

# **EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN WITH CEREBRAL PALSY IN MAHALAPYE, BOTSWANA**

**By**

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## DECLARATION

I hereby declare that: “Experiences of caregivers caring for children with cerebral palsy in Mahalapye, Botswana” is my own work, that all the sources used or quoted have been indicated and acknowledged by means of complete references, and that this dissertation was not previously submitted by me for a degree or any other qualification at another University.

Signature.....

Date:.....31/01/2017.....

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## **ABSTRACT**

### **EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN WITH CEREBRAL PALSY IN MAHALAPYE, BOTSWANA**

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Cerebral palsy is a neurodevelopmental condition that severely impedes a child's development. Many children with this developmental disorder may have complex limitations in self-care functions which renders them completely reliant on their caregivers. This study explores the experiences of kinship caregivers of children with cerebral palsy. The study has been based on the concern that despite extensive research on the experiences of caregivers caring for children with cerebral palsy, little research has been conducted about the experiences of kinship caregivers who care for children with this developmental disorder in a Botswana context.

The aim of this research has been to understand the experiences of kinship carers who care for children with cerebral palsy in Mahalapye, Botswana. The researcher had adopted a qualitative exploratory approach. Non-probability purposive sampling and volunteer sampling had been utilised to select the research participants. Qualitative data had been collected by utilising one-to-one semi-structured interviews. A total sample of 12 participants had been drawn from the pool of caregivers of children between the ages of six and twelve who have been diagnosed with cerebral palsy and who reside in the Mahalapye Village.

The study findings show that caring for a child with cerebral palsy exposes kinship caregivers to many challenges such as burden of care, impaired health, poverty and stigmatisation. Some of these challenges are attributed to the child's disability while some are due to insufficient services provided to caregivers. However, acceptance of the child, religious beliefs and the supportive role played by family members enable the caregivers to adapt to life with a child diagnosed with cerebral palsy.

The study concludes that challenges faced by kinship caregivers raising children with cerebral palsy in Botswana is aggravated by inadequate intervention programmes

and services that could assist caregivers and disabled children, despite a firm and comprehensive national policy on care for people with disabilities. The intervention care programme should bestow more focus on recognising caregivers' challenges and removing such obstacles by providing effective services. A support programme that could ensure continuity of care will benefit caregivers by assisting them in adapting. The study suggests that programmes that have been designed to enhance identified family resilience quality, which help families to adapt following the diagnosis of cerebral palsy of a child, should be implemented.

## **KEY WORDS**

Cerebral palsy

Caregiver

Disability

Children

Mahalapye Village

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## **TERMS AND DEFINITIONS**

Ipelegeng – Casual labour

Mmaboipelego – Social Welfare Officer

## **ACRONYMS**

BP – Blood Pressure

BCSO – Botswana Central Statistics Office

CP – Cerebral Palsy

PWD – People with disabilities

QL – Quality of Life

UN – United Nations

WHO – World Health Organization

WPA – World Programme of Action

## CHAPTER 1

### GENERAL INTRODUCTION

#### 1.1 INTRODUCTION

Although caregiving is a normal expectation of any parent who has a young child, this responsibility takes on new significance when the child suffers from functional limitations that require possible long-term care; a common need shared by children who are diagnosed with Cerebral Palsy (CP) (Huang, Kellett & St John, 2010:1214). Cerebral palsy is a neurodevelopmental condition that severely impedes a child's development and is often identifiable in the first twelve to eighteen months of the child's life (Miller, 2005:33). The term cerebral palsy is commonly used to refer to "a group of conditions that are characterised by motor dysfunction due to non-progressive brain damage, which has occurred early on in a child's life" (Levitt, 2006:1). It affects body functions and structures, activities, participation and quality of life (Liptak & Murphy, 2011:1321). There are associated disabilities as well as emotional and social family challenges that usually accompany CP (Levitt, 2006:1). Olney and Wright (2006:625) identify intellectual disability, sensory impairment and feeding difficulties as problems associated with CP. Although impaired motor function is the hallmark of the cerebral palsy syndrome, many children with this developmental disorder experience intellectual impairments and may have complex limitations in self-care functions which renders them completely reliant on their caregivers (Rosenbaum, 2004:970).

Cerebral palsy is the most commonly diagnosed disability in children, in both developed and developing countries (Miller, 2005:27). There is general consensus amongst researchers that the statistics of CP outnumber other developmental disabilities in the global paediatric population (Miller 2005:27; WHO 2006:29). Blair and Waston (2006:119), more specifically, argue that the incidence of CP is significantly higher in developing countries than in developed countries. Similarly, Mobarack, McConachie, Khan, Munir and Zaman (2003:428) note that most of the children with disabilities live in developing countries. The prevalence of childhood disabilities in developing countries in a population sample of ages two to nine years is estimated to be 70 in 1000 for all grades of disability and more specifically 22 in 1000 for severe disabilities which include CP (Mobarack et al., 2003:427). The estimated prevalence of CP in developed countries is significantly lower at 2.0 to 2.5 per 1000 live births (Mobarack et al., 2003:427).

The World Health Organisation (WHO) (2006:30) reports that there are more than 180 million children with disabilities, the majority of whom live in sub-Saharan Africa and other low-income countries. A significant percentage of the disabilities is developmental disabilities, such as CP (WHO, 2006:30). The global prevalence of CP is estimated to be 2.5 cases per 1000 live births (Blair & Waston, 2006:118). Krigger (2006:91) argues though that this estimated figure of global prevalence is low because of the late diagnoses of many cases and the number of mild cases that remain undiagnosed. Considering these factors, the figure could be as high as 5 cases per 1000 live births (Krigger, 2006:91).

In Botswana, a country with a population of approximately two million people, 2.92% of the total number of people live with disabilities and of the approximate two million people 17% are children, many of whom live in rural communities (Botswana Central Statistics Office [BCSO], 2011:209). Approximately two children in every 1000 live births are diagnosed with CP, in Botswana (Martha, 2010:53). A direct consequence of this is that a considerable number of parents and families in rural communities are burdened with raising a child with CP (Martha, 2010:53).

Caring for a child with CP places great demands on caregivers, demands that far exceed the requirements of average, developing children (Breslau, Staruch & Mortimer, 2007:682). In developing countries, where many families are already living under difficult conditions with few resources and little access to appropriate services the pressure on caregivers caring for children with CP is even greater (Mobarack et al., 2003:601). Compounding the pressures on these caregivers is the fact that CP cannot be cured (Miller, 2005:721). Regardless of this, there are a host of interventions that improve functional disabilities and the quality of life of the child but they require an on-going, active participation by the caregivers in the care of these children, as many of them are cared for at home (Mobarack et al., 2003:601). Martha (2010:58) indicates that there are no respite care facilities within rural communities and the burden of caring for these children is therefore not shared.

Despite this heavy burden not being shared Huang et al. (2010:1217) note that caregivers of children with CP are still required to manage their children's conditions effectively while simultaneously meeting the requirements of everyday living. Greef and Nolting (2013:396) however note that despite the difficulties associated with caring for a child with a developmental disability such as CP, many families have adapted successfully and even thrive following the birth or diagnosis of a child with a disability.

The aim of this study has been to understand the experiences of kinship caregivers of children with CP. The sample of this study has been drawn from a village called Mahalapye, in Botswana. The results of this study might guide social workers and other professionals during the design of intervention care programmes aimed at assisting children with developmental disabilities such as CP, and their caregivers.

## 1.2 DEFINITION OF KEY CONCEPTS

**Cerebral palsy:** Cerebral palsy (CP) is defined as “a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain” (Rosenbaum, Walter, Hanna & Russell, 2007:1359).

**Caregiver:** Family Caregiver Alliance (2015) asserts that a caregiver is an unpaid individual, such as a family member, who provides care to individuals who need long-term care when a chronic condition, trauma or illness limits their ability to carry out basic self-care activities. These activities include bathing, dressing, eating or instrumental activities of daily living such as household chores. In this study caregiver refers to the ‘kinship carer’ in the family unit and will be described as just caregiver(s) hereafter.

**Disability:** Seligman and Darling (1997:89) define disability as “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being, such as a child with cerebral palsy being restricted from participating in a sports event owing to physical limitations”. WHO (2006:30) states that disability is “an umbrella term, covering impairments, activity limitations and participation restrictions”.

**Children:** The Botswana Children’s Act 86 of 2009 defines a child as “a person below the age of 18”.

**Mahalapye Village** with an estimated population of 23 297 is found in the Central District of Botswana (Botswana Central Statistics Office, 2011:3). According to the Botswana Central Statistics Office (2011:204), the Central District had a disability prevalence rate 3.5% higher than the national prevalence rate of 2.9%.

## 1.3 THEORETICAL FRAMEWORK

Greeff and Nolting (2013:396) suggest that parents and families face a period of adjustment and adaptation following the diagnosis of a developmental disability.

They need to re-evaluate the expectations they had for their children, as well as coping with the stresses associated with the demands of daily care.

This research is based on the resilience model of family stress, adjustment and adaptation that had been developed by McCubbin and Associates, in 1989 (Weber, 2011:171). This model is found in theories of resilience which have been proposed by various researchers (Compton, 2005:48; Fletcher & Sarkar, 2013:17; Weber 2011:171). The resilience theories are based on the assumption that there is potential for positive adaptation within significant adversity (Compton, 2005:48).

It is well-documented in the literature that caring for a child with CP has significant challenges that place additional pressure on caregivers. Other investigations however claim that despite difficulties associated with caring for a child with CP many families have been found to be doing well (Greeff & Nolting, 2013:396; McConnell, Savage & Breitzleuz, 2014:833). This is supported by Compton (2005:48) who mentions that there is potential for positive adaptation within significant adversity. Positive adaptation in response to, or despite, the stressors associated with raising a child with disabilities may constitute evidence of resilience in families of children with CP (McConnell et al., 2014:834). Weber (2011:171) defines resilience as the ability to withstand and rebound from adversity while family resilience refers to the characteristics that help families resist disruption in the face of change and adapt in the face of crises. Greeff and Nolting (2013:397) mention that a family's response to a stressor will depend on the unique interaction between the risk factor and the protective factors within the family unit, the socio-cultural and developmental context, and the family's subjective perception of the stressor. Bayat (2007:702) adds that family protective factors, in combination with family recovery factors, facilitate the family's ability to bounce back after a family crisis.

Walsh (2003:5) identifies three domains in family functioning, discussed hereafter, which facilitate the reduction of stress and empower families to become more resilient.

**A family's belief system** provides the family with a shared set of behavioural guidelines based on shared morals and values. For instance, religion and spirituality have been identified as resilience factors during periods of adversity.

**A family's organisational process** refers to a familial process that facilitates coping and adapting such as reframing a crisis as 'a challenge that is meaningful and

manageable'. Numerous studies have found that families who are able to draw meaning from and accept their situations are better able to adapt than those who do not (McConnell et al., 2014:834; Krstic & Oros, 2012:373; Greef & Nolting, 2013: 373). Walsh (2003:5) is of the view that family units in which family members feel they can depend on each other and work together to overcome adversity adapt better than those family units that have little commitment to each other, as this will influence mutual support, understanding the uniqueness of each person within the family unit, collaboration and commitment which includes sharing responsibility, and the ability to mobilise resources (Greef & Nolting, 2013: 398).

**A family's communication skills** that are clear and open will enable constructive conflict resolution and joint decision-making. Communication is described as a key resilience resource employed by families to manage the demands they may face. This is confirmed by Greeff and Nolting (2013:403) who find that a pattern of communication that emphasises and encourages open communication allows family members to reach a shared understanding of their situation and of the changes necessary for them to adapt successfully.

The Resiliency Model of Family Stress, Adjustment and Adaptation provides a theoretical framework that outlines the processes involved during a family's response to a stressor. Weber (2011:172) mentions that within the resilience model of family stress two related processes – adjustment and adaptation – uniquely promote the family's ability to adapt to and recover from a familial crisis.

### **1.3.1. The Adjustment Process**

Greef and Nolting (2013:397) point out that a family faced with any stressors needs to adjust its lifestyle to incorporate the impact of the stressors, thereby restoring harmony and balance to all domains of functioning and achieving a state of well-being and equilibrium. Positive adjustment to a situation is characterised by the restoration of harmony and balance by using existing resources with minimal changes to the established patterns of family functioning (Greef & Nolting 2013:397). Some of the strategies that a family could consider for restoring balance and harmony include adopting more effective communication styles, and seeking help from other people such as friends and relatives (Weber, 2011:177; Krstic & Oros, 2012:374).

The adjustment phase involves the influence of family protection factors that enhance the family's resistance to adversity (Weber, 2011:171). It consists of the variables of

stressor appraisal, the family's level of vulnerability, established patterns of functioning, family resources, and problem-solving and coping (Weber, 2011:172). McCubbin (2001:38) identifies elements that could impact the family's level of vulnerability. These elements include: contextual difficulties created by society that adversely affect family functioning; the family's ability to cope with a crisis; and consequences of the family's efforts in coping.

Families may employ coping strategies that appear to be effective in the short-term but which may to the contrary create greater difficulties in the long-term – accumulation of pre- and post-stress factors such as physical-, emotional- and psychological health. These factors are common and significant when families are dealing with chronic stressors such as caring for a child with a disability. During the adjustment process, a family's level of vulnerability will contribute to the crisis and have an impact on the family achieving harmony and balance (McCubbin, 2001:42).

Fletcher and Sarkar (20013:19) note that the components of the adjustment phase interact to determine the outcome of the family's exposure to a stressor (Weber, 2011:172). In support of this argument, is the view that the family's appraisal of the stressor will significantly influence problem-solving and coping strategies for successfully managing the stress and its related hardships (Krstic & Oros, 2012:374). According to the resilience model, the family's problem-solving skills include the family's ability to regard the stressor as manageable, identify alternative courses of action, and use resources and initiate efforts to resolve the hardship (Weber, 2011:176). Further to this Weber (2011:172) defines stressor as "any demand placed on the family that may produce changes in the family system which may include disruption of family functioning, family income and sibling adjustment". Rosenbaum et al. (2005:627) raise the argument that when caring for a child with CP, the family routine is likely to be disrupted due to the time spent on the child with the disability, and healthy siblings may feel rejected and unimportant. Considering this, the family should establish new patterns of functioning (Weber, 2011:172) to restore harmony and balance (Greef & Nolting, 2013:397). Vijesh and Sukumaran (2007:77) emphasise this point by mentioning that the child's disability may obligate all members of the family to make sacrifices and this may require an adjustment in the family unit's functioning.

Familial resources is a key element in the adjustment phase. It refers to the family's ability and capability to tackle and manage stressors which ultimately lead to

successful adjustment (Weber, 2011:176). Some of the more essential familial resources include social support, cohesiveness, belief system and financial stability. McConnell et al. (2014:833) note that families who have children with disabilities do well or at least better with strong social support and little financial hardship. The family's resistance-resources influence the family's appraisal of the stressor. The family's appraisal of the stressor refers to the family's opinion on the severity of the stressor and its hardships as a setback or a catastrophe (Weber, 2011:176). The family's appraisal of stressors is shaped by the family schema or view of itself in relation to the environment, and its sense of coherence, culture and spirituality/religion (Greef & Nolting, 2013:397).

The result of the adjustment process is either bon-adjustment, mal-adjustment or crisis within the family (Hall, Neely-Barnes, Graff, Krcek & Roberts, 2011:27). Hall et al. (2011:27) report that bon-adjustment happens when families progress through a challenge without difficulty while families in mal-adjustment do not easily attain stability. Of similar view are Greef and Nolting (2013:397) who highlight that when demands exceed capabilities and the family cannot achieve stability the result is a family crisis. A family in crisis is disorganised and needs modifications in the family functioning system and these changes mark the beginning of the adaptation phase (Hall et al., 2011:27; Weber, 2011:177).

### **1.3.2. The Adaptation Process**

The adaptation process involves the recovery factors which promote the family's ability to regain stability following a family crisis (Weber, 2011:177). The success of the adaptation phase is determined by the interaction of the family's patterns of functioning which include both newly instituted and established patterns, the family's internal resources such as cohesion, adaptability, communication, the family's support network system, problem-solving and coping (Weber, 2011:177; Greef & Nolting, 2013:397). Some of these factors are discussed hereafter.

**New family functioning patterns.** The purpose of new patterns of functioning is to bring about change in family dynamics, to manage the stress and to restore family harmony and balance in order for the family to successfully adapt. These include patterns involving changes in: the family's routines; the family's interaction with the community; and rules and boundaries in the family unit. It is, however, possible that these newly instituted patterns of functioning may lead to added strain, for example when families struggle to make sense of their new roles.

**The family's support network.** Families who are able to develop and utilise support network systems are both more resistant to major crises and better able to recover and restore stability after a crisis. The researchers McConnell et al. (2014: 835) and Hall et al. (2011:38) concur that during the adaptation process the family utilises its resources to be able to meet the demands associated with the crisis. Such support systems may include formal sources such as medical and social services, government policies and informal sources such as friends; family members; and work colleagues. McConnell et al. (2014: 835) comment that if reasonably good resources are present in a family's support network the outcomes appear to be good, even in the face of severe stressors. Hall et al. (2011:38) add that access to and availability of resources to parents of children with disabilities are important for family resiliency.

**Problem-solving and coping.** During the process of adaptation, the family employs its problem-solving and coping strategies. The problem-solving process prompts changes within the family as well as in the relationships between the family and the community and environment. Within the Resiliency Model, 'family coping' refers to the attempt made by the individual and the family to reduce or manage the demands on the family system.

The common conclusion drawn from the family resilience framework is that family resilience goes beyond merely surviving a crisis and encompasses the potential for growth that may be borne from adversity, encouraging key processes for resilience. Should this happen the family could emerge from the challenge stronger and more resourceful, should they encounter further challenges in the future.

#### **1.4 RATIONALE AND PROBLEM STATEMENT**

Studies identify cerebral palsy as a neurodevelopmental condition that severely affects a child's development leaving him or her dependent on caregivers (Miller, 2005:33; Liptak & Murphy, 2011:1321). This dependency places demands on the caregivers that exceed the usual requirements of developing children (Breslau et al., 2007:682). Mobarack et al. (2003:601) add that in developing countries, the pressure is even greater because many families are already living under difficult conditions with few resources and little access to appropriate services. Within Botswana, as a developing country, CP is a commonly diagnosed childhood disability and several cases are found in rural communities (Martha, 2010:53; BCSO, 2011:83). Mahalapye

Village is one example of a rural community in Botswana, and it has a significant number of children who have been diagnosed with CP (BCSO, 2011:216).

Despite extensive research on the experiences of caregivers caring for children with CP, there is little research about the experiences of kinship caregivers of children with CP in Botswana, as most studies are international studies. In 2003, Mobarack et al. conducted a study on the predictors of stress in mothers of children who have been diagnosed with CP in Bangladesh. Furthermore, a Canadian-based study conducted by Reid, Imrie, Brouwer, Clutton, Evans, Russell and Bartlett (2011) present parents' reflections on raising a child with CP. The researcher is of the opinion that conducting a similar study in Botswana might provide information that is not available in published literature on the experiences of kinship caregivers caring for children with CP in Botswana. Such information might be valuable for social workers and other professionals during the design of intervention programmes for children with CP. Furthermore, the findings of this study might help the researcher recommend social work intervention strategies that would address challenges faced by caregivers of children with CP.

One of the burdens of a CP diagnosis is that there is no cure. The caregivers of children who have been diagnosed with CP therefore are faced with a lifetime commitment of ensuring that the children receive and are exposed to interventions that improve functional abilities and quality of life. These interventions require caregivers to be active participants in the care for these children (Miller, 2005:721; Mobarack et al., 2003:601). Martha (2010:58) notes that there are no respite care facilities in rural communities where many children with CP reside, therefore the care for these children is the sole responsibility of their caregivers. All these facts motivate the researcher to analyse the experiences of kinship caregivers of children with CP, in Botswana.

Despite the difficulties associated with caring for a child with developmental disabilities, many families have successfully adapted to their new lifestyles (Greef & Nolting 2013:396). The researcher will seek to gain an understanding of how caregivers of children with CP adapt to the demands and stressors. This understanding could guide support interventions efforts for families of children who have been diagnosed with CP.

## 1.5 RESEARCH QUESTION

In this study, the researcher seeks to study, understand and analyse the experiences of caregivers who care for children who have been diagnosed with cerebral palsy. The research question that the findings of this study attempt to answer is: **What are the experiences of caregivers caring for children with cerebral palsy in Mahalapye, Botswana?**

## 1.6 GOAL AND OBJECTIVES OF THE STUDY

### 1.6.1. Research Goal

The goal of this research study had been to understand the experiences of caregivers who care for children with cerebral palsy in Mahalapye, Botswana.

### 1.6.2. Research Objectives

The research objectives were:

- To conceptualise cerebral palsy from literature as a childhood disability.
- To explore and analyse the caregivers' experiences of living with children who have been diagnosed with cerebral palsy.
- To explore and describe the care required for children who are diagnosed with cerebral palsy.
- To suggest strategies for professional interventions that could broadly promote the well-being of the caregivers of children with cerebral palsy.

## 1.7 RESEARCH DESIGN AND METHODOLOGY

In this study the research approach that had been utilised was the qualitative approach. The research design was a descriptive case study. The study population had been drawn from caregivers of children with cerebral palsy who reside in Mahalapye Village. One-to-one semi-structured interviews had been conducted to collect data. Data analysis, details of the research methodology and the ethics involved in the study are discussed in Chapter 3.

## 1.8 LIMITATIONS OF THE STUDY

The main limitation of this study had been identified in the recruitment stage. The study has only been advertised in the occupational unit which means caregivers who do not utilise the rehabilitation services could not take part in the study. Therefore, the views of those living exclusively in the rural community could not be captured.

In addition, due to the research's qualitative characteristic, the study sampling would be too small to generalise the results to a larger population of caregivers of children with cerebral palsy.

Many participants are female as they constitute the majority of the research population. The findings are therefore mainly based from a female point of view and cannot be extended to the male counterparts.

## **1.9 OUTLINE OF THE RESEARCH REPORT**

The following chapters constitute the final research report.

### **Chapter one: Introduction**

This chapter will consist of a general introduction to the study, rationale and problem statement, research question, theoretical framework and the goal and objectives of the study. A summary of the research methodology, literature and definition of key concepts are also discussed in this chapter.

### **Chapter two: Literature review**

This chapter will focus on conceptualising cerebral palsy as a childhood disability, and will review previous studies on the challenges of raising a child diagnosed with CP as well as caregivers' ability to cope with living with children diagnosed with CP.

### **Chapter three: Research methodology, ethical considerations and empirical findings**

The third chapter will describe the research methodology that will be utilised during this study which includes sampling procedure, data analyses procedure as well as ethical considerations. Study findings will also be presented.

### **Chapter four: Conclusions and recommendations**

Based on the study findings this chapter will discuss the conclusions of the study and make recommendations for future research.

The next chapter presents detailed discussions on the challenges of raising a child who has been diagnosed with cerebral palsy.

## CHAPTER 2

### CHALLENGES OF RAISING A CHILD WITH CEREBRAL PALSY

#### 2.1 INTRODUCTION

Raising a child with cerebral palsy is stressful for caregivers because it requires intensive physical engagement as well as emotional reaction to the child's condition (Krstic & Oros, 2012:373). Parents have different modes of adapting to stress and demands caused by this disorder (Croot, Grant, Mathers & Cooper, 2012:1540). The Resilience Model of Family Stress, Adjustment and Adaptation postulates that the utilisation of certain coping strategies facilitates successful family adaptation to the child's condition (Krstic & Oros, 2012:373; McConnell et al., 2014:834).

This literature review section explores issues regarding the care given to children with CP and the quality of life of the caregivers of children with CP. A description of the classification of CP and associated impairments and problems are provided to better describe some of the challenges that the caregivers might face which may impact the family's adjustment and adaptation. The theoretical framework is discussed first, as it gives insight into the resilience factors which contribute to a family's adjustment and adaptation when it is exposed to the prolonged stress of living with a child diagnosed with CP. The main concepts that relate to the study will also be discussed in greater detail.

#### 2.2 CONCEPTUALISATION OF CEREBRAL PALSY

Cerebral palsy is first identifiable when a child fails to reach motor skills milestones and displays qualitative differences in motor function development, such as asymmetric gross function or unusual muscle stiffness or floppiness (Rosenbaum et al., 2007:1359). Miller (2005:726) concludes that these limitations can result in the child requiring long-term care which exceeds the usual requirements of children as they develop. The intensity of the care required will also vary depending on the type of CP that the child has been diagnosed with.

##### 2.2.1. Characteristics of Cerebral Palsy

Experts in the field agree that cerebral palsy is a combination of characteristics attributed to brain injury (Miller, 2005:31; Levitt, 2006:1; Rosenbaum et al., 2007:1359). A commonly used definition of CP describes the condition as "a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the

developing foetal or infant brain” (Rosenbaum et al., 2007:1359). This condition is the most common disability amongst physically disabled children and the most diverse with respect to degree of severity (Rosenbaum et al., 2007:1360). Liptak and Murphy (2011:1321) are of the view that impaired control of motor functions, which has a potentially negative effect on the overall development of the child, is the most visible characteristic of CP. Problems associated with the deficit of motor skills include muscle weakness, fatigue and incoordination (Liptak & Murphy, 2011:1321). Depending on the affected area of the brain, the child with CP may experience hearing loss, poor vision (Levitt, 2006:2; Miller, 2005:33), or emotional and behavioural problems (Sipal, Schuengel, Voorman, Van Eck & Becher, 2009:75).

### 2.2.2. Types of Cerebral Palsy

There are three types of cerebral palsy which are characterised according to which part of the brain is affected and what the symptoms are. These are: spastic; dyskinetic; and ataxic and are discussed below (Rosenbaum et al., 2007:1359).

- **Spastic cerebral palsy** is the most common form of CP and is characterised by hyper-excitability of the stretch reflex that leads to a velocity dependent enlarge in tonic stretch reflexes with exaggerated tendon jerks (Abdel-Gawad, Abdel-Karim & Mohammed, 2015:270). Abdel-Gawad et al. (2015: 270) further explain that the contraction of the spastic muscle groups will cause skeletal deformities that limit the patient’s activity because the brain cells which control movement are damaged. Jones, Morgan, Shelton & Thorogood (2007:150) contend that spastic CP speaks to the disorder, and the difficulty of a person’s movement is a result of stiff and tight muscles. Stiffness of the muscles in spastic CP in children occurs when there are defects or damage in the brain’s corticospinal pathways (Jones et al., 2007:150). Jones et al. (2007: 150) identify spastic CP as the most common type of CP, occurring in approximately 70 to 80 percent of children who have been diagnosed with CP.
- **Dyskinetic cerebral palsy** results from an abnormality in the group of brain cells which help coordinate movement. An injury to these cells causes uncontrollable movements of the limbs and body. The most common form of dyskinetic CP is athetosis which is characterised by low muscle tone, slow, writhing movement patterns and involuntary jerking of the head or of the arms and legs as well as the muscles of the face and the tongue, causing grimacing or drooling (Ross & Deverell, 2004:189). This type of CP is also associated with speech production

problems, and unexpected changes in the rate and volume (Ellison & Semrud-Clikeman, 2007:102).

- **Ataxic cerebral palsy** is a defect of the cerebellum at the base of the brain. It is characterised by balance problems, weakness, uncoordinated movements and difficulties with fine motor skills. Rosenbaum et al. (2007:1359) highlight that children with this type of cerebral palsy are often unsteady and find it difficult to balance and coordinate gait.

Furthermore, there are three classifications that are characterised by the types of cerebral palsy. These are: quadriplegia, when all the limbs are equally affected but sometimes the arms are affected more than the legs; diplegia, when all the limbs are affected but the arms are less affected than the legs; and hemiplegia, when only the limbs on one side of the body are affected (Levitt, 2006:5). Quadriplegia is usually characterised by either spastic or dyskinetic CP while hemiplegia is usually characterised as a spastic type of CP (Levitt, 2006:5). Rosenbaum et al. (2007:1361) note that many children with CP have a combination of two or more of these classifications which influence the degree of their impairments.

### **2.2.3. Causes of Cerebral Palsy**

Although a variety of factors contribute to cerebral palsy, it is often the combined cause of a complex interplay of numerous factors. Ross and Deverell (2004:188) highlight that damage to the brain can occur during the prenatal, perinatal or postnatal stages as a result of conditions that affect both the mother and the foetus or child. Factors that affect the child directly include infections such as meningitis, malaria and measles; low birth weight; complications arising from premature birth; and head injury/ies. Maternal conditions such as rubella, AIDS, bleeding during pregnancy and multiple pregnancies are also factors that cause CP in the child (Ross & Deverell, 2004:188). Prenatal risk factors associated with CP include hypoxia, genetic disorders, metabolic disorders (such as maternal diabetes), multiple gestations, intrauterine infections, maternal fever, exposure to toxins (such as toxic substances in X-rays), malformation of brain structures, intrauterine growth restriction, abdominal trauma, vascular insults, rubella in the mother during the first trimester of pregnancy and maternal anoxia (Ross & Deverell, 2004:188; Rosenbaum, 2004:973). Risk factors during the perinatal stage include breech delivery, placental abruption, cord prolapse and instrumental delivery.

The postnatal risks factors attributed to complications that could occur after the process of delivery may include some cerebral infections such as: catastrophic infections; and cerebro-vascular accidents (Kriger, 2006:95).

Rosenbaum (2004:973) further highlights that causes of CP change based on time and context. He highlights that in developing countries the incidences of CP are significantly more than in developed countries, and are influenced by a variety of sociological variables which include access to resources, the effects of low socio-economic conditions, the absence of public education programmes and traditional practices of healing. Young (2004:125) concurs that the socio-economic status of the family is significant regarding the onset of CP in the paediatric population in a developing country. This is agreed upon by Levin (2006:287) who highlights that poverty plays a pivotal role in placing neonates at risk for significant biological risk, including conditions which may result in CP. This is because mothers are rarely able to afford prenatal care, they have been exposed to communicable diseases and they receive inadequate nutrition. Levin (2006) further explains that rural communities are, for the most part, far away from health care facilities and due to the relative geographical isolation, access to specialised care and intervention is not possible. These sociological variables however are not well-defined or recognised in developing countries and are overlooked as contributing factors of CP (Rosenbaum, 2004:973). In developed countries, the factors that cause CP are well-defined and are therefore preventable, which results in proportionately fewer diagnoses (Rosenbaum, 2004:973).

In Botswana, the common cause of CP is not clearly defined due to limited research in the field. However, Martha (2010:52) highlights that maternal illnesses such as HIV/AIDS, anaemia and obstetric complications seem to have a strong link to the onset of developmental disabilities which includes CP, in Botswana.

#### **2.2.4. Impairment and Disabilities Associated with CP**

Children with CP often experience disabilities which may cause complications, affecting their quality of life and life expectancy (O'Shea, 2008:36). When combined with other disabilities, these complications could have a greater effect on the child's development. For instance, Liptak and Murphy (2011:1321) mention that delayed motor function affects the development of the child's capacity to actively explore.

Motor function defects or dysfunction is the most common characteristic of CP. This is due to the disorganised and delayed development of the neurological mechanisms of postural control and movement (Liptak & Murphy, 2011:1321). Liptak and Murphy (2011:1321) state that the muscles activated during movement are inefficient and uncoordinated. Some of the complications associated with motor impairment include underdeveloped bones and joints, joint contractures caused by immobility, osteoporosis and deformities such as scoliosis (Ross & Deverell, 2004:189).

Ross and Deverell (2004:189) state that although movement and posture are the primary characteristics of CP, most people with CP present with associated problems, some of which are results of the primary brain damage as well as restricted environmental and learning opportunities. Of the same view is Levitt (2006:2) who points out that brain damage, in CP, may also be responsible for sensory defects in vision and hearing, abnormalities of speech and language, epilepsy and irregularity of perception. Levitt (2006:9) adds that hearing loss of a specific high frequency is associated with dyskinetic CP which is caused by kernicterus. Perceptual problems, especially of body and spatial relationships, are more common in spastic CP (Levitt, 2006:9). Additionally, Olney and Wright (2006:625) identify intellectual disability and feeding difficulties as problems associated with CP. Malik, Zafar, Razza, Butt, Khan and Mughal (2007:16) mention that growth failure in children with CP is due to an inability to independently access food and the occurrence of recurring infections. Some of these associated problems of the disorder are discussed below.

#### **2.2.4.1 Visual and hearing impairments**

Visual and hearing impairments are common amongst children with CP and are caused either by the neurological damage that caused the CP or by secondary complications (Levitt, 2006:9; O'Shea, 2008:36; Ross & Deverell, 2004:189). O'Shea (2008:36) reports that approximately 23% of children who have been diagnosed with CP suffer from visual impairment too. Similarly, Odding, Roebroek and Stam (2006:188) add that a significant percentage of individuals with CP have some kind of visual impairment. Levitt (2006:9) supports this and goes into greater detail by highlighting that children with CP have a greater chance of suffering from poor muscle control and this result in squints, damage to the optic nerve, and long- and short-sightedness. Similarly, Ross and Deverell (2004:189) comment that eye movement in children with CP are affected by abnormal muscle control.

People with CP also experience difficulties with auditory perception (Ross & Deverell, 2004:189). Levitt (2006:9) identifies two common types of hearing problems associated with CP, namely, high frequency deafness and auditory agnosia. Should caregivers fail to seek intervention for the hearing and visual impairments as soon as possible these impairments could interfere with the child's developmental progress (Jan, 2006: 126).

#### **2.2.4.2 Speech and language problems**

The inability of someone with CP to communicate is frequently one of the most restricting impairments (Ross & Deverell 2004:190). Cerebral palsy is a result of brain damage, and the cerebral lesion(s) impact(s) the neuromuscular control of the speech mechanisms, and therefore the higher cerebral functions such as language and communication are frequently affected, known as dysarthria (Jan, 2006:129). Ross and Deverell (2004:190) concur that the speech of many people with CP can be unintelligible owing to poor motor and sensory control for speech production. A significant proportion of individuals with CP have impaired language skills which may be due to brain damage but it could also be a result of environmental deprivation caused by the individual's limited mobility and social isolation (Levitt, 2006:3; Ross & Deverell, 2004:190).

### **3 Epilepsy**

Seizure disorders occur in up to 35% of children with cerebral palsy and are associated with behavioural problems, cognitive dysfunction and a range of psychosocial problems (Ross & Deverell, 2004:189). Similarly, Odding et al. (2006:184) found that at least one third of children with CP experience seizures which are influenced by the degrees of motor and cognitive disabilities. Odding et al. (2006:184) further add that the presence of epilepsy in children with CP can be an indication of the severity of the neurological damage. Other studies indicate that epilepsy in children with CP is associated with social stigmatisation and this places extra burdens on caregivers (Ross & Deverell, 2004:189).

### **4 Behavioural problems**

Children with cerebral palsy have been found to show elevated levels of emotional and behavioural problems, including disruptive behavioural problems such as high impulsivity and externalising behaviours such as disobedience and aggression (Sipal et al., 2009:75).

Sipal et al. (2009:83) find that children with CP who have high levels of pain are the ones with the highest level of behavioural problems. However, Goodman and Yude (2000:116) argue that milder forms of CP could be just as stressful because the individuals with CP may feel uncomfortable in the presence of their peers because they always need help with self-care. On the contrary, however, a study finds that even though children with CP have more behavioural problems in comparison to their normally developing peers, their negative behavioural problems diminish over time as they gradually adjust to their impairments (Hinton, Nereo, Fee & Cyrulnik, 2006: 472).

### **2.2.5. Management of Cerebral Palsy**

There is no cure for cerebral palsy, however, children who have been diagnosed with CP can receive rehabilitation therapy (physiotherapy, occupational speech therapy) and undergo surgical procedures to help them reach their potential (Miller, 2005:721). Professionals and parents can, by working together, minimise the secondary problems associated with CP to ensure that each child achieves as much of their potential as possible (Miller, 2005:721). Supporting this, Brandao, Olivera and Mancini (2014:563) mention that collaborative actions between family and therapist are essential in the rehabilitation process, as they could be catalyst mechanisms for the positive outcomes achieved by children with CP.

The central goal of the rehabilitation process is to promote the child's participation in significant life context, so it is therefore paramount that different rehabilitation professionals are consulted (Brandao et al., 2014:564). Stanger and Oresic (2003:579) contend that rehabilitation professionals have an ethical responsibility to utilise and apply therapeutic techniques and intervention strategies that will generate improved functional limitations as well as efficiently utilise resources when there is a reasonable prognosis for improvement and change. Jones et al. (2007:227) report that other than promoting function, the rehabilitation professionals help in the acquisition of new skills and educate caregivers on the daily care needed by children with CP. Some of the roles of these professionals are outlined hereafter.

Children with CP will often exhibit a broad spectrum of impairments. The physiotherapist should determine which of these impairments impact the child's functioning and ability to participate (Stanger & Oresic, 2003:579). Physical therapy aids in motor development and in the prevention of muscle deterioration, and orthotic devices and braces are utilised to stretch spastic muscles, which can improve

balance and motor development (Jan, 2006:123). Studies that have been conducted that determine the effectiveness of physiotherapy in children with CP reveal that the physiotherapy promotes normal motor development and therefore prevents deformity and contractures following early intervention (Capjon & Bjork, 2010:183). The authors add that successful physiotherapy requires sound planning, realistic goal-setting and a high degree of motivation by the child and the parents.

A variety of orthopaedic problems are associated with cerebral palsy. For instance, the spastic muscles in CP may lead to progressive joint contractures, hip deformities or dislocation (Jan, 2006:127; Abdel-Gawad et al., 2015:270). The orthopaedic surgeon will therefore need to treat severe contractures of muscles that have been identified as limiting the child's mobility (Jan, 2006:127). Krigger (2006:94) agrees that the responsibility of the surgeon in the management of CP is prevention and correction of contractures, deformities and dislocations. Krigger (2006:94) states that common orthopaedic surgical procedures for children with CP include: wrist function; and tendon transfers in the upper limbs. In a study which investigates the functional outcome of orthopaedic surgery, findings indicate that prevention of deformation by correction assist in the development and training of the necessary movements of the child (Abdel-Gawad, et al., 2015:270). The authors add that after orthopaedic surgery, the child may be given orthopaedic products such as prosthetics and orthopaedic devices which make it possible for the child to move and ensure stable retention of limb segments in their correct positions.

Speech therapy aids the development of communication and language skills (Jan, 2006:129; Chen, Liu, Chung & Wu, 2010:417). Chen et al. (2010:417) point out that speech therapy for someone with impairment should be focussed on the assessment of speech, language and communication and the treatment should be focussed on the integration of the aspects of speech control. Miller (2005:166) states that the malfunctioning of feeding and swallowing in children with CP is evaluated by the speech therapist. Miller (2005:166) further highlights that many paediatric hospitals have multidisciplinary feeding clinics, in which the speech therapist is a key member, for children with complex oral motor dysfunction.

Occupational therapy focuses on the functional activities of daily living and the fine motor skills of the upper extremities (Miller, 2005:651). The same author states that upper extremity splinting, to improve function or prevent contractures, is an important practice in occupational therapy. Oien, Fallang and Ostensjo (2010:560) add that the

focus of rehabilitation occupational therapy is dependent on the age and the functional ability of the child with CP. For instance, management of CP in early childhood would focus on activities such as self-feeding, removing clothes, fine motor skills such as using scissors, and writing skills. While middle childhood intervention would focus on fine motor skills development such as writing skills, self-dressing and toilet training (Oien et al., 2010: 560; Reid et al., 2011:171).

Although CP management requires a multidiscipline team approach, Mobarack et al. (2003:601) identify caregivers as the primary role-players in the rehabilitation of children with CP. The rehabilitation programme relies primarily on mothers being trained in specific skills to be able to help their children develop. Similarly, Rosenbaum (2011:68) mentions that the family of a child with a disability plays a central role in the well-being of the child. The family of the child, more specifically the primary caregiver, needs to be actively involved in the rehabilitation process of the child (Rosenbaum, 2011:69). Brandao, Oliveira and Mancini (2014:564) emphasise that collaborative action between family and therapist is essential for developing individualised rehabilitation strategies to effectively promote the child's functionality. However, the authors single out the involvement of caregivers as being of paramount importance – the parents of children with CP are highly knowledgeable regarding their children's skills and needs and therefore play a significant role in designing the rehabilitation programme.

Oien et al. (2010: 561) concur that parental involvement in the decision-making process about therapeutic goals is an important element and cannot be omitted from the rehabilitation process. This is supported by Lammi and Law (2003:289) who claim that intervention could only be optimised if professionals recognise the role of parents in the therapeutic process.

A study that explores parents and professionals' perspectives regarding the establishment of meaningful goals for families of children with CP, finds that the involvement of parents in establishing therapeutic goals could increase feelings of competence and participation (Oien et al., 2010:561). Brandao et al. (2014:564) conclude that participation of caregivers in the rehabilitation process give them opportunities: to seek information that is useful for improving the children's functional performance in daily living activities; to transfer the learning acquired in the therapeutic environment to the domestic context; and to gain insight into the impairments and disabilities of their children.

Given the importance of the roles played by the various professionals in the rehabilitation of children with CP, some investigations have noted dissatisfaction in the relationships between caregivers and professionals (Fereday, Oster & Darbyshire, 2010: 625; Reid et al., 2011:170). Reid et al. (2011:170) find that, in general, parents are dissatisfied with the amount of information that is provided regarding the diagnosis and its impact on the child and the family despite interacting with the professionals more often. Similar findings have been found by Fereday et al. (2010:627) – caregivers report that there is a lack of transparency and specificity about the child’s diagnosis which inhibits their support for their child’s eligibility and access to much needed support. Dempsey and Keen (2009:43) believe that an unsupportive professional relationship exacerbates the difficulties faced by parents and families of children with disabilities. Fereday et al. (2010:625) describe professional support as the strongest predictor of family quality of life, when considering child and family characteristics and support from the extended family.

#### **2.2.6. The Role of Traditional Practitioners in the Management of Cerebral Palsy**

There is consensus among scholars that traditional practitioners play a significant role in the management of CP (Levin, 2006:288; Ross & Deverell, 2004:39). Levin (2006:288) reports that the beliefs and practices of traditional healers differ from those of Western practitioners. Traditional healers regard CP much like other disorders – as having magical, ancestral and spiritual meaning (Levin, 2006:288; Ross & Deverell, 2004:39). Their treatments of children with CP involve making peace with the ancestors and attempting to restore the person’s physical, psychological and spiritual world by utilising various plant and animal remedies, and ritual sacrifices (Ross & Deverell, 2004:39). In contrast, Western medicine aims to correct the disorder itself through various interventions as discussed earlier.

Although it is reported that a significant percentage of families of children with disabilities seek the services of traditional healers, Levin (2006:288) mentions that imbalances in the health care system push families of children with disabilities to resort to seeking help from traditional practitioners. The author points out that rehabilitation services in the public sector are not sufficiently developed. Few public hospitals provide cohesive management for children with CP, and few families are able to afford quality services in the private sector because of the financial burden of long-term rehabilitation. Thus, families of children with CP resort to consulting

traditional healers who are accessible in terms of affordability and geographical distance. The researcher believes that consulting with traditional healers may, at times, worsen the condition as the degree and prognosis of impairment may not be sufficiently understood.

### **2.3 THE ROLE OF SOCIAL WORKERS IN FAMILIES WITH CHILDREN DIAGNOSED WITH CEREBRAL PALSY**

There is a strong association between psycho-education, family support and positive outcome (Kriger, 2006: 97; Ross & Deverell, 2004:192). A social worker identifies community resources and makes referrals for children with CP for early childhood programmes (Kriger, 2006:97). Another significant role of a social worker in the management of CP is educating caregivers on the conditions of their children. Ross and Deverell (2004:192) mention that at times the parents of children with CP report that they do not necessarily understand the terminology utilised by health care providers, which often creates a barrier that results in caregivers being unable to access information on available resources for the prognosis of the condition. This creates an opportunity for social work interventions to ensure that parents understand their children's diagnoses. A social worker can also introduce parents to assistance networks which could include housing, health, recreation and educational services (Mackelprang & Salsgiver, 1999:233).

Other than the therapeutic social intervention previously discussed, a social worker plays a significant role in preventative interventions to address the needs of people with disabilities and that of their families. Discrimination and indifference towards people with disabilities persist despite comprehensive legislation and policies protecting and promoting the rights of disabled people (Marini, 2012:46). It is therefore, in that context, that the social workers sensitise and draw the public's attention to the social problems faced by people with disabilities (Myers, 2007:97).

Furthermore, as agents of social justice social workers explore legislative barriers regarding discrimination of disabled persons and influence changes in legislation and policies to improve access and equal rights for persons with disabilities (Marini, 2012:46).

Mackelprang and Salsvigier (1999:242) are of the view that social workers have a professional obligation to provide services to persons with disabilities and their families by creating a supportive environment. This supportive environment should

make it possible for people with disabilities and their families to define their own needs and challenge service provision constraints. On this note, a social worker should integrate an intervention into the lives of the disabled persons and their families. The researcher believes the social workers could also advocate for the support of disability forums such as committees for people with disabilities, support groups and societies aimed at empowering and strengthening the functionality of people with disabilities.

## **2.4 CULTURAL INFLUENCE ON THE CARE OF CHILDREN WITH DISABILITIES**

Eskay, Onu, Igbo, Obiyo and Ugwuanyi (2012:473) highlight that in every culture, disability is perceived differently and such perceptions shape the kind of services that are rendered. Wilson (2003:5) concurs with this view by stating that a mother's culture will determine the way she responds to the fact that she has given birth to a baby that is different from the one she had wished for.

For example, studies identify that a universal trait associated with Chinese culture is reciprocity (Holroyd, 2003:4). Parents give to children when they are young and these children, when they become adults, must return the gifts and services to their parents. Children will therefore be nurtured with the expectation that they will in turn nurture their parents. Therefore, children born with a disability in Chinese culture cause a disruption to the exchange as giving good things to a disabled child will be perceived as pointless in the usual cultural sense (Holroyd, 2003:4). This is supported by Marini (2012:04) who mentions that people with disabilities are devalued and perceived as less than human in some cultures as there is the belief that disabled people consume resources without providing anything in return.

Furthermore, another study finds that culture may influence attitudes and reactions to the level of caregiving given to children with disabilities (Wilson, 2003:8). In some cultures, Wilson (2003:8) finds that the children are perceived as the extension of the parents' bodies, and the impairment to the children's bodies may seem like an impairment to their parents' bodies which they are unable to accept. In this context, the maternal instinct will not function and the children are rejected by their mothers (Wilson, 2003:8). However, in a culture where disability is perceived as a temporary condition, caregivers of disabled children may see themselves as chosen for this important role (Wilson, 2003:8). WHO (2006:79) concludes that the cultural beliefs and stereotyping of people with disabilities is still a pervasive problem that is

threatening and that affects the physical, psychological and emotional health and well-being of people with disabilities. The researcher therefore believes that culture could prevent some individuals from coming forward for diagnosis and treatment.

## **2.5 BOTSWANA'S NATIONAL POLICY ON CARING FOR PEOPLE WITH DISABILITIES**

People with disabilities is an important socio-economic developmental problem in developing countries, where the systems established for the integration of disabled persons are inadequate (United Nations General Assembly, 2006). The United Nations General Assembly (2006) notes that if the issue of disability is not addressed, the impact of disability on the socio-economic development at all levels of society would be an enormous problem for the country in the long run. This observation has led to an emerging recognition that only a national response, which engages all sectors of the society meaningfully in the care for people with disabilities, is required – such as a disability policy. Baciú, Alexiu and Birneanu (2015:43) are of the view that a disability policy is an important indicator of social inclusion of persons with disabilities and the enhancement of their civic participation. This represents a global desire which is pivotal in the area of human rights and participation.

The National Policy on Care for People with Disabilities outlines the national response to the demand for coordinated delivery of services and care for people with disabilities in Botswana (Republic of Botswana 1996:3). The development of this policy is influenced by the World Programme of Action (WPA) which concerns persons with disabilities and is a strategy outlined in the International Year of Persons with Disability which had been adopted by the General Assembly of the United Nations (UN) in December 1982 (Republic of Botswana 1996:2).

According to the views of the UN (1982) “the purpose of the World Programme of Action concerning Disabled Persons is to promote effective measures for prevention of disabilities, rehabilitation and realization of the goals of full participation of disabled persons in social life and development of equality”. Considering the above stated views, the objective of the Republic of Botswana’s National Disability Policy is “to combat the incidence of disability and to promote the quality of life for people with disabilities” (Republic of Botswana, 1996:3).

Important principles and objectives regarding care as stated in the National Policy are: that people with disabilities should be provided with care that is effectively

coordinated, in a spirit of cooperation and beneficial interaction; to recognise that care of people with disabilities is a continuous process requiring more family participation, rehabilitation support, universal accessibility, community involvement and less institutionalisation; and to care for a person with a disability in the family context. These set objectives will only be implemented effectively if the government ensures that the welfare of people with disabilities has its rightful place in development programmes in the broad educational, health, social, physical and economic spheres (Republic of Botswana, 1996:5-6). In addition, the policy principles regard human rights in line with the country's constitution. It states that in the provision of care there should be recognition and protection of the human rights and dignity of every individual.

It is within this framework that disability issues are mainstreamed in all development programmes, policies and strategies in Botswana. In this context, the policy provides guidelines for the responsibilities of the various bodies involved in the system of care for people with disabilities.

Critics of the National Policy on care of people with disabilities argue that while the entities that are relevant for the area of disability are many following the adoption of the mainstreaming model, inadequate funding of programmes geared towards persons with disabilities persists (Mmatli, 2012:21). Furthermore, the services provided are so similar to the services provided for able-bodied people that the focus on disability is lost (Mmatli, 2012:21). The author further points out that many of the policies, programmes, strategies and plans do not specifically mention people with disabilities as beneficiaries as none of the documented plans adequately incorporate the issues experienced by people with disabilities. The researcher adds that although the policies and programmes are meant to address the issues of persons with disabilities, their contributions are not clearly stated and do therefore not adequately address the needs of persons with disabilities.

## **2.6 CARE PROGRAMMES FOR CAREGIVERS OF CHILDREN WITH DISABILITIES**

Many parents report significant stress caused by caring for a child with developmental disabilities (Chan & Sigafos, 2006:27). The authors identify the development of effective support services to assist families in the care of children with developmental disability as important. Of similar view is Oliver (1996:16) who mentions that the family of a child who is severely or profoundly disabled, such as a

child with CP, has to adjust to a routine of constant care and attention which will not change significantly as the child grows older, such families will therefore need supportive care programmes. Chan and Sigafoos (2006:28) explain support care programmes as those services that assist families with care, leading to reduced levels of stress and preventing possible family breakdowns. These such support care programmes may include respite care facilities and economic support services.

### **2.6.1 Respite Care Facilities**

Respite care has gained importance amongst the array of services that have been developed to support families who have children with developmental disabilities, such as CP, as the level of care required by these children can be substantial (Chan & Sigafoos, 2006:27). Respite care refers “to the use of an organised service that is designed to provide temporary relief from the caretaking responsibilities associated with parenting a child with a developmental disability” (Chan & Sigafoos, 2006:27). The authors assert that respite care mitigates the effects of stress due to caregiving and at the same time may provide caregivers with the opportunity to look for employment. It is, however, argued that such services are not available in rural communities (Martha, 2010:58).

Martha (2010:58) states that certain characteristics of a child’s disability will influence the use of respite care facilities and such characteristics may include severity of disability and the level of care required. The author mentions that families who have children with more severe levels of disability are more likely to utilise respite care. This is supported by Chan and Sigafoos (2006:29) who suggest that there is a link between carer stress and severity of disability which in turn influences the decision to utilise a respite care facility. To support this argument, the authors mention that children who require higher levels of personal care from family members are more likely be involved in respite care.

Other than the characteristics of the child’s disability, the utilisation of respite care services is influenced by the available level of social support network systems, as perceived by caregivers. Chan and Sigafoos (2006:33) are of the view that families who utilise respite care tend to be those who lack a network of support either from home or outside the home. This is confirmed by Moore (2009:1022) who reports that families who utilise respite care tend to be those who lack a network of support outside the home.

### **2.6.2. Economic Support**

In caring for children with cerebral palsy caregivers assume full-time caregiving roles and this may entail opting out of their employment which may have financial implications for the entire family (Rosenbaum et al., 2005:627; Ross & Deverell, 2004:192). The National Policy on the care of people with disabilities had recently introduced monthly disability allowances of P300, for individuals who are severely and profoundly disabled, in an effort to support families of people with disabilities (Republic of Botswana, 2013:18). It is believed that this allowance will create a buffer between families, especially caregivers of people with severe disabilities, and the effects of poverty (Republic of Botswana, 2013:18). This allowance is coupled with the provision of food baskets to ensure food security for families of people with severe disabilities. The guideline however stipulates that although the target is for the severely and profoundly disabled, allowance is made. Despite the defined characteristics, individuals do not automatically qualify, they are to be assessed to determine their social-economic statuses before they are approved for the programme.

## **2.7 THE PSYCHO-SOCIAL IMPLICATIONS FOR CHILDREN WHO HAVE A FAMILY MEMBER WITH CEREBRAL PALSY**

Manuel, Naughton, Balkrishnan, Smith and Koman (2005:198) highlight that one of the challenges of caring for any child is the considerable resources, including time and money, which are required. They additionally highlight that when caring for a child with a disability the demands are often significantly multiplied as the child requires more time from the caregivers and the cost of medical care is double the average cost for children without disabilities (Manuel et al., 2005:198). Rosenbaum et al. (2005:627) identify one of the main challenges for caregivers as being able to manage their children's chronic health problems effectively while maintaining the requirements of everyday living.

The provision of such care can impact on the healthy functioning of the family, family income (which extends to the whole family) and sibling adjustment (Rosenbaum et al., 2005:627; Ross & Deverell, 2004:192). These issues are discussed in greater detail hereafter.

### **2.7.1. Functioning of the Family Unit**

The effects of a disability on family life often lead to the deconstruction of many families (Levin, 2006:288). Ross and Deverell (2004:192) highlight that parents who have children with CP have to adapt daily activities, an adaptation that might be difficult to make. Simple activities such as bathing, dressing and feeding need to be considered. Of a similar view is Manuel et al. (2005:199) who point out that parents often have to spend inordinate amounts of time with their children because of the problems they might be presented with. Manuel et al. (2005:199) emphasise this by highlighting that some children have multiple medical needs and have to be seen by medical personnel for multiple investigations. Frequent visits to health facilities will require more time from the caregiver (Manuel et al., 2005:199). Ross and Deverell (2004:192) add that the effects on the integrity of families, survival of marriages and endurance of close relationships within families and between friends can become pernicious. This is supported by Levin (2006:288) who points out that the breakup of families is often a consequence of having a child with a disability because of traditional beliefs, social value systems, and financial stressors which means mothers need to work and consequently leave their children in the care of others. Some studies maintain that a child's disability evokes powerful emotions in the parents, restructures the family and creates an environment that is prone to conflict (Levin, 2006: 288; Oh & Lee, 2009:150). The added stressors of blame, guilt and anxiety regarding the child's diagnosis may place greater strain on a marital relationship (Vijesh & Sukumaran, 2007:78).

In many cultures, disability is either viewed as unacceptable, or believed to be punishment by angered ancestors, or is regarded as retribution for acts of sin. And in these cultures fathers will leave the home permanently and have no contact with the child or the mother again, leaving the burden of care to the mother (Levin, 2006:288). The author points out that even though the burden of care of children with CP is left to women, many are disempowered because they are unemployed, illiterate or uneducated. Oh and Lee (2009:151) comment that following the birth of disabled children, mothers experience less satisfactory marriages and appear to have greater direct responsibility in childcare, and are therefore more vulnerable to stress associated with the children's disabilities. Other researchers conclude that marital statuses appear to be the best predictor of coping for mothers of children with disabilities, indicating spousal support as a coping factor (Al-Gamal & Long 2013: 624). Oh and Lee (2009:151) similarly note that maternal demographic

variables such as a married status correlate with life satisfaction experienced by mothers of children with disabilities.

### **2.7.2. Family Income**

For a person with a disability, the cost of living is significant. Caring for a child with a disability places a substantial burden on the caregiver who assumes that responsibility (Bryns, 2013:503). This cost would include but is not limited to basic expenses such as food, transportation, clothing, health-related needs, additional expenses incurred as a result of the person's disability and opportunity costs (Bryns, 2013:503; Ross & Deverell, 2004:192). Additional expenses that are incurred for persons with disabilities include respite care, specialised adaptive equipment, environmental modifications and therapeutic services (Bryns, 2013:504). These are common needs of children with cerebral palsy. For instance, the liberal usage of adaptive equipment may support the early development of capacity, such as the ability to move about independently which improves overall development, however this comes at a cost as free provision is scarce (Rosenbaum, 2004:972).

Besides the daily caring of a child with cerebral palsy, parents should source appropriate medical and rehabilitation personnel and make decisions regarding the rehabilitation approaches and medical choices (Ross & Deverell, 2004:192). As a direct result of these, changes in financial planning and medical insurance plans may have to be made to accommodate the child's needs. This paralyses the financial status of the family because of the financial requirements of long-term rehabilitation (Levin, 2006:288). WHO (2006:46) explains that the costs of "formal care" (long-term residential or nursing-home care) and "informal care" (unpaid care by family members, including their lost opportunity to earn income) are astronomical when they are quantified. Considering the above, the researcher concludes that this will shake the family's financial stability.

A number of studies have shown that the majority of children with CP are raised by poor families with unstable finances, who reside in rural communities where there is little access to appropriate services (Martha, 2010:53; Mobarack et al., 2003:601). Ample evidence is presented in the study findings of a research conducted in rural communities in South Africa which reflects that although children with CP qualify for government assistance in the form of 'Care Dependency Grants', this money is usually the family's only source of income and not all the money is spent on the child (Harvey, 2011:4). Bryns (2013:504) agrees that even if the child receives state

benefit it often does not cover the cost of caring for a person with a disability. Caring for a child with cerebral palsy incurs many additional costs not usually associated with able-bodied children such as frequent trips to clinics and hospitals, special food, and disposable nappies/diapers (Harvey, 2011:504). Bryns (2013:504) adds that the cost of caring for a disabled child is especially burdensome when a single parent cares for that child. This financial burden does not end simply because the child has reached the age of majority especially when the disability is severe, such as with CP, because of associated impairments (Bryns 2013:504).

### **2.7.3. Sibling Adjustment**

The siblings of children with cerebral palsy are required cope on their own as more emphasis is placed and time is spent on their sibling who has CP than on them. They therefore have to find a balance between their own identities and that of their sibling who has CP (Ross & Deverell, 2004:192). Rosenbaum et al. (2005:627) share the same view and posit that the family routine is likely to be disrupted due to the time spent with the child with the disability, and healthy siblings may feel rejected and unimportant. Cerebral palsy is associated with numerous medical needs and the child has to be seen by medical personnel for multiple investigations which at times lead to frequent hospitalisation (Manuel et al., 2005:199). In addition, siblings may be affected by parental anxiety about the disabled child, particularly during the periods when the child is hospitalised (Ross & Deverell, 2004:194).

In a study of parents' reflections on raising a child with cerebral palsy, it is noted that siblings' lives are impacted by the necessary adjustments that need to be made as a result of living with a sibling with CP, such as few or missed vacations, little one-on-one time, and playing a supportive and caring role to their sibling with the disability (Reid et al., 2011:175). This is confirmed by Hartley, Ojwang, Baguwembu, and Chavuta (2004:172) who find that siblings of children with disabilities play a role in caregiving, most often as a companion or providing short periods of respite for the mother to carry out other household and familial tasks which to some extent could be stressful as their free time is infringed upon by such responsibilities. Vijesh and Sukumaran (2007:77) conclude that a child's disability may obligate all members of the family to make sacrifices.

Siblings of a child with cerebral palsy may experience embarrassment and difficulty in explaining their sibling to their peers or strangers and feel that the disability reflects negatively on the family (Ross & Deverell, 2004:193; Rosenbaum et al.,

2005:627). This is supported by the argument that in many cultures, disability is viewed as unacceptable hence the stigma towards individuals with disabilities (Levin, 2006: 288; Green, 2003:1362). Green (2003:1362) explains that those negative public reactions do not only affect those in possession of the prejudiced characteristics, but it also tends to spread to others with whom the child with the disability is associated, such as siblings.

## **2.8 THE IMPLICATIONS OF CARING FOR A CHILD WITH CEREBRAL PALSY**

Caregiver burden is conceptualised as a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience (Oh & Lee, 2009:150). Parents who have children with CP are reported to have a poor quality of life (QL) and higher levels of burdens than parents of normally developing children (Carona, Pereira, Moreira, Silva & Canavarro, 2012:971). Carona et al. (2012:971) state that these parents present with a marginally poorer psychological well-being when compared to parents of healthy (without disabilities) children. Al-Gamal and Long (2013:624) concur that caregivers of children with disabilities are more likely to suffer from depression and distress, emotional distress and cognitive problems as well as significantly poorer physical and mental health than the general population. Al-Gamal and Long (2013:624) further state that the caregivers' psychological health is adversely affected by the increasing disability in the children and by deficits in cognitive and sensory function, problems commonly associated with CP (O'Shea, 2008:35; Liptak & Murphy, 2011:132). The poorer psychological health of the caregivers could be attributable to the extra daily tasks that prevent the caregivers from adequately taking care of themselves (Vijesh & Sukumaran, 2007:79).

Parental stress in relation to children's functioning and care needs have also been found to have an impact on the quality of life of caregivers. Krstic and Oros (2012:373) argue that raising a child with CP is stressful for the parents because it requires intense physical engagement as well as the ability to cope with any emotional reactions to the child's condition, hence the parents' poorer QL. Potential sources of stress for parents caring for and raising a disabled child can include strained family relationships, and social isolation because of the child's limited mobility or behavioural problems (Sipal et al., 2009:74). Hartley et al. (2004:172) agree that stress among caregivers of children with severe disabilities could be attributed to isolation from community activities because of time spent attending to

the child at home. Uldall (2013:203) mentions that a normal child is expected to progress into an independent adult. The author is of the view that this is not possible with a child with a disability, and parents are expected to experience emotional distress because they are raising their child without the hope of a future for the child.

Fernandez-Alcantara, Garcia-Caro, Laynez-Rubio, Perez-Marfill, Marti-Garcia and Berrocal-Castellano (2015:93) assert that for caregivers the birth of a child with cerebral palsy is associated with feelings related to loss and grief as well as depression, anxiety and post-traumatic stress. Fernandez-Alcantara et al. (2015:97) highlight that parents experience a wide range of emotions related to the experience of loss which may include feelings of sorrow and desperation. Feelings of sorrow reappear at various times such as when new complications are discovered, when parents think about the future of their children, or at developmental milestone such as the moment of speaking or walking (Fernandez-Alcantara et al., 2015:97).

Al-Gamal (2015:288) asserts that parents' reactions to the diagnosis of a chronic, long-term disability in their child can include disbelief, fear, loss of a normal family life, hopelessness, despair and feelings of being unable to cope. These responses are considered the primary indicators of anticipatory grief. The author elaborates that when anticipatory grief occurs, parents have to live through a long period of uncertainty – death of or permanent damage to their child. Fernandez et al. (2015:93) add that caregivers of children with CP experience profound loss when their children do not meet their expectations. This viewpoint is supported by the argument that when a child is conceived, parents begin to imagine her or his life in accordance with the master narratives relevant to their familial and cultural context (Green, 2002:21). The diagnosis of a disability violates these narratives in dramatic and intense ways leaving mothers with a profound interpersonal loss (Green, 2002:21).

Stigma has also been found to impact the emotional well-being of caregivers of children with disabilities. Stigma is defined as an adverse reaction to the perception of a negatively evaluated difference (Green, 2003:1361). Green (2003) states that caregivers who do feel the effects of stigma, tend to experience increased emotional distress and isolation. This is supported by one scholar who finds that mothers of children with disabilities, who do believe that people with disabilities are prejudiced by others in the community, experience emotional distress in the form of subjective burden that may include embarrassment, guilt, shame, resentment, worry and other

emotional upset (Blum, 2008:10). Hartley et al. (2004:173) also mention that members of the community may believe that children with disabilities are shameful or are an embarrassment to the family and should be hidden from other people. Such perceptions are a consequence of social stigma hence the isolation and loneliness felt by caregivers that may lead to emotional distress.

Cultural values and expectations may also result in stigmatisation which may lead to the poorer psychological well-being of individuals caring for disabled persons. A Chinese study finds that giving birth to a child with a disability is regarded as a disruption to the ancestry, especially when the disability is visible and leads to social stigma. It is in direct contrast to the Chinese collective value and cultural expectation that professes the importance of not being different from others (Huang, Kellett & St John, 2011:190). Similarly, Levin (2006:288) report that many cultures in South Africa consider disability to be unacceptable, believe it to be a punishment by angered ancestors or retribution for acts of sin. This stigma in turn causes psychological distress on caregivers. Levin (2006:288) however argues that the impact of stigma on social participation and emotional well-being of caregivers may not be such an important contributing factor. Negative emotional and social consequences are related to the objective burden of caring for a person whose disabilities create disruptive behaviours and who needs assistance with everyday activities which, in turn, disrupts daily life and reduces available time, energy and money for other activities.

Other than the emotional turmoil experienced by caregivers of children with CP, parents of 'more dependent' children experience higher levels of bodily pain (Byrne, Hurley, Daly & Cunningham, 2009:700). This is attributable to the greater demand for assistance required by children who are physically more dependent on others to carry out their daily tasks (Byrne et al., 2009:700). Similarly, Sharan, Ajeesh, Rameshkumar and Manjula (2012:1891) point out that musculoskeletal disorders such as pain in the back, shoulder, knee, etc. are common ailments of full-time caregivers of children with CP. The causes are repetitive heavy lifting and carrying, maintaining an awkward posture for a long duration, ignoring own health issues, and not addressing musculoskeletal injury (Sharan et al., 2012:1891). During therapy sessions, the caregivers are required to maintain specific positions while holding the child. Sharn et al. (2012:1892) mention that carrying a child in those positions create postural imbalances that could lead to lower back pain and other musculoskeletal

disorders, over time. Te-Shiang and Tzu-Hsien (2008:1339) are of the view that the patho-mechanics that most often lead to back pain is the repetitive lifting of children, considering the fact that parents are lifting an average weight of 20 to 25 Kilograms 10 to 15 times per day, as the child with CP needs assistance with all daily activities and for movement as well (Sharan et al., 2012: 1892).

## **2.9 BURDEN OF CARE IN CAREGIVERS OF CHILDREN WITH CP**

Despite the changes in gender norms, women remain more personally invested in caregiving than men. Hartley et al. (2004:172) is of the opinion that the burden of everyday caregiving and attending to the child's bodily needs falls primarily on the mother in the family and in the absence of the mother, the grandmother usually cares for the child. The author adds that fathers are usually not involved in daily caregiving, although some mothers report shared responsibility with their husbands. An Australian time use survey study finds that during a 5-day working week the father's time for personal care and leisure is unaffected while the mother of children with disabilities has 5 hours less time for personal care and leisure (Brandon, 2007:669). Many hours are instead spent helping the child with daily activities such as eating, personal care and creating a supportive social network for the family (Uldall, 2013:203). Hartley et al. (2004:172) state that "fathers often had the particular role of controlling access to funds and making decisions about the child's treatment".

Levin (2006:288) concurs that the burden of care for children with CP in many families is borne by women, many of whom are disempowered due to being unemployed, illiterate or uneducated. Many of these women have very little knowledge about available professional services and are also more likely to experience depression linked to parenting issues than their male counterparts (Vijesh & Sukumaran, 2007:80). Uldall (2013:203) comments that, mothers of children with disabilities usually work part-time jobs following the birth of the child with disability while the fathers' employment is unlikely to change after the birth of a child with disability.

Uldall (2013:203) also finds socio-structural constraints to be the main burden of care in caregivers of children with CP. "Socio-structural constraints refer to the general contact with authorities and assistance with the child's needs" (Uldall, 2013:203). Children with CP have multiple needs but studies identify that a

considerable number of unmet needs that have been reported by caregivers increase the burden experienced by caregivers. This has attributed to difficulties in accessing sufficient services and bureaucracy associated with the required assistance for caring for children with disabilities.

### **2.9.1. Coping Strategies Employed by Caregivers**

Croot et al. (2012:1540) assert that there is a wide variation in coping strategies that are utilised by parents of a disabled child or children, at different times and in response to different circumstances. This is confirmed by a study that examines the coping strategies utilised by caregivers of children with disabilities which finds that parents have very different individual coping profiles (Trute, Benzies, Worthington, Reddon & Moore, 2010:37). Croot et al. (2012: 1543) mention that strategies of acceptance of the child, faith, and social support which include the utilisation of external support such as family members and relatives is considered helpful by caregivers in managing the challenges of raising a disabled child. Avoidance of difficult situations is also considered to be significant in the adaptation of caregivers of children with disabilities. Some of these strategies are discussed below and the impact of social support in caregivers warrants a closer look.

#### **2.9.1.1 Acceptance of the child**

Croot et al. (2012:1548) point out that following the birth of children with disabilities, parents' ideas about disabilities change over time and this transition influences their experience and management of their situations. Croot et al. (2012:1548) mention that the negative ideas about disability arise from caregivers' previously held ideas about disability and those of close associates like family and society; reframing the disability as a medical condition or a blessing empowers parents to challenge this view and in doing so facilitate acceptance of the child. Bayat (2007:707) suggests that positive perceptions about a situation serve as a buffer for the stresses associated with caring for a child with disabilities. Greeff and Nolting (2013:402) also find that following the birth of a child with a disability, parents adopt the position that there is nothing they can do to change the situation and therefore have to accept it and make the most of it. The researcher considers this viewpoint to be aligned with one of the assumptions of the family resilience framework of stress, adjustment and adaptation which places emphasis on viewing a crisis as manageable.

### **2.9.1.2 Faith**

This is described as a strength factor that contributes to adaptation in family units, during difficult circumstances. Several parents turn to religious sources for help after their child is diagnosed with a disability (Croot et al., 2012:1548; Greeff & Nolting, 2013:402) and this can serve to alleviate the caregiver's stress.

### **2.9.1.3 Avoidance of difficult situations**

Some parents who are raising disabled children have coped with difficult situations by avoiding them; such as not taking their children to events where they would meet many people or in some cases when they do not expect their children to behave within expected norms. Krstic and Oros (2012:374) however comment that the avoidance strategy may reduce stress for a short time, but it leads to mal-adaptive family functioning.

### **2.9.1.4 Utilisation of external resources**

Scholars of the family resilience framework concur that accessibility and utilisation of external support services serve as a buffer in adverse situations. For instance, Oh and Lee (2009:151) mention that a key to successful parental adaptation lies in the capacity of the families to access appropriate resources and services that both support them in coping with their child's needs and reduce disability related problems. This is supported by Ross and Deverell (2004:199) who point out that the success of family coherence and adaptation in caregivers of children with CP is influenced by access to the support of rehabilitation therapists and health personnel.

Chan and Sigafoos (2006:27) concur that the development of effective support services to assist families in the care of children with disabilities is of obvious importance. These services would assist families with care and lead to reduced levels of stress, thereby preventing possible family breakdowns and long-term effects of being a caregiver of a child with a disability. An example of such a service is a respite care facility which has been previously discussed. The researcher supports the view that effective support services is of paramount importance to caregivers of children with disabilities as such services will serve the purpose of supporting caregivers and their children who are in extreme need but not able to provide for themselves.

### **2.9.1.5 Education**

Awareness of disability in the community is an important element that could help families of children with disabilities to cope and adapt in caregiving (Ross & Deverell,

2004:198). Researchers have reported stigmatisation of individuals with disabilities which may lead to poor adaptation of caregivers or influence family functioning (Huang et al., 2011:190; Levin, 2006:288; Green, 2003:1361), it is therefore of paramount importance to educate the community on disabilities to correct negative attitudes and witchcraft ideologies, thereby promoting the adaptation of caregivers (Ross & Deverell, 2004:199). Of the same view is McConnell et al. (2014:836) who assert that positive adaptation of families raising children with disabilities is at least influenced by societal accommodation of persons with disabilities which may include non-stigmatising cultural values as well as education.

The researcher agrees with scholars on education aimed at creating awareness on issues of disability. The researcher however argues that education will not be sufficient to only create awareness at community level, but it would be equally essential in extending awareness to policy makers. This could assist policy makers on identifying societal and environmental barriers which will lead individuals with disabilities being stigmatised or excluded by society.

### **2.9.2. Impact of Social Support on Caregivers of Children with CP**

A social support network might include relatives, neighbours, co-workers and friends who assist the family in caring for the child with a developmental disability, such as cerebral palsy. Research identifies social support as a coping resource in optimising caregiver well-being and health outcomes among parents of children with chronic developmental disabilities (Oh & Lee, 2009:151). For instance, several studies concur that the level of available informal social support is consistently associated with fewer reports of depression and better physical health in caregivers (Al-Gamal & Long 2012:629; Croot et al., 2012:1245). Similarly, Pfeider, Silva, Lopes, Matsukura and Santos (2013:364) show that caregivers of disabled family members in difficult socio-economic circumstances but with relatively high social support have managed better than those with less social support. Pfeider et al. (2013:368) further highlight that satisfaction with social support networks is associated with more positive caregiver attitudes and personal well-being. This is confirmed by the study findings which conclude that a non-critical family network is associated with low psychological distress in mothers of children with disabilities and that having a social network has predicted positive family adjustment hence promoting positive well-being (Fraid, 2009:127). Of similar view is Al-Gamal and Long (2012:629) who comment that the mothers of children with CP are more at risk of depression than other mothers, but

the promotion of social support may have the effect of enhancing maternal adaptation. Although several authors have discussed social support as the greatest potential buffer in adaptation of caregivers of children with disabilities, Croot et al. (2012:1546) argue that in many cases where support is available it is to help cope with unusual or crisis situations rather than be a regular commitment to share the work of caregiving. Oh and Lee, (2009:160) also comment that it is not the extent or frequency of social contacts that matters, but rather individuals' satisfaction with their relationships. Krstic and Oros (2012:374) conclude that the level of social support in the early period after learning about the child's health condition is crucial and it can affect both short-term and long-term coping adaptation.

In summary, the literature has shown that caring for a child with CP has significant challenges that apply pressure on caregivers. The challenges that have been identified are attributable to the nature of the disability due to its associated impairments that limit children's functioning, rendering them dependent on caregivers for activities of daily living. The burden of caring for a child with CP not only places strain on the health of caregivers but also has a significant impact on the emotional well-being of caregivers and the functioning of the family as a unit. The demands of caring for a child with CP persist throughout childhood, requiring continuous adjustment and adaptation by family members to on-going challenges. The Resilience Model of Family Stress, Adjustment and Adaptation depicts how the family responds to a crisis; like raising a child with CP. The components of this framework are coping strategies employed by caregivers living with a child diagnosed with a chronic disability such as CP. Management of children with CP requires a multidiscipline approach and caregivers play a significant role in the success of the treatment. Furthermore, effective support services which assist families such as are defined in the policy and programme in care of people with disability is of obvious importance in facilitating coping in the caring process.

The following chapter presents the research methodology utilised in this study as well as the empirical findings of the study.

## CHAPTER THREE

### RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

#### 3.1 INTRODUCTION

The researcher has noted the limited information in the published literature regarding the experience of kinship caregivers of children with cerebral palsy in the Botswana context, despite extensive research on the phenomenon. It is important to understand the experience of living with a child who has been diagnosed with CP as a significant number of children in Botswana are diagnosed with CP. This insight might be valuable to professionals during the design of intervention care programmes for children with CP.

This chapter focusses on the presentation and analysis of the qualitative data collected from participants during one-to-one semi-structured interviews. The aim has been to gain insight into the experience of caring for an individual with CP, a condition characterised as needing constant care, and to understand how caregivers adapt to living with a child with a disability.

An overview of the research design and methodology that had been utilised in this study is provided. The discussion begins with identification of the research goal and objectives followed by the research methodology. Presentation and analysis of the data will conclude the chapter.

#### 3.2 THE GOAL AND OBJECTIVES OF THE STUDY

##### 3.2.1. The Goal of the Research Study

The goal of this research study had been to understand the experiences of caregivers who care for children with cerebral palsy in Mahalapye, Botswana.

##### 3.2.2. Objectives of the Research

The researcher had formulated the following objectives and achieving them has meant that the study has attained its goal.

##### The research objectives were:

- To conceptualise cerebral palsy from literature as a childhood disability.
- To explore and analyse the caregivers' experiences of living with children who have been diagnosed with cerebral palsy.
- To explore and describe the care required by children who are diagnosed with cerebral palsy.

- To suggest strategies for professional interventions that could broadly promote the well-being of the caregivers of children with cerebral palsy.

### 3.3 RESEARCH QUESTION

The research question that had guided this study was: **What are the experiences of caregivers caring for children with cerebral palsy in Mahalapye, Botswana?**

Bless, Higson-Smith and Sithole (2013:71) state that the research question is the focal point of the study and it determines the type of the research, the way the sample is created, the way data is collected and analysed, and ultimately the way in which the results are reported. Thus the research question guides the design of the research and the conducting of it. Further to this Denscombe (2002) as cited in Fouché and De Vos (2011:80) identifies three important functions that the research question performs. Firstly, it explains the purpose of the research, the motivation behind the enquiry and what the research intends to discover. Secondly, the research question allows the reader to evaluate the research by providing benchmarks against which to judge what the project has aimed to achieve and what it has set out not to do. Lastly, a defined research question provides the researcher with a good platform from which to conduct the inquiry.

Braun and Clarke (2013:44) point out that in qualitative research, the research question should have some social relevance and originality. For originality the research question could be based on the assumption that the investigated issue has never been studied in a specific context and this may generate new knowledge (Braun & Clarke, 2013:44). The research question in the current study is original in that the experiences of kinship caregivers caring for children with cerebral palsy has not previously been explored in a Botswana context. The social relevance that is depicted by the research question is that the issue that has previously been silenced is brought to light (Braun & Clarke, 2013:44). For instance, the experiences of caregivers and the challenges that are associated with raising a child with cerebral palsy could be better understood, calling for intervention care programmes.

### 3.4 RESEARCH APPROACH

The researcher had adopted a qualitative exploratory approach. Fouché and Delpont (2011:96) state that an exploratory research could arise from a lack of basic information on a new area of interest. Similarly Bless et al. (2013:60) mention that exploratory research is called for when limited knowledge or information exists about

a subject and the purpose of the research is to gain an understanding of the phenomenon. The researcher has a vested interest in understanding the experiences of caregivers who care for children with cerebral palsy, in the Botswana context, but realises that little regarding this phenomenon has been documented prior to now.

By utilising a qualitative approach, the complex nature of the phenomenon is understood from the participants' points of view (Fouché & Delpont, 2011:64). From the prospective research the experiences of caregivers who have been caring for a child who has been diagnosed with cerebral palsy is better understood. The advantage of this approach has been that the reality is interpreted from the respondent's frame of reference therefore the phenomenon is understood in its natural context (Bless et al., 2013:16). However, due to the size of the sampling population the findings from a qualitative approach cannot be generalised to a whole population (Braun & Clarke, 2013:22).

### **3.5 TYPE OF RESEARCH**

Classification of research arises from the reasons why the research had been conducted (Bless et al., 2013:56). This study had adopted 'applied research', a type of research associated with "the researcher's motivation to assist in solving a particular problem facing a particular community" (Bless et al., 2013:59). The aim of this study had been to gain a better understanding of the experiences of caregivers caring for children with cerebral palsy which has provided insight into the care required by children diagnosed with the condition and the challenges that are faced by caregivers as a consequence of their caregiving. Based on the findings the researcher intends to propose recommendations on intervention strategies that could broadly promote the well-being of the caregivers of children with CP in the future.

### **3.6 RESEARCH DESIGN**

A descriptive case study had been selected as the research design, for this study. Creswell (2013:98) proposes that the intent of a case study may be to understand a specific issue or concern by analysing and interpreting the data. In a descriptive case study, the primary aim is to describe, analyse and interpret a particular phenomenon (Fouché & Schurink, 2011:321). In this study, the researcher had aimed to describe and analyse the experiences of caregivers who care for children with CP. The descriptive case study design has enabled the researcher to gain information on the

experiences and challenges that are faced by caregivers of a child who has been diagnosed with CP and how they have adapted to life with the disability.

In a descriptive case study, a small number of instances are selected to produce a detailed description of these cases (Fouché & Schurink, 2011:321). However, the ultimate goal is not to understand a broad social issue, but to describe the case being studied. A small number of caregivers of children with CP had been selected to share their experiences of caring for a child with CP. The researcher has focussed on the analysis of themes for understanding the complexity of the case from a qualitative approach and not for generalising beyond the case. Instances with multiple perspectives have enabled the researcher to establish patterns and themes which have assisted the researcher in gaining a detailed description of the caregivers' experiences.

Qualitative researchers are interested in the meaning that subjects bring to their life experiences (Fouché & Schurink, 2011:320). Thus, the descriptive case study from a qualitative approach, places events in contexts that are understandable by participants themselves (Babbie & Mouton, 2015:272). This design has enabled the researcher to gather the perceptions of the participants regarding their own personal experiences as well as the meanings they have attached to these experiences.

During the process of designing the case study, several caregivers of children with CP qualified as participants for the study (Creswell, 2013:101). Certain characteristics that have been detailed in the sampling method have been utilised as the selection criteria to define the unit of analysis (Strydom, 2011:223).

### **3.7 RESEARCH METHODS**

The following research method had been utilised.

#### **3.7.1. Study Population and Sampling**

In this study, the population consists of all caregivers of children who have been diagnosed with cerebral palsy in the Mahalapye Village, in Botswana. Population refers to the individuals who possess or display the specific characteristics that the researcher has identified as criteria, which sets boundaries for the study (Strydom, 2011:223). The population group for this study had been drawn from potential participants and it is from this group that the researcher has attempted to generalise the results of the study.

### **3.7.1.1 Sample**

The sample had been drawn from a population that met three criteria: they are caregivers of children who have been diagnosed with cerebral palsy; they reside in Mahalapye Village, in Botswana; and they attend rehabilitation treatment at the Mahalapye District Hospital. By using non-probability purposive sampling 12 caregivers of children who have been diagnosed with CP had been selected to participate in the study. The data collection process had continued for as long as new elements or facts were found and had only been halted when no new information became available. This method is supported by Bless et al. (2013:179) who support the possibility that not all participants may provide valuable information. As a result, the onus had been on the researcher to continue collecting data until he/she was satisfied that a sufficient amount of data has been collected.

### **3.7.1.2 Sampling Methods**

The researcher had utilised purposive and volunteer sampling. Bless et al. (2013:177) assert that purposive sampling rests on the assumption that the researcher knows what type of participant is needed. For this research study, caregivers of children with CP meet the criteria of the type of participant who was required. In this sampling technique there are certain characteristics that have been used as the selection criteria which is believed to be the most appropriate for the purpose of the study (Strydom, 2011:223).

Caregivers who have participated in the study had to meet the following criteria:

- Have a child aged between six and twelve who has been diagnosed with CP by a medical doctor.
- Have identified themselves as the primary caregiver of the child with CP.
- Reside in Mahalapye Village.
- Give consent to participate in the study by signing a letter of informed consent.

The advantage of this method has been that the researcher had been able to control the applicability of the participants to the research population as the participants had to meet the inclusion criteria (Strydom, 2011:223; Bless et al., 2013:177). The study also utilised volunteer sampling, as indicated earlier. During the recruitment phase, the occupational therapist had explained the purpose of the study to caregivers which enabled them to volunteer to be part of the study.

### **3.7.1.3 Recruiting participants**

Braun and Clarke (2013:59) report that potential participants need to be informed about the research, through some form of advertising. The researcher, had therefore advertised the study in the Occupational Therapy Unit in the Mahalapye District Hospital, where the caregivers of children with CP had gone for the children's therapy sessions. The method of advertising and contacting the potential candidates is detailed hereafter.

- The study had been communicated to the therapists in the Occupational Therapy Unit in Mahalapye District Hospital, where caregivers of children with CP attended rehabilitation services.
- Based on the selection criteria, caregivers attending rehabilitation therapy sessions in the Occupational Therapy Unit at Mahalapye District Hospital had been informed about the study, by the therapists. By completing the information letter, potential participants provided their names and contact details to the therapists.
- Potential participants had been contacted and dates for the interviews had been set up by the researcher.
- The researcher had followed the selection process until data saturation had been reached.

### **3.7.2. Methods of Data Collection**

Semi-structured interviews are the most popular manner in which qualitative interviews are conducted (Braun & Clarke, 2013:78). The researcher had used one-to-one semi-structured interviews to collect data from the participants. This technique had guided the participants and provided them with opportunities to discuss issues that are important to them and that the researcher had not anticipated (Braun & Clarke, 2013:78). When caregivers raised unanticipated issues the researcher gained in-depth and rich information regarding issues surrounding the care of children with CP (Bless et al., 2013:197; Braun & Clarke, 2013:78). The advantage of this approach had been the potential for rich and detailed data about individuals' experiences and perceptions as the researcher had been able to probe and ask unplanned questions (Braun & Clarke, 2013:80). Due to the semi-structured nature of the technique, the researcher had established rapport with the participants by avoiding sensitive questions and had therefore been able to gain valuable information (Braun & Clarke, 2013:80).

A semi-structured interview schedule had been utilised to guide the interview sessions in this study, which has been attached in **Appendix E**. The interview schedule had assisted the researcher in building trust with participants, which is described as a key component in interactive data collection (Braun & Clarke, 2013:81). “Where there is trust participants will feel comfortable disclosing personal information to the researcher” (Braun & Clarke, 2013:81). Furthermore, the interview schedule had been well-planned questions which assisted the researcher in generating rich and detailed accounts relevant to gaining insight into the experiences of caring for a child with CP, as described by caregivers. During the interview process the researcher had observed participants noting their reactions. This had enabled the researcher to obtain in-depth information regarding the issues of concern and therefore she was able to formulate themes and sub-themes that assisted her in generalising the findings from the data that had been collected.

### **3.7.3. Methods of Data Analysis**

Creswell (2013:182) mentions that to analyse qualitative data, the researcher should engage in the process of moving in an analytic circle – one enters with data of text or images and exits with an account or a narrative. During this cycle, the researcher would touch on several facets of analysis and therefore circles around and around (Creswell, 2013:182). The researcher, while processing and analysing the data, had utilised the data analysis spiral as suggested by Creswell (2013:182), and which is discussed hereafter.

#### **3.7.3.1 Planning for the recording of data**

The researcher had utilised a digital recorder to ensure quality. After gaining permission from the participants an appropriate space had been sought where the interviews were conducted and recorded. The interviews had therefore taken place at the caregivers’ houses. During the recording, it had only been the researcher and the participant in the venue. The recorded interviews were later transcribed and translated.

#### **3.7.3.2 Data collection and preliminary analysis**

Schurink, et al. (2011:405) state that data analysis in qualitative inquiry necessitates the utilisation of a two-fold approach. This involves data analysis at the research site during data collection and data analysis off site, following the period of data collection. For this study the researcher had utilised this two-fold approach to make

sense of some of the data while still in the field. Field notes had been taken during the interviews and these were later compared with the transcribed scripts.

### **3.7.3.3 Organising the data**

During this stage the researcher had organised the data into folders, and converted the files to an appropriated text unit (Creswell, 2013:183). The researcher had listened to the digital recordings, transcribed the interviews verbatim and coded the participants to maintain their anonymity, thereby protecting their privacy.

### **3.7.3.4 Reading and writing memos**

The transcription of interviews had been read and compared to one another before dissecting them into sections for analysis. The researcher had made notes or memos in the margins of the transcripts to gain a sense of the interview as a whole. During this stage, the researcher had repeatedly read the collected material and some ideas on how to categorise the data had emerged (Bless et al., 2013:342).

### **3.7.3.5 Coding the data**

The researcher had considered the similarities and patterns as well as the topics addressed in the data. The researcher wrote down words and phrases that represented these topics and patterns and those words and phrases were coded into categories. The process of coding had involved aggregating the text into small categories of information.

### **3.7.3.6 Generating categories, themes and patterns**

Themes in qualitative research are broad units of information that consist of several categories and therefore need to be reduced to small and manageable sets of themes (Creswell, 2013:186). The themes and categories that had been identified from the data which was obtained from the participants are based on direct quotes from the participants. The researcher had refined these categories by focussing on the elements that are most alien to the study. All the while considering the research question.

### **3.7.3.7 Testing emergent understandings**

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

### **3.7.3.8 Searching for alternative explanations**

As categories and patterns are discovered in the data, the researcher should critically engage in challenging the very patterns that seem so apparent (Schurink et al., 2011:417). The researcher had searched for other possible explanations for the data and the links among participants' responses, and did not solely rely on the literature that had been reviewed for possible explanations to address the issues in question. This approach is supported by Creswell (2013:187) who points out that interpreting metaphors as a rich source of multiple meanings is of paramount importance.

### **3.7.3.9 Interpreting the data**

The interpretation of data had been based on discussions on and data analysis of the actual phrases stated by the participants which had then been verified by the literature review. The interpreted data has been then presented in text, tables and figure forms and this has been done in report writing.

### **3.7.4. Trustworthiness**

To make sure that the findings of the study are worth taking account of, the researcher had ensured that the constructs discussed below had been adhered to (Babbie & Mouton, 2015:276; Lietz, Langer & Furman, 2006:444; Bless et al., 2013:236).

#### ***Credibility***

This construct has been achieved through the strategies that are discussed hereafter.

**Prolonged engagement:** The researcher had conducted interviews with caregivers until data saturation occurred. When that had occurred, the researcher had some evidence for believing the topic is exhausted.

**Referential adequacy:** A digital voice recorder had been availed to document the findings and it had been used for all the interviews. Furthermore, to increase credibility the study employed member checking.

**Member checking:** This strategy had ensured that there had been a good fit between the researcher's interpretation and the representation of the caregivers' experiences and their own understanding of their experiences (Braun & Clarke, 2013:283). In the recruitment phase, caregivers had been informed about this process and were invited to participate in it. During the interviews the researcher had

conducted member checking in which participants had been given feedback on their responses for them to rephrase and interpret. This strategy had provided participants with the opportunity to confirm the conclusion that had been drawn from their responses (Lietz, Langer & Furman, 2006:453). This approach had ensured that both the researcher and the participants understand the phenomena in the same way. Additionally, the researcher has utilised sufficient verbatim quotations which has allowed the reader to read exactly what respondents said and how the researcher has interpreted the information. The researcher has translated these quotations and edited them for ease of reading.

**Peer debriefing:** Debriefing sessions had been held with the supervisor since she had a general understanding of the study. As a matter of quality control an experienced researcher (supervisor) had verified the logic and implementation of each step of the methodology.

**Utilisation of reflexivity:** During data analysis the researcher had engaged with occupational therapists who assisted in uncovering hidden meanings in participants' responses as having multiple perspectives could enhance the analysis of the data (Lietz et al., 2006:447).

**Transferability:** This refers to the extent to which the findings could be applied in other contexts or with other respondents (Babbie & Mouton, 2015:227). This construct is characterised by description of inquiry and purposive sampling (Anney, 2015:278). In the present study, the researcher had detailed all the research processes from data collection and the context of the study to production of final report which constitutes a description of the inquiry. This description will assist other researchers to replicate the study with similar conditions in other settings (Anney, 2015:278). Furthermore, the researcher has focussed on kinship caregivers of children with cerebral palsy as key informants as they are believed to be knowledgeable regarding the issue under investigation. This technique is known as purposive sampling which facilitates transferability of inquiry (Anney, 2015:278).

**Dependability:** The researcher has clearly described how the data had been collected, recorded, coded and analysed. For instance, the utilisation of one-on-one semi-structured interview schedules and digital recording of all interviews had ensured uniformity during data collection. The researcher could therefore be

confident that if the study is to be repeated with a similar data collection method the findings would be similar.

**Conformability:** Babbie and Mouton (2015:278) suggest that adequate information regarding the sources should be left to determine whether the conclusions and interpretations can be traced. The researcher had therefore availed the raw data of digital recordings and written field notes to her supervisor. Materials that related to the intentions of the study had included the research proposal as well as the data reconstruction and syntheses such as themes that had developed. Findings, conclusions and a final report had been drafted to determine the degree to which the findings were the product of the focus of the inquiry and not the biases of the researcher (Babbie & Mouton, 2015:227; Bless et al., 2013:236).

### **3.7.5. Pilot Study**

Strydom (2011:236) makes the argument that a pilot study is one way in which prospective researchers can orientate themselves to the project they envision. Strydom (2011:237) furthermore defines a pilot study as a “procedure for testing and validating an instrument by administering it to a small group of participants from the intended test population”. For this study, the interview schedule had been tested on two caregivers of children with cerebral palsy in another village from the same district who did not participate in the main research study. The same sampling methods and techniques that had been utilised in the main research study had been utilised to select these participants. The goal had been to test whether the interview schedule would generate relevant data in the main research.

From the pilot study, the researcher had realised that although the questions were organised and flowed logically, the first questions that had been asked sounded leading and sensitive in nature. Leading was then avoided in the main study by ensuring that such questions were asked later during the interview. Another observation from the pilot study had been that by probing participants while they answered encouraged them to provide more details to their answers. This strategy was therefore employed in the main research.

## **3.8 ETHICAL CONSIDERATIONS**

Strydom (2011:113) is of the opinion that the recognition and handling of ethical aspects are imperative if successful practice and research are the goals. The ethical consideration that has been considered is discussed hereafter.

### **3.8.1. Informed Consent and Voluntary Participation**

Obtaining informed consent implies that all possible or adequate information regarding the aim of the investigation – the expected duration of the participants' involvement, the procedure which will be followed during the investigation, the possible advantages and disadvantages, and the danger to which participants will be exposed to – should be clearly defined and provided to the participants (Strydom, 2011:117). In this study, an information sheet (**see Appendix A**) had outlined the nature and purpose of the study and it had been provided to the Occupational Unit where the recruitment had been done. Given the accurate and complete information, participants had fully comprehended the details of the investigation and therefore had freely made the decision about their participations.

An important aspect that the researcher had considered had been that participants had to be psychologically competent to give their consent (Braun & Clarke, 2013:63). Participants had also been informed that letters of consent needed to be signed by them and that a digital recorder would be utilised during the interview. Furthermore, the data will be kept at the University of Pretoria for a period of 15 years. Sufficient information had provided the research participants with an opportunity to assess, for themselves, whether or not they would like to partake in the proposed study (Bless et al., 2013:32).

### **3.8.2. Avoidance of Harm**

Subjects could be harmed in a physical or psychologically manner during the course of a study (Strydom, 2011:115; Babbie & Mouton, 2015:523). It is therefore the responsibility of the researcher to minimise risk and protect participants from any physical or psychological harm while the study is being conducted. For this study, respondents had been told beforehand that sharing experiences of caring for a child with CP may induce painful emotions. Such information had enabled the research participants to withdraw from the study should they had wished to do so (Strydom, 2011:115). Furthermore, the researcher is of the belief that since the study had been critically evaluated by the Research and Ethical Committee of the University of Pretoria before approval had been obtained, it the potential harm to the research participants had been minimised.

### **3.8.3. Violation of Privacy/ Confidentiality/ Anonymity**

To ensure confidentiality, the researcher had not referenced participants' names nor disclosed their particulars or any other information that may make them identifiable in

the research report. The participants in this study had been identified by caregiver given participant numbers (#) abbreviated as **CgP#**. Braun and Clarke (2013:63) mention that recording audio raises ethical concerns because voices are more difficult to disguise. Therefore, during this study, the digital recorder that had been utilised had been kept in a locked container that had only been accessible to the researcher.

#### **3.8.4. Debriefing of Participants**

Participants had been debriefed by the researcher after the data had been collected. This assisted participants in dealing with the emotions that may have been induced by their participation in the study (Strydom, 2011:122). The researcher had referred participants who seemed to be affected to a therapist at the rehabilitation unit where they discussed their feelings and emotions, in an effort to prevent potential harm.

#### **3.8.5. Action and Competency of the Researcher**

Researchers have an ethical obligation to ensure that they are competent and adequately skilled to undertake the investigations they propose (Strydom, 2011:124). To undertake this study, the researcher had been equipped with the theory from the research module as well as the supervision of an experienced researcher who had guided her accordingly. As a social worker, the researcher has interviewing skills that were utilised to explore the issues regarding caregivers' experiences in caring for children with cerebral palsy.

#### **3.8.6. Publication of Findings**

One of the motivations for conducting this research had been the limited literature regarding the experiences of caregivers of children with cerebral palsy in the context of Botswana as a developing country. Publishing the findings of this study will enrich the existing literature of the experiences of caregivers who care for children with disabilities in developing countries.

While this section has provided an overview of the research methodology followed in this study, the next section presents research findings and analysis.

### **3.9 EMPIRICAL FINDINGS**

This section presents the findings of the research study that had been conducted on the experiences of caregivers of children with cerebral palsy, in Mahalapye Botswana. In this research study the data had been collected by means of semi-

structured one-to-one interviews. The section discusses the profile of participants which includes biographical profiles of caregivers who had participated in the study, characteristics of the children, and children’s limitations as described by the caregivers. The discussion of study findings by means of themes and sub-themes will also be presented in this section.

### 3.9.1 Profile of the Participants

The biographical profiles of participants have been created by collecting information from caregivers who participated in the study.

#### Biographical details (n)

|                                                              |    |
|--------------------------------------------------------------|----|
| <b>Age (in years)</b>                                        |    |
| 30-40                                                        | 4  |
| 41-50                                                        | 3  |
| 51-60                                                        | 2  |
| 61+                                                          | 1  |
| <b>Gender</b>                                                |    |
| F                                                            | 11 |
| M                                                            | 1  |
| <b>Kinship with the child who has been diagnosed with CP</b> |    |
| Mother                                                       | 7  |
| Father                                                       | 1  |
| Grandmother                                                  | 4  |
| <b>Marital status</b>                                        |    |
| Married / Stable relationship                                | 4  |
| Divorced                                                     | 1  |
| Single                                                       | 7  |
| <b>Number of dependents (children)</b>                       |    |
| 1-2                                                          | 2  |
| 3-4                                                          | 7  |



|                                                  |   |
|--------------------------------------------------|---|
| 5-6                                              | 2 |
| 7-8                                              | 1 |
| <b>Age distribution of dependents (in years)</b> |   |
| >1                                               | 2 |
| 5-9                                              | 3 |
| 10-14                                            | 6 |
| 15-19                                            | 1 |

|                                       |   |
|---------------------------------------|---|
| <b>Educational level</b>              |   |
| Primary                               | 4 |
| Secondary                             | 7 |
| Tertiary                              | 1 |
| <b>Employment</b>                     |   |
| Ipelegeng (temporary / casual labour) | 3 |
| Self-employed                         | 1 |
| Permanently employed                  | 3 |
| Not working                           | 5 |
| <b>Source of income</b>               |   |
| Social grant                          | 2 |
| Employment                            | 7 |
| Family members                        | 3 |

TABLE 1: BIOGRAPHICAL DETAILS OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY (N=12)

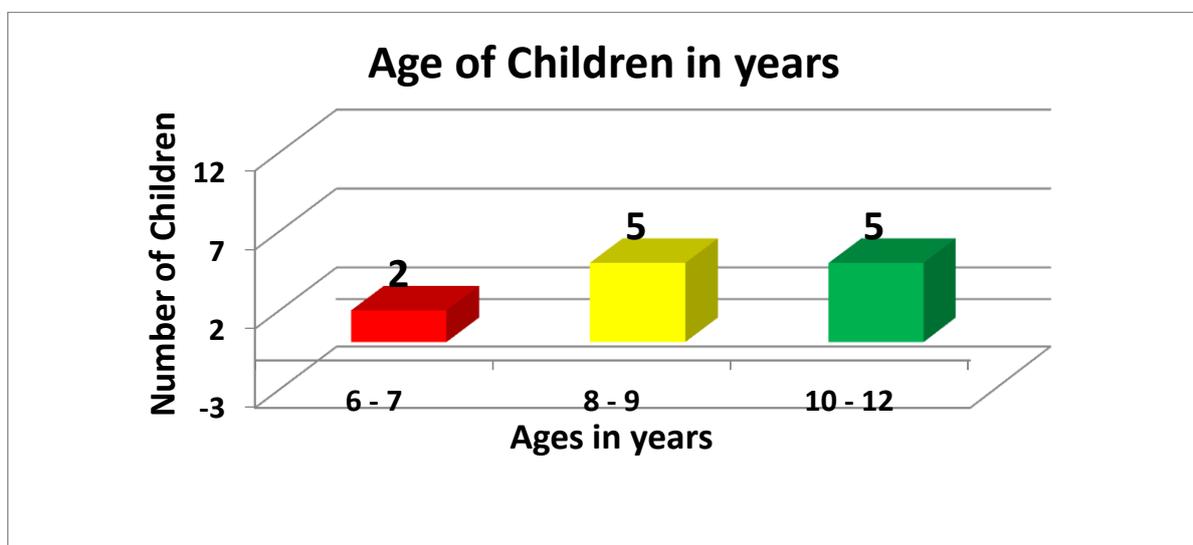
A total number of twelve caregivers had participated in the research study of which eleven participants had been female, seven of whom are single mothers. Only one participant had been male. The results confirm previous findings that women shoulder the responsibility of everyday caregiving despite changes in gender norms (Hartley et al., 2004:172). The majority of those who had stated that they were married mention that the husbands' involvement is very little while a small number had reported shared responsibility with their husbands. This agrees with the

literature that fathers are not usually as involved in daily caregiving (Hartley et al., 2004:172).

Five of the participants had reported that they were not working and those participants who had stated that they had jobs, were either temporarily employed in Ipelegeng (casual labour) or had permanent jobs as cleaners or security guards, reflecting minimum wage. Five of the participants had classified themselves as having low socio-economic status as they depend on either social grant or contributions by family members. The financial status of the participants correlates with the literature that majority of children with cerebral palsy are raised by poor families with unstable finances (Martha, 2010:53; Mobarack et al., 2003:601). Table 1 has presented demographic details of the caregivers who had participated in the study. In addition, only one participant spoke English and is identified as CgP6 in the study while the remainder of the participants spoke Tswana.

### 3.9.2 Demographics of children with CP (n=12)

The following three graphs illustrate the current ages of the children, the ages at which they had been diagnosed with cerebral palsy and the type of CP that they had been diagnosed with.



**FIGURE 1: CURRENT AGES OF THE CHILDREN**

Figure 1 shows the distribution of the ages of the children whose caregivers had participated in the study. The study had targeted caregivers of children between the ages of six and twelve years. According to the figures, the majority of participants are caregivers of children from eight to twelve years.

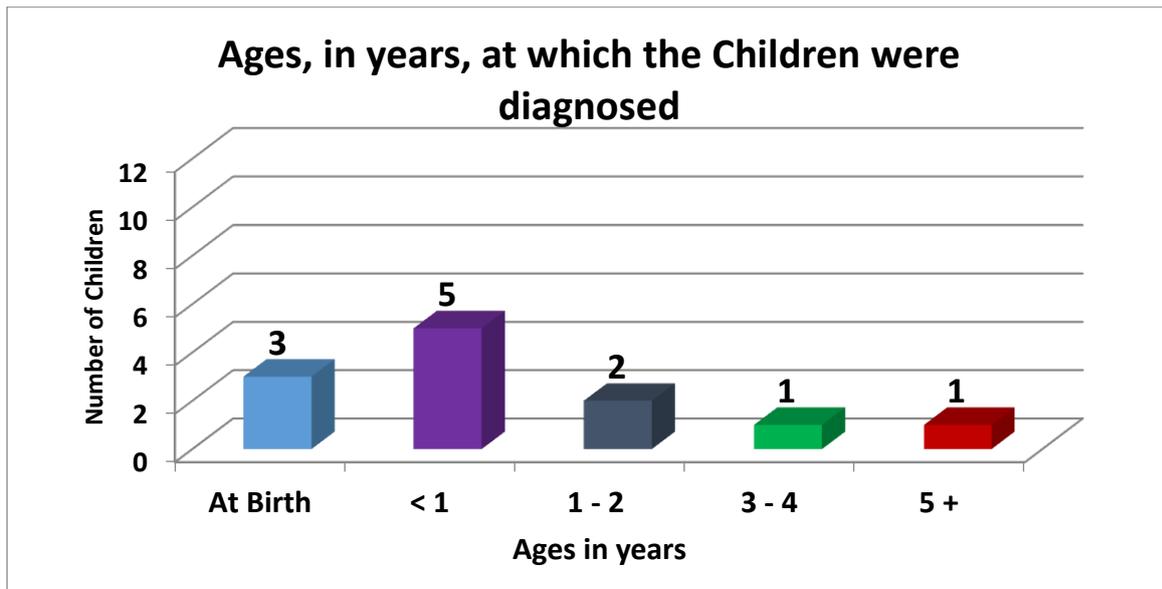


FIGURE 2: AGES AT WHICH THE CHILDREN HAD BEEN DIAGNOSED WITH CEREBRAL PALSY

Figure 2 graphically depicts the ages at which the children had been diagnosed with cerebral palsy. Although some of the children in the study had been diagnosed at birth, most caregivers had reported the onset of the disability as being from four months when the children failed to attain expected developmental milestones. This finding correlates with literature that states that CP is first identifiable when children fail to reach their motor skills milestones and display qualitative differences in motor function development (Rosenbaum et al., 2007:1359).

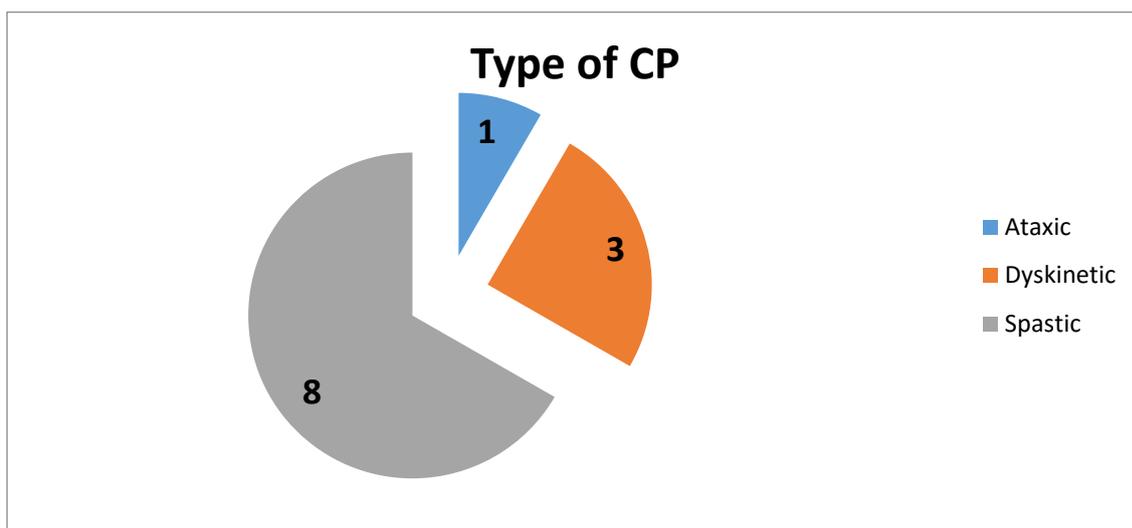


FIGURE 3: TYPES OF CEREBRAL PALSY THE CHILDREN HAVE BEEN DIAGNOSED WITH

Figure 3 depicts the types of cerebral palsy that the children had been diagnosed with. The majority of the children had presented with spastic cerebral palsy, findings that are verified by literature (Abdel et al., 2015:270; Jones et al., 2007:150).

| Limitations of the child as a result of cerebral palsy | Number  |
|--------------------------------------------------------|---------|
| Sensory deficits                                       |         |
| ◦ Hearing impairment                                   | 3       |
| ◦ Visual impairment                                    | 1       |
| Motor dysfunction                                      |         |
| ◦ Cannot walk or sit                                   | 8       |
| ◦ Poor fine motor skills                               | 6       |
| ◦ Delayed developmental milestone                      | 9       |
| Activities of daily living                             |         |
| ◦ Totally dependent on others                          | 8       |
| ◦ Needs assistance                                     | 2       |
| Communication                                          |         |
| ◦ No speech                                            | 5       |
| ◦ Laboured speech                                      | 3       |
| Other associated problems                              |         |
| Epilepsy, growth failure, isolation                    | 2, 4, 3 |

TABLE 2: LIMITATIONS OF THE CHILDREN AS A RESULT OF CEREBRAL PALSY (N=12)

The following discussion presents the themes and sub-themes which classifies the experiences of the caregivers of children with cerebral palsy.

### 3.9.3 Themes and Sub-themes

This section focuses mainly on the primary aim of the study which is to explore the experiences of caregivers of children with CP. The themes and sub-themes that have emerged from the research participants are presented in the table below (Table 3). Each theme is then discussed which is substantiated with translated quotes, literature and theoretical framework. Six themes had been identified from specific patterns that had emerged in issues that were discussed. The first two themes focus on the challenges that are experienced by participants while the third, fourth and fifth themes discuss factors that have assisted participants in adapting to the children's

diagnoses. The last theme identifies the needs that are associated with caring for children with CP, as described by participants.

The following themes and sub-themes have been identified in the collected data.

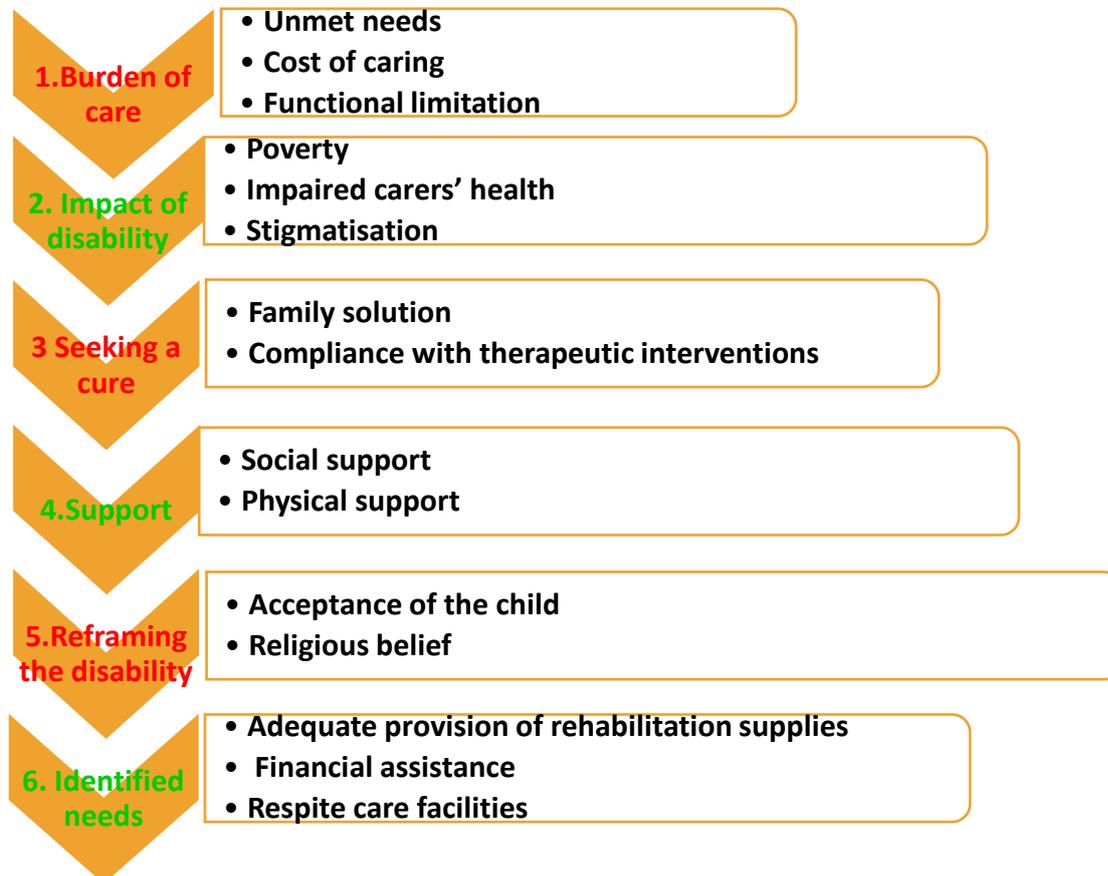


TABLE 3: THEMES AND SUB-THEMES

### 3.9.3.1 Theme 1: Burden of care

One of the themes that research participants had been identified in the responses in their experiences of caring for a child with cerebral palsy is 'burden of care'. Issues that characterise this theme are: unmet needs; cost of caring; and functional limitations of the child. These issues are discussed as sub-themes hereafter.

#### Sub-theme 1.1: Unmet needs

The participants had indicated that there are a couple of needs that have not been fulfilled which have contributed significantly to the challenges they have experienced. The significance of unmet needs in participants' experiences that had been mentioned by three participants, had been reflected when they spoke about services that were meant to assist them in caring for their children. Specific reference had been made to the shortage of adaptive devices more especially wheelchairs which would assist them in carrying for their children. Other participants had pointed out the

bureaucracy in service provision as a stumbling block in meeting their needs. Some of the participants' statements are documented hereafter.

*“Fa e ka bo a nale wheelchair, ke kabo ke mokgarametse go etela ba bangwe, jaanong o bokete go ka mo kuka, go be go ray a gore ke nna fela fa”, (CgP8).*

***If she has a wheelchair, I could visit other people, now I am stuck here because she is too heavy to carry (CgP8).***

*“Ke sa le ke kopetse ngwana wheelchair mme le gompiano, selo se se ntirela tiro bokete le go feta,” (CgP7).*

***I requested a wheelchair for my child a long time ago but I still don't have one, which is making my job more difficult (CgP7).***

*“Mmaboipelego (social welfare officer) o tla a ne a sale a tsile go assessa, a bo o nna ngwaga yotlhe o sa bone thuso, fa o botsa, o tla bolelelwa gore go sa mpe go emetswe tseletso ya thendara”, (CgP12).*

***The social welfare officer will come do an assessment and then you wait longer than a year without receiving any help. When you ask, you are told about the tendering process (CgP12).***

*“Ditsamaiso tsa puso nako tse dingwe di re kgoba marapo go ya go kopa dithuso, o tla isiwa kwa le kwa a bo o feletsa o ithobogile, ka gore go go okeletsa stress”, (CgP5).*

***The processes in government departments discourages us to ask for help because you are sent around, which is stressful and you end up giving up (CgP5).***

The unmet needs that have been mentioned by participants refer to the insufficient supply of physical aids and difficulties in accessing services. Identifying unmet needs as a burden of care correlates with the literature which had highlighted the socio-structural constraints as burden of care in caregivers of children with cerebral palsy (Uldall, 2013:203). The findings suggest that there are difficulties in accessing sufficient services and adaptive devices which are needed for caring adequately for children with CP as described by participants. These difficulties in accessing sufficient services have indicated socio-structural constraints.

Children with cerebral palsy have many needs and unfortunately studies have identified that a considerable number of these needs are unmet which increases the burden experienced by caregivers (Uldall, 2013:203). With reference to the Resilience Model of Family Stress Adjustment and Adaptation, the unmet needs that

have been described by participants put the caregivers at risk of mal-adaptation to life with a child who has been diagnosed with cerebral palsy. The resilience model believes that the success of adaptation of family in crises such as 'raising a child with CP' is determined by the family's network system of friends and relatives (Weber, 2011:177). Furthermore, available resources and accessibility to these resources are important to family resilience (Hall et al., 2011:38). The implication of unmet needs for participants is that there is an element of social isolation as caregivers cannot interact with other people due to the restricted movement caused by the children's immobility, depriving them of the social support they could have gotten. In addition, the inability to access services has perpetuated the difficulties of caring for children with CP and has therefore intensified the stress experienced by caregivers therefore making it difficult to cope.

### **Sub-theme 1.2: Cost of caring**

Five participants have indicated that there are associated costs of raising children with CP which require finance. They have described this financial implication as a burden. Other than monetary costs participants also relate the cost of caring to time needed for the caring of children with CP. This sentiment is reflected in the following responses made by participants.

*"Ngwana o dirisa dipampers mme kwa clinic ga re di bone, ba re ga bana size ya bana, a bo go raya gore madinyana a re a bonang re a beela go reka dipampers..ene go bokete", (CgP1.)*

***My child uses diapers but we do not get any diapers from the clinic because they do not have small sizes. So whatever money I get, I save to buy diapers and it is difficult (CgP1).***

*"Ga a kgone go ja dijo tse re dijang, ka o palelwa ke go tlhafuna, nako tse dingwe rona re lala ka tlala re direlela fela gore re tle re kgone go mo rekelase a ka sejang," (CgP7).*

***He can't eat what we eat because he has difficulties chewing. Sometime we go to bed hungry so that we can buy him something to eat (CgP7).***

*"Ngwana o sedilwa fela kwa sepatela, mme re ya teng beke le beke, jaanong ka ga ke kgone go motsholetsa ke fira koloi, go le thata ka ga ke bereke," (CgP2).*

***The child gets physiotherapy at the hospital, every week and since I cannot carry her I have to hire a care and it is very difficult since I do not work (CgP2).***

*“Thokomelo ya ngwana yo e tsaya nako yame yotlhe, ga kena nako ya me le fa e le ya bana babangwe”, (CgP5).*

***Caring of this child take all my time. I don’t have time for myself or the other children (CgP5).***

The participants’ views are aligned with the literature which had highlighted that caring for a person with a disability has significant financial implications and is very time consuming, especially when the disability is severe (Bryns, 2013:504). Manuel et al. (2005:198) state that the demands of caring for children with cerebral palsy require more time from the caregivers. This opinion is supported by the view that caring for a child with a disability places substantial strain on the caregiver who has assumed the responsibility because of the associated costs (Bryns, 2013:503).

The cost of caring has specifically referred to the everyday needs of the child such as special food, diapers and transportation for visiting in the community or seeing to medical professionals. The burden of caregiving may have associated demands which according to the resilience model would create more stress which may disrupt family functioning and family income (Weber, 2011:172), hence increasing the family unit’s vulnerability.

### **Sub-theme 1.3: Functional limitation**

Another element that had been identified as a burden of care is functional limitation of the child which renders the child dependent on the caregiver for daily living activities. Participants have described the extent of functional limitation of the children as a burden because it is emotionally draining. Furthermore, the role that is played by other family members in caregiving for the children with CP is minimal, which means most of the daily care remains the responsibility of the primary caregiver. This had been described in the following comments.

*“Ngwanayo mmereko wa gagwe o mo ntsi, mo o iphitlhelang o lapile mogopolo”, (CgP10).*

***This child is a lot of work which leaves you emotionally drained (CgP10).***

*‘Ngwana yoke morwalo wa me ke le nosi ... fa ke mo tlogetse ka nappy ha gona yo a ka mo chenjang, go tla bo go emetse nna’, (CgP2).*

***This child is my sole responsibility. If I do not change her nappy no one will change it. They all expect me to do it (CgP2).***

The themes that had been identified in the findings suggest that participants experience everyday caregiving as a burden which they attribute to: unmet needs; cost of caring; and functional limitations of the child. An implication of experiencing burden of care has been that participants have ineffective coping strategies. The family resilience model believes that accessibility and utilisation of external support services serve as a buffer in adverse situations (Oh & Lee, 2009:151). The findings have suggested that there is a lack of external resources which could have assisted the caregivers of children with cerebral palsy in adapting to their situations. Similarly, when the participants had been isolated they were deprived of opportunities to access social support which could have helped them to cope. Many of the participants had also experienced difficulty when they had tried to access services which had increased the burden of care, worsening their situations.

The findings had revealed that participants' responses are in agreement with the literature that states that other family members are reported as playing a role in caregiving, however their role is primarily that of companion or for providing short periods of respite for the mother to carry out other household activities (Hartley et al., 2004:172).

### **3.9.3.2 Theme 2: Impact of disability on caregivers**

One of the main impacts that had been identified in the participants' responses had been that a child's disability often contributes to poverty, impaired health of the caregivers and stigmatisation.

#### **Sub-theme 2.1: Poverty**

One of the consequences of caring for a child with cerebral palsy, as described by participants, had been poverty. Based on the responses, poverty could be arranged into two categories namely, lack of money to attend to the child's needs and food insecurity. Employment difficulties were also linked to poverty by most participants.

#### **Lack of money**

Lack of funds for necessities particularly for the care required for the child with the disability had been reported by many participants. Specific reference had been made to purchasing diapers, special food and transportation to go to medical reviews. Furthermore, the effects of a lack of funds as had been described by participants as having extended to the entire family. Below are some of the comments that had been made by participants.

*“Ka gore ga gona eng, re kgagola disheet tse dikgologolo, a bo re direla ngwana, dipampers ka tsone”, (CgP1).*

***Since we have nothing, we end up cutting up old sheets to make pampers (CgP1).***

*“Kgwedi tse pedi tse di tthomaganang tse, ga ke a mo isa check-up ka ke tshwanelwa” ke go fira koloj, jaanong kena le two months ke sa theogela mo lpelegeng,”*

*(CgP2).*

***We didn’t go for check-ups these past two months because I have to hire a car and I have not worked lpelegeng [casual labour] for two months (CgP2).***

*“Bongwanake ga bana ditlhako tsa sekolo ka bonyenyane jo ke bo bonang boya ko ngwaneng yo, ke rile keya go ikuela ko go Mma –boipeleg o e bile ke itlhobogile,”*

*(CgP12).*

***My kids don’t have school shoes since the little that I got, goes to this child (disabled child). I went to seek assistance at Mma-boipelego but I have even given up (CgP12).***

The participants’ reflections support the literature that states that cerebral palsy is characterised by special needs that require finances (Bryns, 2013:205), as free provision is scarce (Rosenbaum, 2004:972). With reference to the characteristics of participants as illustrated in Table 3, it is evident that there is lack of money in the households.

Most of the employment opportunities for participants have minimum wages and are temporary. However, their caregiving duties incur many costs as they have other dependents, which means the disproportionate earning may lead to poverty. The above argument is based on the finding that most participants are employed by lpelegeng, for which they might only work for one month and be paid P500. This money is then utilised to cover the needs of the child with the disability as well as caring for their other children who need clothes, toiletries and food. The lack of funds in the household could affect the caregivers’ abilities to cope with having to raise a child with cerebral palsy since financial stability in the resilience model had been described as being essential in adjusting to an adverse situation (Weber, 2011:176).

## **Food insecurity**

Lack of food or food instability had been highlighted by participants as a challenge. Below are some of the comments that had been made by participants.

*“Malwapa a mangwe mo gae mo a ja gararo ka letsatsi, rona e tla bo e le tshegofatso ya modimo”, (CgP8).*

***Other families in our village eat three times in a day. For us, it will be by God’s grace (CgP8).***

*“Fa letsatsi le tlhaba o ipotsa gore le tsile go tlhola le jele eng, selo se se oketsang stress”, (CgP7).*

***Every morning you wonder what you are going to eat for the day, something that increases the stress that you already have (CgP7).***

*“Kana fa MmaBoiboipelego e ka bo a re thusa ka dijo, lehuma le kabo le fokotsegile le yone khutsafalo ya go tlhokomela banaba e kabo e le botoka,”(CgP12).*

***If MmaBoipelego could assist us with food, it would reduce our poverty as well as the pain of taking care of these children (CgP12).***

The participants’ responses had reflected food insecurity as an indicator of poverty for their households. This had been attributed to a lack of money in the households and failure of the social welfare services to provide food baskets. The literature highlights that failure to access social welfare services has perpetuated the low socio-economic status of caregivers of children with disabilities (Bryns, 2013:505).

### **Employment difficulties**

Raising a child with cerebral palsy has been described by participants as a challenge when either looking for a job or while working. Reference had been made to the daily care required for a child with cerebral palsy which varies depending on the child’s limitation. Some of the comments that had been made by participants regarding employment difficulties are noted hereafter.

***I had to take unpaid leave because my days at work was finished and she was getting ill frequently and staying without money has affected me a lot (CgP6).***

*“Ngwana yo o lerile lehuma mo lapeng, ga ke kgone go bereka, ka gagona yo ke ka mo tlhogelang le ene kwa ntleng ga mme yo le ene a sa mokgonene ka o nale le mmereko o montsi”, (CgP12).*

***This child has brought poverty to the family. I can’t look for a job because there is no one I can leave her with except my mother who finds it difficult to take care of her (CgP12).***

This view is supported by the literature which states that parents of children with disabilities often have to spend inordinate amounts of time with their children because of the problems they might be presented with (Manuel et al., 2005:199), and being employed is therefore difficult. The reality of this is evident in the employment statuses of the participants as tabulated in Table 3 – three participants had been engaged in temporary employment while five participants had no employment. Vijesh and Sukumaran (2007:78) emphasise that a child’s disability may affect a family’s economic status and one of the reasons would be that caregivers assume full-time caregiving roles and may opt out of their employment which would have financial implications that extend to the entire family (Rosenbaum et al., 2005:627; Ross & Deverell, 2004:192). However, when one considers the resilience model, opting out of employment could be seen as a problem-solving and coping technique that is employed by caregivers to meet the demand of caregiving. The resilience framework states that a family employs problem-solving strategies when faced with a crisis and this prompts changes within the family, leading to adaptation (Webber, 2011:177).

### **Sub-theme 2.2: Impaired health of caregivers**

A total of four participants had stated that raising a child with cerebral palsy has associated emotional pain, physical pain and frequent illness which is attributable to stress. These are discussed below.

#### **Emotional pain**

Emotional pain had been observed while participants described their feelings following the diagnoses of their children. Participants had shown more emotional pain while they described giving birth to a child with a disability as a loss. Some of the comments that were made have been noted hereafter.

*“.....ke ne ka seka ka tshoga fela ke ne ka amega le mo maikutlong, ka tshwanelwa ke go tsamaya tshidilo maikutlo ka tota ke ne ke sa solofela ngwana wa bogole e bile jwa mofuta oo”,(CgP12).*

***I was so afraid and emotionally disturbed that I had to go for counselling. I didn’t expect a disabled child and a disability of this nature (CgP12).***

*“Se se neng sa nkutlusa botlhoko e ne e le bokamoso jwa ngwana yo, selo se ke sampe ke se ipotsagore, fa ke ka swa ke mo tlogela go ya go diragalang ka ene,” (CgP7).*

***What hurt me the most was the future of this child. Something that I still wonder about. If I die, what would happen to him, (CgP7).***

*“...kana ngwanake e ka bo a bala standard 5 jaaka balekane ba gagwe, ene selo se ka di nako tse dingwe se nkutlusa botlhoko,”(CgP9).*

***My child could have been in standard 5 like her peers and at times knowing this is painful to me (CgP9).***

The above reflections by the caregivers of children with disabilities aligns with the literature which states that parents raising children with disabilities are expected to experience emotional distress due to hopelessness about their children's futures (Uldall, 2013:203). Fernandez et al. (2015:93) add that caregivers of children with CP experience profound loss when their children do not meet their expectations. The resilience model highlights that families' subjective perception of the crises influence their adaptability in the face of adversity (Greeff & Nolting 2013:397). When the caregivers perceive giving birth to a child with a disability as a loss it becomes difficult for them to adapt to living with a child with a disability. Thus, negative appraisal by caregivers following the birth of a child with a disability makes them vulnerable to mal-adjustment.

### **Physical pain**

Bodily pains had been reported by some participants which are associated with the assistance given to children with disabilities. Participants believe that the physical pains they experience are aggravated by the non-provision of wheelchairs which could have been assisting them in carrying the children. Some statements that had been made by participants are recorded hereafter.

*“Ke mokuka ke mo tsenya mo bateng tsatsi le le tsatsi jaanong ke setse ke bolaiwa ke magetla”, (CgP4).*

***Every day I have to put her in the bath, and now I have pains in my shoulders (CgP4).***

***When the child goes for exercise I have to carry her on my back because there is nothing else I could use. So these back pains I experience will not heal (CgP6).***

This experience which is shared by participants is supported by the literature that states that an increased amount of assistance is needed by children who are physically more dependent on others to carry out their daily tasks which leads to

bodily pain among caregivers (Byrne et al., 2009:700). Sharan et al. (2012:1891) mention that the causes are repetitive heavy lifting and carrying. The absence of facilities that could provide temporary relief care in communities such as Mahalapye perpetuates caregivers' physical health problems. The resilience model postulates that contextual difficulties that are created by society adversely affect family functioning and a family's ability to cope with a crisis (McCubbin, 2001:39).

### **Frequent illness**

The participants have mentioned various illnesses which they frequently experienced and attributed them to the stress of caregiving. Other than the illnesses as reported by participants, stress is evident among participants as they repeatedly mention their levels of fatigue coupled with body aches. The participants had described their ill health in the following comments.

*"Tota se se tsholetsang BP (Blood Pressure) ya me ke gore ke nna fela fa, le tsone diphitlho ga ke di tsamae", (CgP8).*

***What constantly raises my BP (blood Pressure) is just being stuck here, not even attending funerals (CgP8).***

*"Fa e sale ke tshola ngwana yo ke motho yo ke robalang ko sepatela kgapetsa kgapetsa, kena le tlhogo e e nnang e opetse ruri, mme ke belaela stress,"(CgP7).*

***Since giving birth to this child I am hospitalised more often because of a continuous headache which I believe is caused by stress (CgP7).***

*"Mmele o wa me o nna fela o thuba ke sena tokololo," (CgP11).*

***My body is always aching and I have no energy (CgP11).***

This finding has confirmed the views of Al-Gamal and Long (2013:624) who assert that caregivers of children with disabilities are more likely to experience poorer physical and mental health than the general population. Vijesh and Sukumaran (2007:79) suggest that this poorer psychological health could be attributed to the extra daily tasks that take caregivers' time away from adequately taking care of themselves. The resilience model states that when families are dealing with chronic stressors such as caring for a child with a disability, there is an accumulation of pre- and post-stressors which may include poor health and this has an impact on the family's level of vulnerability in a crisis (McCubbin, 2001:42).

### **Sub-theme 2.3: Stigmatisation**

Four of the participants had reported stigmatisation as a challenge. Consequences of stigma had been reported by participants as being isolation, loneliness and unstable relationships.

### **Isolation and loneliness**

The participants had described how giving birth to a child with a disability had isolated them. Some participants had stated that there is element of subjective burden regarding stigmatisation.

*“...batho ga basa tlhole ba tsena fa kana ba tshaba gore batla na parelwa ke bogole, ga ke itse,” (CgP1).*

***People no longer visit us. I don't know if they are afraid that they will get a disability (CgP1).***

*“Ga gona ope yo a tle a mpotse gore a ngwana o teng, o a tsoga, o kgona go bona fela gore baagisanyi, ga bana kgatlego”, (CgP12).*

***No one ever asks me how the child is doing, an indication that my neighbours are not interested (CgP12).***

*“Ngwanake o ne a tewa maina a lesotlho, selo se se neng se ntshabisa go tsena fa gare ga batho,” (CgP5).*

***My child was given inhuman names; something which makes me fearful of interacting with people in my community (CgP5).***

*“ke amega maikutlo thata, fa ke tshwanelwa go itsese ngwana batho , ke ipotsa gore batho ba go nteba jang,” (CgP10).*

***I become emotionally distressed when I have to introduce my child because I wonder how people will react (CgP10).***

The consequences of giving birth to a child with a disability reiterates what had been highlighted in the literature – it creates perceptions which result in social isolation and loneliness (Hartley et al., 2004:173). The finding of the subjective burden that has been raised by participants is supported by the literature which states that mothers of children with disabilities who believe that people with disabilities are stigmatised, experience emotional distress such as embarrassment and shame (Blum, 2008:10).

The family resilience framework assumes that in order for families to adapt and cope effectively in their given crises, they may rely on guidelines and reactions from the

community. When these are inappropriate the families experience a greater degree of tension regarding their situations (McCubbin, 2001:47).

### **Unstable relationships**

The participants had mentioned unstable relationships, which they associate with the social stigma regarding disabilities, despite them having reported that they received support from their partners. Some participants had revealed that giving birth to a disabled child not only affected current relationships but future relationships too.

***After my husband learnt that the child has a disability he left the family for three months, even his relatives didn't come visit me, or communicate with me (CgP6).***

*“ wa re ngwana o nale bogole, rona ga iseke ope a tshole ngwana yo o ntseng jalo ko ga rona, ....fa e sa le a bua jalo ga ke mmone fela jaaka lantlha,” (CgP3).*

***“You are saying our child has a disability! No one in our family has given birth to a child with a disability.” Since he said those words I don't see him like I did before (CgP3).***

*“Rraagwe ngwanake o ne a bona gore go botoka a tlhokomele ngwana a sanne fa, seemo se ke sa itseng gore a o tla kitla a boela molwapeng,” (CgP11).*

***The father of my child finds it better to take care of the child by not staying in the house. I don't know if he will ever come back (CgP11).***

*“Fa e sale ke nna le ngwana yo o naleng bogole, ga gona monna yo a tle a nkgatlhegele, ke dumela gore ga ba tshabe morwalo, mme ba tshaba gore ke tloga ke ba tsholela ngwana yo o naleng bogole,” (CgP7).*

***No man has been interested in me since I gave birth to a child with a disability and I believe that it is not the fear of burden of care, but the fear that I might give them children with disabilities should they want kids (CgP7).***

The quotes above have highlighted one scholar's view who had mentioned that in many cultures disability is viewed as unacceptable, believed to be punishment by angered ancestors or retribution for acts of sin and in this context fathers will leave the home permanently and will have no contact with the child or the mother again (Levin, 2006:288).

Despite the level of stigma described by participants, positive acceptance of the child into the family unit has been reported; something that participants consider as a strength in their everyday caregiving.

The sub-themes that had been discussed in this section have shown that raising a child with cerebral palsy has significant impact on the well-being of caregivers, such as poverty, impaired health and stigmatisation. A possible explanation for this is given by Krstic and Oros (2012:373) who argue that raising a child with cerebral palsy is stressful for the parent because it requires an intensive physical engagement as well as coping with emotional reactions to the child's condition, hence the parents' poorer quality of life.

The sub-themes that have been identified have also shown that the impact of disability on participants is significant in determining adjustment and adaptation to raising a child with cerebral palsy. Based on the study findings, there is evidence that are few external resources which the resilience model has posited as facilitating coping behaviour (Oh & Lee, 2009: 151). The reported lack of money has had significant impact on participants who continue rehabilitation treatment which could improve the child's condition meaning that the caregiver is less frustrated. In this context, the rehabilitation treatment serves as an external resource that may assist participants in coping. The difficulties of being able to access rehabilitation treatment attributed to financial instability.

The caregivers have fallen ill numerous times as a result of providing care to children with cerebral palsy. These include: high blood pressure; headaches; physical pains; and body aches. The stress of providing care without sufficient mobility aids had been linked to the illnesses that participants have experienced.

The stigma that has been described by participants have impacted their relationships and community interaction which has led to isolation and loneliness which results in caregivers experiencing difficulties while adapting to life with disabled children. Scholars of the resilience model maintain that positive adaptation of families raising children with disabilities is influenced by societal accommodation of persons with disabilities.

### **3.9.3.3 Theme 3**

Seeking a cure had been among the themes that emerged from the study. Participants had mentioned that they constantly search for a cure for their children's impairments. The two common means of seeking a cure had been family solutions and adherence to rehabilitation treatment, which are discussed hereafter.

#### **Sub-theme 3.1: Family solution**

Four participants had mentioned that they went to both traditional healers and hospitals when they found out that their children have disabilities. Participants further identified challenges that they had experienced during the process of seeking a cure.

*“E rile re lemoga gore ngwana o nale bogole re ne ra mo isa kerekeng, le fa go iseke go nne le mosola o o kalokalo, (CgP5).*

***When we discovered that the child has a disability we took her to the church, though nothing much has changed (CgP5).***

*“Tota ke ne ke batla go tlhaloganya bogole jwa ngwana, ke ne ka ya ko sepatela fa ke bona a ntse a sa tsamae mme dingwaga di fetile gore e ka bo a tsamaya,” (CgP7).*

***I wanted to understand the child’s disability, so I decided to take him to the hospital where I enquired about him not being able to walk (CgP7).***

*“Go leka ntlha tsotlhe gone ga dira gore ke tle mo seemo sa go amogela ngwana,” (CgP11).*

***Trying both sides helped me to come to terms with accepting my child’s disability (CgP11).***

*“Re tsamaile dingaka ka go farologana mme ga gona botoka bope bo bo neng ba nna, se se fedileng ke madi,” (CgP5).*

***“We went to so many doctors and traditional healers but the child didn’t get any better. A lot of money have been spent (CgP5).***

The literature has described cerebral palsy as a complex disorder because of associated impairments (Levitt, 2006:1; Olney & Wright, 2006:625) as such caregivers are compelled to seek a cure as shown in the above quotes. The participants’ efforts of seeking a cure is an indication of their problem-solving skills when faced with crises. According to the resilience model, the family’s problem-solving skills include the family’s ability to utilise resources and initiate efforts to resolve the hardship (Weber, 2011:176). The findings have shown that seeking a cure has helped participants come to terms with their children’s disabilities.

The findings further revealed that although seeking a cure had been meant for the child’s discovery, the participants had experienced a number of challenges such as failure to heal, spending much money and consulting traditional healers.

The struggle of families in an effort to find a cure appears to be in line with the resilience model which maintains that families adopt a coping strategy that appears

to be effective but which produces difficulties (McCubbin, 2001:55). In addition, Levin (2006:288) concludes that imbalances in the health care system push families of children with disabilities to resort to consulting traditional practitioners and this, with reference to the resilience model, has created difficulties that adversely affected family functioning (McCubbin, 2001:39).

### **Sub-theme 3.2: Compliance with therapeutic interventions**

The participants' responses had revealed that despite challenges regarding therapy such as transport and insufficient mobility aids, they are committed to the rehabilitation treatment. They had identified the education during therapy sessions as beneficial.

*“Pele ga ngwana a sedilwa o ne a sa kgone le fa e le go ipitekolola, mme go tloafoalela tshidilo re ne ra bona pharologanyo, selo se se re kgothatsang go ya tshidilong, le fa go le bokete ka gore ke a mmelega” (CgP7).*

***Before the child went for physiotherapy he couldn't turn himself while sleeping. But since taking it seriously there has been a difference, something that encourages me to go despite the challenge of carrying him with my back and it is difficult (CgP7).***

*“Fa re ile ngakeng re rutiwa gore fa re tsena kwa gae, re dire jang di exercise, jaanong ke a leka tota, gore bogolo fa sengwe sone a ka kgona go sedira go tlabo go kanna le pharologanyo,” (CgP10).*

***At the therapy sessions we are being taught how to do those exercises at home and I am trying my best, because I have hope that something different and positive might come out of that (CgP10).***

*“Bogole ba gagwe fa ntse a gola le bone bo tsile go gola le dingwaga, selo se ke se itemogetseng. Mme ke kgona go amogela ka gore ke tthaloseditswe,” (CgP4).*

***It was explained to me that as she grows up her disability will also change for the worst, something that I have also realised. But I am coping with these changes because it has been explained to me (CgP4).***

The participants' sentiments that have been expressed in their comments are supported by literature which highlights that the success of the rehabilitation programme depends heavily on training mothers in specific skills to help their children develop (Mobarack et al., 2003:601).

Participants had revealed that during therapy sessions, therapists share information that helped them understand their child's diagnosis and therefore how to cope with their children's disability. Brandao et al. (2014:564) is of the view that participation by caregivers during the rehabilitation process gives them opportunities to seek information that is useful for gaining insight into the impairments and disabilities of their children. As stated by the resilience model the success of family adaptation, especially caregivers of children with cerebral palsy is influenced by the support of rehabilitation therapists and health personal (Ross & Deverell, 2004:199).

The sub-themes that had been discussed pointed out strategies that had been employed by participants that helped them to adapt to living with a child with cerebral palsy. Croot et al. (2012:1540) highlight a variation of coping strategies that are utilised by parents of disabled children. The commitment to the rehabilitation treatment has given caregivers insight into their children's impairment and has met their efforts of seeking a cure following the onset of the disability. The findings had revealed that seeking a cure had some limitations that could perpetuate poverty as much money is being spent. The strategies are evidence of the participants' efforts to resolve the hardship of raising a child with CP thereby adapting to life with the child. This appears to be in line with the resilience model's assumptions which have identified problem-solving skills as an important element in influencing the family's resistance to adversity (Weber, 2011:171).

#### **3.9.3.4 Theme Four: Support**

The theme of support had been found to be common in the responses that had been given by the majority of caregivers who had participated in the study and who had described it as a key factor in participants' coping strategies. Sub-themes that had emerged from the support theme are social support, as reported by six participants, and physical support, as reported by three participants.

##### **Sub-theme 4.1: Social support**

The participants had discussed the supportive role that is played by family members following the birth of a child with a disability. Some participants had highlighted financial assistance as part of the support they received while others had specified emotional support.

*"...batsadi bame baleka go nthusa fa ba kgonang teng, ba nkgothatsa mo moeng,"*  
(CgP9).

***My parents are trying to help me where they can, and they encourage me emotionally (CgP9).***

*“.....Ba le lwapa la me le bone ba ntshidila maikutlo mme ka kgona go amogela seemo se ke tshelang ka sone,” (CgP12).*

***My family gave me emotional support which enabled me to accept the situation that I am living with (CgP12).***

*“Re ne ra nna le letlhoko la madi molwapeng, ke gone fa mme a neng a reke batle piece jobs, o tla nna a sala le ngwana,”(CgP3).*

***At one point I was faced with financial difficulties, then my mother told me to go and look for jobs, and she looks after the child when I am at work (CgP3).***

*“Bo monnawe fa ba tswa sekolong ba ntshalela le ene, mm eke kgone go dira ditiro tse dingwe jaaka go ya dishopong,” (CgP2).*

***Her younger sisters stay with her after school and then I am able to do other things like going shopping (CgP2).***

*“Bo malomaagwe ke bone baba nthusang ka madinyana mme ke bo ke kgona go morekela dijo tse a kgonang go dija,” (CgP1).*

***My uncle helped me with some money, so I am able to buy him the food that he can eat (CgP1).***

The quotes above have identified family unity as an important factor in the adaptation process of raising a child with a disability. The findings correlate with literature which had revealed that the support by family members and relatives is helpful to caregivers as it assists them with navigating with challenges of raising a child with a disability (Croot et al., 2012:1543). Cohesion among family members during difficult times has been noted as a factor for successful adaptation by the resilience model (Weber, 2011:177).

Pfeider et al. (2013:364) share this view and mention that caregivers of family members who have disabilities who experience difficult circumstances but who have a relatively high level of social support manage better. Regardless of the supportive role played by family members, the daily caregiving of the child remains the sole responsibility of the caregiver as illustrated in the discussion on functional limitations.

Participants had stated that the support they received from family had helped them to deal with the emotions of giving birth to a child with a disability and therefore they experienced less stress. This finding correlates with the literature which has shown

that social support may serve as a coping resource in optimising caregiver well-being and health outcomes among parents of children with chronic developmental disabilities (Oh & Lee, 2009:151).

#### **Sub-theme 4.2: Physical support**

Very few participants had mentioned physical support, in the form of professional interventions and availability of resources, as an important resource that had helped them to adjust and adapt to life with a child who had been diagnosed with cerebral palsy.

#### **Professional interventions**

Professional interventions primarily referred to counselling that had been received following the diagnosis of the child. However, participants had felt that it would be more beneficial if it was done frequently. Some had stated that the medical procedures that had been done to reduce the effects of the impairment gave them hope which had helped them adjust to the child's condition. This sentiment is reflected in the following comments.

*“Gone go le thata gore ke dumele fa ngwana a nale bogole, mme Mmaboipelego (Social Worker) go nna a ntse a ntshidila maikutlo, ke gone ka itlhoboga ka amogela seemo,” (CgP12).*

***It was difficult for me to accept that the child has a disability, but through counselling given by the social worker, I accepted the situation as it is (CgP12).***

*“Fa e sale fela ba re kgothatshafa re sena go bolelelwa gore ngwana o nale bogole, mme kana jaaka a ntse a gola jaana, mathata le one a a gola”, (CgP1).*

***We were only given encouragement after the diagnosis, but as the child grows, problems also increase (CgP1).***

*“Ke ne ke tshela ka stress ka gore ke ne ke sa itse gore tota ke ka dira jang gore ngwana a kgone go ja, mme ba sepatela ba dira operation gore ngwana a kgone go jaka lethumbo,” (CgP7).*

***I was living with so much stress because I didn't know how to feed my child, but the hospital helped me by doing an operation in which they inserted a naso-gastric tube that I now use to feed my child (CgP7).***

The participants' responses had revealed how professional intervention had assisted them in addressing challenges they experienced following the birth of a

child with a disability. Experts in the field had asserted that caregivers of children with disabilities present with poor psychological well-being (Carona et al., 2012:971) which is associated with the caregiving experiences (Oh & Lee, 2009:150) and thus professional intervention will be of paramount importance. The literature on resilience has stated that a key to successful parental adaptation lies in the capacity of the families to access appropriate resources and services that both support them in coping with their child's needs and reduce disability related problems (Oh & Lee, 2009: 151).

### **Availability of resources**

The participants had made reference to the presence of rehabilitation personnel during therapy sessions. They also acknowledged that the provision of assistive devices aided their adaptation of caring for their children.

*“Le fa gone go nale mathata a go tla tshidilong, gone go a kgothatsha go itse gore o a go kopana le ngaka, yo o tla go fang dikgakololo (CgP10).*

***Despite the challenges we are facing to go to physiotherapy, the fact that therapists are always there for sessions and will give you guidance is encouraging (CgP10).***

*“Bana ba bogole jwa mofuta oo ba changer fela o sa solofela, mme go kopana le ba bongaka gangwe le gape go re fa tshone ya go botsa go tlhaloganya gore go direga eng,” (CgP7).*

***Children with this type of disability change suddenly, and having to meet with therapists frequently gives us the opportunity to understand those changes (CgP7).***

*“Pele ga ba red cross bamo fa wheelchair, ke ne ke itlhela kena le mathata fa ke batla go ya kerekeng, jaanong re kgona go tsamaya rotlhe,” (CgP2).*

***The Red Cross donated a wheelchair to her, now we can go to church together. Before that it was really difficult for me (CgP2).***

The above quotes have highlighted the fact that other than promoting function for the child with cerebral palsy, the rehabilitation professionals help in the acquisition of new skills and educate caregivers on daily care (Jones et al., 2007:227). The participants' reflections align to the notion, in the literature, that adaptation in caregivers of children with cerebral palsy is influenced by access to the support of rehabilitation therapists and health personnel (Ross and Deverell, 2004:199). The family resilience model has noted that during the adaptation process, the family

utilises resources such as medical services in order to meet the demands associated with their situation (Webber, 2011:177; Greef & Nolting, 2013:397).

The sub-themes have confirmed previous findings that social support is a potential buffer in the adaptation of caregivers of children with disabilities. According to Webber (2011:177), families who are able to develop and utilise support systems are both more resistant to major crises and better able to recover and restore stability after a crisis. The findings had singled out family unit as the most important social support network.

Family cohesiveness during difficult times is an element identified by the resilience framework as an important factor in adaptation following a crisis (Webber, 2011:177).

### ***Theme Five: Reframing the disability***

Reframing the disability had been found to be helpful for adapting to life with a child who had been diagnosed with CP, as had been noted by eight participants. In this theme, two sub-themes that had been identified were acceptance of the child and religious belief which stated that giving birth to a child with a disability is God's will. These are discussed below.

#### **Sub-theme 5.1: Acceptance of the child**

Eight participants had considered the acceptance of the child as an important element in adjustment and adaptation to raising a child with CP. Some had attributed the acceptance to being a strength factor in their caregiving process. Reflecting on the acceptance of the child, participants made the following comments.

*“Ga gona sepe se re neng re ka tlhola re se dira,mme go ithuta go tshela le ngwana,” (CgP9).*

***There is nothing we could do but to learn to live with the child (CgP9).***

*“Ngwana ga gona sepe se a se dirang mme re ntse re mo tsa a fela jaaka bana ba bangwe. Fa o tla o reketse bana diaparonyana le ene o mo teng,” (CgP4).*

***The child doesn't do anything on her own, but we treat her like any other child in the family – when you buy some clothes for other kids you also include her (CgP4).***

*“Re setse re mo tlwaetse, mo eleng gore ga re sa tlhole re mmona a na le bogole,” (CgP10).*

***We are used to the child and no longer see her as having a disability (CgP10).  
At first I thought I will never have another child but gradually I accepted the  
child, that's why I ended up having another one (CgP6).***

*“Go amogela ngwana jaaka a ntse go re beile mo seemong sa gore seemo se ke se  
re tsileng go tshela ka sone,” (CgP4).*

***Accepting the child and who she is, prepared us to accept that this is the  
situation we are going to live with (CgP4).***

*Bogole bo tshwana fela le lesa, bo kgona go diragelela mongwe le mongwe nako  
engwe le engwe....fa o le mo seemong seo, o tshwanelwa ke go ikamogela, o tla  
bona gole motlhofo”, (CgP1).*

***Disability is like death, it can happen to anyone, anytime. So you have to  
accept yourself when you are faced with that situation and you will find things  
not as difficult (CP1).***

The element of ‘acceptance’ in participants’ comments is supported by Croot et al. (2012:1548) who point out that parents’ ideas about disabilities had changed following the birth of children with disabilities and this transition had influenced their experience and management of their situation. Similarly, Greeff and Nolting (2013:402) mention that after having given birth to a child with a disability, parents realised that there is nothing they could do to change the situation and thus had to accept it and make the most of it. Acceptance of the child by participants aligns with the literature on resilience which had highlighted the importance of family members showing understanding for the uniqueness of each person within the family unity (Greeff & Nolting, 2013: 398).

### **Sub-theme 5.2: Religious belief**

The participants had made specific reference to the belief that it is God’s will to have a disabled child and this religious behaviour had been employed following the birth of the child with the disability. The following comments were made.

*“.....Se sengwe se se ntshegeditseng le go feta ke go inneela mo modimong. Ke  
tsaa gore ke thulaganyo ya modimo go nna le ngwana yo o ntseng jaana,” (CgP12).*

***What keeps me going more is to give myself to God because I believe it is  
God’s plan to have such a child (CgP12).***

*“Ke dumela gore modimo o ne o batla go bona gore kemo tshepha gole kae, ke  
sone se a refileng ngwana yo, mme re tshwanetse go mo rata go bontsha modimo  
gore ke modimo ka nako tsotlhe, (CgP5).*

***I belief God is testing my faith, that's why he gave me this child, and I have to love the child to show God that I still believe in him (CgP5).***

*“Re batho ba re dumelang mo thapelong, ke sone se re itsesepetseng le fa go le thata jang,” (CgP9).*

***As a family we believe in prayer, that's why we are strong despite how difficult it is (CgP9).***

*“Go nna tlhaga mo ditrong tsa kereke, go dirile gore ke bone support,” (CgP10).*

***Being actively involved in church activities enabled me to get support (CgP10).***

Turning to a religious source for help after a child's diagnoses could serve as a buffer and alleviate caregiving stress (Croot et al., 2012:1548; Greeff & Nolting, 2013:402). The participants' responses have confirmed this by indicating that religious belief has been a strength factor in the adaptation of living with a child with a disability. For instance, religious behaviour such as prayer has been seen enhancing personal coping behaviour. This aligns with the resilience model that identifies a family belief system as a domain in family functioning which empowers the family to become resilient during periods of adversity (Walsh 2003:5).

The sub-themes that had been discussed have shown that attributing a positive meaning to a crisis, such as giving birth to a child with a disability, has assisted individuals in adapting better. This is supported by the literature on resilience which has maintained that the families who are able to draw meaning from and accept their situation are better able to adapt (McConnell et al., 2014:834; Krstic & Oros, 2012:373; Greeff & Nolting, 2013:373). Thus, positive perceptions about a situation serve as a buffer against the stressors associated with caring for a child with a disability (Bayat, 2007:707).

### **3.9.3.5 Theme Six: Identified needs**

The previous themes that have been discussed had revealed that the nature of cerebral palsy as a developmental disorder has exposed caregivers to a number of challenges, regardless of the coping strategies they have employed. Considering this aspect, participants had been asked during the interviews to identify their needs as well as provide suggestions for interventions that could be beneficial in caring for children with disabilities. The needs and suggestions that had been made by the participants are discussed as sub-themes hereafter.

### **Sub-theme 6.1: Adequate provision of rehabilitation services**

A significant number of participants had stated that their children's main needs were assistive devices such as wheelchairs, diapers and transport to go to medical reviews. Wheelchairs are the most needed devices.

*Re lebanwe ke kgwetlho ya tlhalelo ya di dirisiwa, fa gone go ka tokafadiwa seo, (CgP4).*

***We are faced with a serious shortage of rehabilitation supplies, if that could be improved ... (CgP4).***

***I think if the government could provide us with the necessary aids, especially wheelchairs, that would assist us in with transportation to health facilities or wherever you want to go (CgP6).***

*“Selelo sa rona se se tona ke transport e e ikanyegang bogolo jang go ya go bona specialist kwa ntle”, (CgP12).*

***Our main outcry is reliable transport to go for medical reviews with specialists especially the one outside the village (CgP12).***

The participants' responses had indicated the inadequate provision of services. This sentiment concurs with the argument that inadequate funding of programmes geared towards assisting people with disabilities persists despite comprehensively develop policies which guide the rendering of services to people with disabilities (Mmatli, 2012:21). For instance, the National Policy on care of disabled persons stipulates that care of people with disabilities should include rehabilitation support at no cost and universal accessibility (Republic of Botswana, 1996:5). The participants' experience proves that this element of the policy is not enforced. The inadequate provision of services which had been indicated by participants is condemned by the resilience framework as the framework maintains that a key to successful parental adaptation during adversity lies in the capacity of the families to access appropriate resources and services that support them in coping with their children's needs (Oh & Lee, 2009:151).

### **Sub-theme 6.2: Financial support**

Financial assistance is another need that had been identifiable in the responses of many of the participants. Related to this is the limited opportunities for caregivers to search for employment because of the children's total dependence on them. One participant had highlighted in the following statement.

*“Re tlhoka go thusiwa ka madi eseng fela gotwe ke a ngwana, mme le rona batlhokomedi, kana re nale bana babangwe, mme ga re kgone go ya go batla tiro re tlogela ban aba seemo se”, (CgP1).*

***We need to be assisted with allowance not only for the child’s needs but also for us as caregivers because we can’t leave the children with this condition to go and look for work, yet we have personal needs. We have other children to take care of (CgP1).***

According to the literature that had been reviewed, caregivers assume full-time caregiving roles and this may require them to stop working which may have financial implications that extend to the entire family, and this in turn could lead to poverty (Rosenbaum et al., 2005:627; Ross & Deverell, 2004:192). Financial support is therefore of paramount importance as it creates a barrier between the caregivers of people with disabilities and the effects of poverty (Republic of Botswana, 2013:18). Families that are financially stable cope better during times of adversity than families who struggle financially. According to the resilience model, financial stability is a resistance resource that ensures positive adjustment and adaptation during periods of adversity (McConnell et al., 2014:833).

### **Sub-theme 6.3: Continuous supportive counselling**

Continuous supportive counselling as a need had been identified as another sub-theme within the participants’ responses.

*“Bogole, tlhokomelo go oketsega le ene jaaka a ntse a gola, moo iphetlelang o fe letswe ke tshepo”, (CgP3).*

***Disability – the care required increases and you find yourself helpless (CgP3).***

The participant’s concern, as noted above, is related to the fact that as the child becomes older the challenges increase. This has mirrored the sentiment of Uldall (2013:203) who mentions that a normal child is expected to progress into an independent adult and this is not possible for a child with such a disability. The parents will therefore continue to experience emotional distress. Similarly, Oliver (1996:16) points out that the family of a child who is severely or profoundly disabled such as a child with CP has to adjust to a routine of constant care and attention which will not change significantly as the child grows older. Taking this into consideration, the researcher suggests that social workers in collaboration with

rehabilitation therapists should design a support programme that will continuously address the psycho-social needs of caregivers.

#### **Sub-theme 6.4: Respite Care facilities**

Another need that had been identifiable in the participants' responses is the need for a rehabilitation centre that could provide holistic care in terms of intensive rehabilitation care and respite care.

***I think there should be a rehabilitation centre where we can leave our children and so that we can do something. It is difficult because you are always with the child. And also, they should have daily physiotherapy because at the hospital it is once a month which at times you fail to go to it because of different reasons (CgP6).***

*“Fa nne go ka nna le ditlamelo tse di tshwanang le ko ditoropong fa re ka tlogelang bana teng motshegare...” CgP4).*

***If there could be those facilities like in town where we could drop kids during the day... (CgP4).***

The participants' responses had reflected a need to be relieved from caretaking responsibilities. The participants believe that such a service would benefit both them and the children. Respite care as suggested by the participants is an important service in the array of services that have been developed to support families who have children with developmental disabilities, as the level of care required for these children can be substantial (Chan & Sigafos, 2006:27). Martha (2010:58) however indicates that there are no respite care facilities within rural communities and the burden of caring for these children is therefore not shared – a reality for the participants of the study.

The sub-themes that have been discussed in this section reflect the gaps in support services that are currently being provided to children with disabilities and their families, despite a firm and comprehensive National Policy on care of people with disabilities. Although the suggested support strategies are important in addressing the needs of participants, temporary relief had been singled out as the most effective support strategy that would be beneficial to caregivers. Chan and Sigafos (2006:27) is of the belief that respite care mitigates the effects of stress of caregiving and may provide caregivers with opportunities to look for employment. The literature on resilience has highlighted that if adequate services are present in a family's support

structure, the outcomes appear to be good even in the context of severe stressors (McConnell et al., 2014:835).

### **3.10 SUMMARY**

The findings in this section is comprised of the demographic characteristics of the participants and the analysis of themes that characterise the participants' experiences of caring for a child with cerebral palsy. The study findings have suggested that caring for a child with cerebral palsy exposes caregivers to many challenges such as burden of care, impaired health, poverty and stigmatisation. Some of these challenges are directly attributed to the child's disability while some are due to insufficient services provided to caregivers.

During the caregiving process, caregivers are faced with inadequate implementation programmes and services which had been designed to assist caregivers and children with disabilities. The lack of assistive devices and difficulties in accessing services such as welfare programmes are some of the examples that have been discussed. There is a need for an intervention programme that will address the challenges that are experienced by caregivers and remove the obstacles that have been identified. The study findings have revealed resilience factors in participants, which include religious belief, supportive roles played by family members and acceptance of the children which had been the most effective coping strategy. These findings suggest that these resilience qualities need to be identified in each situation and strengthened which would aid in designing intervention care programmes that promote adaptation in individuals who have difficulty adjusting and adapting to life with a child with a disability.

This study had been based on the Family Resilience Model of Stress, Adjustment and Adaptation. The model is based on the belief that there are protective factors which facilitate a family unit's ability to overcome a crisis. Cerebral palsy is a condition that is associated with lifelong challenges both for the child and the family, creating a significant strain in the caring process. The Resilience Framework that has been utilised to assist in identifying the protective factors that could assist caregivers of children who have been diagnosed with cerebral palsy to emerge from these challenges as stronger individuals.

The conclusions and recommendations of this study have been based on the study findings and are discussed in the next chapter.

## CHAPTER FOUR

### CONCLUSIONS AND RECOMMENDATIONS

#### 4.1 INTRODUCTION

In this chapter, a summary of the conclusions that have been drawn from the study findings as well as any recommendations which have been based on the study findings are presented. How the goal and objectives of the study have been reached will be discussed too by highlighting the key findings of the study.

#### 4.2 THE GOAL AND OBJECTIVES OF THE RESEARCH STUDY

##### 4.2.1. The Research Goal

The goal of this research study had been to gain an understanding of the experiences of caregivers who care for children with cerebral palsy in Mahalapye, Botswana.

##### 4.2.2. The Research Objectives

The goal had been met through the achievement of the following objectives.

##### **4.2.2.1 Objective 1: To Conceptualise Cerebral Palsy as a Childhood Disability from Literature**

This objective is met in Chapter One Section 1.1, Chapter Two Section 2.2 and Chapter Three Section 3.8.2. Cerebral palsy is described as a neurodevelopmental condition that severely impedes a child's development and is often identifiable in the first 12 to 18 months of the child's life (Miller 2005:33). Various factors contribute to the onset of cerebral palsy – maternal conditions such as rubella, and factors affecting the child directly such as infections and complications arising from premature birth.

Globally, this condition is more prevalent than other types of developmental disabilities in the paediatric population with an estimated 2.5 cases per 1000 live births (Blair & Waston, 2006:118). However, the rate of incidence is higher in developing countries than developed countries. Botswana, as a developing country, has approximately two children per 1000 live births who have been diagnosed with cerebral palsy (Martha, 2010:53).

##### **4.2.2.2 Objective 2: To Explore and Analyse the Caregivers' Experiences of Living with Children who have been Diagnosed with Cerebral Palsy**

This objective is met in Chapter 2 and Chapter 3. There is consensus between the literature and the responses of the participants who raise children who have been

diagnosed with cerebral palsy. The participants had explained how living with a child who has been diagnosed with cerebral palsy has many challenges that affect them as individuals as well as the whole family. The caregivers often experience burden of care following the birth of a child with a disability which is attributable to the care required, poverty (lack of financial resources), food insecurity, employment difficulties, impaired health, and stigma associated with other people's attitudes towards disability.

The participants had indicated that certain factors had helped them to adapt to their life with a child with a disability despite the challenges. These factors include acceptance of the child, adherence to rehabilitation treatment, support given by family members and religious beliefs.

#### **4.2.2.3 Objective 3: To Explore and Describe the Care Required for Children Who are Diagnosed with Cerebral Palsy**

This objective is met in Chapter One Section 1.1, Chapter Two and Chapter Three. Children who have been diagnosed with cerebral palsy experience limitations that can result in the individuals requiring long-term care. This is discussed in the literature review and reiterated by the findings of the study.

Key points related to the required care had been:

- Assistance for daily living activities – Participants had explained that the functional limitations of the children meant that they needed assistance in activities of daily living. These include feeding, bathing and movements related to the inability to walk.
- Management of the condition – Participants had indicated that children with CP should be taken for rehabilitation therapy sessions regularly to reduce the effects of associated impairments. These therapy sessions require active participation by caregivers in terms of taking the child to treatment and continuity of therapy sessions at home.
- Finance – Participants had explained that children with CP have special needs, such as adaptive devices, diapers, special food and transportation to go for medical reviews. All these things cost money and require a steady income.
- Time and commitment related to the provision of everyday care as described by the participants.

#### **4.2.2.4 Objective 4: To Suggest Strategies for Professional Interventions that could Broadly Promote the Well-being of the Caregivers of Children with Cerebral Palsy**

This objective is met in Chapter 3 and Chapter 4. The participants had described the supportive counselling following the diagnoses of a child as insufficient. It had been suggested that social workers in collaboration with therapists should design a support programme that would ensure continuity of counselling thereby promoting the well-being of the caregivers. The participants had indicated that access to social welfare programmes required assessments which take “ages” to be conducted. It is therefore recommended that the social worker should advocate for affirmative action that will exempt caregivers of children with disabilities from having to be assessed to qualify for social welfare programmes. Access to social welfare programmes may significantly contribute to the reduction of poverty for caregivers and promote adaptation to living with a child with a disability.

### **4.3 KEY FINDINGS OF THE STUDY**

Key findings of the study were as follows:

- Participants’ children had been diagnosed with cerebral palsy either at birth or before the age of six years. Many of the participants had confirmed their children’s disability before the age of one.
- Different emotions following the birth of a child with a disability are experienced by participants. Some participants had shared that it had been a loss of their ideal child while others were more concerned about the future of the child.
- Women had emerged as the primary caregivers of the children. In the absence of the mother, the grandmother would take over. In the study, female participants had outnumbered their male counterparts.
- Children experience functional limitations because of the nature of their disabilities and this renders them reliant on their caregivers for activities of daily living. These activities include bathing, feeding and being able to move around. The level of dependence ranges from total dependence on others to merely needing assistance.
- There is a consensus that raising a child with cerebral palsy has associated challenges which impact on the caregivers as individuals and the whole family. Some of these challenges are poverty, stigma and burden of care. The study findings have indicated that insufficient service provision is compounding the pressure.

- The care that is required places financial constraints on the caregiver and its implications extend to the entire family.
- There is an association between the caregiving process and the ill health of the caregiver. The participants experience frequent illnesses and physical pains that are attributed to the demands of caregiving.
- The seeking of a cure for the child's disability has had some limitations which has perpetuated the element of poverty as much money is being spent in the process.
- Certain coping strategies had been employed by participants which has helped them to adjust and adapt to living with a child who has been diagnosed with cerebral palsy. Acceptance of the child has proven to be the most effective strategy. Family support has made a significant contribution towards the adaptation of caregivers. These factors are resilience qualities possessed by the participants.
- Although therapeutic interventions had been identified as contributing to the adaptation process, the role of professionals in the adaptation process had been small as it had been identified by only a few participants.
- The establishment of a rehabilitation centre that could provide both therapeutic intervention and respite care had been identified as a resource that could be beneficial to the participants.
- In summary, the information that had been collected during the study has revealed that raising a child with cerebral palsy has significant associated challenges which increase the burden on caregivers. The Family Resilience Framework has assisted the researcher in identifying factors that would assist participants in overcoming the challenges of raising a child with a disability.

#### **4.4 CONCLUSIONS**

Based on the literature review and the empirical findings of the study the following conclusions have been drawn.

- The study findings conclude that many parents who are raising a child with cerebral palsy have to deal with problems and challenges associated with the care that is required.
- A family who has a child with CP will experience many challenges such as poverty, impaired health, and stigmatisation. Some of these are attributable to the child's limited functioning.

- The effects of financial constraints do not only affect the caregiver but extend to the entire family.
- The parents of a child with cerebral palsy experience emotional distress associated with the loss of their ideal child.
- The researcher has concluded that there are inadequate intervention care programmes and services' which have been designed to assist caregivers and children with disabilities. The lack of adaptive devices have aggravated the challenges faced by caregivers of children with cerebral palsy in Botswana, despite the comprehensive National Policy on care of people with disabilities. The study therefore concludes that the effectiveness of the National Policy addressing issues of persons with disabilities needs to be reviewed.
- Furthermore, although the findings of this study cannot be generalised to the larger population of caregivers raising children with cerebral palsy, the study concludes that there are certain resilience factors that appear to have facilitated adaptation in caring for a child diagnosed with CP. These factors include acceptance of the child, reframing the disability, and the supportive role played by family members. The intervention care programmes that have been designed to support caregivers of children with cerebral palsy could be aligned to these resilience factors.

#### **4.5 RECOMMENDATIONS**

Based on the key findings and the conclusions of the study, the following recommendations are made.

- Intervention care programmes that are designed to assist caregivers and the child should focus on identifying problems that are faced by caregivers and should remove any obstacles. For instance, the study findings had revealed the stress experienced in caregiving. The programme design should therefore focus on improving the psycho-social care of caregivers and provide assistance with coping when stressful situations are encountered. Furthermore, the programme should identify and strengthen resilience qualities that have been deemed to be of assistance to caregivers of children with disabilities.
- The study strongly recommends that the Government provide financial support to caregivers of children with developmental disabilities due to the complex dynamic related to the disabilities. The disability allowance should not be limited to the child's needs but should extend to the caregivers' needs too.

- Financial support has proven essential in adapting to a stressful situation such as raising a child with a developmental disability such as cerebral palsy. The study's findings do not differ significantly from the literature that had been reviewed. Successful intervention strategies for assisting caregivers of children with cerebral palsy strategies should be adopted in Botswana.
- Community-based rehabilitation programmes that have a component of respite care should be established and strengthened in rural communities like Mahalapye. These programmes could reduce the stigma attached to disability, create awareness on disability, and positively impact individuals who live with a person who has a disability. The programme could support families even further by meeting their needs through temporary caregiving relief.
- Future research could consider the efficiency of services provided to children with disabilities and their families; to propose improvement or strengthening of these services for the betterment of quality of care for children with disabilities and their caregivers.

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## APPENDIX A INFORMATION SHEET

### English

#### **Research Title:** EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN WITH CEREBRAL PALSY IN MAHALAPYE, BOTSWANA

#### **Introduction**

My name is Thabiso Diseko, a Health Care (SW) Masters student at the University of Pretoria, South Africa. As part of the requirements of my degree, I am conducting a research project focusing on exploring experiences of caregivers of children with cerebral palsy residing in Mahalapye village. We are inviting you to participate in this research project because you are a caregiver of a child with cerebral palsy (CP) in Mahalapye village.

#### **What will I be asked to do if I agree to participate?**

You are humbly asked to participate in an interview either at your home or at Mahalapye District hospital and the interview will be approximately one hour. Where there is need for further interview, arrangement will be made for additional session in agreement with you. Topics in discussion will be based on your experiences of caring for a child with cerebral palsy.

#### **Would my participation in this study be kept confidential?**

The researcher will ensure that confidentiality is maintained and no information identifying you will be disclosed. This research project involves audio recording of the interview with your consent. The recording is being made so as to enable the researcher to accurately capture the information. The researcher and supervisor will have access to the recordings. The transcribed interviews and recordings will be stored in the Department of Social Work and Criminology, University of Pretoria for 15 years.

#### **What are the risks of this research?**

There is no risk of physical harm, however those who will experience psychological discomfort will be referred to therapist in Rehabilitation Unit at Mahalapye District Hospital. Lastly, you are free to withdraw at any time without any penalty.

### **What are the benefits of this research?**

This research project is not intended to benefit you personally. Findings of this study will be used in recommending interventions that can broadly promote the well-beings of the caregivers of children with cerebral palsy. There will be no reward for participating in this research project.

### **What if I have questions?**

If you have any questions about the research study itself, please contact Thabiso Diseko at P.O. Box M447, Kanye, Botswana. Tel: +267 72788022. Email: [thabisodisk@yahoo.com](mailto:thabisodisk@yahoo.com).

Thank you.



## APPENDIX A: Dintlha tsa botlhokwa

Setswana

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**Setlhogo sa dipatlisiso:** Maitemogelo a batlhokomedi ba bana ba ba tshelang le bogole jwa cerebral palsy mo Mahalapye, Botswana.

### Matseno

Ke bidiwa Thabiso Diseko. Ke dira dithuto tse di kgolwane tsa boipelego mme ke lebagane le tsa botsogo, ko Yunibesithi ya Pretoria ko lefatsheng la Aferika Borwa. Ke tlaabo ke dira dipatlisiso tse di lebaganeng le setlhogo se se fa godimo e le bontlha bongwe jwa dithuto tsame. Ke go laletsa go nna karolo ya dipatlisiso tse, ka gore o tlhokomela ngwana yo o tshelang le bogole jwa cerebral palsy mo motseng wa Mahalapye.

### Se se tlaa diragalang mo dipatlisisong fa o dumalana go nna karolo

Mmatlisisimogolo o kopa gore o nne karolo ka puisano e e tlaa tshwarelwang ko motseng wa gago kana ko sepateleng se se golwane sa Mahalapye. Puisano e, e tlaa tsaya selekanyo sa oura fela. Fa go ka tlhokega gore go nne le puisano e nngwe, thulaganyo e tlaa dirwa fa e le gore o a dumalana. Setlhogo sa puisano se tlaabo se lebagane le maitemogelo a gago jaaka o tlhokomela ngwana yo o tshelang le bogole jwa cerebral palsy.

### Bosephiri jwa se go tlaa buiwang ka sone

Mmatlisisimogolo o tlaa netefatsa gore ga gona yo o tlaa itseng se re buileng ka sone, e bile dintlha tsotlhe ka wena ga di na go bolelelwa ope. Puisano ya rona e tlaa gatsiwa mo sekapamantswing ka tetla ya gago. Se se direlwa gore mmatlisisimogolo a kgone go reetsa se go buileng ka sone. Mmatlisisimogolo le mogolwane wa gagwe go tswa ko Yunibesithi ya Pretoria ko lefatsheng la Aferika Borwa ke bone fela ba tlaa itseng se go builweng ka sone. Dikgatiso tsotlhe tsa puisano di tlaa bewa sentle mo lefelong le le babalesegileng ko Yunibesithi ya Pretoria, ko lefatsheng la Aferika Borwa dingwaga tse di lesome le botlhano.

### **Bodipatsa yo bo ka nnang teng mo dipatlisong**

Ga gona bodipatsa bope mo dipatlisong tse, mme yo o tlaa nnang le matshwenyego mangwe o tlaa isiwa ko go mma-boipelego yo o berekelang ko sepateleng se se golwane sa Mahalapye go sidilwa maikutlo. Sa bofelo, o kgona go ikgogela morago mo dipatlisong fa o batla, mme ga o kitla o otlhaelwa go dira jalo.

### **Bomosola jwa dipatlisiso**

Go nna karolo ya dipatlisiso ga gona dipoelo dipe e bile ga o na go duelelwa, mme fela dipatlisiso tse di tlaa thusa gore go tliwe ka mananeo a a ka thusang bathokomedi ba ba tlhokomelang bana ba ba tshelang le bogole jwa cerebral palsy.

### **Fa o na le dipotso**

Fa o na le dipotso o ka ikgolaganya le mmatlisimogo Mme Thabiso Diseko ko mogaleng wa +267 72788022 kana Email: thabisodisk@yahoo.com. Kana o ka mo kwalela ko P.O. Box M447, Kanye, Botswana.

Kea leboga



## APPENDIX B

English

Date:

### LETTER OF INFORMED CONSENT FORM

#### SECTION A: Research Information

**Title of the study:** Experiences of caregivers caring for children with cerebral palsy in Mahalapye, Botswana

**Researcher:** Thabiso Diseko

**Purpose of the study:** To understand the experiences of caregivers who care for children with cerebral palsy

I have been asked to participate in a research study that is intended to explore, understand and analyse experiences of caregivers of children with cerebral palsy. The reason for participating is for the researcher to interview me in order to find out about:

- Care required for a child diagnosed with cerebral palsy
- My experiences of living with a child diagnosed with cerebral palsy

#### **Procedures:**

If I agree to participate, the following will occur:

I will be required to participate in an interview, in a venue and at a time that suits both me and the researcher. I will be contacted to arrange a place, time and date. The interview will be voice recorded with my permission. The data will be transcribed and will be used for research purposes only. A pseudonym or false name will be given to me and my identity will never be linked to the data or research report. The interview will take approximately one hour. I understand that there is no right or wrong answer and that the researcher purely wants my opinion. I understand that I will not benefit directly from this study. I will also not be compensated for my participation in this research study.

#### **Confidentiality:**

I understand that the data collected, which include the digital voice recordings and the transcribed interviews will be stored in the Department of Social Work and Criminology, University of Pretoria for 15 years. I also understand that my identity will remain anonymous. I also understand that data will be reported in the research

report and scientific journals, but will not include any information that can identify me or any participants in this study. If at any point I experience any difficulties during or after the study I will contact the researcher Ms Thabiso Diseko in the following contacts. P.O. Box M447, Kanye, Botswana. Tel: +267 72788022. Email: thabisodisk@yahoo.com.

**Please sign the consent form in the next page.**

Kind regards

Thabiso Diseko

Researcher

### **Section B: Research Consent**

I, \_\_\_\_\_ (Full name and surname of participant) hereby acknowledge that I have been informed about the research study. I am aware of what is required of me as a participant. I have read and understand how the process will be followed. I have asked questions I may have had and I am aware of the confidential nature of the study. As a participant I also understand that my identity will be kept anonymous. Finally, if at any point I choose to withdraw from the study I understand I will not suffer any negative consequences.

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Researcher:**

I have explained the study to....., and provided him/her with a copy of the participant information sheet.

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_



**APPENDIX B:**

Lokwalo lwa tumalano (*Setswana*)

=====

**Setlhogo sa dipatlisiso:** Maitemogelo a batlhokomedi ba bana ba ba tshelang le bogole jwa cerebral palsy mo Mahalapye, Botswana.

**Mmatlisisimogolo:** Mme Thabiso Diseko

**Maikaelelo a dipatlisiso**

Ke kopilwe go nna karolo ya dipatlisiso, tse maikaelelo a tsone e leng go sekaseka le go tihaloganya dikgwetlho kana maitemogelo a go tlhokomela bana ba ba tshelang ka bogole jwa cerebral palsy. Maikaelelo a go nna karolo ya dipatlisiso tse ke gore mmatlisisimogolo a kgone go mpotsa tse di latelang:

- Tlhokomelo e e tlhokwang ke ngwana fa ba bongaka ba sena go supa gore o na le bogole jwa cerebral palsy.
- Maitemogelo a go tlhokomela ngwana yo o nang le bogole jwa cerebral palsy.

**Se se tlaa diragalang mo dipatlisisong**

Fa ke dumalana go nna karolo ya dipatlisiso, go tlaa dirwa tse di latelang:

Ke tlaa kopiwa go tsaya karolo mo puisanong e e tlaa direlwa ko lefelong ga mmogo le ka nako e e siametseng nna le mmatlisisimogolo. Ke tlaa itsisiwe lefelo, nako le letsatsi la puisano. Puisano e tlaa gatsiwa mo sekapamantsweng fa ke sena go fa tetla, mme dikgatiso di tlaa dirisediwa dipatlisiso tse fela e seng sepe gape. Ke tlaa fiwa leina le e seng la nnete go netefatsa bosephiri jwa puisano. Puisano e tlaa tsaya oura fela. Ke a tihaloganya gore mo puisanong e, ke gololesegile go buwa maikutlo ame ke sa tshabe sepe. E bile ke tihaloganya gore ga ke na go duelelwa go nna karolo ya dipatlisiso.

**Bosephiri**

Ke tihaloganya gore dikgatiso tsothe tsa puisano di tlaa bewa sentle mo lefelong le le babalesegileng ko Yunibesithi ya Pretoria, ko lefatsheng la Aferika Borwa dingwaga tse di lesome le bothano. Mme e bile ke tihaloganya gore ga gona gope fa leina lame le tlaa tlhagelelang teng mo dipatlisisong. Ke tihaloganya gape gore se go builweng ka sone mo puisanong e, se tlaa dirisediwa dipatlisiso tse fela, e bile ga gona ope yo o tlaa itseng gore ke bo mang ba ba neng ba tsaya karolo mo dipatlisisong tse. Fa nka nna le bothata dipatlisiso di tswelletse kana di fedile ke itse gore ke ka ikgolaganya le Mme Thabiso Diseko ko mogaleng wa +267 72788022 kana Email: thabisodisk@yahoo.com. Kana ke ka mo kwalela ko P.O. Box M447, Kanye, Botswana.

### **Monwana wa motlhokomedi**

Ke le..... (leina le sefane) ke netefatsa gore ke tihaloseditswe sengwe le sengwe ka dipatlisiso tse. Ke tihalogantse tsothe tse di tlhokwang mo go nna. Ke ne ka fiwa sebaka sa go botsa dipotso, e bile ke tihalogantse bosephiri jo bo tlaa nnang teng mo dipatlisisong tse. Ke tihaloganya gape gore leina lame le tlaa sirelediwa gore le seka la tlhagelela mo dipatlisisong tse. Sa bofelo ke tihaloganya gore fa ke batla go ikogela morago mo dipatlisisong tse, ke gololesegile go dira jalo mme ga kena go otlhaeiwa go dira seo.

**Monwana:**..... **Letsatsi:**.....

### **Monwana wa mmatlisisimogolo**

Ke netefatsa gore ke tihaloseditse .....(leina le sefane) sengwe le sengwe ka dipatlisiso tse. Mme e bile ke mo file mokwalo o o tihalosang sengwe le sengwe ka dipatlisiso tse.

**Monwana :**..... **Letsatsi :**.....



## APPENDIX C



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Research Ethics Committee

5 September 2015

Dear Prof Lombard

**Project:** Experiences of caregivers caring for children with cerebral palsy in Mahalapye, Botswana  
**Researcher:** TN Diseko  
**Supervisor:** Ms N Bila  
**Department:** Social Work and Criminology  
**Reference number:** 14260043 (GW20150911HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 1 October 2015. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

**Prof Karen Harris**  
**Acting Chair: Research Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail:Karen.harris@up.ac.za**

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

**Research Ethics Committee Members:** Prof KL Harris(Acting Chair); Dr L Blokland; Dr JEH Grobler; Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Ms KT Andrew (Committee Admin), Mr V Sithole (Committee Admin)



## APPENDIX D

TELEPHONE: 363 2766  
FAX: 391 0647  
TELEGRAMS: RABONGAKA  
TELEX: 2818 CARE BD



Republic of Botswana

MINISTRY OF HEALTH  
PRIVATE BAG 0038  
GABORONE

REFERENCE NO: HPDME 13/18/1 X (58)

21 September 2015

Health Research and Development Division

Notification of IRB Review: **New application**

Thabiso Nthathanyane Diseko  
P O Box M447  
Kanye

Protocol Title: **EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN WITH CEREBRAL PALSY IN MAHALAPYE, BOTSWANA**

|                           |                   |
|---------------------------|-------------------|
| HRU Approval Date:        | 21 September 2015 |
| HRU Expiration Date:      | 20 September 2016 |
| HRU Review Type:          | HRU reviewed      |
| HRU Review Determination: | Approved          |
| Risk Determination:       | Minimal risk      |

Dear Madam

Thank you for submitting new application for the above referenced protocol. The permission is granted to conduct the study.

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Approval is for academic fulfillment only. Copies should also be submitted to all other relevant authorities.

### **Continuing Review**

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 7A.7 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomoiso Motlhanka, e-mail address: [kgmmotlhanka@gov.bw](mailto:kgmmotlhanka@gov.bw) As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form



## APPENDIX D CONT...

### Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 7A 7 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: [kgmotlhanka@gov.bw](mailto:kgmotlhanka@gov.bw). In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

### Reporting

Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at [pkhulumani@gov.bw](mailto:pkhulumani@gov.bw), Tel +267-3914467 or Lemphi Moremi at [lamoremi@gov.bw](mailto:lamoremi@gov.bw) or Tel: +267-3632754. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours faithfully

P. Khulumani  
**For/ Permanent Secretary**



MINISTRY OF HEALTH

**Vision:** Model of Excellence in Quality Health Services

**Values:** Botho, Equity, Timeliness, Customer Focus, Teamwork, Accountability



## APPENDIX E

### SEMI-STRUCTURED INTERVIEW SCHEDULE

#### Goal of this study

To understand the experiences of caregivers who care for children with cerebral palsy in Mahalapye, Botswana.

#### SECTION A: BIOGRAPHICAL DETAILS OF THE PARTICIPANTS

##### 1. Age distribution

|           |  |           |  |           |  |           |  |           |  |           |  |
|-----------|--|-----------|--|-----------|--|-----------|--|-----------|--|-----------|--|
| 20-25 yrs |  | 26-31 yrs |  | 32-37 yrs |  | 38-42 yrs |  | 43-47 yrs |  | 48-50 yrs |  |
|-----------|--|-----------|--|-----------|--|-----------|--|-----------|--|-----------|--|

##### 2. Gender

|        |  |      |  |
|--------|--|------|--|
| Female |  | Male |  |
|--------|--|------|--|

##### 3. Marital status

|        |  |         |  |          |  |         |  |                     |  |
|--------|--|---------|--|----------|--|---------|--|---------------------|--|
| Single |  | Married |  | Divorced |  | Widowed |  | Living with partner |  |
|--------|--|---------|--|----------|--|---------|--|---------------------|--|

##### 4. Language

|         |  |          |  |
|---------|--|----------|--|
| English |  | Setswana |  |
|---------|--|----------|--|

##### 5. Area of residency

|      |  |
|------|--|
| Ward |  |
|------|--|

##### 6. Sources of income (mark all those are applicable)

|              |  |          |  |         |  |                |  |
|--------------|--|----------|--|---------|--|----------------|--|
| Social grant |  | Employed |  | Partner |  | Other, specify |  |
|              |  |          |  |         |  |                |  |

##### 7. Education level

|                   |  |                     |  |                    |  |                |  |
|-------------------|--|---------------------|--|--------------------|--|----------------|--|
| Primary education |  | Secondary education |  | Tertiary education |  | Other, specify |  |
|-------------------|--|---------------------|--|--------------------|--|----------------|--|

### 8. Number of dependents

|     |  |     |  |     |  |     |  |    |  |
|-----|--|-----|--|-----|--|-----|--|----|--|
| 1-2 |  | 3-4 |  | 5-6 |  | 7-8 |  | 9+ |  |
|-----|--|-----|--|-----|--|-----|--|----|--|

### 9. Age distribution of dependents

|        |  |        |  |        |  |           |  |           |  |           |  |        |  |
|--------|--|--------|--|--------|--|-----------|--|-----------|--|-----------|--|--------|--|
| < 1 yr |  | 1-4yrs |  | 5-9yrs |  | 10-14 yrs |  | 15-19 yrs |  | 20 -21yrs |  | 22yrs+ |  |
|--------|--|--------|--|--------|--|-----------|--|-----------|--|-----------|--|--------|--|

### 10. Caregiver's relation to the child diagnosed with Cerebral Palsy?

|        |  |        |  |                |
|--------|--|--------|--|----------------|
| Mother |  | Father |  | Other, specify |
|--------|--|--------|--|----------------|

### 11. Current age of the child with Cerebral Palsy?

|        |  |        |  |        |  |           |  |          |  |
|--------|--|--------|--|--------|--|-----------|--|----------|--|
| < 1 yr |  | 1-4yrs |  | 5-9yrs |  | 10-14 yrs |  | 15-19yrs |  |
|--------|--|--------|--|--------|--|-----------|--|----------|--|

### 12. Age at which child was diagnosed with Cerebral Palsy

|        |  |     |  |      |  |       |  |      |  |        |  |
|--------|--|-----|--|------|--|-------|--|------|--|--------|--|
| < 1 yr |  | 1yr |  | 2yrs |  | 3 yrs |  | 4yrs |  | 5 yrs+ |  |
|--------|--|-----|--|------|--|-------|--|------|--|--------|--|

## SECTION B: Understanding of Cerebral Palsy

1. What is your understanding of your child's diagnosis?
2. What is the cause of the condition- Cerebral Palsy?
3. How did you feel when your child was diagnosed with CP?

## SECTION C: Experiences of caring for a child with cerebral palsy

1. What are the child's limitations as a result of cerebral palsy?
2. What are the challenges you experience regarding caring for your child with cerebral palsy?
3. Do you get the necessary support to address these challenges? Explain in what manner do you get support?
4. What are the services you get regarding care of your child with CP?
5. Are you happy with the manner that these services are provided?  
If yes, explain what is happening that makes you happy?  
If no, how do you want these services to be provided?
6. Do you feel that you get support from these people:
  - Family
  - Community members
  - Hospital staff- rehabilitation therapists, social workers and doctors

Explain in what way you get support from these people.

7. What are your needs regarding caring for your loved one?
8. What are your recommendations regarding services for children with Cerebral Palsy?

**Thank you**



## APPENDIX F

### MAHALAPYE DHMT

FAX:  
TELEPHONE:



P.O. BOX 49 MAHALAPYE

Republic of Botswana

REFERENCE NO: MH/DHMT/1/7/7 (12)

05/ 10/ 2015

To: Ms Thabiso Nthathanyane

Dear Madam

**Protocol Title:** EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN WITH CEREBRAL PALSY IN MAHALAPYE, BOTSWANA

**Notification of IRB Review:** New application

**Approval Status:** Approval

**Risk Determination:** Low risk

The Mahalapye DHMT thanks you for submitting the documents for the above captioned protocol for evaluation. The application was reviewed and awarded an approval. This approval is valid for a **period of 1 year effective 21<sup>st</sup> Sep 2015 (Expiry date: 20<sup>th</sup> Sep 2016)**. The research should be conducted as outlined in the approved proposal. Please notify the Mahalapye IRB when you start collecting data. Any changes to the approved proposal must be submitted to the Mahalapye IRB and the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hard copy to The Mahalapye IRB within three months of completion of the study or notify its publication.

Thank you for your commitment in protecting human subjects in Research in the Mahalapye DHM

Yours faithfully you have any questions/queries, please contact DrS. T. Tshitenge at stephane.tshitenge@mopipi.ub.bw. Tel +267 3554762, + 267 71550036 or Mr M Ralethaka (Mahalapye DHMT IRB Secretary) at amralet@yahoo.com. Cell: 71922235

Thank you for your commitment in protecting human subjects in Research in the Mahalapye DHMT.

Yours faithfully

  
**DR STEPHANE TSHITENGE**  
SPECIALIST-FAM PHYSICIAN  
(UL, MEDUNSA)

**Dr Stephane Tshitenge**  
Mahalapye DHMT IRB CHAIR



30 January 2017

To whom it may concern

**DECLARATION OF PROFESSIONAL EDIT**

I, Benita Bohnen, from Phrase It Right (Pty) Ltd have re-edited the research proposal entitled: Experiences of Caregivers of Children with Cerebral Palsy in Mahalapye, Botswana. I have rectified language errors that had previously been overlooked.

I declare that I have edited and proofread this thesis, according to SA English. My involvement has been restricted to language usage and spelling, completeness and consistency, and formatting of headings and the Table of Contents. I did no structural rewriting of the content, nor can I ensure the student did not inadvertently plagiarise.

Sincerely,



Benita Bohnen  
Associate Member of the Professional Editors' Group  
Cell: 074 840 5980  
Email: [benita@phraseitright.com](mailto:benita@phraseitright.com)