have a special wheelchair that she can use. She used to have a government wheelchair and because she cannot balance she fell out of the wheelchair and lost her teeth. She cannot balance her when she is sitting - it is difficult to travel with her because she does not have a wheel chair so I have to carry her around and yet she is twelve years old. If I have to go to the doctor, move her around the home or anywhere, I still have to carry her"*

Similar sentiments were shared by **participant 12**;

*"Well we need something that can make us comfortable. It's always difficult when we need to go somewhere because I need to carry him and he is a bit heavy for me. He once had a wheel chair but now he has overgrown it, it's now too small and I don't have another and I am failing to get one."*

Similarly, **participant 14** had this to say that:

*"I don't know what to do since the child does not have any special equipment to use and he cannot walk…. All I know that I have to do is a burden to me to move around...I don't have any option but to just carry around the child. I have tried the government but still I have not received assistance of a walking frame."*

Caregiving is a crucial service to most of the care recipients in the care process. The children with physical disabilities mostly have problems to move from one place to the other. This is worsened by the lack of special equipment that is appropriate for the children with physical disabilities. Some of the primary caregivers stated that the role of carrying the child around is becoming a burden to them as some of the children are now big and heavy. The caregivers also highlighted that because of their age they were facing challenges in carrying the children around. The primary caregivers mentioned that the children with physical disabilities who are not mobile have to be carried around to enable them to relieve themselves at the toilet, to go to the bathroom, to go out of the house and various life activities. Primary data also revealed that the primary caregivers faces huge tasks of having to carry the children from the play area to the sleeping area especially in the absence of special equipment that could have aided them to carry the children with physical disabilities. The primary caregivers stated that at night or during the course of the day, they turn the child or shift the child so that they would not have sores because of sitting or sleeping in one position. Whenever the primary caregivers have to go out for other activities outside the homestead, they carry the child to the place. This they stated is big challenge because of the weight of the care recipient.

Though some received the special equipment, the children have outgrown the equipment and care givers were struggling to secure new ones thereby making it burdensome to carry the children. This supports the findings of a study conducted in Botswana which highlighted that most caregivers had challenges to carry the children in their care every-day (Kubanga, Sinkamba and Maripe, 2015). As the children grow older the special equipment becomes smaller and hence the need for new equipment. Thus this impacts heavily on the primary carer of the child with a physical disability in regards to carrying the child around.

#### 4.3.1.4 Bathing of children under care

Most of the children in the study needed help in various aspects of their lives. The caregivers thus played an integral role in ensuring that the children's' needs are met. Maintaining good hygiene of the children is a necessity. It emerged that the participants actually had to bath some of the children with disabilities because the children faced challenges in trying to bath themselves. While some participants indicated that the children could bath themselves they also agreed that it was prudent to ensure the children were clean.

**Participant 1** said that;

*"Like bathing it's a problem. He is not becoming clean when he baths on his own……. like in a month I have to take 1 week to wash him properly. Though he complains that he has grown up, I see that I have to assist him in bathing otherwise he will get sick from poor hygiene."*

Similarly, **participant 2** noted that;

*"Like bathing or taking her to the toilet, the child needs help always. But most of the times I do it myself because it's my responsibility, so I cannot rely or ask someone to do that or demand or say do this so I have to take care of her".*

**Participant 7** had this to share;

*"I am the one who bathes him every day but these days I can't bath him well because of his condition and he is also too heavy. The child has grown up that is why it is now difficult to bath him but I try to bath him well".*

Primary data from the research indicate that the primary care givers had the responsibility of ensuring the good hygiene of children with disabilities which is essential in ensuring good health. The participants indicated that they bath the children on average twice a day. Bathing of the children with physical disabilities was one of the key duties that the primary caregivers played in the care continuum. The participants stated that it was important for them to bath the children on their own as this helped in ensuring that the care recipients are clean. The primary caregivers of children with physical disabilities observed that due to the bond created between them and the care recipients it was very difficult for other family members to bath them as they would at times refuse. The refusal by the care recipients to be bathed by other family members only reflected on the role that the primary caregiver plays.

Some of the caregivers stated that they face a number of challenges when bathing the children as a result of the weight of the children with physical disabilities as well as their own frail health. Primary caregivers also noted that the bathrooms were a challenge as they were not conducive enough for the children with physical disabilities to be bathed in. In addition, they faced challenges or difficulties as the children grew up to be able to provide optimum care when it comes to bathing the children. In line with this finding Brazil, Thabane, Foster, & Bédard (2009)

explains that, to ease the responsibility of bathing the disabled they should be considered in designing of the bathrooms to allow them to access and be able to bath themselves. This however would ideally apply to caregivers with children that can bath themselves while those with highly incapacitated children are left to bath the child even if they are grown up.

#### 4.3.1.5 Taking the children with physical disabilities for medical check-ups

In the care continuum it is very important to ensure that the care recipient remains healthy. In the study the participants managed to outline one of the roles they play in the care process. The participants stated that it was their duty to take the children for medical check-ups at the various health centres.

According to **participant 7**;

*"We receive the medication once per month but for medical check-ups I take him whenever he is not feeling well".*

**Participant 12** explained that;

*"I normally take the child to the clinic for medical check-up every month. The clinic is nearby so we just walk to get there…"*

**Participant 13** also noted that;

*"She was only a year in the hospital...when there are sicknesses I take her to the hospital. The child goes to the hospital and the distance is over 120km ..."*

Children with physical disabilities do need special care and medication and thus constantly visit the hospitals. The caregiver's role is thus to ensure that the children are taken to the health facilities. According to some participants, the reasons why they take the children for medical check-ups are to ensure that they regain their movement. Some of the participants indicated that they only go for medical check-ups or treatment only when necessary s because of the feedback from the doctors which they found to be discouraging. The primary caregivers had to ensure that the children with physical disabilities comply with the prescribed medication for them to remain healthy. Primary data indicated that the caregiver's role was not only to take the children for medical check-ups but to constantly supervise the child to make sure that they took the

medication as prescribed at the hospital or by the doctor. The participants highlighted that they experienced some challenges in getting the children with physical disabilities under their care to take the medication. The participants mentioned that they had to use various ways like putting the medication in water in order for the care recipient to take the medication.

The participants also mentioned that though they faced challenges like falling sick, this was not an option to consider of not missing an appointment with the health professionals. Data from the research showed that the participants would rather borrow money or entrust someone to take the child with the physical disability to the hospital, clinic or doctor for the medical check-up. The participants thus committed themselves with their role and thus fulfilled it to ensure that the care recipient was assisted at the health centres.

According to Leiter et al. (2004) all children may need to go for medical check-ups. However, children with disabilities may need to go for medical check-ups more often than the children without disabilities. This can be a positive or a negative experience for the mothers who are the sole caregivers (Resource for Cerebral Palsy, 2011). According to Leiter et al. (2004), caring for a child with physical disability often requires specialised knowledge, far-reaching collaboration with health care workers, and the gaining of skills by caregivers or parents who are in constant communication with health care workers. In the study, the primary carers of children with cerebral palsy indicated that it was a prerogative that they should take the child with physical disabilities to the physiotherapists on a regular basis. This they mentioned was to give hope to the child to ensure that she/he functions much better. The study revealed that participants had scheduled appointments for their children with medical personnel. Graungaard and Skov (2006) state that the initial contact between the parents and the health professionals may determine how the parents are going to cope with the kind of disability that the child has. This thus may determine the frequency of visits to the health centres for medical care by the caregivers. Rural caregivers in the research noted of the long distance they travel to get to the health centre for appointments. Elford (2015) agrees with the notion of the challenges of travelling long distances for medical appointments and their consequences in the towns by the primary carers of children with physical disabilities.

### 4.3.2 Objective 2: Exploring the financial implications of caring for children with physical disabilities

The second objective of the study was to explore the financial implications of care giving to children with disabilities. The cost of care is high because of the special needs of children who are having physical disabilities. This thus increases the cost of care because of the needs of the child and the fact that most of the primary caregivers are not employed. The participants highlighted that they travel long distances which was costly to them as well as having to spend more time on the road. The services were also not responsive to the needs of children with disabilities. Most of the caregivers in the study do not have a source of income for themselves and rely on the care recipient's grant as well as families and friends. The limitation in availability of funds thus hinders the quality of care offered to the children and as well as the caregiver. The caregivers in the study indicated that lack of enough funds to care for the children has got negative effects on the care offered as they need the money to buy basic care goods.

#### 4.3.2.1 Sources of care giving funding

Sources of funding are critical in determining the extent of funds for the caregiver and the amounts that are spend to care for the child with physical disability. Most of the caregivers rely on the grants that they receive from the government. The government policy for disability states that people who are 18 years and above are adults and hence receive a higher amount than those below. In the study two of the children were 18 years old and receiving amounts of N$1000. The caregivers in the study are receiving amounts of N$250 per month on behalf of their care recipients. Some of the participants are employed and hence add their salaries to the grants received to supplement the deficit in budget. Some of the participants also mentioned that they are involved in small businesses to ensure that they live a decent life as caregivers. Participants outlined the various sources of funds that they use on a daily basis to help them in providing the care to the children with physical disabilities. The government of Namibia has put in place safety nets to ensure that at least the children with disabilities receive some grants from the state. This they hope it will aid in easing the financial burdens of caring for children with disabilities. It's also important to note that other income generating activities are vital to ensure that there is adequate money to care for the child and to support the needs of the caregiver. The study showed that the majority of the participants indicated that they are receiving disability grants from the government. The participants had this to say;

**Participant 2** said that;

*"I get money from the church where I fellowship, from the family and from my friends. It's not like I have to lean on them, I have to find other ways of finding money. I need money you know. The amounts are not fixed but I try to make sure that she gets all that she wants in time. It's a whole struggle very month".*

**Participant 16** mentioned that;

*"…because I have a small business. I make cakes, sweets and bread to sell to the community and this helps to cater for the shortfall that I receive from the government".*

**Participant 6 said** that;

*"As parents we have decided to limit the responsibility of his care to ourselves as it is only the leg and nothing major. So we did not see the need for us to apply for the government grant and the fact that the money is not that much from the government".*

This study showed the great role that the practitioners played in assisting the care givers to access the government fund. The family was also noted as playing an important role in giving information to the careers on where to source funds to help them in the care process for children with physical disabilities. The care givers however indicated that the funds from government were stretched and other sources of income included assistance from family members while others went into debt to provide for the needs of the child. The researcher was touched by the change in countenance by one participant during one of the interviews and therefore paused a while to allow the participant to calm down before continuing. The indicator understood that the financial issues where taking a toll on the mother of two disabled children in this case of whom the other is mentally challenged. In notable instances the caregivers indicated that they then ask for money from the child`s father in most cases who is not staying with the child. Some of the primary caregivers also indicated that they rely on the church to augment the funds for caring for the child. The participants who get some funds from the church were however quick to state that the funds are always not constant and hence cannot be relied on. Primary data from the research also indicated that the primary caregivers oftenly receive funds from friends to help them to cater for their needs as well as those of the child. The participants stated that the funds are not much

but help a lot in the care process as any financial help improves their financial wellbeing. Apart from government grant, there are some care givers who are doing small projects to meet their everyday needs. Some of the primary caregivers stated that they are involved in small businesses that help them to improve the finances of the household. The businesses are done at the place of care and hence the primary caregivers can always look after the child with physical disabilities. The research also noted that the some of the participants are engaging in part time jobs to meet their financial needs. The part time jobs are mainly done within the community and the primary caregivers are able to take their care recipients to the place where they are carrying out part time jobs. Some of the participants also get additional funds from volunteering at a local centre that looks after children with disabilities in the area and they get N$500.

The research thereby deduced that the level of income and the extent of disability contribute to the financial implications of the care giver. Inherent within caregiving is the cost of care which increases with time. This is supported by Emerson, Hatton and Blacher, (2006) who state that families find that their expenditure increases and simultaneously their capacity to earn and eke out a proper living is reduced. High costs are incurred with respect to the special diets for some disabilities in children, fuel, transport, relocation to more suitable and conducive homes, and all place extra financial strain on the families (Michalak,2013)

#### 4.3.2.2 Effect on household budget

When participants were asked about the effect of caring for children with disabilities on the household, many indicated that they were experiencing challenges to ensure that the family budget stayed positive. The household funds were not matching the needs of the family and this increased because of the special needs of most of the children with physical disabilities.

**Participant 10** had this to say:

*"Yes, indeed the money issue is a challenge because apart from their care, we also wish to live in comfort thus we have our own responsibilities such as payment for furniture and water bills. We also have a few goats and needs to buy farming needs thus the monthly household income is not enough……. Well if it goes extremely bad we sometimes sell from our goats to fill the gaps but every farmer knows that you cannot just keep selling. You need time for others to give birth*

*and grow before selling and this can take time but it is important for the cycle so that we have animals".*

These sentiments were shared by **participant 20** who noted that:

*"Looking after my child has affected the family budget so much. My cousin whom I stay with at the house is not working and you can you can imagine how much that costs. Though my mother is working, she is an alcoholic and the pressure is just too much financially…… (Sobbing). We cannot even have enough on our plate to cater for our needs".*

**Participant** 7 emphasised that;

*"…I don't have a separate budget for him, I buy food for the entire family including him, I pay for water and electricity which we share and also buy diapers for him……We also struggle to get adult diapers in our town; they are only available in Windhoek which is about 380km away.""*

Caring for a child with a disability increases household expenses thereby straining the household budget. The majority of participants agreed they received a monthly government grant of at least N$250 yet their monthly requirements about are N$1000 on average. Without taking away efforts made by the government, this shows a clear financial deficit for the care givers. Participants who indicated that they did not receive government grants also expressed challenges in meeting their monthly needs. These may in most situations be worse off than the care givers who are receiving grants especially in cases where there is no definite monthly income or where they rely on other family members to take care of them. Some family members who drink too much alcohol also put a strain on the family budget as money which was supposed to aid in the caring of the child was now being used for other activities. Some of the participants' families had to sell their livestock and other properties in order to ensure the financial security of the family.

The participants further added that it also strains the budget due to the travelling costs to go and get the diapers and other special items that are needed for the children with physical disabilities under their care. These special needs are added to the household budget specifically for the disabled child while expenses such as electricity are shared by all household members. It can also be noted that women and low income primary caregivers may face additional challenges. This substantially reduces family revenue while the child's care expenditures increases, although

the costs are varied (Olsson and Hwang, 2006; Anderson et al., 2007). The majority of care givers from this study are mothers who are not employed. Employment levels of mothers of children with disabilities have repeatedly been found to be substantially below those of other mothers of children without disabilities a (Olsson and Hwang, 2006). In addition, the mothers are unable to work full time so that they may provide care for their disabled children. According to Larson and Miller-Bishoff (2014) some carers work part time to augment the income of the family and rely on government grants or other members of the family to provide care while some caregivers' preference was to be employed on a full time basis. He added that the adequacy of care and sufficiency of income was complex and care givers managed them in different ways. Kimura and Yamazaki (2013) added that offering care to several children with disabilities puts a lot of strain on the care giver financially and psychologically.

According to Michalak (2013) the special needs of the disabled child translates to high costs which place an extra financial strain on the families. Brehaut et al. (2011) adds weight to this finding by arguing that, offering care for a child with a special health need puts a strain on family finances due to needs such as elevated medical expenses and also put strain on the care giving. To add weight to this finding a study in the United States of America by Anderson et al. (2007) showed that 40 percent of families with children with disabilities who require special health care needs face financial challenges as a result of the disability of the child. The study indicated that the care givers cannot completely separate their needs from those of the disabled child.

This explains that apart from meeting the needs of the child the care givers also have their own personal needs which they may have to forego so that they are able to adequately provide for the child with a disability. This supports a Canadian study that indicated that 63.6 per cent of Canadian women believed that it was a parent's responsibility to sacrifice their own wellbeing for the benefit of the disabled children (Burton et al., 2008). The participants also indicated that they struggle to make ends meet Nelson (2002) and Smith and Smith (2000) share the notion supported by this study that primary carers of children with physical disabilities face immense challenges in meeting the needs of the child as well as that of the carers. The grant received is for the disabled child, there is no grant for the caregiver in Namibia, unlike in the UK where the caregiver is also given a grant. This enhances the financial challenges faced by the care giver. It is however of note that government programmes which support the disabled help alleviate

financial implications (Lukemeyer et al., 2000). The study showed that in addition to the disability grant there are participants who have received wheel chairs through the government supported programmes. The study therefore showed that there are financial implications related to care giving disabled children.

### 4.3.3 Objective 3: The psychosocial experiences of primary caregivers of children with physical disabilities

The third objective of the research was to explore the psychological experiences of the primary care givers in the care process of children with physical disabilities. This objective is important in as it gave the researcher a better understanding of the psychosocial experiences in the care continuum of children with physical disabilities from the primary caregivers' view point. The themes that emerged from the data analysis are as follows;

#### 4.3.3.1 Emotional state of the caregivers

Some participants experienced difficulties in accepting disability and were so heart-broken to have to care for such children. Some of the participants reflected on the journey of being lifetime caregivers to the children with physical disabilities and the toil it had had on them. From the participant' view point, the role of being a caregiver of a child with physical disability "is not an easy one as it entails a lot of sacrifices and emotions one has to deal with such issues as stress, depression, fatigue and low self-esteem which in the end undermine the emotional wellbeing of the primary caregiver". Participants were asked about their feelings with regard to having to care for a child with physical disability.

##### 4.3.3.1.1 Acceptance

Acceptance of the role of being a caregiver has implications for the emotional well-being of the caregiver. For most of the caregivers it was a first for them as they were also the mothers of the children. The participants experienced acceptance in different ways.

For instance, **Participant 2** commented as follows;

*"I am a strong person actually the 1st time it was hard to face the condition. But as years went by, I spoke to myself to accept the situation. I trust in God a lot and all time because it happens a lot. There is nothing that you can do without God. He is the one who created her, so he knows*

*what He has in store for her, so for me I am fine. In the beginning it was a problem, but as time went by, I accepted the situation. There is nothing u can do or try to blame someone……It's something that I did not ask (starts to cry) …. it's not easy… (Sobbing) I did not ask for it... but I talked to myself and said it's all good and everything happens for a purpose (sobbing as she talks). There is no way you can reject a child. No way can you give her to dogs. It's yours and she belongs to me. So I motivated myself that it's a challenge from God and that I should face the battle. God is the one who comforts, no matter what. He is the creator of the heavens and earth. And it is in His image that He created her and I should accept her and move on no matter what. So for me I love her no matter what (still sobbing)".*

**Participant 1**mentioned that;

"*It was affecting me very badly. You know the 1st day I saw the child, the 1st question which came into my head is why me, why am I given this child, what have I done wrong...so those are things that affected me emotionally. But later on my grandmother talked to me and informed me that it's not me, you are not the only ending up having this kind of child. Just accept what you have been given, so later on their words usually came to me and made me strong. So checking up upon the family background, my uncles two of them have got disabilities so I ended up understanding it better……. the problem was when he was still young if I go with him to the shops or somewhere like that, the reaction from the people the way they were staring at us, later on I ended up saying I am leaving my child at home because the attention was too much on us. Later on people would end up calling look at that child who does not have arms or what, but now it's ok, we have accepted and used to it even himself, he is ok.1st was crying but later on I got used to it and accepted it".*

**Participant 9** shared her experiences and remarked;

*"Mmmmmmmmmm yaaaah from birth I did not realize. But from 6 months I discovered that he has a problem. Later on from 1 year he did not crawl like other child, he was just rolling and not talking. I realized that he was different from other children and so it became very difficult but later on it became normal after getting used and accepting the situation as it is…. I am still getting used to it. Sometimes I get stressed a little bit but because there is no one to take care of him so I have to soldier on and be strong hence do not really stress. It's my sole responsibility!!"*

The participants highlighted that it was difficult for them to accept the new role that they were to face of being primary caregivers for the children with physical disabilities. The emotional states varied from depression, stress and fatigue. The participants stated that many of the children took time to manifest clinically of the conditions, for example when the child was late in sitting or crawling. This was both useful and confusing to caregivers. It was useful because it gave them time to adjust to the fact that their child was not going to be like other children nonetheless confusing because in the beginning the child "was born healthy". Even when the diagnosis was made at birth, recognising the long-term implications was difficult. Caregivers expressed their difficulty with initial acceptance of the disability as noted by responses from most of the primary caregivers. The participants in the research stated that there was uncertainty in regards to the actual diagnosis of the child. The primary data indicated that the primary caregivers in most cases the mothers had difficulties with not knowing what the diagnosis would mean themselves and their respective families. The participants also stated that they were not sure whether they were going to able to handle a child with physical disabilities. The primary caregivers stated that they were worried about the future of the child and hence this took time for them to accept the condition of the child who was having a disability. The notion agrees with findings by Elford (2015) who stated that it took time for the mothers of newly diagnosed children to accept the condition and also worry about the future of the child.

Most caregivers struggled to accept the diagnosis that the child had a disability. This is quite evident in the study as most of the participants indicated that they struggled in the beginning to deal with the fact that the child had a disability. Woolfson (2004) stated that parents also felt hopeless and isolated within their own community because of the disability of the child. In the study it was observed that many of the participants found their own ways of coping and adjusting to their child's disability and hence made acceptance easy. Most of the caregivers seemed to have accepted the disability of their children. Primary data revealed that some of the primary caregivers blamed themselves for having caused the disability. One participant said that the disability of the child came as a result of her sleeping with a relative. The participant took time to accept the disability of the child and new role that she had to play as a primary carer of a physically disabled child.

#### 4.3.3.1.2 Caregiver stress

The participants pointed out the role of being the primary caregiver is normally a source of stress for them. The feelings sometimes emanate from unresolved feelings arising from difficulties during the child's birth, financial hardships and other social deprivations. Feelings of isolation, hurt, anger, depression and a sense of hopelessness were clearly indicative of caregivers' emotional stress. Caregivers described a life of hardship with financial burdens, problems in finding money to pay for transport to get to the hospital and dealing with family tensions as well as personal hardship. Difficulties surrounding birth and poor perinatal care contributed to caregivers' stress.

This is captured in the following sentiments expressed by **Participant 19** who mentioned this;

*"I stress a lot because of my children with disabilities. When you have such children you tend to worry a lot and always wondering if they are calm and didn't venture into the streets or if others will take care of them the way you do especially if I die".*

Similarly **participant 3** shared this;

*"I experience a lot more of stress because the care is demanding; I fail to cope at times".*

**Participant 11** mentioned that;

*"It is always difficult to deal with the double role of being the father, the mother and caregiver…this is just too much for me. Many times I get stressed or depressed because of the things that I am supposed to do but cannot, because of this child. I take anti-depressant pills at times because of the challenges that I face".*

The participants in the study managed to reflect on their emotional experiences in regards to the care they offer to the children with physical disabilities. Caring for the child involved concern over the child's health, daily management with many of the children requiring constant attention as well as dealing with the child's severe activity limitations and communication difficulties. The burden of care is high and although, as already mentioned, some caregivers receive practical help and support from family members. The primary data from the research indicate that several of the participants were on a regular basis getting depressed. One participant indicated that she regularly takes anti-depressant medication. The participants stated that the major source of stress

was the lack of support from the family. Another source of caregiver stress is the daily hardship of life associated with poverty as well as financial difficulties. Financial hardships reduce the funds available for transport to the hospital, particularly in rural areas. The primary data in the study indicate financial hardships as a major source of stress for the primary carers offering care to children with physical disabilities. The participants pointed out to the cost of diapers, special food as well as the cost of travelling for medical check-ups with the children they are caring for. The participants stated that the cost was too high and that their income could not make up for the shortfall. The participants stated that this leads them to stress a lot because they cannot just cope with the demands of caregiving. The participants also indicated that the absence of activities for the children with physical disabilities that they are caring for is a factor that leads them to stress. The participants stated that they have to spend more time with the care recipient instead of being productive and hence this increases the stress for them. The primary data of the research revealed that there were no schools or activities that are meant for the children with physical disabilities in the region.

Laurvick, Msall, Sillburn, Bower, De Klerk, & Lenord (2006) believe that there are issues like the difficult of care, gender, age and conduct of the children with physical disabilities can have a damaging effect on the physical wellbeing of the caregiver. Bathing and giving medication are instruments of everyday living which can lead to psychological burden. Lonsdale (1992) and Gulliford and Upton (1992) stated that the wellbeing of the body and mind is more critical and important for primary caregivers caring for the children with disabilities and those without disabilities. The findings confirm the views of Girard (2010) and Office (2010) concerning the psychological burdens experienced by the primary caregivers. In a study on the health and wellbeing of parents of children with disabilities who have special health needs, Smith and Grzywacz (2014) observed that parents of children with disabilities who have special health care needs had more depressive signs over a period of time and more declines in instrumental activities of daily living than parents of normal developing children. Primary carers of children with physical disabilities (cerebral palsy) tend to experience more stress than those caring for mild disabilities (Ribeiro, Sousa, Vandenberghe and Porto, 2014). The social health of the carer can be affected as a result of the carer's (normally the mothers) guilt feeling, blaming themselves for the care recipient's disability (Burton et al., 2008).

Caregiver stress related with looking after a child with a disability in a well-resourced setting has been frequently described in the literature (Hassall, Rose, McDonald, 2005). The participants in the study stated that their communities are not resourced to cater for their needs as primary caregivers. Services available are not caregiver friendly which increases the stress level and the assertion agrees with observations by Hassall et al. (2005) who stated that an under resourced community will likely increase the stress levels of primary caregivers. Mobarak, Khan, Munir, Zaman, & McConachie (2000) observe that in third world countries, the burden on caregivers is likely to be bigger. With fewer resources available in the form of experienced teachers and therapists, respite facilities (places where families can leave their children for a few days), assistive devices and support services, the physical and emotional burden of care carried by the primary caregiver is heavier. The participants in the current research lamented the absence of appropriate special equipment for use by the children with physical disabilities. The primary caregivers stated that this resulted in huge workloads and thus increases their stress levels when they want to go out. One participant mentioned that it was more stressful to go out than to sit at home because of the lack of special equipment that she could use to put the child in. Moreover, caring for a child with physical disabilities may result in compassion fatigue in the caregivers (Figley, 1995). Figley (1995) states that compassion fatigue is characterised by exhaustion and dysfunction within biological, psychological and social domains due to deep emotion of compassion and distress for someone who is suffering and hence the robust need to alleviate the pain and remove its cause.

#### 4.3.3.2 Psychological experiences

The participants managed to relate to a number of subthemes that they experienced in the care continuum. The themes that came out from their social experiences include effects on social relationships, trusting other people to care for the child in their absence as well as treatment from community members to disability and caregiving.

##### 4.3.3.2.1 Social relationships

Social relationships are important for the primary caregivers to function optimally. As noted from the participants they help to lessen the burden of care and also to ensure that the caregivers have respite time. Participants highlighted their experiences in regards to the kind of relationships that they had and their effect on their social lives and caregiving.

In this regard, **participant 2** said:

*"Mmmmmm like I said before, besides being liked by the other family members, there are sometimes I feel like it's hard because I have to go out but not to that extent. I don't drink so it helps a lot in terms of hanging out I can still visit my friends. But it's not really that bad in terms of the social ties…… I always say that it's my responsibility. I have to do it. So I don't really demand much from them and hardly force them to be with me. So my relationships with them …It's very fine. But the issue is I don't demand help from them…if they want to help and if they don't want to its fine as well. (Puts in a big emphasis on "I don't demand, it's my responsibility)"*

**Participant 12** pointed out that;

*"I don't have friends, it's not even an issue to me whether I come together with them or not…. the bottom line it's my child and I have to look after him…. I can't even move…. if my family goes somewhere I have to sit here alone with him there is also my other brother to take care off".*

Similar sentiments were also expressed by **participant 9**, she said:

*"I don't really have friends anymore because of caregiving….for me, I cannot even go and see people. The only time I go out is when I go to the church…. I lost my friendships when I realized that my son needs more time with me and more care and I don't go out anymore……. yah I don't have to go and see people or hang out with families or frends.im just most of the time here".*

It is evident from the participants that their social relationships have been negatively affected because of the caregiving role they have assumed. Before they were caregivers, the participants stated that they had perfect social ties. However, after disability came into play, their social ties somehow were affected in a negative way. Most of them hardly go out or hang out with their friends because they have to spend that time with the care recipient. The participants stated that they have lost their friends because of the time they are spending with the child they are caring for. The participant's level of interaction has thus been minimised and can only spend time at the church with the children. However not all participants have severed their ties with friends and family members. Some of the participants have maintained their friendships. The participants

also stated that they still have time to go out with their friends despite the caregiving tasks that they have to perform.

Difficulties in maintaining social relationships were also reported in a study conducted in Melbourne (Davis, Shelly, Waters, Boyd, Cook and Davern, 2009). Social relationships are difficult to maintain in the advent of change in roles in life. Oruche et al. (2012), state that the nature of the disability which might require special care can lead to grave disruptions on the family relationships thereby impacting heavily on the primary caregiver's social ties. In most cases the caregivers who are mostly affected are those whose care recipients have severe physical disabilities. Raina et al. (2005) suggest that the functionality of the family is a key factor in the psychological and physical health of carers. This assertion is buttressed by evidence on ground which suggests that there is greater association between the functionality of poor families and the high levels of burden faced by the caregiver (Tremont, Davis, Bishop & Fortinsky, 2008).

#### 4.3.3.2.2 Relationship to the care recipient

It is vital for the primary carer to have a good relationship with the care recipient to ensure that their wellbeing. The participants in the study mentioned that they had good relationships with the children with physical disabilities they were caring for. The sound relationship helps in ensuring that the care offered to a child with physical disability is of high quality. Participants had this to say;

**Participant 1** said that;

*"relationship is good…. (Sighs) It's Very difficult to look after a disabled child let me say from the young age everything he is doing you have to there……especially I was having a problem if he runs. I don't want him to run because if he falls, he will just come and fall automatically as there is nothing to support himself. So there, I was kind of no don't run and don't do what. So you have to be next to the child, still even now I am still asking/telling him don't run/ jump the wire but what I must I do but he will say no mama I can handle it, so still kind of scared that something bad will happen to him because he doesn't have balance……. Aaaaah he will just say mama I can handle myself, I am kind of used to the situation now…he knows that I love him and he loves me too".*

**Participant 2** mentioned that;

*"Ah she knows my voice very well (laughs). She's good in responding, knows her name very well. Sometimes she can be stubborn (laughs) but we understand each other very well".*

**Participant 11** shared similar sentiments and she said;

*"Our relationship is quite good. It helps me a lot to know that she is happy when she is with me. We try to live as normal as possible, no arguments and fighting, but at times she can be really naughty".*

It is evident from the responses of the primary caregivers that they enjoy good relationships with the children with physical disabilities they are caring for. The participants highlighted that the good relationships were essential in the care continuum as they helped to remove the social barriers that might have existed as a result of a bad relationship. The good relationships were noted to improve trust and bonding between the primary carer and child being cared for by the primary caregivers in the research. The primary caregivers stated that it was of great significance for the existence of a good relationship as it helped them to identify the needs of the child. The primary caregivers stated that they loved their care recipients unconditionally and hence the result is a sound relationship with the child.

Most of the participants in the research indicated that the role of caregiving led to straining of relationships with other children of the household. The primary caregivers stated that they had developed a trend to pay less focus as parents to the development of other children because of the demands of caregiving for the child with physical disabilities. The mentioned experiences of neglect of other relationships were confirmed by a study by Stroud (2002) on the experiences of parents of autistic needs. The rapport of the carer and the child with physical disability was noted to have an effect on the relationship between the care recipient and other children in the household. Some of the participants stated that the relationships with other children were strained as a result of the attention the child with physical disability was getting. The primary caregivers noted that the child with physical disability gets to spend a lot of time with them to compensate for the disability and hence this created feelings of anger, frustration bitterness towards the child with physical disabilities by the normal children. The same behaviour was noted by Barry and

Singer (2001) in their study of children with autism who stated that the siblings are bound to express anger, frustration and bitterness towards children with physical disabilities.

#### 4.3.3.2.3 Trusting other people to offer care to the child

A key sub theme that emerged from the study is the level of trust to care for the child with physical disabilities that the primary caregivers can allow someone to offer care in their absence. Trusting someone to offer care for the child seemed to be a problem as some of the participants highlighted that whenever they leave the child in the care of someone, the child always gets sick.

For instance, **participant 2** remarked that;

*"I don't really trust people (slight laugh) because maybe she knows the way I do things with her. She's used to me. So when I am away I think about how the person is caring after her and whether they are really getting along well. That's all I can say"*

**Participant 3** noted that;

*"I get worried because the child doesn't like to be removed from the house to go and stay somewhere else…. The child feels a lot of pressure if at another place"*

Similar sentiments were also expressed by **participant 20**;

*"When I am away I always think of my child wondering if she is not crying or are people not screaming at her because others will not have the patience to take care of her. With a lot of questions on my mind whenever I am away, I am very restless and sometimes I cry when her father takes her for two days then I ask him to return her home … I have no choice but to take her back".*

A bond created between the caregiver and the temporary caregiver is critical in the caregiving continuum as it strengthens the care offered and meeting of complex needs for the care of child with physical disabilities. From the participants it was noted that trust and ability to care for the children in their absence were the key issues that they felt the people around them could not do properly in their absence. The primary caregivers in the research noted that caregiving for a child with physical disabilities requires someone who is strong, patient and resilient and thus leaving

the child in the care of someone is not easy. The primary caregivers stated that the absence of such qualities amongst most family members of friends led them not to trust to care for the children with physical disabilities.

Most of the caregivers felt that the attachment that they had with the children was too strong and hence alternative caregivers would not cope. The primary caregivers stated that the children with physical disabilities would have problems to adjust to a new caregiver who only has a short time with them and hence they might resist care from such a person. In one instance a participant stated that whenever she leaves the child in the care of the father, the child would fall sick. However, some of the participants enjoyed cordial relationships with family members and hence they would feel that the children would be safe in their hands.

#### 4.3.3.2.3 Use of help in decision making

Decision making in regards to care offered to the child with physical disabilities was observed as important aspect in the care continuum. The primary caregivers highlighted that they needed the help in regards to certain aspects of caregiving. The participants had this to say;

**Participant 2** stated that;

*"Yes …. There is no way that I can say I don't need help. I need someone to advise me on how to do certain things. Like try this, try that you know…. It starts with me like I have to do this. If someone comes and say let's drink alcohol, I would not make use of that person but will always consult people that I know would really give sound advice".*

**Participant 1** in agreement stated that;

*"Yah I have to consult to consult the father to help me like now, he is a grown up man, he needs the fatherly figure inside, if I tell him this, he won't hear me much better than father so I have to contact the father and the father will help me".*

**Participant 19** said that;

*"Only sometimes that I need help to make decisions that's when I will really make use of someone or some people…… but I normally consult the women's council from our church to make certain decisions in regards to the caregiving process".*

Participants in the research indicated that they needed help in the decision making process that pertains to caregiving. The participants indicated that though they might not be leaving with the fathers of children, they still consult them to ensure that they fathers' influence can be exerted on the child with physical disability. The primary caregivers mentioned that before they make big decisions in respect to any caregiving activity for the child, they always seek advice. In the study a number of participants stated that they use the church in decision making. They stated that the women's council helps them to make decisions on how to best offer care for the child they are offering care for. Participants in the study however stated that it was not every decision made that they consulted someone. The notion is supported by a study on decision making by Browder (2002) who states that the primary caregivers often consult other adults prior to making the final decision in the care continuum. The majority of the participants stated they will always make use of advice from anyone whom they think will make a huge difference in the caregiving process.

#### 4.3.3.2.4 Stigma from community members

If communities are supportive and accept disability the most of the caregivers would have fewer burdens. Stigma is rampant in most of the communities as evidenced by the primary data obtained. Stigma has been noted to have adverse effect on caregiving and hence the need to address it holistically. The participants highlighted the various challenges that they faced from the communities they live in. The participants had this to say;

**Participant 1** had this to say*;*

*"Close family members did not have a problem, only those ones who were far were kind of like asking a lot questions like how did she end up having a child like this a lot, so I blocked them ...You don't want to listen to them. In a community where I grow up still we were having a disability so people it was not something which came first in the community, there was already disability things so but they were just wondering how did the kid end up not having arms, the kid is normal but only the problems of not having arms that one was a kind of a big question……They were talking rumours but you end up blocking them……."*

The problem of stigmatisation was explained further by **participant 20** who noted that:

*"As a sickness and always discriminate the child…other kids push her and mock her. They do not respect disabled people… some rape the disabled even when people are seeing laughing and watching it like a movie. But if it was a normal person being raped people could have called the police or help……. Yes, I feel like I should fight the person. In some instances, sometimes when my child is hungry at school (Lebenshceule) they do not feed her then report that she did not eat. I do not want children with disabilities to be treated badly"*

**Participant 2** had this to say*;*

*"Eish…. Mmmmmm my goodness, ok our people in Mariental people are very secretive. If this one is like this, the other one will come over and talk to someone it shows that someone is a caring although they don't bring something for the baby but the mere visit and asking of the health of the baby shows that at least they care. So I can't say my community, ok those close to me, they really care though they don't offer financial support. But the fact that someone ask makes me feel good. People are not comfortable to talk about it…… they ask how the baby got disabled. I mean the support is there and they know the causes of disability, but I won't go into detail explaining the causes. I don't want people who are negative around me. So if you cannot say anything positive then I don't want you around. So far I don't have negative thoughts…… No not all… never…like I said I never had someone say you are useless. But you find those kinds of people in our community".*

The participants were able to relate their experiences of stigma from the community. It was evident that the community's perception of disability and caregiving is still negative. In most African states, disability is still viewed in a negative way. This assertion is supported by an article in The Namibian newspaper of (2014) which talks about the prevalence of negative traditional perceptions in Namibian communities. The families frequently state that the person with the disability is not a major burden for them but the burden comes from the community at large who still have attitudes which are judgmental, stigmatising. It is evident that the communities are rejecting the person with the physical disability as well as the family that is offering care. Some of the participants stated that the community judged them when they gave birth to children with physical disabilities. The participants stated that the community members stated that it was deserved judgment because of their misconduct. Primary caregivers of children with disabilities in the Western countries have noted the presence of discrimination, stigma and

exclusion amongst community members for them and their care recipients (Huffstutter et al., 2007). The primary caregivers stated that they were no longer comfortable to take their care recipients to the public places due to the level of stigmatisation against children with physical disabilities. It was noted that most of the community members are used to calling names people with physical disabilities. The primary data from the research indicate the primary caregivers experienced stigma even at the church by some community members. The participants noted that the community members are of the view that the people were cursed and hence the disability within the household. The participants stated that this had a negative effect on their wellbeing as caregivers to the extent that at times they leave the children at home because of the fear of stigma and discrimination.

In Uganda, studies on caregiving has shown that the primary caregivers caring for children with disabilities who mostly are the grandmothers and mothers face stressors in the caregiving process and this lead them to have less time for doing other tasks for the house (Hartley et al., 2005). Exclusion from mainstream activities can thus lead the primary caregiver to have challenges in the care offered to the child who is living with a disability. In the current study some of the participants indicated that their families were leaving them out of family events or programmes because of the disability and the role that they play. The participants indicated that the families give reasons which include that the primary caregivers are always busy and that they do not have anyone to leave the child with and hence cannot participate fully in the family programmes. Many African communities still lack programmes, amenities, and resources that permit for the full inclusion of persons with disabilities.

#### 4.3.3.2.4 Continued growth and development

Caregiving was noted to affect the personal growth of the caregivers. Most of the participants were of the view that the task of having to care for the child round the clock was affecting them to take other life enhancing activities.

**Participant 9** had this to say:

*"Yah yah yah I do because I was supposed to go now on a trip for training for three weeks for sewing but now I can't because of him. If I leave him with another person for more than a day I fear that he will get sick. So I cannot leave for a longer period because he will get sick. So if I go*

*for a day or 2 then I must come back… sometimes I have free time but I do other things that I feel like I want to do. So I wash the clothes, clean the house, house chores".*

**Participant 16** had a different view and had this to say:

*"No because if I go to a place I take them to my daughter and then I can go for a workshop also my spiritual mother can look after her".*

The participants in the study pointed out the role of being a caregiver had greatly affected their capability to partake in personal growth activities. Some of the participants mentioned that they are no-longer employed or looking for jobs because of the nature of care that they have to offer to the child. The primary data on the personal growth of the primary caregivers reveals that most of them have given up on seeking formal employment because of their inability to cope with caregiving and full time employment. The participants in the research indicated that the level of growth has stunted as they have to devote most of the time offering care to the child with physical disabilities.

The participants also mentioned that even if they decide to take short trainings on capacity development, they will not fully be attentive because of the thoughts of the child at home. However, some of the participants stated that they were experiencing growth as they had people at home who were equally capable of looking after the children in their absence. They managed to attend various training programmes that have seen them enhancing the quality of care offered to the children with physical disabilities.

### 4.3.4 Objective 4: Exploring the options needed in order to support caregivers of children with physical disabilities.

The fourth objective of the study was to consider the options needed in order to support primary caregivers of children with physical disabilities. Support is essential in the care continuum as it helps to minimise the effects of burden in the care process. As noted in the previous discussions, mothers or caregivers caring for school-going children with physical disabilities may experience stress and challenges as they have to find ways of fitting into their new role, have diverse prospects about their child, and cope with important social, emotional, physical and financial burdens because of their child's disability. The following issues were identified as the various options that would help the participants to cope with caregiving:

#### 4.3.4.1 Psychosocial support to the care givers

The research noted that the primary carers of children with physical disabilities lack the necessary psychosocial support in their communities. Psychosocial support may be one key component to supporting families and caregivers of children with physical disabilities. Key elements of psychosocial support include physical, emotional, and psychological support. This psychosocial support includes respite care and counselling which are minimal or close to non-existent in the region. Psychosocial support is a critical component in the care continuum as helps to improve the wellbeing of primary caregivers caring for children with physical disabilities. Participants in the study noted that they needed this support in an attempt to enhance the quality of the care offered to the children with disabilities.

**Participant 17** stated the following;

*"There is nowhere I can go to get any one who can give me advice on the care and just to talk to me about the care am providing for the child. This is very stressful and I am not coping and hence I sleep every time and I can no longer bear the burden of care".*

**Participant 7** had a different experience and had this to say;

*"No, I'm not sure what their reasons may be perhaps they think it's my grandchild thus my responsibility. All they are saying is that I'm getting old and its time for me to give the child to his mother. They feel she should carry the responsibilities now to learn already in the event that I'm not there anymore. And I'm actually already old and no one can determine one's death".*

**Participant l0** stated that the caregivers in Hardap region do not get any support or respite in the caring of the child with disabilities

*"In my household I have to conduct the caring plus my other duties as a wife of the household. There is no special holiday or reprieve for me and I had to give up my job inorder to care for the children as they are growing up... I cannot do anything else while the two are here, I need to keep an eye on them all the time even if I'm tired and want to take an afternoon nap I can't do it if they are not ready to sleep as well. There are times that I just need to talk to someone but I cannot".*

The above data highlights that there is lack of psychosocial support mechanisms in the area for the primary carers who are offering care to children with disabilities. This is in line with the African traditional setup that neglects children with physical disabilities (Bunning et al., 2014). Some of the participants stated that their families had stopped offering support to them and now find it very difficult to care for the children with physical disabilities. Respite care is an important component of the care continuum as it gives a comprehensive caregiving break to the usual primary carer of the child with physical disabilities. The participants highlighted that they have to spend most of the time caring for the children and hardly get time to recover from the burden of care. This came about because of the absence of support from the families to give respite care to the caregiver of children with physical disabilities. The participants stated that the only rest they get is when the care recipient is sleeping or resting. When they are not caring for the child, they have other responsibilities waiting for them which respite care could help to provide the necessary positive feeling for the primary carer and the care recipient as well as learning new social skills (Chesson, 2001). Participant number 7 states that family members told her that they had stopped supporting her because she was old and wanted the mother of the child to assume the role of being the primary carer despite the mother having neglected caring for the child way back. This mirrors the observation by Worall (2005) that caregivers often take up the role of primary carer because of the incapability of the parents to care after the child.

The study also revealed that the caregivers experienced challenges as no professional services were rendered to them to ensure their psychosocial wellbeing. The participants stated that they needed counselling just to let out their emotions to the counsellors. The role of counselling is done by social workers in the region and hence their availability to the communities was minimal. The primary caregivers thus lamented the low visibility and availability of such services for them. Counselling of primary caregivers thus should be available to the primary caregivers or the professionals giving their listening ear to the caregiver (Jorgensen, Ramsey, Parsons & Jacobs 2009). The mental health and social functioning of the primary carers vastly improved as a result of psychosocial interventions done (Oyebode, 2005).

#### 4.3.4.2 Absence of NGOs dealing with disabilities

The research noted that there was clear absence of non-governmental programmes which supported the caregivers of children with disabilities in Hardap region of Namibia. The area only has got one centre that deals with children with physical disabilities. This centre is not conveniently located and easily accessible for the caregivers of children with disabilities. Some of the participants lived about 300kms away from the centre. This is very far for the caregiver to access the services provided by the centre. Participants stated that they hardly know of any civil society organisations that were dealing with disability issues in the region a

**Participant 4** stated that:

*"There are no Non-Governmental Organisations in our community…. If there is any I have not heard about it"*

**Participant 15** expressed similar sentiments and had this to say:

*"Mmmmmm I have not heard of any or seen any Non-Governmental Organisation that deals with disability issues".*

**Participant 17** said that;

*"In our area there is no Non-Governmental Organisation that I know of that helps people like us…. the only one that is there deals with HIV and AIDS. We cannot get help there because they only help people living with HIV or AIDS".*

The participants stated that there were no Non-Governmental Organisations (NGOs) offering services in their areas. Civil society organisations are critical in complementing work donor by the government to make sure that the primary caregivers of children with physical disabilities cope. The NGOs' absence has thus created a gap in the care continuum for the communities. The participants highlighted the various aspects that need to be improved to ensure that that they are able to be resilient in the care process. According to Montgomery and Feinberg (2003) the lack of service providers for primary carers of children with physical disabilities is an indication of the lack of priority given to. It can be noted that the Namibian government does not prioritise this minority grouping thereby increasing their levels of vulnerability. According to Harknett (2006) children with disabilities and their caregivers are very vulnerable and often neglected groups in

the society. Most of the participants highlighted the limited role or the absence of NGOs. In most of the communities there were no services that were being rendered by NGOs to the primary carers of children with physical disabilities. Evident amongst a number of the participants was the role of other NGOs that were catering for other social issues in the community other than disability. However, some of the participants pointed out that they did not know of the existence of such NGOs. Most NGOs do not publicise themselves to the community which makes it difficult to access their services. NGOs should publicise their organisations and services they render to the community (Borchard, 2011). The same findings are supported by Harknett (2006) who argued that caregivers of children with disabilities are not benefitting from services offered by NGOs because they are not visible in the communities. Some of the participants mentioned that they had no knowledge of NGOs or the scope of services they offer. This is in agreement with Harknett (2006) who stated that some primary caregivers might not be aware of the services that are available to them.

#### 4.3.4.3 Support groups for caregivers

A key component in support for primary carers is support groups which play a pivotal role in the wellbeing of the caregivers of children with physical disabilities. Support groups are essential for the primary caregivers of children with physical disabilities as it helps them to cope with the caregiving for children with physical disabilities. Support groups thus help the primary caregivers to discuss their problems, share information about services that are available to them from within and beyond and receive professional guidance in their sessions. The research noted that there are no support groups in the region for primary carers of children with physical disabilities. The whole region has got one support group that is barely functional and cannot cater for the whole area. The research participants noted that there is nothing much to gain from the support group as they rarely meet and offer proper service to the primary caregivers.

**Participant 1** said that;

*"I have not heard of such a group of that, so I can say that there is no support group".*

Similar sentiments were also stated by **participant 10** who said that;

*"There is no support group in our community".*

**Participant 17** also stated that;

*"Aaaaaaah no idea of the existence of such a group in our community…. maybe others know but I have not heard of any group around".*

The general consensus amongst most of the participants in the study was that their there are no support groups in their communities. The primary data gathered revealed that there is limited knowledge on the existence of support groups for primary caregivers of children with physical disabilities. However, in one community there was a support group which was functioning minimally. The participants highlighted that if such groups existed they would help to ensure their wellbeing. The findings are in line with the observations made by Oyebode (2005) that support groups help to reduce social isolation of caregivers. The participants thus lacked information which could have been shared in the support groups had they been available in their communities.

Tucker (2004) argues that support groups should be proactive to ensure quick interference as some family primary carers might not look for help until there are higher levels of a crisis. This might be prevalent in the region as some of the caregivers were reluctant to respond when asked about their readiness to join such groups. Trainings in care responsibilities, adequate support from the beginning of caregiving and at regular intervals, information sharing are elements that will benefit the primary caregivers of children with physical disabilities in the care continuum. Caregiver support groups are helpful for the primary carers of children with physical disabilities as they are able to enjoy the mutual benefits of such groups which include psychosocial support and practical support they get from such a group (Tucker 2004).

#### 4.3.4.4 Use of professionals for support

Professionals are a key component in the wellbeing of primary caregivers who are offering care for children with physical disabilities. The professionals help in guiding the participants in the upkeep supervision of children with physical disabilities. The participants in the study were not sure of how the view the professionals in regards to support offered by them. The participants indicated that the professionals were not visible enough for them to utilise their services. The participants reflected on the professionals;

**Participant 1** had this to say;

*"I know of social workers in our town but I have hardly interacted with them. Actually this is the 1st time to talk to one in a very long time…. We really need all the professionals who deal with disability issues to do their job".*

**Participant 7** shared similar sentiments, she said;

*"I know of Naomi (medical rehabilitation officer) at the hospital and our relationship is good… but I am not sure whether I am getting the right services because I only get in touch with her when I am going for check-ups, but besides her there is no one who really deals with disability that I know of …even the services we are supposed to receive I am not sure of them. At the clinic when I go with the child some of the nurses are not good…. They at times shout at us whilst we wait with the child because the child restless and that time we did not have the wheelchair for the child, so I had to carry her".*

**Participant 20** shared her experiences and she said;

*"I don't go to them anymore. Some of the nurses are not friendly and so on some of them do not have patience. You can't even leave the kid in the hospital and go home. If you come back, you will find the kid lying in pi (urine) and crying and so on. I don't really trust them, the health people nurses and the other professionals there…even the medical rehabilitation…The nurses and the people at the hospital are eating the food when the child is admitted at the hospital…. They don't give us the caregivers food stating that it's only the child who is a patient even if the doctors say we should get the food….so how do they expect me to stay with the child at the hospital when I am not a patient …. they don't give us nappies or any help".*

The rapport between primary caregivers and helping professionals is of significant importance as it helps the primary caregiver to cope with caregiving. In the study the participants acknowledged to a lesser extent the help that they are given by the professionals. The professionals who are supposed to help them in the fields of their speciality like mental health, psychology, speech and language, occupational therapy, neurology, physiotherapy and social work. The participants reported largely of negative encounters they have encountered at the hands of the professionals at the various health centres, clinics and hospitals. The participants

indicated that the relationship between them and those who are supposed to support them to cope with the burden of care is not good. Some of the participants stated that they are no longer comfortable in visiting the treatment centres because of the behaviour and conduct of some of the professionals at these centers which is negative.

The primary caregivers reflected on the encounters they had experienced at the hands of the professionals at the health institutions when they took their children for various medical check-ups. The participants would get angry over the treatment that they got from the various professionals at a health institution. The above encounters of participants in the current study are strongly reinforced by a study on professionals by (Billington, McNally and McNally, 2000) who states that if the professionals create a feeling of hopelessness and helplessness the primary caregiver would feel anger and disempowerment. The participants also pointed to low visibility of the professionals in their communities. The research data shows that social workers and physiotherapists in the region are not visible enough to offer their services to the primary carers of children with physical disabilities.

#### 4.3.4.5 Availability and accessibility of special schools

Special schools are an important component in the care process of children with physical disabilities. Special schools help the children with physical disabilities to receive special education that is suitable for them because of the nature of their disability. This will in turn help lessen the burden of care of the primary carer as the child or care recipient will be receiving special attention from qualified personnel. In the study it was noted that there were hardly schools that were offering special education to children with severe physical disabilities especially those that were not admitted into the mainstream educational system. The participants had this to say;

For instance, **participant 9** had this to say;

*"My child is not attending school because he does not talk and walk…he is not doing anything by himself. So I don't know if he will be learning there even if he goes to school because I am the one who is doing all the things for him. In our region there is no school for children with disabilities. The only one that I have heard of is in Windhoek which is very far for such a small child".*

Similarly, **participant 13** mentioned that;

*"The child is not attending school though she is old enough to have been in school. Even if she goes to school she is not good enough. The school here did not accept her because of her disability. They said we should take her to Windhoek which helps children with disabilities with special education"*

**Participant 10** shared her experiences and she said;

*"The children are not attending school because they cannot walk or talk… Firstly communication will be a problem at the school because we raised them we are the only ones that can tell from their gestures and behaviour if they are hungry, tired and sick other people will not be able to communicate with them. I have never taken them to the special schools in Windhoek but we have enquired about such.....The Windhoek schools required us to bring the children at our own expense and then travel back and forth again at our own expense. During the holidays we have to take them as well as during mid-term break again at our own. The children do not have proper control of their bodies thus you can't travel with them in other people's vehicles because of the mess they create …. However, the time we received that information we were both not working and it was going to be a costly process. So we decided not to send the children".*

The primary caregivers in the study noted that there were no special schools for people with disabilities in the region. Most of the participants stated that the absence of special schools had affected their coping capacity as it increases the burden of care. The participants highlighted that the presence of such schools near their communities would help in reducing the amount of time spend caring for the child with physical disabilities. The primary caregivers also acknowledged the presence of special schools for children with disabilities in Windhoek which is a distant away from the region. The participants highlighted the distance between their places of care to the special schools as one of the deterrents for them to send their children. The primary caregivers also pointed out that the cost of taking the children was very high and could not afford sending the children to the schools in Windhoek. The participants highlighted that the absence of the special schools in the region had greatly affected them as they have to offer round the clock care to the children with physical disabilities.

From the primary data gathered, the participants stated that the conventional preschools and schools were not able to meet the special education needs of their children. The participants in the current study also stated that most of the conventional schools are not willing to accommodate the children with severe physical disabilities because of behavioural problems. In a study by Davis (2001) he noted that the mainstream schools were not willing to accommodate his child because of a disability he had. The participants stated that the mainstream schools would state that they were not able to accommodate the children because of the nature of the disability. The mainstream schools also lack qualified personnel to manage the children with physical disabilities.

#### 4.3.4.4 Use of religion

Religion was noted to play an important part in supporting and improving the coping mechanisms of the primary carers caring for children with physical disabilities. This is the only source of motivation for the primary carers in the region to be able to deal with the challenges that come as a result of caring for children with physical disabilities. Participants indicated that religion and personal faith played a significant part in helping caregivers to accept and deal with the child's disability.

**Participant 9** stated that;

*"I am a prayerful person. I ask God for strength always. I always try to stay positive because after Him there is no-one. He's always keeping me busy. So my religion has a played a greater role in the way that I care for the child and for me to be positive."*

Similar sentiments were also expressed by **participant 1**, who said that;

*"Aaaaah …Let me say, I ended up coming closer to my God, keeping my faith there thinking way back, that this is His will and let me do it".*

**Participant 3** also acknowledged the great role of faith, and said;

*"I go to church; sometimes I go to crusades where they pray for sick or people with disabilities. Prayer, prayer, prayer…. there is nothing more important than this…This has helped me to get strength to go on…. I just prayed to God that I understand and it has helped me a lot".*

The participants agreed that they derived greater satisfaction from their religions. The results showed that most of the participants used religion as a coping mechanism in order to accept the new role that they were playing. The participants still have a belief that the new role they are playing of being a caregiver is as a result of God's will and hence they were content with such. Lopez, López-Arrieta, & Crespo (2005) examined the coping mechanisms used by primary carers and established that religion was related with satisfaction of the primary caregiver, whereas emotional voicing and blaming oneself were negatively connected with satisfaction. Most of the caregivers believed in a higher being and included prayer as a source of strength and perseverance in their caregiving tasks. The caregivers thus attended church services to get that extra strength for them to cope with the role of being caregivers. Many caregivers feel spirituality is a great source of support during difficult situations (Sanders, Ott, Kelber, & Noonan, 2008). The participants reflected that religion played a great role in providing the psychological and emotional support to them as primary carers of children who are living with physical disabilities. The primary data from the current study shows that the most important element that led to the primary caregivers accepting their new role was their faith. Johnson and Yanca (2007) state that for the caregiver's role to be more positive there has to be a relationship between the caregiver's spiritual support and that of the maker. Phelps, Hodgson, McCammon & Lamson (2009) state that spirituality may provide valuable means of guidance and purpose throughout the challenging experience of having the child diagnosed with a disability. This was also reflected in the caregiver's responses as they indicated that God had a purpose in the whole situation.

The primary carers of children with physical disabilities noted that the church played a critical role for them to adjust with the burden of caregiving. The participants mentioned that prayer was a tool they used in order for them to adjust and to deal with the stresses of caregiving. Chitando (2007) in a study on African churches agrees with the primary caregivers that churches play a vital role in making sure that their spiritual needs are met. Primary data from the research noted

that most of the participants noted that prayer was a distinctive contribution from the church that had helped them to cope. In Uganda it was observed that caregivers were coping without rehabilitation programmes because of their faith (Hartley et al., 2005). Some studies conducted in Botswana and Mexico indicated that the birth of a child who is having a disability was regarded as a sign of God's expectation in the caregivers' capability to be able to look well after the child with physical disabilities (Ingstad, 1988). From the study it was observed that religion functioned as an important channel of support to the primary caregivers. It is thus important to acknowledge that religious or spiritual beliefs often fluctuate over time and are greatly influenced by the environments in which they operate (Hebert, Dang & Schulz, 2007). In the current study, the participants felt much closer to God in order for them to cope with the burden of caregiving. The results of the interpretation emphasized that religion brought caregivers the reality of hope that allowed them to express themselves as being closer to their maker (Pierce, Steiner, Havens, & Tormoehlen, 2008).

## 4.4 CONCLUSION

Chapter 4 provided the findings, the analysis and interpretation of the research findings in relation to the objectives of the study. Several themes were identified and discussed under the four study objectives, namely, the nature of care, the financial implications, the psychological experiences and the options for support. The significant findings of the chapter include the challenges that the primary caregivers face in caring for a child with physical disability. The next chapter of this dissertation will provide an overall conclusion, bringing together the research objectives, analysing whether they have been met by this study. The chapter will also give recommendations based upon the research findings as well as areas for future research.

# CHAPTER 5

# SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

## 5.1 INTRODUCTION

The study explored the experiences of primary caregivers caring for children with physical disabilities with specific focus on Hardap Region of Namibia. This chapter presents a summary of the research findings, conclusions that can be drawn from the findings and recommendations.

## 5.2 SUMMARY OF FINDINGS

The findings are summarized as follows:

### Objective 1: Nature of care provided to children with physical disabilities

The first objective was to establish the nature of care provided to children with physical disabilities. Participants identified the following activities as constituting the care they provide to children with disabilities: provision of special aiding equipment, carrying the children, feeding the children, bathing them and taking them for medical checks. The study revealed that participants helped children with disabilities to have access to special equipment. The study also revealed some participants did not approach the government for assistance but rather made use of their own resources. Such responsibilities as carrying, bathing and feeding were huge responsibilities as some of the children were incapacitated to do any of the things on their own.

### Objective 2: The financial implications of caring for children with physical disabilities

The second objective of the study was to explore the financial implications of caring for the children with physical disabilities. The main findings under this objective were that the care activities increased the household budget making it difficult for households to meet their basic needs and they relied on supplementary funds from other family members, friends as well as the child disability grant. The child disability grant is not adequate to meet the budget needed to look after the primary caregiver and the recipient. The participants indicated caregivers do not receive funding from the government which strains the family budget. Some of the participants stated

that they borrow money from other people in order to meet the budget of the family. Some participants mentioned that they also supplement the budget for care through income from the small businesses they are involved in. The participants however revealed that though this support was available it was not adequate as requirements for the care are expensive. The study also indicated that the personal financial needs of the caregiver were left un-catered for or in deficit as they sacrificed their personal needs in order to meet the care needs of a child with disability. The findings also reveal that family disunity affects the family budget. The families do not pool their funds together and hence this impact negatively on the caregiver as funds are diverted for other uses.

**Objective 3: Psychological experiences of primary caregivers of children with physical disabilities**

The third objective of the study was to explore the psychological experiences of primary caregivers of children with physical disabilities in Hardap Region of Namibia. Participants revealed that they experienced challenges in accepting their new roles as primary caregivers of children with physical disabilities. The participants mentioned that they had emotional breakdown and were not able to cope. Their stress levels increased as a result of them not accepting the situation they faced. The participants indicated they were stressed by the amount of work and the nature of special care they had to provide to the children in a continuous process of caring.

The findings of the study also indicate that some of the participants were not able to cope with the physical demands of caregiving as a result of their old age. This led them to have health problems which they attribute to the burden of caring for a child with physical disabilities. The stress is compounded by the burden of medical costs and unmet financial needs. The participants indicated they fail to cope with the caregiving as a result of stigma and discrimination which increases their stress levels as they are not able to socialise with the community at large. The participants indicated that they faced increased emotional breakdown as a result of the care offered to the care recipients when they are away from them.

**Objective 4: Options to support caregivers of children with physical disabilities**

The fourth objective was to consider options needed in order to support caregivers of children with physical disabilities to cope with the burdens of care. The findings indicate that the

availability of respite care for the caregivers would help in reducing the burden of care. The families are the major source of respite care and hence they need to be fully involved in respite care. Social workers should play a vital role in availing counselling services to the caregivers to ease the burden of caregiving.

Findings of the study indicate the need for the state to co-ordinate social safety nets systems in an attempt to help in the reduction of burden of care. The state needs to ensure that the civil society organisations and other non-state actors come on board and offer services that will help ease the burden of care. The state should build special schools for children with disabilities in the regions where the caregivers reside as this will help reducing the burden of care for the participants. The participants in the study indicated that the health professionals should establish good working relationships with the primary caregivers where they share information as this will help in reducing the burden of caregiving.

The research findings indicate that there is need for support groups to be formed that will help to mitigate the stressors of caregiving. The support groups would strengthen the individuals' coping capacity as they would be able to relate to the needs of caregiving. The professionals should thus avail their services to the support groups to help in growth and coping capacities of group members. The findings of the research also indicate the need for families to play an enabling role in the care continuum. The participants stated that they need the family members to help them with alternative care or respite care.

Religion is playing a critical role in motivating the primary caregivers to continue in the provision of care to the children with disabilities. Other participants provided mixed accounts of spirituality, religiosity, as a means of support. Through their spiritual beliefs some participants felt a sense of control and ability to make meaning of their experiences and the experiences of the children with physical disabilities.

## 5.3 CONCLUSIONS

The conclusions that can be drawn from the study are that the quality of care for the children with disabilities was compromised by the lack of adequate funding and special equipment for the children with disabilities. Though the caregivers showed commitment to their responsibilities they face challenges that result in them being stressed and emotional. These include difficulty in accepting the condition of the child and the financial stress as well as the burden of care. There are minimal support options for the caregivers such as counselling and respite care. This results in increased burden on the primary caregivers. The needs of the caregivers for children with disabilities are not being met. More needs to be done by the government, NGOs and families in order to o strengthen the coping capacities of the primary caregivers. Families are not playing an active role that would help reduce the burden of care for the caregivers of children with physical disabilities. The participants did not have reliable and adequate sources of income which is and hence the burden of care is increased because the financial needs are not met as a result of high cost of caregiving. The care activities by the caregivers which include bathing, carrying the children around and feeding the children have got potential to create burden on the caregivers. These activities require detailed application, take time as well as being laborious which increases the burden of care of the primary caregivers of children with physical disabilities.

## 5.4 RECOMMENDATIONS

The following recommendations are made based on the primary data of the research collected.

**1. Policy:**

The Government of Namibia needs to strengthen existing policies that will ensure that the financial, social and psychological needs of care givers are met. For instance, the government needs to introduce a grant for primary caregivers.

**2. Practice:**

The government in partnership with non –state actors should ensure the provision of support at centres that offer counselling services to individuals, groups or families who have children with disabilities.

**3. Respite care**

The government with support from non-state actors should educate families on how they can assist caregivers of children with disabilities. These include taking care responsibilities such as bathing, feeding or carrying the children with disabilities to allow care givers rest and time to perform other duties.

**4**. **Empowering primary care givers**

Private-public partnerships can be used to develop programmes or projects that will financially empower primary care givers to be self-employed from home. These can be small businesses.

**5. Support groups**

Social workers, churches and welfare organisations should facilitate and promote support groups for primary caregivers who are providing full-time care for children with physical disabilities.

## 5.5 Areas for Further Research

There is need to establish the support systems available to care givers in across the various regions in Namibia

## 5.6 Conclusion

The study managed to highlight the challenges that the caregivers faced in the care continuum of children with physical disabilities. However various recommendations that would help in mitigating the effects of the challenges were discussed.

# APPENDICES

## APPENDIX 1: INTERVIEW SCHEDULE

**1.1. Respondent's Profile**

**1.2.** Age of respondent

1.3. Sex of the respondent

1.4. Marital status

| | | | |
|---|---|---|---|
| **Single** | | **Married** | |
| **Cohabiting** | | **Separated** | |
| **Widowed** | | **Divorced** | |

1.5. Relationship to the care recipient

1.6. Educational Level

| | | | |
|---|---|---|---|
| None | | Primary | |
| Junior Secondary | | High School | |
| Vocational | | Tertiary | |

1.7. Home language

1.8. Are you residing at the place of care (YES/NO?)

1.8.1. If yes, how many family members are residing with you?

1.8.2. Is the accommodation adequate? State why?

1.8 Are you employed or in any job that gives you an income? If yes how much do you earn?

1.9 What is the total income of the household on a monthly basis? Tick the appropriate box

| Amount | Tick |
|---|---|
| N$0-600 | |
| N$601-1500 | |
| N$1501-3000 | |
| N$3001-4000 | |
| N$4001-5000 | |
| 5001+ | |

**2.0 Information of the child with Physical Disability**

2.1 Age of the child

2.2 Sex of the child

2.3 What is the nature of the disability of the child?

2.4 Is the child attending school? YES/NO

2.4.1 If no, explain why?

2.4.2 If yes, where is the child schooling?

2.4.3 What grade is the child?

2.4.4 Are there any challenges that the child faces at school? Explain

2.4.5 What do you think can be done to address these challenges?

2.4.6 How often do you interact with the class teacher(s) of the child?

**3.0 Physical Well-Being of the Primary Caregiver**

3.1 How equipped is the house to meet the needs of the child?

3.2 Are there any special equipment requirement for the child as a result of his/her disability? Yes/No

3.2.1If yes, what type of special equipment?

3.2.2 How did you obtain the equipment?

3.2.3 If the child does not have the special equipment, does this affect you?

3.3 How often does the child with the disability go for medical checkups?

| | |
|---|---|
| Daily | Once a year |
| Once a week | Never |
| Once a month | Other (specify) |

3.3.1 Where are medical checks for the disabled child done?

3.3.2 How far is the Medical Centre from your home?

3.3.3 Do you need transport to get there? Yes/N

3.4 Do you need assistance with the physical care of the child such as lifting and positioning the disabled child? Yes/No

If yes, what kind of assistance?

**4.0 FINANCIAL IMPLICATIONS**

4.1 Is the disabled child receiving a grant from the government?

4.1.1 If yes how did you become aware of it?

4.1.2 If no, could there be any reason why the child is not receiving?

4.2 What financial costs/implications are you facing from caring for the child living with a disability?

4.3 Are there any sources for additional finances to cater for the needs of the child and you as the caregiver?

4.4 To what extent does it impact on the family budget?

**5.0 EMOTIONAL WELLBEING**

5.1 Tell more of the impact caregiving has had on concentrating on other activities?

5.2 What are your experiences in caring for the child living with a disability?

5.3 Describe how caregiving affects you emotionally?

5.4 Has caregiving for the child with a physical disability affected your social ties? If yes, tell me more about it.

5.5 What support do you receive from family and friends? Explain if any

**6.0 SOCIAL WELLBEING OF THE CAREGIVER**

6.1 What has been your experience in care giving in line with its effect to your relationship with the care recipient?

6.1.1 What has been your experience in care giving in line with its effect to your relationship with your extended family members and friends?

6.2 Describe your interaction with the community?

6.3 What do you do in your spare time?

6.4 Do you often change your personal plans or avoid making plans outside of caregiving because of caregiving tasks?

6.5 Who assists you in your caring role when you cannot?

6.6 Share your experiences of how you feel when you are away from your care recipient

6.7 Are there times that you feel you need help to make decisions in the caregiving process?

6.7.1 What kind of social support do you receive in making decisions?

**7.0 PSYCHOLOGICAL WELLBEING**

7.1 Will you share how caregiving impacts on you mentally?

7.2 Please indicate the type of feelings you experience with regards to care you offer to a child with physical disability

7.3 How does your family react to your caregiver role?

7.3.1 How do these reactions affect you?

7.4 What are the communities' perceptions and reactions in regards to disability?

7.4.1 How have the perceptions and reactions affected you?

**COPING MECHANISMS**

8.1 What coping mechanisms do you use as a care giver for the child with a physical disability?

8.2 Who are the key people that are within the community that deal with disability issues?

8.2.1 Describe your relationship with the professionals that deal with disability issues?

8.3 Which resources are available in your community that helps you in caring for the child with a physical disability? (If not, proceed to 8.4)

8.3.1Please explain how you got to know about these resources and are they adequate?

8.4 What other resources do you want to have in the community that can help to reduce the burden of caregiving?

8.5 Are you involved in any societies/communities groups that help you in meeting some of your needs with regards to the care of the disabled child? Yes/No

Why?

8.5.1 Explain the improvements or changes that you would like to see happening in the mentioned groups?

8.6 Are there any non-governmental organisations in your community that render services?

If yes explain the services they provide

8.7 Are there any programmes that you would like to see the government implementing that will benefit the primary caregivers of children with physical disabilities?

8.8 What kind of support is needed to help reduce the burden of care?

**APPENDIX 2: PARTICIPANT INFORMATION SHEET**

School of Human and Community Development

Private Bag 3, Wits 2050,

Johannesburg,

South Africa

Tel: (011) 717-4500 Fax: (011) 717-4559

Topic: The experiences of primary caregivers in caring for children with physical disabilities in the Hardap Region of Namibia.

Good day sir/madam

My name is Allan Ndadzungira and I am a postgraduate student registered for the degree Masters in Social Work at the University of Witwatersrand, Johannesburg. I am conducting a research based on the topic: The burden of caring for children with physical disabilities: The experiences of primary care givers in the Hardap Region of Namibia. This research intends to explore the burdens that are faced by the primary care givers of children with physical disabilities focusing on physical, psychosocial, financial and policy challenges. The results of the study may assist the government and other organisations to formulate programmes and policies that will help address these challenges.

I therefore wish to invite to be one of the participants in my research. You are free to refuse to participate as your consent should be entirely voluntary. With your approval, I will make arrangements for an interview at a time and place suitable for you. The interview will last for approximately an hour in a language that you prefer. You have the right to withdraw your participation or not to answer question s you are not comfortable with.

With your approval I will tape-record the interview for record purposes and only the researcher and the supervisor will have access to them. These recordings and the interview schedules will

be secured for two years following any publications or for six years if no publications emanate from the study. Please be assured that your name and personal details will be kept confidential and no identifying information will be included in the final research report. In the event of participants feeling emotionally upset during or after the interview, arrangements have been made with the social workers from the region to provide counseling. The social workers are from the Ministry of Health and Social Services and they are based in Hardap Region. They may be contacted on +264 245264 or +264 245521

Please if you need to get in touch with me you may contact me on: +264 816857116 or andadzungira@yahoo.com or my supervisor Professor Edwell Kaseke from the University of the Witwatersrand in Johannesburg South Africa. If you have any questions regarding the study, we shall answer them to the best of our ability. Should you wish to receive a summary of the results of the study; an abstract will be made available on request.

Thank you for taking time to consider participating in the study.

Yours Sincerely

Allan Ndadzungira

**APPENDIX 3: CONSENT FORM FOR PARTICIPATION IN THE STUDY**

DECLARATION BY THE PARTICIPANT

I hereby consent to participate in the research project. The purpose and procedures of the study have been explained to me. I understand that:

- Participation in this interview is voluntary.
- That I may refuse to answer any questions I would prefer not to.
- I may withdraw from the interview at any time.
- No information that may identify me will be included in the research report.
- The study has no direct benefit, nor any foreseeable negative consequences in participating.
- Would unanticipated negative consequences arise there are contact details available and assistance, to contact these institutions will be given if needed.
- I consent to the researcher using direct quotes in his dissertation, with reference to a general code-named – so my identity will not be included in the research, and that I understand that the researcher will keep responses as anonymous as possible.

Name of Participant: _____

Date: _____

Signature: _____

**APPENDIX 4: CONSENT FORM FOR AUDIO-TAPING OF THE INTERVIEW**

I _____ consent to the recording of the interview, as part of the study of experiences of primary caregivers of children with physical disabilities.

I understand that:

- The audio files and transcripts will not be seen or heard by any, other than the researcher and the supervisor, and the information will only be processed by them.
- The audio files and transcripts will be kept in a safe and secure location, with only the researcher and the supervisor having access to these materials.
- All audio files and transcripts will be destroyed upon the obtainment of the degree. The tapes will be destroyed two years after any publication arising from the study or six years after completion of the study if there are no publications.
- No identifying information will be used in the transcripts or the dissertation and where direct quotes are used within the dissertation there will be no identification credited to the quote. References to all participants within the dissertation will be conducted with a generic alias. I understand that my confidentiality will be maintained at all times.

Date: _____

Signature: _____

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