



**UNIVERSITY *of the*
WESTERN CAPE**

FACULTY OF COMMUNITY AND HEALTH SCIENCES

DEPARTMENT OF PHYSIOTHERAPY

**CHALLENGES EXPERIENCED BY MOTHERS OF CHILDREN WITH
CEREBRAL PALSY IN NDOLA, ZAMBIA**

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**A thesis submitted in partial fulfillment of the requirements for the Degree of Master of
Science in the Department of Physiotherapy, University of the Western Cape.**

May 2012

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ABSTRACT

About 10% of children world-wide experience developmental disorders and require access to the health care system. These disorders also require extensive care giving, often throughout childhood and into the adult years. Cerebral palsy (CP) is one such chronic condition, and can serve as a major cause of childhood disability. It is the commonest cause of neurological impairment in childhood and is associated with functional limitations and lifelong disability. Providing the high level of care required by a child with long-term functional limitations can become burdensome and may impact on both the physical and psychological health of the care giver. To prevent problems suffered by mothers of children with CP, it is important to explore the challenges experienced. All studies conducted previously on cerebral palsy in Zambia focus on impairments and difficulties experienced by children with CP and none of the mothers' challenges have been explored. The aim of this study therefore was to explore the challenges that mothers of children with cerebral palsy experience in Ndola, Zambia. The study was conducted at two rehabilitation centers (Twapia and Mushili) under the Community Based Rehabilitation (CBR) catchment area in Ndola. A qualitative research design was employed. The mothers were stratified and purposefully selected and interviews were stopped once theoretical saturation was reached.

Permission to conduct the research was obtained from relevant bodies and ethical issues were observed throughout the study. Sixteen (16) mothers of children with CP were interviewed. In-depth interviews were done using an interview guide which was designed after extensive review of literature. The interviews were audio recorded. The recorded data was transcribed verbatim and thematic analysis was used to analyze the data. The results showed that the mothers faced many challenges which included emotional, physical health, socio-economic, environmental, misdiagnosis of the condition of their children, marital problems and lack of implementation of policies regarding children with CP by the Zambian government

KEY WORDS

Ndola, Zambia

Cerebral Palsy

Challenges

Experiences

Difficulties

Perceptions

Needs

Mothers

Environmental

Physical

Psychological



ABBREVIATIONS

ADLs	Activities of Daily Living
CBR	Community Based Rehabilitation
CP	Cerebral Palsy
CSO	Central Statistics Office
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning Disability and Health
ILO	International Labour Organization
MCDSS	Ministry of Community Development and Social Services
MOH	Ministry of Health
PHC	Primary Health Care
SES	Social Economic Status
TDRC	Tropical Disease Research Centre
UN	United Nations
UNESCO	United Nations Education, Scientific and Cultural Organization
UNPD	United Nations Development Programme
WHO	World Health Organization
ZAFOD	Zambia Association for the Disabled



DEFINITION OF TERMS

Attitudes

Attitudes are described as a state of readiness by an individual or a tendency to respond in a certain manner when confronted with a certain stimuli and can either be negative or positive (Oppenheimer, 1992).

Caregivers

This is an individual who can be a family member, physician, nurse, social worker or paid helper who is involved in direct care of children, the elderly or chronically ill individuals (Mitnick, Heffler & Hood, 2010).

Challenges

A challenge is a general term referring to things that are imbued with a sense of difficulty and victory (Online Dictionary, 2010).



Disability

This is defined as an umbrella term for impairment, activity limitation and participation restriction, created through an interaction between a disease or injury and contexture factors that include both environmental and personal factors (WHO, 2001).

Discrimination

This is treating people differently through prejudice (Wendell, 1996).

Environmental Challenges

Constitute a component of ICF, and refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning.

Environmental factors include the physical world and its features, the human-made physical world, other people in different relationships and roles, attitudes and values, social systems and services, and policies, rules and laws (WHO, 2001).

Experience

Experience is a general concept comprising knowledge of a skill of something or some event gained through involvement in or exposure to that thing or event. An experience may be positive or negative (The Picker Institute, 2008).

Impairment

Impairments are the occurrences of problematic bodily functions or structures. Impairments can also be described as the loss or damage of body organ that affect physiological or psychological functioning (WHO, 2001).

Physical health

This is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 2001).

Physical limitation

In the context of physical disability, refers specifically to bodily impairments resulting to the restriction towards functional activities (WHO, 2006).

Psychological distress

This is when individuals are faced with stressors which are threatening or very hard to deal with, leading people to experience stress. Psychological symptoms of stress include anxiety and tension, uncontrollable worrying, irritability, distractibility, and difficulty in learning new

things. Physical symptoms include difficulty in sleeping, loss of appetite or excessive appetite, fatigue, and aches and pains (Keil, 2004).

Rehabilitation

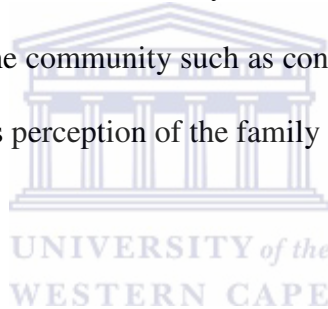
This is a process aimed at enabling persons with disabilities to reach and maintain their optimal, physical, sensory, intellectual, psychiatry and social higher functional levels thus providing them with tools to change their lives towards a higher level of independence (UNDP, 1994).

Socio-economic status

A family's socioeconomic status is based on family income, parental education level, parental occupation, and social status in the community such as contacts within the community, group associations, and the community's perception of the family (Demarest et al, 1993).

Stigma

This is a sign of social unacceptability. An attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one (Cornish, 2006)



DECLARATION

I hereby declare that “Challenges experienced by mothers of children with cerebral palsy in Ndola, Zambia” is my own work that has not been submitted for any degree or examination in any university and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

Carol Singogo

Signature:.....



Witness: Prof. A. Rhoda

Signature:.....

May, 2012

DEDICATIONS

With sincere gratitude and appreciation, I dedicate this thesis to my husband Luke and our two lovely children Gomezyani and Natasha Singogo.

Also

To the mothers of children with cerebral palsy who without a pay bravely and courageously take care of their angels with cerebral palsy despite all the hardships and challenges they face.



ACKNOWLEDGEMENTS

I would like to thank the Lord God Almighty for granting me the grace and an opportunity to further my studies. For his grace, mercies and provision throughout my studies I am humbled and deeply grateful.

For all the guidance, advise and unwavering support given in a graceful manner, I would like to sincerely appreciate my supervisor Prof. A. Rhoda for all her help. I would not have made it if it were not for you. God bless you.

I fail to find the right words to appreciate my husband Luke Singogo. Thank you for believing in me and for supporting me (morally, financially and through your prayers). Thank you for allowing me to further my studies even if you had to be alone for a long time. You have always been my source of inspiration and a pillar of strength. I will always love you.

Mrs N. Mlenzana, thank you for all your advice, guidance and contribution towards my research.

To my sister Cynthia, only the Lord God can repay you for all you have done for me. Not only have you given up your life at the moment to ensure I succeed with my studies, but you have embraced my kids as though they were yours. I am truly grateful. May the good God bless you abundantly and may good things come your way.

I would like to thank all the mothers of children with cerebral palsy for their strength and dedication in raising their children with cerebral palsy. Special thanks to the mothers that participated in this study.

I was a bit worried when I was told that I was going to be the only woman in class. My fears were thwarted as soon as I met all the gentlemen in my class (Nesto, George, Haleluya,

Pierre, Sam, Simon, Paul and our Rwandan colleagues who have already graduated). Thank you for all your support and contributions towards my thesis. The 'crocodile notion' really worked for us. God bless you all.

For all those I have not mentioned, thank you for all your contributions towards the success of this thesis. God bless you all.



TABLE OF CONTENTS

ABSTRACT.....	ii
KEY WORDS.....	iii
ABBREVIATIONS.....	iv
DEDICATIONS.....	ix
TABLE OF CONTENTS.....	xii
APPENCICES.....	xvii
CHAPTER ONE.....	1
1.1 Background.....	1
1.2 Problem Statement.....	6
1.3 Motivation.....	6
1.4 Aim of the study.....	7
1.5 Objectives of the study.....	8
1.6 Outline of Chapters.....	8
LITERATURE REVIEW.....	10
2 Introduction.....	10
2.1 Definition of CP.....	10
2.2 Aetiology of CP.....	11
2.3 Prevalence of CP.....	13
2.4 Clinical Manifestations of CP.....	14
2.5 Management of CP.....	16
2.6 Role of Physiotherapy.....	19
2.7 Rehabilitation services in Zambia.....	20
2.8 Experiences of Mothers.....	22
2.8.1 Immediate reactions.....	22
2.8.2 Effects of CP on the family.....	24

2.8.3	Accepting coping and adaptation.....	26
2.9	Challenges experienced by mothers of children with CP	28
2.9.1	Psychological challenges	28
2.9.2	Physical health challenges	31
2.9.3	Socio-economic Challenges.....	32
2.9.4	Environmental Challenges	37
2.9.5	Marital challenges.....	42
2.9.6	Challenges with implementation of policies.....	43
2.9.7	Challenges with diagnosis of the condition of CP.....	45
2.10	Summary	47
METHODOLOGY		49
3	Introduction	49
3.1	Research Setting.....	49
3.2	Research Design.....	51
3.3	Population and Sampling.....	52
3.3.1	Study population	52
3.3.2	Sampling Frame	52
3.3.3	Sample.....	53
3.4	Data Collection.....	54
3.4.1	Interviews.....	54
3.4.2	Procedure	55
3.4.3	Trustworthiness.....	56
3.5	Data Analysis	58
3.6	Ethical consideration	60
RESULTS		61
4	Introduction	61



4.1	Summary of Demographic Data of Participants	62
4.2	Emotional challenges	63
4.2.1	Perceived depressive Symptoms.....	63
4.2.2	Perceived stress	64
4.2.3	Perceived anxiety	65
4.3	Physical Health Challenges	66
4.3.1	Musculoskeletal Disorders.....	66
4.3.2	Physiological Disorders	68
4.4	Socio-economical challenges	69
4.4.1	Education	70
4.4.2	Employment.....	71
4.4.3	Poverty	72
4.5	Environmental challenges	73
4.5.1	Social environmental challenges.....	74
4.5.2	Attitudinal environmental challenges	75
4.5.3	Physical environmental challenges	76
4.6	Marital Problems	77
4.7	Lack of implementation of policies regarding children with CP in Zambia.....	78
4.8	Challenges with diagnosis of the condition of CP	80
4.9	Summary	82
DISCUSSION		84
5	Introduction	84
5.1	Relationship between demographic characteristics and challenges experienced.....	84
5.1.1	Ages of the mothers	84
5.1.2	Ages of the children with CP	85
5.1.3	Level of education and employment of the mothers.....	86

5.1.4	Marital Status of the mothers	87
5.2	Emotional challenges	88
5.2.1	Perceived depressive Symptoms.....	88
5.2.2	Perceived stress	89
5.2.3	Perceived anxiety	90
5.3	Physical Health Challenges	91
5.3.1	Musculoskeletal challenges	92
5.3.2	Physiological health challenges	93
5.4	Socio-economic challenges	94
5.4.1	Poor educational background.....	94
5.4.2	Lack of employment	95
5.4.3	Poverty	96
5.5	Environmental Challenges	97
5.5.1	Social environmental challenges.....	97
5.5.2	Attitudinal Environments.....	99
5.5.3	Physical environmental challenges	101
5.6	Marital challenges	103
5.7	Lack of implementation of policies regarding children with CP	104
5.8	Challenges with diagnosis of the condition of CP	106
5.9	Significance of the study	107
SUMMARY, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS		109
6	Introduction	109
6.1	Summary	109
6.2	Conclusion.....	111
6.3	Recommendations	111
6.4	Further Research	114

6.5 Limitations of the study..... 115
REFERENCES 116



APPENDICES

- A** Ethical Clearance Letter from University of the Western Cape
- B** Application letter to Tropical Disease and Research Centre (TDRC), Zambia
- C** Permission Letter from TDRC
- D** Application Letter to Ndola, CBR.
- E** Permission Letter from Ndola, CBR
- F** Consent Form for participants (English)
- G** Consent Form for participants (Bemba)
- H** Information sheet for participants (English)
- I** Information sheet for participants (Bemba)
- J** Interview guild for this study
- K** Table of themes and sub-themes



CHAPTER ONE

INTRODUCTION

1.1 Background

It has been estimated that about 10% of children world-wide experience developmental disorders and require access to the health care system. These disorders also require extensive caregiving, often throughout childhood and into the adult years (Stanley, Blair & Alberman, 2000). Cerebral palsy (CP) is a chronic condition which presents in early childhood as a set of functional limitations that stem from disorders of the developing brain (Bax, Goldstein, Rosenbaum & Leviton, 2005). Cerebral palsy is the commonest cause of neurological impairment in childhood and is associated with lifelong disability (Brannen & Heflinger, 2006). The current estimated incidence of CP is 2.0–2.5 per 1000 live births world-wide (US Census Bureau, 2004). Although impaired motor function is the hallmark of cerebral palsy, many children also experience sensory and intellectual impairments, and may have complex limitations in self-care functions such as feeding, dressing, bathing, and mobility. Other impairments that accompany CP could include; cognitive, communication, perception and a seizure disorder may occur. In addition, learning difficulties and behavioral problems can also be seen in this condition.

Owing to functional limitations, some children with CP, are dependent on others for assistance with activities of daily living leading to long term care giving that far exceed the usual needs of normal developing children (Resch et al, 2010). Care giving is the normal role of being the parent of the young child whereas this role takes on an entirely different significance when the child experiences functional, sensory and intellectual limitations and poses possible long term dependence (Tonga & Duger, 2008). Consequently, parents often

shoulder the principle multifaceted responsibility of long term disability management on their own. Providing the high level of care required by a child with long-term functional limitations can become burdensome and may impact on both the physical and psychological health of the caregiver as alluded to by Raina et al (2005). Moreover literature has revealed that having a child with a disability affects the functions of parents, but the daily lives of mothers are more affected than that of fathers as they are the primary caregivers of their children with CP (Raina et al, 2005; Pelchat, Lefebvre & Perrault 2003; Green, 2003).The responsibility for child care in families with a disabled child falls mainly on mothers and as a result their work lives, social lives and emotional states of mothers are more affected than those of the fathers (Tekinalp, 2001). In most cases, the fathers' expectations are tuned to life outside the home and the actual day-to-day tasks related to the child's care are not their priority (Pelchat, Lefebvre & Perrault 2003). For this reason, only mothers of children with CP were considered in this research as studies have found that in general they are the primary caregivers of their children with CP (Raina et al, 2005; Ones, Yilmaz & Cetinkaya, 2005; Ermason, 2003).

The main challenge for mothers is to manage their children with CP while maintaining the requirements of everyday living. In some cases, the provision of such care can prove detrimental to both the physical health and the psychological well-being of mothers and may have an impact on family income, family functioning, and sibling adjustment (Shillitoe & Christie, 1990). Health care systems have exerted a shift toward outpatient community and home-based settings, which in turn have increased the responsibilities of informal caregivers which in this case are the mothers (Talley & Crews, 2007). Consequently the task of caring for a child with complex disabilities at home might be somewhat challenging for mothers (Gona, Munga'la-Odera, Newton & Hartley, 2010).

Mothers of children with CP experience many challenges which could include psychological, physical health, socio-economic and environmental challenges. Other challenges that could be experienced may include marital problems, lack of implementation of policies regarding children with CP and delays or misdiagnosis of the condition of CP on the children (Borst, 2010; Tonga & Duger, 2008; UNPD, 2007).

There is a growing body of evidence to suggest that caring for children with disabilities such as cerebral palsy, is a source of psychological distress (Resch et al, 2010; Plant & Sanders, 2007; Sen & Yurtsever, 2007). For instance, depression, stress and anxiety have been indicated as some of the psychological problems experienced by the mothers (Edward, 2009). This could be as a result of parenting responsibilities for mothers of children with disabilities which require a significant amount of time to complete, can be demanding, can disrupt family and social relationships, and can adversely affect the mothers' employment (Borst, 2010; Brannen & Heflinger, 2006). In a similar way, individuals involved in the care of children with disabilities such as those with CP are at risk of experiencing physical health problems (Talley & Crews, 2007). This is due to activities such as bending, lifting carrying, pulling and pushing during bathing, dressing, transfers and feeding which increases stress on the musculoskeletal structures leading to the musculoskeletal problems suffered by the mothers of children with CP (Tonga & Duger, 2008). Other than the physical activities that lead to musculoskeletal disorders on mothers, the long term effects of caregiving induces distress and affects the health of caregivers in many ways. Distress is associated with sleep problems, risky health habits, poor diets and sedentary lifestyles (Ones, Yilmaz & Centinkaya, 2007).

The socio-economic challenges emanate from poor support structures. The mothers have no one to help them look after their children with CP and find it difficult to enroll their children in regular day-care centres as most of these centres are not prepared to take children with

disabilities, thus mothers are forced to quit their jobs in favor of caring for their children with CP (Thyn et al, 1999). In other instances, some mothers have poor educational backgrounds which limits their ability to find work leading to limited finances and resources (Parish et al, 2008).

The ability to move safely and independently, referred to as mobility is a fundamental part of basic activities of daily living of human beings. However, most of the challenges mothers of children with CP face are often associated with a lack of environmental receptivity (Eker & Tuzan, 2004). One of the neurological consequences of cerebral palsy is the limitation in mobility that leads to dependency in activities of daily living for some children (Patla & Shumway-cook, 1998). This coupled with architectural structures within the built and non-built environments in most cases are not conducive for mobility of their children and especially those using assistive devices (Verbrugge & Jette, 2004).

Another challenge faced by the mothers is how to maintain their marriages despite having children with CP. The mothers are socially withdrawn as they need extra time for their children with disabilities and they do not have enough time for themselves, other siblings or their spouses (Emerson, 2003; Lawton, 2001). Their husbands feel left out and normally turn to extra marital affairs, neglect their wives and offer little or no support leading to marital breakdowns (United Nations Development Plan (UNDP), 2007).

The relief felt by some mothers on learning about their child's diagnosis suggests that they needed some certainty, a possible picture of the future, and direction for starting treatments and management (Graungaard & Skov 2006). However, this is not the case as most mothers receive wrong or delayed diagnosis of their children with CP (Tattersall & Young 2006). Delays in effective diagnosis not only increased mothers' mistrust and dissatisfaction with

physicians' knowledge and skills, but also fuels their hopelessness and aggravated anger about receiving a better prognosis (Fitzpatrick et al, 2007).

In most cases, policies regarding childhood disability are not implemented leaving mothers without any support or help from governments (Camerot & Tveit, 2011; Flem and Keller, 2001). The lack of implementation of policies by the government leaves mothers lacking in many aspects. Their children's disabilities are overrepresented due to poverty levels among most of the mothers as they cannot afford many things including assistive devices.

Another challenge for the mothers is how to maintain safety for themselves and their children with CP. Some mothers expose their children to all sorts of dangerous situations (Taylor, Mangenello, Lee & Rice, 2009). They neglect their children and expose them to intimate aggressive partners. They use harsh ways which include physical and psychological maltreatment in bringing up their children with CP as was also noted by the following researchers (Paolucci & Violato, 2004; Grocan, 2004).

The management of a child with CP requires an interdisciplinary team approach that draws upon the expertise of many specialists including Physiotherapists (Patel, 2005). According to Mayston (2004), physiotherapy used in treating children with CP has been shown to improve muscle strength, endurance, overall joint range of motion and fulfills the active participation of the child. For others, physiotherapy also works to improve balance, gait, mobility, posture control and improves on transfers (Singhi, 2004). However, physiotherapists cannot achieve this without the help of the children's caregivers who in this case are the mothers of the children. Involving mothers in decision making concerning their children's care, leads to greater satisfaction, less anxiety, adherence to recommendations, improved physical outcomes, decreased rates of hospitalization and fewer complications (Chierello & Palisano,

1998). Further more the collaboration between mothers and physiotherapists puts mothers at the centre of the rehabilitation process and promotes child-parent interaction programs that guide them in understanding and responding to their children's behavior, interests and needs (Novac, Cusik & Lannin, 2009).

1.2 Problem Statement

Care giving is a role of every parent, but when a child experiences functional limitations and possible long term dependence, care giving becomes a significant role (MacDonald & Callery, 2007). Mothers caring for their children with CP is a crucial role in society as it preserves the lives of the children with CP. Equally, this saves the health systems from spending millions of dollars in providing adequate coverage in terms of care giving to children with disabilities. Studies have shown that mothers provide an overwhelming annual cost savings to healthcare systems through their informal contribution (Arno, Levine & Mommotti, 1999). Mothers of children with cerebral palsy face many challenges while caring for their children. Rehabilitation and other health care providers have been reported to be inadequate in providing support to mothers of children with CP in their distressing times (Sen & Yurtsever, 2007). This does not only impact on the health of mothers, but leads to a delay in the rehabilitation process of the children with CP and an overall poor quality of life for mothers (Plant & Sanders, 2007). Perhaps, health care providers are not aware of the challenges faced by mothers of children with CP. It is therefore important to explore the challenges experienced by mothers of children with CP in Zambia.

1.3 Motivation

As a prominent member of a rehabilitation team, the researcher observed that most mothers did not frequently attend the cerebral palsy classes that were offered to children with CP twice every week at Kitwe Central Hospital's physiotherapy's department in Zambia. The

researcher took it upon herself to find out what made the mothers miss the classes as some would even miss for as long as Six (6) months despite the classes being for free. The researcher was concerned as the children of the mothers who kept missing the rehabilitation sessions were not improving and were becoming worse. This the researcher thought was leading to major delays in the rehabilitation of the children with CP. The researcher was saddened by what she heard from the mothers and realized that as long as the mothers had these problems, there would be a delay in the rehabilitation of their children. The researcher as a healthcare professional and a physiotherapist was compelled to undertake this study that explored the challenges experienced by mothers of children with CP in Ndola, Zambia in the hope of creating awareness among the different health professionals and respective government organs, non-governmental organizations and well-wishers to render the necessary help and support to mothers of children with CP. It has been shown that by addressing the challenges experienced by mothers of children with disabilities, one enhances the rehabilitation of the child and maintains the mother's well-being (Raina et al, 2005). In addition to that, the non-availability of published information regarding challenges experienced by mothers prompted the researcher to undertake the study. Most studies previously done on cerebral palsy in Zambia focused on impairments and difficulties experienced by children with CP and none of the mothers' concerns were explored. It is also unfortunate to note that challenges faced by mothers of children with cerebral palsy are not considered at rehabilitation centres in Zambia.

1.4 Aim of the study

To explore challenges experienced by mothers of children with CP in Ndola, Zambia.

1.5 Objectives of the study

1. To explore the emotional challenges of the mothers of children with CP.
2. To explore the physical health challenges of the mothers of children with CP.
3. To explore the socio-economic challenges of mothers of children with CP.
4. To explore the environmental challenges of mothers of children with CP.

1.6 Outline of Chapters

Chapter One

As shown above, this chapter gives the background of the study. Cerebral palsy and how it leads to functional limitations that lead to dependence for activities of daily living is explained. The world-wide prevalence of CP is shown. The psychological, physical health, socio-economic and environmental challenges experienced by the mothers is introduced. The problem statement, research question, aims of the study and the objectives of the study are highlighted. The terms used in the study and outline of the chapters are followed.

Chapter Two

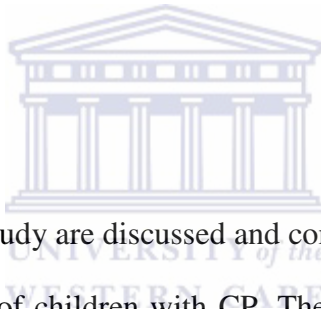
This chapter presents a review of literature relevant to this study. The definition, aetiology, clinical manifestation, management of CP and the role of the physiotherapist are discussed. The immediate reactions of mothers upon learning about their children's conditions are presented. How CP affects families and the ability of families to accept, cope and adapt to their children with CP are shown and finally the challenges experienced by the mothers of children with CP are discussed.

Chapter Three

This chapter presents the background of the methodology used in this research. The research setting, study design, sampling methods, inclusion and exclusion criteria and the procedure followed in the data collection are described. The methods of qualitative data analysis are described and finally the ethical considerations are outlined.

Chapter Four

This chapter presents the results of the study which are presented under various themes following the data analysis. A number of themes were extracted from the data and the challenges experienced by the mothers are presented including the quotes that support the different themes.



Chapter Five

In this chapter the results of the study are discussed and compared to findings of other studies related to challenges of mothers of children with CP. The consequences of such challenges and implications for healthcare providers are highlighted. The limitations of the study and the relevance of the findings to healthcare providers are equally highlighted.

Chapter Six

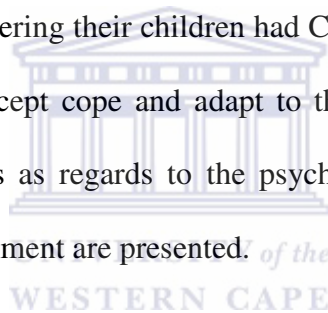
This is the final chapter comprising the summary, conclusion, significance and recommendations to physiotherapists, other healthcare providers and government. The researcher has included steps that could be followed in trying to help mothers of children with CP.

CHAPTER TWO

LITERATURE REVIEW

2 Introduction

This chapter presents a review of literature regarding challenges experienced by mothers of children with CP. Due to the paucity of the literature published regarding this topic in Africa, most of the studies reviewed are international. A general background of information on CP which includes the definition, aetiology, prevalence, clinical manifestations of CP, its management, the role of Physiotherapists in the management of CP and rehabilitation services in Zambia are outlined. This information will be followed by the experiences of mothers immediately after discovering their children had CP. The effects of CP on the family and the ability of mothers to accept cope and adapt to their children with CP are equally presented. Finally the challenges as regards to the psychological, the physical health, the socio-economical and the environment are presented.



2.1 Definition of CP

Cerebral palsy was first described by William Little in 1840 and is said to be a common developmental disability in children (Sankar & Mundkur, 2005). According to Bax et al (2005), CP has been known to cover a group of non-progressive, but often changing motor impairments which are secondary to lesions or abnormalities of the brain arising in the early stages of its development. It is generally agreed that CP is a heterogeneous condition in terms of aetiology as well as in types and severity of impairments (Gorter et al, 2004). Cerebral palsy mainly affects the cerebrum and involves connections between the cortex and other parts of the brain. Palsy refers to disorder of movement. However, "paralytic disorders" are not cerebral palsy. Paneth et al (2007) states that cerebral palsy is caused by damage to the

motor control centers of the developing brain and can occur before, during and after birth. Accordingly, there is a general alteration in the development of an infant with the core feature being abnormal motor control (Ashwal et al, 2004). The loss of motor control is characterised by various abnormal patterns of movements and posture related to defective co-ordination of movements or regulation of muscle tone which leads to activity limitations as alluded to by Aliasson et al (2003).

Regarding other neurodevelopment impairments that accompany CP, sensory impairments can include hearing, vision loss or disturbance in sensation. Both global and specific cognition can be affected. Expressive/receptive communication may equally be affected depleting social interaction skills in affected children. The capacity to interpret and incorporate sensory and cognitive information known as perception may be affected. Behavioural problems are seen in the context of psychiatric problems e.g. autism, ADHD, mood or anxiety disorders. Virtually all seizure types and epileptic syndromes may be seen in patients with CP (Beckung & Hagberg, 2002).

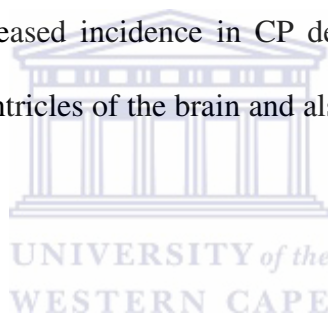
CP is classified according to the nature and typology of the motor disorder. There are three main types which include spastic, dyskinetic and ataxia based on the predominant neuromotor abnormality (Gorter et al, 2004). None of the many types of CP has a known cure. Usually, medical intervention is limited to the treatment and prevention of complications that arise from the condition (Jacobsson, 2007).

2.2 Aetiology of CP

Most cases of CP have an unknown aetiology; however, certain factors may contribute to an enhanced likelihood of the occurrence of this condition. Koman, Smith and Shilt (2004) indicated that factors that significantly increase the risk of developing CP include; newborn

babies who do not cry in the first 5 minutes following their delivery due to birth trauma, asphyxia or distress, prematurity and some degree of cerebral bleeding. Diamond and Armento reported that babies who have congenital malformation of the kidneys, cardiac system and spinal cord are also at a significantly higher risk of developing CP (Diamond & Armento, 2005). Rosenbaum Paneth and Leviton (2007) argue that none of these factors, however, categorically define whether or not an individual baby will develop CP and even those babies born prematurely or with a low birth weight have less than a 90% chance of developing the condition. Another contributing factor noted in literature is maternal cigarette smoking which has been linked to a decreased birth weight in babies and a contributory factor to the development of CP (Nelson & Chan, 2008). Similarly, it is very common that CP can result from births with complicated histories. Events such as seizures may deprive the brain of oxygen temporarily resulting in permanent damage which may in turn result in the development of CP (Ashwal, 2004). Albertsen et al (2004) reported that congenital malformation of the brain during ontological development is often undetected by sophisticated methods of antenatal diagnostic imaging due to several factors that may contribute to this including prolonged exposure to certain chemicals, such as alcohol in cases of foetal alcohol syndrome. In this instance the neurological system is damaged and there may be an elevated incidence of foetal liver and kidney damage caused by excessive alcohol consumption during pregnancy. The use of recreational drugs by pregnant women is statistically linked to damage in the foetal circulatory system alongside central nervous system impairment as indicated by Lynch Turner and Godwin (2007). According to Revello and Gerna (2002), CP is rarely a result of severe physical trauma in pregnancy or an episode of maternal systemic infection, such as toxoplasmosis, rubella or cytomegalovirus, during which the foetal upper motor neurone system is irreversibly damaged. The human immunodeficiency virus is a known causative factor of brain damage in babies, although it is

usually characterized by a degree of mental impairment rather than CP (Wiley & Achim, 1994). Prematurity at birth has been known as a key risk factor in the development of CP. According to a study, prematurity is as a result of the timing and subsequent body mass at birth. Babies born with a birth weight below 1500g are more likely to develop CP than babies born at full term weighing 2000g or more (Nelson & Chang, 2008). Hemming, Hutton and Pharaoh (2006) also reported an increased incidence of cerebral haemorrhage in babies with a low birth weight, with a serious complication being much less likely in babies born with a birth weight of 2000g. It is common in babies who develop any form of cerebral haemorrhage to result in significant damage to motor function, and for a diagnosis of CP to follow thereafter (Wu et al, 2010). Whelan (2004) indicated that the occurrence of periventricular tumors are indicative of an increased incidence in CP development as this usually leaves residual cysts surrounding the ventricles of the brain and also the area in the brain responsible for motor function.



2.3 Prevalence of CP

The worldwide estimated incidence of individuals with CP is 2.0 to 2.5 per 1000 live births in developed countries (Hagburg & Hagburg, 2001). It is fair to assume that this data is not different from findings in other parts of the world. For example the prevalence of CP in China is reported to be 1.6 per 1000 children under the age of 7 (Liu, Li, Lin & Li, 1999). In the USA, the prevalence stands at 2.12 per 1000 inhabitants with a higher prevalence for males and a non-significant higher prevalence in black people (Dolk, Patterden & Johnson, 2001). The prevalence in Australia stands at 2.0 and 2.5 per 1000 live births (Redibough & Collins, 2003). In the UK, the prevalence of CP is 3.3 per 1000 live births in the most deprived quartiles and 2.08 per 1000 live births in the most affluent. According to Dowding and Barry (1990), there is a clear social gradient as socio-economic factors influence the risk

and incidence of CP. This is seen especially in African countries even though not much is known about the prevalence of CP in these countries (Shawky, Abakhail & Soliman, 2002). The prevalence of CP in South Africa is not known though a study on the incidence of CP in rural South Africa estimated the incidence to be between 2 and 3 per 1000 live births (Kromburg et al, 1997). Research has shown that potentially brain damaging illnesses are more prevalent among the poorer communities of developing countries (Kibel & Wagstaff, 1995). Being one of the poorest nations in Africa, Zambia has accepted an extrapolated incidence of 3 per 1000 live births (US Census Bureau, 2004). In a study by Wu et al (2010) it was found that women with a low level of education were at higher risk of having children with CP. Low birth weight has equally been seen as a major contributing factor to the high prevalence rates as alluded to by Dolk, Patterden and Johnsen (2001). A study found a high correlation between low birth weight and socio-economic status (Martin, 2007). In this same study, it was reported that African/black mothers were more likely to have infants of low birth weight. This could explain the high prevalence rates of CP in Africa and in particular Zambia.

2.4 Clinical Manifestations of CP

It has been reported that approximately 80% of patients with CP have spastic clinical features (Kriger, 2005). Affected limbs may demonstrate increased deep tendon reflexes, tremors, muscular hypertonicity, weakness and a characteristic scissors gait with toe walking (Ashwal et al, 2004). Dysfunction manifests itself in three basic areas which are; neuromuscular problems, abnormal patterns of movement and musculoskeletal problems (Flett, 2003). The neuromuscular problems include problems of spasticity, dystonia, incoordination, the loss of selective motor control and weakness. Depending on the parts affected the symptoms manifest in monoplegia, hemiplegia, diplegia, triplegia and quadriplegia.

The athetoid type of CP affects 10-25% of patients and is characterised by slow writhing movements of the hands, feet, arms and legs that are exacerbated by stress and are absent during sleep (Taylor, 2005). According to Rapin (2005), there is a constant fluctuation of tone between flaccid and spasticity among children with this type of CP.

Bass (1999) reported on the more rare type of CP affecting about 5-10% of children known as ataxia. This predominantly impairs balance and coordination. The patient walks with a wide base gait with intention tremors which impede activities that require fine motor movements. The condition, whether linked to an exacerbated or deficient degree of muscle tone, impact upon the ability of a child with CP to maintain a positional state of stability, whether in the stance or swing phase of the gait cycle. Patients equally struggle to maintain the position of the head on the neck due to weak musculature of the neck (Taylor, 2005).

Musculoskeletal problems and osseous conditions such as hip subluxation mentioned in studies by Gajdosik and Cicirello (2001), may also significantly delay a child's ability to walk. This is linked to the impact of hypertonic or hypotonic musculature in children. Taub et al (2004) found that in about 50% of patients who are diagnosed with CP, excessive muscle tone means that a deliberate and conscious effort has to be made to perform basic functional tasks, such as picking up objects and putting them down again. Abnormal patterns of movement manifest themselves in the child's inability to carry out functional movements due to muscle contractures, bony deformities, muscle weakness and failure to obtain fine manipulative movements as indicated by Flett (2003). Edwards (1999) indicated that problems of communication and eating are common in cases of severe spasticity and athetosis.

Intellectual impairment is seen in about two thirds of patients with CP and of great significance is epilepsy which is found in about 50% of the patients and may vary considerably in intensity between child to child (Ashwal et al, 2004). Other conditions such as attention deficiency, hyperactivity disorder, specific learning difficulties and mental disorders have been reported to occur with CP (Kriger, 2005). Neurological abnormalities such a impaired vision, hearing and abnormal sensations to touch have also been (Taylor, 2005).

Co-pathologies in CP are common though not all of them are associated with specific brain injury, but most of them are linked to neurological dysfunction.

2.5 Management of CP

Management of cerebral palsy requires an interdisciplinary approach that draws the expertise of many specialists in different disciplines (Patel, 2005). According to Liptak (2005), early intervention, interdisciplinary team approach and family focused intervention strategies are essential in the rehabilitation of children with CP. A modern team approach focuses on total patient development not on improvement of single patient symptoms (O'Connor, 2009). Treatment programs encompass physical and behavioral therapies, pharmacological, surgical, external aids and management of associated medical conditions (Michaud, 2009). Approaches to management could include; neurodevelopment therapy (NDT), sensory integration, electrical stimulation and weighted tread mill training among others (Singhi, 2004). Specific treatment of patients depends on the patient's symptoms and may range from physiotherapy to medication use and even surgery (Patel, 2005).

Neurodevelopment therapy (NDT) is a common cerebral palsy approach that uses techniques to control muscle tone, reflexes, abnormal movement patterns, posture control, sensation,

perception and memory through the use of specific handling techniques (Reine, 2007). However a report by the American Academy of CP and Developmental Medicine (AACPDMD) stated that “although patients treated with NDT showed immediate improvements in dynamic range of movement, there was no consistent evidence that NDT changed abnormal motor responses, prevented contractures or facilitated more normal motor development” (Butler & Darrah, 2001: P. 780).

Popular interventions for physiotherapists are muscle strengthening and fitness programs, however, advocates for NDT advise against the use of resistance exercise as it is believed to increase spasticity (Rapin, 2005). In contradiction however, recent studies have shown that resistance training does not increase spasticity, but increases muscle strength, walking velocity and gross motor activities in persons with CP (Andersson, Grooten, Hellsten & Mattsson, 2003; Dodd, Taylor & Damiano, 2002; Fowler, Ho, Nigwe & Dorey, 2001).

Occupational, speech and language therapy are another significant field of healthcare practice in the management of CP. These provide specific expertise in aiding children to communicate effectively and improve their level of interaction with their peers. Occupational therapy on the other hand improves a child’s level of activities of daily living. Coupled with physiotherapy it is often possible to aid independent sitting, enable walking and ultimately improve self-perception and engage with society in general (Hayes, Lukas & Schoendorf, 2008).

Literature states forms of brain lesions lead to patterns of motor dysfunction, spasticity and contractures may arise in most incidences (Mayer, Esquenaz & Childers, 1997). Botulinum A (Botox) formulation derived from a bacterium clostridium botulinum which produces a protein that blocks the release of acetylcholine has been found to relax hypertoned muscles

(Baker et al, 2002). Following a review of literature there was no evidence to support or refute its use in the treatment of spasticity in patients with CP.

Surgical interventions in the management of spasticity includes selective dorsal rhizotomy which is intended to minimize or eliminate spasticity by selectively cutting dorsal roots from spinal cords L1 to S2 as reported by Hodkinson et al (2001). A meta analysis study of three (3) randomized controlled trials revealed a direct relationship between dorsal root transections and improved gross motor functions in children with CP (McLaughlin et al, 2002). Other forms of non invasive interventions exist such as abduction braces for hip dislocations, soft tissue release and major reconstruction of femoral bones or pelvic osteotomies and proximal femoral resections (Settecerri & Karl, 2000).

Orthoses are commonly used in conjunction with physiotherapy, botox, neuro or orthopedic surgery to prevent inappropriate joint movements. There has however been poor evidence based supporting the use of orthoses to prevent deformities and improve activities in children. Some studies have found electrical stimulation effective (Wright & Granat, 2000) whereas others have not (Dali et al, 2002; Sommefelt, Berg & Markestad, 2001). It is however important to note that cerebral stimulation to the medial cerebral cortex by a controlled current can reduce seizure activities, primitive reflexes and athetoid movements in patients with CP (Davis, 2000).

Nasogastric tube feeds are used in children with secondary conditions such as temporomandibular joint contractures, severe vomiting, precipitation hypoxemia and pneumonia associated with gastro esophageal reflux as reported by Samson-Fang, Butler and O'Donnell (2003).

A multi-disciplinary approach ensures an appropriate means of referral from one practitioner to the next with the patient being the center of this approach. Other team members may include psychologists, pediatricians, nurses orthopedic and neural surgeons (Backheit et al, 2004).

2.6 Role of Physiotherapy

Physiotherapy plays a central role in the management of CP as it focuses on function, movement and optimal use of the child's potential (Rosenbaum et al, 2007). Physiotherapy used in the rehabilitation of children with CP has been shown to improve muscle strength, endurance and overall joint range of motion (Patel, 2005). A physiotherapist also uses physical approaches to promote, maintain and restore physical, psychological and social well being of children with CP. Bax et al (2005) reported that a physiotherapist uses strategies to prevent deformities, stimulation of sensory pathways and supporting mothers and/or carers of children with CP are employed. Stanger and Oresic (2003) reported that a physiotherapist also designs, modifies and orders adaptive equipment for children with CP. Physiotherapists working with young children instruct parents, relatives and other cares to reinforce therapy. According to Morris, they also teach parents how to handle their children at home in terms of feeding, bathing, dressing and give advice on mobility equipment (Morris, 2002).

This makes physiotherapy services important in supporting mothers and caregivers in their management of children with CP, both at early stages and as they become older. In an earlier study, mothers of younger children with CP ranked physiotherapy as the most important for their children (Parkers et al, 2002). The main reason is that, the physiotherapist may be the only person in the medical team with whom the parent/children spends the most time over a reasonable period. However, Backheit et al (2004) argued that the effectiveness of physiotherapy is not supported by any clear and firm evidence based intervention data. The

researcher further reported that physiotherapy can only be effective if part of a multi-disciplinary team. Flett (2003) elaborated the important tasks performed by a physiotherapist as part of the multi-disciplinary team in the management of CP. These included defining the child's disability, providing a baseline functional and biomechanical assessment, providing mobility aids, therapy, castings, orthoses and providing targeted motor training or exercises for the parents or carers to implement. The importance of physiotherapist performing a comprehensive assessment of children with CP prior to management has also been reported by Bhatia and Joseph (2001). In this same report, physiotherapists were able to note associated disabilities in 43% of the 82 children in their review which were not recognized on the initial referral. The physiotherapist's assessment therefore helps in locating associated disabilities, hence enabling effective management and rehabilitation.

2.7 Rehabilitation services in Zambia

Rehabilitation services for children with CP in Zambia are mainly provided for at tertiary hospitals in Zambia as well as at community based rehabilitation (CBR) centres mostly run by the Catholic Church (Central Statistics Office (CSO), 2002). Ideally, children diagnosed with cerebral palsy should be under the care of a multi disciplinary specialist team which includes various healthcare professionals such as pediatric doctors, physiotherapists, occupational therapists, speech therapists and psychologists (Patel, 2005). The concepts of multidisciplinary teams are not common in Zambia as there is a limitation of human resources. Some healthcare providers such as occupational therapists and speech therapists are almost non-existent in Zambia (WHO, 2001). Currently there is only one such team at the University Teaching Hospital (UTH) in Lusaka, Zambia where children with CP are referred for a plan of treatment and the team together with the parent or the caregivers plan a rehabilitation program. Physiotherapist teaches the parent/caregivers the exercises for the children and are

encouraged to carry them out at home on a daily basis and they are monitored or supervised occasionally by the team (Personal communication with a physiotherapist at UTH). The UTH has partnered with CP Africa and have established a centre for children with CP called Action Against Disease and Disability (ADD). So far it is the only referral hospital with such a centre in Zambia.

In others parts of Zambia, rehabilitation services for children with CP are mainly offered by physiotherapist in tertiary hospitals or in CBR centres. Physiotherapy treatment mainly includes exercises to move limbs to prevent contractures, deformities and to improve on mobility. They also enhance independent skills such as rolling, sitting, standing etc and are responsible for ordering orthotics and advising caregivers on positioning and stretching exercises for the children. However, very few physiotherapists are trained in the neurodevelopmental therapy popular for treating children with CP (Birberk, 2007).

South Africa, like in most developing countries offer professional rehabilitation services for children with CP through multidisciplinary teams that includes physiotherapists, occupational therapists, speech therapists, orthopedic and neurosurgeons, psychologists and pediatricians as reported by Levin (2005). As a legislative, South African healthcare graduates have to work on community service for a year before gaining full registration with the Health Professions Council, hence many more communities are receiving more rehabilitation services (Cans et al, 2004). The most common approach of management for children with CP in South Africa like in most developing countries is the NDT described under section 2.5 of this study. The use of special medications such as botulinium A toxin (botox) and surgical procedures such as bilateral tendon releases done on children have enhanced and improved function and mobility of children in developed countries (Nelson, 2003). South African healthcare professionals like in developed nations have adopted the family centred approach

where therapists understand the need for caregivers to receive community and environmental support and they encourage the establishment of support groups and networks though still few and far between (McConachie, 2000). According to Michael and Ray (2008), most first world countries are even more advanced in the management of CP as they have adopted the use of high technology equipment such as the Voice Output Communication Devices (VOCD), powered wheelchairs and many other devices in the management of CP.

Zambia, on the other hand has a few trained physiotherapists in NDT (Cerebral palsy Africa (CPA), 2007) they lack special equipment used in the management of CP and most caregivers cannot even afford wheelchairs and other assistive devices. Family centred approaches have not yet been adopted and there are no support groups for caregivers in place (ZAFOD, 2006).

2.8 Experiences of Mothers

Having a child with CP makes mothers go through several experiences. The family dynamics changes to accommodate the child with CP. Under this heading, the immediate reactions of mothers to the diagnosis of CP on their children will be discussed. The effects of CP on the family as well as how families accept, cope with and adapt to children with CP will equally be discussed.

2.8.1 Immediate reactions

Learning of a child's diagnosis of disability has been considered to be catastrophic for parents (Hatton et al. 2003). Many react in different ways, but in most cases the reactions are common. Shock is inevitable in the early stages as often every parent desires or expects to have a normal and healthy baby. Many other feelings such as anger, denial, fear of the unknown, unpredictable futures of their children and guilt may arise (George et al, 2007; Skov 2006; Ho & Keiley, 2003). Parents usually go through emotional stages which

according to Huang, Ursula, Kellet and St John (2010) these reactions are applicable across a broad range of disabilities and illnesses and are believed to be cross-cultural. These reactions are often manifestations of mourning the loss of an ideal dream and mothers go into a state of grieving. Ross and Deverell (2004) describes grieving as the process of separating oneself from something significant that is lost. It is a re-evaluation of the individual's existential values. According to some studies, common examples of emotional stages could include; shock and disbelief, denial, anger, bargaining and guilt (Abidoglu & Gumuscu, 2007).

Shock and Disbelief: This is usually one of the initial reactions, and is common if the diagnosis is unexpected. This state is generally characterised with crying, lack of response and feeling of helplessness (Ozsenol et al, 2003).

Denial: This is another manifestation of grieving, particularly in the early stages, and may manifest in rejection of the diagnosis itself and 'shopping around' in search of an 'acceptable' diagnosis. Denial is a valuable defence mechanism that protects the psyche from the trauma that the affected person is not yet ready to deal with. In addition, denial is used to 'buy time' needed to find inner strength to deal with the problem (Abidoglu & Gumuscu, 2007).

Bargaining: This is characterised by 'fantasy thinking' whereby mothers engage in bargaining within themselves, with God, or with their clinician, where they make promises to be ideal parents or withhold from certain behaviours if they can expect significant improvement in the life of their children with CP (Abidoglu & Gumuscu, 2007).

Guilt: This is present when an individual has an actual theory about what has caused the impairment, such as a mother who contracted a disease during her pregnancy, or the belief that the impairment was a form of punishment for past misdeeds, or the belief that one gets what one deserves (Schmitke & Schlomann, 2002).

Anger: Anger is an integral part of grieving, and may be displaced onto the child with a disability, the spouse, siblings, other children or professionals. In some instances, anger may be translated into a ‘death wish’ where a parent or caregiver may fantasise about killing the child so that the situation will be over and everyone can get on with their lives (Abidoglu & Gumuscu, 2007).

In most cases, mothers overcome these emotional stages, but a recent study by Masterson (2010) identified mothers who demonstrate failure to overcome these emotional stages and they go into chronic sorrow. Chronic sorrow has been defined as a permanent and reoccurring experience of pervasive sadness and loss which underlies the life experience and which recurs over time for the mother of a child with developmental, medical, or behavior issues as seen in CP that prevents a child from participating in society in a way previously anticipated (Kendall, 2005).

2.8.2 Effects of CP on the family

According to Ross and Deverell (2004), parents jubilate and are expectant of the child they are bringing into the world. However, this may immediately change when the child is born with a disability. For many, this may be overwhelming; sorrow and grief as described in the previous section begin to set in as the reality of lost hopes and dreams becomes apparent (Huang, Kellett & St John, 2009). A study by Lynch (2007), it was indicated that in addition to the emotional problems experienced by parents have to deal with, they also have to cope with the attitudes of friends, relatives and the community at large (Lynch, 2007). Seltezer et al (2001) found that parents are concerned about social acceptance and what the neighbors may think, while family members may claim that if the condition is hereditary, the affected gene was not on their side of the family. A study involving caregivers of children with disabilities revealed that as many as 95% of the participants reported that the most hurtful

aspect of raising a child with a disability was that neighbors and friends would not allow their children to play with the child with a disability, thus causing social isolation for the child (Emerson, 2003). It has also been reported that due to the social isolation that results from strong social stigma attached to physical and mental impairment, marital breakdown are very common (Martz & Livneh, 2007). A study showed that from the time a diagnosis is made, the father tends to receive most of the information about his child from the mother, and as a result, gradually begins to retreat into a secondary role because he feels less expert than his wife (Sen & Yurtsever, 2007). When fathers retreat into this role, mothers are compelled to assume immediate responsibility of day-to-day care for the child. The gradual withdrawal of the father may evoke anger and resentment in the mother. Furthermore, the dependency of the child on the mother and the gradual restrictions on activities can adversely affect the development of healthy family relationships. Parents become emotionally detached to each other due to inability to share their grief and disappointment. The father who finds his own needs unmet, may direct his anger and resentment at his wife or the child with CP as reported by Tattersall and Young (2006).

Caring for a child with a disability is time consuming, and this may place stress on the family. Siblings may react in a number of ways, including feelings of love, empathy, guilt, anger, support, resentment, and embarrassment. According to Burke (2004), siblings living with a sibling with a disability, may sometimes feel excluded from mainstream activities. A child born with CP does not only affect the immediate family, but affects the Grandparents as well. One of the main concerns is how the parents will convey this news to the grandparents and how this news will affect their relationship with them (Gallagher et al, 2008). It has been reported that some grandparents are aggrieved and disappointed especially if the child with CP is their first grandchild which adds to feelings of guilt and despair (Burke, 2004). On the

other hand, grandparents may provide additional support, both on an emotional and a physical level. Whether relationships between the child with the disability, the parents, siblings, grandparents and extended family members are positive or negative depends on factors such as lifestyle, child-rearing practices, the type and severity of the disability, coping mechanisms utilized by the family, as well as the type and quality of support services available within the community (Uchino, 2009).

2.8.3 Accepting coping and adaptation

Parenting a child and attempting to provide a safe environment that fosters the physical, social and emotional growth is a complex task. In many instances families fall apart as a result of poor coping skills, lack of support structures, or in response to money struggles, addictions, abuse, health impairments, or plain unhappiness (Resch, 2010). According to Sen and Yurtsever (2007), mothers often feel guilty about bringing a child with a disability into the world, thus they experience more stress than the fathers. Research that has so far been done regarding marital discord in families of children with disabilities has been inconclusive as alluded to by Vijesh and Sukumaran (2007).

Studies have shown that irrespective of the difficulties associated with raising a child with disabilities, many families have accepted the condition of their children with CP. Adaptation has also been indicated (McCubbin, 2002; Patterson & Garwick, 1994). In helping to understand family adaptation and coping strategies, a researcher introduced the resilience model of family stress, adjustment and adaptation. “The resiliency was developed to explain why some families are more resilient than others and are better able to adjust and adapt to stress, distress and crises by examining the family system as a unit. The severity of the stressor is determined by the degree to which the stressor threatens the stability of the family

unit or places significant demands on its resources and capabilities, the result of which could threaten the family's integrity and well-being over time” (McCubbing, 2002: P. 104). Family demands include stressors that happen before and after the baby with disabilities is born. These may include financial problems as most of the roles change. The life cycle and work of some parents are affected immediately. Some families are able to meet the demands imposed on them due to accumulated family resources and also due to their coping capabilities.

Social support from individuals, family, and community level resource is most often viewed as one of the primary mediator between stress and psychological well-being. Most families cope because of the much needed support they receive from others. This may explain why some families cope well irrespective of the challenges faced (Raina et al, 2005). Social support has been seen to allievate many socio-psychological problems experiences by families of children with disabilities. This support has been reported to be effective only if it meets the needs (Cohen, 2010). Positive impacts of social support have also been reported in a study by Middlemiss (2005). Social support has been said to come from friends family and community members. However, most members of the community are not aware of issues pertaining disability and in most cases they distance themselves from the child with disabilities (Chimedze, 1999). A study has shown that most families of children with disabilities live in isolation and are far from receiving social support either formal or informal (Tanyi, 2006). While social support has been seen as a mediating factor in mediating stress, studies that have correlated parental well-being to social support have been inconclusive. In the previous study (Heller, 1999: P. 419-423) stated that “one of the reasons for confusion about the mechanisms linking stressors, sources of support, and outcomes has been a lack of contextual specificity”. Coping includes measures to keep families united even if it means

using up all the family resources to restore stability and ensure satisfaction despite the stressing event (McCubbing & McCubbing, 1996).

2.9 Challenges experienced by mothers of children with CP

There are many challenges experienced by mothers of children with CP. Some of them could include; psychological challenges due to care giver demands and uncertainties (Sajedi, Alizad, Malekkosravi, Karimlou & Vameghi, 2010; Glasscoe, Lancaster, Smyth & Hill, 2007), physical health challenges that emanate from excessive stress and through constantly assisting their children in activities of daily living (Tonga & Duger, 2008), socio-economic challenges as many mothers are lack employment opportunities (Borst, 2010), environmental challenges as environments are said to be unfriendly (Lollar, 2008), marital challenges (Vijesh & Sukumaran, 2007), Challenges with implementation of policies regarding childhood disability (Makinde, 2005), challenges with diagnosis of the condition of CP (Huang, Kellett & St John, 2010) and finally safety challenges (Taylor, Mangenello, Lee & Rice, 2009).

2.9.1 Psychological challenges

Mothers of children with CP have been known to experience psychological problems (Vijesh & Sukumaran, 2007). These could include depression, stress and anxiety. Depression is a state of low mood and aversion to activities that can affect a person's thoughts, behavior, feelings and physical well-being. Interest in pleasurable activities is lost and affected people may suffer cognitive impairments (Quinn & Gordon, 2011). The birth of a developmentally disabled child is a stressor to a family. According to Robert and Steele (2010), mothers often feel guilt than other family members and involve themselves into compensation strategies which makes them end up with depression. In a study, Ones et al (2005) found that mothers

of children with CP had depressive symptoms and a lower quality of life. In addition, Manuel et al (2006) reported 30% of the mothers of children with CP had symptoms of depression above cutoff on Center of Epidemiology Studies-Depression Scale (CES-D). Mothers have been said to experience depression due to emotional demands placed on them as they remain alone with their children with CP (Glidden & Schoolcraft, 2003). Mothers depression is also as a result of being over burdened by the demands of care giving, earning a living and other responsibilities as potrayed by Buming, Gunal and Tukel (2008). According to Mu, Kuo and Chang (2010), epilepsy in children with CP is an extra burden and mental retardation in epileptic children has a significant impact on a mother's depressive symptoms which has been seen to affect the quality of life in mothers of children with CP.

Stress has been described as the inability to cope with a perceived threat to one's mental, physical, emotional and spiritual well-being which can affect one's physical health. These perceptions are rooted in feelings of fear and anger which broods frustration, depression and anxiety (De Kloet, Joels & Holsboer, 2005). Previous studies have shown the existence of high levels of stress among mothers of children with CP (Barbra, Chaud & Gomes 2008; Baker et al, 2003). The different stressors are well documented in literature (O'Neil et al, 2001; McConachie, 2000; Mobarak et al, 2000; Law et al, 1998). The birth of a normal child comes with some stressors for most, the stresses are more significant if a child is born with a disabilities. Due to cultural beliefs, society welcomes the birth of a normal child, but display negative attitudes towards the birth of a child with disabilities (Raina et al, 2005). A study has shown that economically, mothers are stressed due to added hospital/medical costs, diets and assistive devices which are very expensive for their children with CP (Pelchart et al, 2003). Donavan, VanLeit, Crowe and Keefe (2005) found that some mothers have to give up their jobs in order to look after their children with CP. The fear of rejection by friends and

relatives, leads to nonexistent social lives for mothers causing more stress as mothers depend on support from others to avert stress. Glen et al (2008) related the high levels of stress to role restriction, poor spousal support and feelings of isolation in addition to looking after their child with CP. Barlow, Cullen-Powell and Cheshire (2006) in their UK study found that the stress and anxiety levels in mothers were due to the sleep difficulties of their children. Other researches correlated the higher levels of stress to the severity of the child's disability and perceived social support (Skok, Harvey & Redihough, 2006). Some researchers however reported that even though mothers are at risk of above average stress level, stress is not inevitable (Eisenhower, Baker & Blacher, 2005; Byrne & Cunningham, 1985). Anxiety on the other hand is a psychological and physiological state characterized by somatic, emotional, cognitive and behavioral components (Seligman, Walker & Rosenbaum, 2005). This can occur in the presence or absence of stress. According to Bouras and Holt (2007), anxiety creates feelings of fear, worry, uneasiness and dread. When a child is diagnosed with CP, grief and worry are natural reactions. Studies have shown that reactions may differ between mothers, but often they experience periods of panic, anxiety, helplessness at which point they face overwhelming depression, apathy and bitterness (Huang, Killett & St John, 2010). A study revealed that mothers struggle to learn everything they can about the condition and in most cases they suffer from periods of clinically anxious moods (Hammen, 2005). Many studies have found that mothers of children with CP have greater or higher levels of anxiety compared with population female norms (Glen, Cunningham, Poole, Reeves & Weindlings, 2008; Barlow, Cullen-Powell & Cheshire, 2006; Press et al, 2000 & Breslau et al, 1982). Rudolph, Rosanowski, Eysholdt and Kummer (2003) found that the burden of care giving plays an important role in the course of anxiety. Other studies found that mothers had clinically anxious moods due to reduced energy levels, sleep disturbances and increased emotional reactions (Olsson & Hwang, 2001). Psychological challenges among mothers of

children with CP are global as shown in studies done in the UK, USA, Malaysia, India, China and Ghana (Sen & Yurtsever, 2007; Hartley et al, 2004). There are a few studies in Africa which have shown the psychological impact on mothers of children with CP.

2.9.2 Physical health challenges

Cerebral palsy has been reported to be a common childhood impairment that can sometimes lead to severe physical disability (Brehaut et al, 2004). Many children with the condition have limitations in self-care function leading to long term dependency which places demands on mothers (Campbell, 1999). As a result of limitations in physical activities and self-care, mothers constantly assist their children with ADLs several times a day leading them to overload their musculoskeletal structures. According to Tonga & Duger (2008), musculoskeletal disorders if not treated may lead to chronic conditions. A study showed that some of the risk factors to musculoskeletal disorders among mothers of children with CP include heavy lifting, improper lifting techniques, frequent bending, repetitive work and psychosocial factors including depression (Hales & Bernard, 1996). “The cognitive, sensory, emotional and mental disorders that accompany CP create numerous problems especially in ADLs leading to increased level of assistance from the mothers to the children with CP” (Duger, Yilmaz, Aki, Kayihan & Karaduman, 2008: p.1190). Researchers have different opinions when it comes to reasons for musculoskeletal problems on mothers. For instance Tonga & Duger (2008) reported that musculoskeletal problems are due to working in static unsuitable postures where as Duger et al (2008) in their Australian study found that the mechanical overloading on the musculoskeletal structures was due to environmental barriers such as height from the floor of threshold, switches, plugs, shelves etc in the mothers’ homes which were higher than international standards.

Studies examining the effects of care work on the physical, emotional and social health of mothers found that mothers had more physical limitations, disease symptoms, chronic conditions and poor immune function (Singer, Biegel & Ethridge, 2009; MacDonald & Callery, 2007). According to Revello (2002), distress and poor health habits elevate stress hormones stimulating further physiological activities that can lead to negative health outcomes such as hyperglycemia, hyperinsulinemia, higher blood pressure and poorer immune functions. Poor immune functions include reduced ability to fight tumor cells, poor anti body production in responses to viruses and slow wound healing responses. These conditions if prolonged can compromise health. MacDonald and Callery (2007) reported that some children with severe disability are institutionalised not because of a significant change in their health status, but because of the increasingly poor health of the mothers. A study that investigated the physical health of mothers indicated that they engaged in unhealthy lifestyles, they did not exercise or eat well and they had no time to seek medical attention for themselves. To add on to that, the mothers were lacking sleep and had a low quality of life (Cummins, 2001). Some physical stress for mothers are suggested by researchers to affect the health of mothers than some forms of psychological stress (Sullivan et al, 2002).

2.9.3 Socio-economic Challenges

Under this heading, the social-economic challenges are presented. The poverty levels and the socio-economic status of women in Zambia are presented. The relationship between poverty and childhood disability is also presented.

2.9.3.1 Socio-economic challenges of mothers of children with CP

A family's socioeconomic status is based on family income, parental education level, parental occupation, and social status in the community such as contacts within the community, group associations, and the community's perception of the family (Demarest et al, 1993). There is a

strong body of evidence that suggests that the level of education among mothers of children with CP in both developing and developed nations is very low and tending towards low income (Parish et al, 2008; Murphy, Christian, Caplin & Young, 2006; Ong et al, 2005; Schor et al, 2003). These mothers have less job opportunities outside their homes limiting their finances and resources as reported by Ong et al (2005). Having inadequate resources and limited access to available resources can negatively affect families' decisions regarding their young children's development. Lloyd and Rosman (2005) reported that when families do not have enough income, fundamental prerequisites for good health are difficult to obtain. There is inadequate shelter, hygiene and infections can easily be contracted and passed on. Furthermore, the presence of cockroaches, rodents and other allergens in low-income minority households aggravate chronic conditions and as a result of these factors, childhood disabilities are overrepresented among children living in poverty (Wise, Wampler, Chavkin & Romeo, 2002). While the economic load that the child brings to the family is high, the care, the treatment and education causes an even greater burden to the family as was reported by Press et al (2000). Added to that, a study showed that the loss of the mother's income when they quit work to care for their child with disability causes the family to experience financial difficulties (Talley & Crews, 2007).

Some of the expenses that come with children with CP include in-home care, architectural modifications to the home, specialized medical equipment, medical expenses, transportation to and from appointments, babysitting for other siblings, special diets and specialized day care (Hogan & Msali, 2002; Meyers, Brady & Seto, 2000). For families where budgets are already stretched to the limit, these economic demands may hit them hard as they have little in their reserve (Bernheimer, Weisner and Lowe, 2003).

Some studies have shown that mothers of children with CP do not receive sufficient financial support from their governments and that they experience financial difficulties (Emerson, 2003; Mutla, Denir, Kerem & Livanelioglu, 2003; Gokcan, 2002), while other studies reported that mothers do not receive subsidies as they are not aware of the available programs or they believe that they are not eligible (Urhan, 2002; Blau & Tekin, 2001).

2.9.3.2 Poverty levels in Zambia

According to United Nations' report on populations below poverty lines (UN, 2007: Poverty report accessed from www.undp.org), "about 68% of Zambians live below the recognised national poverty line, with rural poverty rates standing at about 78% and urban rates of 53%. Zambia ranked 117th out of 128 countries on the 2007 Global Competitiveness Index, which looks at factors that affect economic growth. Per capita annual incomes are currently at about one-half their levels at independence and, at \$395, place the country among the world's poorest nations. Social indicators continue to decline, particularly in measurements of life expectancy at birth (about 40.9 years) and maternal mortality (830 per 100,000 pregnancies) (Holmes & Slatter, 2010)". Economic growth has been failing due to issues such as HIV/AIDS which have placed a strain on the economy. The Zambian economy has primarily depended on copper mining, however the price of copper has been dropping on the international markets. This has led to a decline in the number of investors and uncertainties over privatisation. There has been a rebound in the prices of copper production mainly due to privatization even though improvements in the world copper market have brought about an increase in revenues and foreign exchange earnings, but most Zambians live below the poverty lines.

A survey conducted by the Central Statistical Office of Zambia (CSO, 2006), revealed that the employment rate, in Zambia among persons 12 years old and above was 14% of which

68% were males and 32% females. The highest unemployment rate for females was recorded in the capital city, Lusaka at 41% followed by 40% on the Copper Belt where the research setting is found. The mean monthly income for a Zambian household was approximately \$100. Only about one in three households had a mean monthly income that exceeded \$80, implying that the majority of Zambian households or approximately 65% of Zambians had incomes below the basic needs basket. Fifty four percent of rural dwellers had no access to a health facility. Access to safe and clean water was higher in urban (89%) than in rural areas (43%). Fifty nine percent of households in Zambia own a pit latrine. 7.3% communal latrines, 4.6% used neighbours latrines, only 15% used flush toilets and about 13% regrettably did not own a toilet. Only 3.2% of rural households had access to electricity compared to the 49.3% of their urban counterparts. The child nutrition status report stated that overall, 54.2% of children aged 3-59 months were stunted in Zambia.

According to another survey on the socio-economic profile of a Zambian woman (Zhou, 2010), 19% live in households that do not have enough money for food and about 40% said their households have money, but only for food. About 20% had no money at all. Regarding education, 48% had secondary education, less than 10% had post-secondary education or beyond and 18% had no formal education. Ninety one percent have access to a hospital, health centre or clinic, and 79 percent have access to a doctor or healthcare worker, but less than 5% have health insurance.

2.9.3.3 Relationship between poverty and childhood disability

“There is a strong relationship between childhood disability and socio-economic status” (Anderson & Phohole, 2003: p170). Hutcherson (1991) noted a strong correlation between poverty, educational level, nutrition, and the prevalence of disability. In addition, it is reported that children in poor families are at risk of acquiring chronic health problems and

disabilities, and caring for these children can impose substantial costs to their families. Globally it is reported that there are about 140 million disabled children of whom 97% are found in poor countries where rehabilitation services are either lacking or inadequate (Emerson & Hatton, 2005). Furthermore, Bhorat, Poswell and Naidoo (2006) found that of the total number of disabled children globally, approximately 98% of them lack education and 90% will not survive beyond five years. This has huge implications for healthcare workers working in the field of child health, both from a research and a practical point of view.

According to Young (2004), children with disabilities in developing countries lack knowledge on health matters and social services. Some of the socio-economic problems faced expose these families to disease and having poor access to healthcare places the children at a higher risk of developing CP while poverty plays a major role in exposing children to conditions which may result in cerebral palsy (Levin, 2005). It has also been reported that mothers, particularly in rural areas, live in conditions that are not fit for human habitation as in most cases they live in unsanitary conditions and are exposed to all sorts of diseases (UNDP, 2007). Bhorat, Poswell, and Naidoo (2006) found that in many poor communities, mothers do not have access to pre natal care and thus expose themselves to diseases. Furthermore, health literacy is poor because most mothers, particularly in rural areas have received limited or no education and therefore do not have access to, or the ability to interpret and use information healthcare matters (Nutbeam, 2000).

The United Nations Development Programme (UNDP, 2007) states that a key indicator to poverty is the degree to which people are excluded from accessing basic goods and services. Poor people do not have sufficient income to purchase goods. In addition, they live in under-developed areas where there is a lack of sanitation, water, electricity, health services, job

opportunities, and education and recreational facilities. Furthermore, it has been reported that poor people are at greater risk of disability (Anderson and Phohole, 2003). The birth of a child with a disability within a family often places heavy demands on family morale, thrusting it deeper into poverty. The white paper on an integrated national disability strategy indicated that there is a higher proportion of disabled people among the very poor, but also that there is an increase in families living in poverty as a result of disability (UNDP, 2007).

2.9.4 Environmental Challenges

The social modal of disability considers disability to result from the interaction between individuals and their environments rather than something within the individual. Participation is determined by the social, the physical and the attitudinal environments around the individual (Abberly, 1987). The International Classification of Function Disability and Health (ICF) (WHO, 2001) defines participation as involvement in life situations and environmental factors such as the social, attitudinal and physical environments in which people live. Therefore in considering environmental challenges mothers of children with CP face, the social, attitudinal and physical environments will be considered.

2.9.4.1 Social environmental challenges

Society develops a culture through a plurality of shared norms, customs, values, traditions and social roles. Socialization is therefore the means by which social and cultural continuity are attained (Lahey, 2002). The social lives of mothers of children with CP are affected due to their inability to set aside time for themselves and other members of the family (Raina et al, 2005; Mutla et al, 2003). This they reported was because mothers quit their jobs to care for the children with CP. The work lives, social lives and emotional lives of mothers are more affected as they are the primary caretakers of their children with CP (Green, 2003; Pelchat, Lefebvre &Perreault, 2003). The majority of responsibilities for child care fall on the mothers

who in turn abandon the other roles of motherhood and decrease their participation in social activities (Emersson, 2003; Tekinalp, 2001). Other researchers have agreed that caring for a child with CP constrains the social activities of the mother (Eker & Tuzan, 2004; 2003; McNaughton & Bryen 2002). Abidoglu & Gumuscu (2007) in their study found that the mother's social constraint was a result of her fear of the reactions of others to her child. Duger, Yilmaz, Aki, Kayihan and Karaduman (2008) in their study reported that environmental factors that are said to be restrictive in mobility with assistive devices outside and within home areas made mothers opt not to participate in social activities as the transport, terrain and buildings do not support mobility of their children. Raina *et al*, (2005) thought disturbed family relations were a major cause of social constraints. Skok, Harvey and Reddihough (2006) in Australia also found that lack of social support structures, constrained women socially. McNaughton and Bryen (2002) in their study in Australia blamed the poor educational policies in developing nations as a social challenge to mothers of children with CP. Eker and Tuzan (2004) in their study in Turkey blamed financial constraints as a social concern. Studies have proved that there are communication problems between mothers and their children with CP (Pennington & McConachie, 2000). Mothers blamed their inability to communicate with their children with CP as a social constraint this mostly seen among mothers in developing nations as this situation has been addressed through the use of assistive devices such as the augmentative and alternative communication devices (AACD) and the voice output communication in developed nations (Michael & Ray, 2008). More studies on social challenges need to be done as studies prove that despite the disability grants, healthcare/family and social support structures, assistive devices, mothers in developed countries were still socially withdrawn (Abidoglu & Gumuscu, 2007).

2.9.4.2 Attitudinal Environmental Challenges

Mothers of children with CP face many attitudinal challenges (Westbrook, Legge & Penny, 1993). Attitudes are described as a state of readiness by an individual or a tendency to respond in a certain manner when confronted with a certain stimuli and can either be negative or positive (Oppenheimer, 1992). Attitudes toward children with disabilities are predominantly negative (Lynch, 2007; El-Sharkawy, Newton & Hartley, 2006; Corrigan, Markowitz, Watson, Rowan & Kubiak, 2003). Disability is often viewed as a form of deviance and dependency leading to patronization, prejudice and exclusion from the rest of society (MacDonald & Nail, 2005).

It has been reported that many negative attitudes toward children with disabilities are influenced by the culture which often plays a major role in shaping society's beliefs and behaviors towards people with disabilities (Rao, Sharmila and Rishita, 2003; Bakheit and Shanmugalingam, 1997). Some of the negative attitudes displayed by community members are due to traditional beliefs (UNPD, 2007). In most African cultures, people associate childhood disability with witchcraft, promiscuity of the mother during pregnancy and punishment from ancestral spirits, evil spirits and/or by God (Chimedze, 1999). Rees (2003) reported that attitudes towards disability on a societal level have changed very little if at all. According to Pritchard (2005), the physical and social environments send the message to people with disabilities that their presence in society is not equivocally either welcome or vital. Finkelstein (2010) had similar findings in his study and reported that people with disabilities regard society's prejudices as more restrictive than the practical difficulties faced as a direct consequence of a person's impairment. Studies in the west have shown mothers of children with disabilities were discriminated, stigmatized and were not included in social activities (Corrigan et al. 2003; Rosenzweig & Huffstutter 2004; Huffstutter et al. 2007).

There is little research from Africa addressing these issues. Studies from Uganda reveal that carers of children with disabilities, who are mainly mothers or grandmothers, suffer from social isolation due to prejudice and stigmatization (Bwana & Kyohere 2001; Hartley, Ojwang, Baguwema, Ddamulira & Chavuta, 2004). In Ghana, there is a widespread belief that children with disabilities are 'spirit children' who are sent to destroy families and are not meant for this world (Agbenyega, 2003). A review of literature has demonstrated that mothers of children with disabilities including CP experience negative attitudes from families and the community.

2.9.4.3 Physical Environmental Challenges

Disability is a condition that limits mobility, lessens vision or aural acuity, reduces stamina and inhibits a person's ability to manipulate the environment with a minimal degree of effort (WHO, 2006). Accordingly, physical environmental barriers are those aspects of the built environment which lessens access for a child or anyone with a disability (Lollar, 2008). These may include parts of buildings, landscapes, walkways, parking areas, high curbs lack of ramps, narrow sidewalks, heavy doors etc. (Bodde, 2009).

The ability to move safely and independently, referred to as mobility is a fundamental part of basic activities of daily living of human beings. One of the neurological consequences of cerebral palsy is the limitation in mobility that leads to dependency in activities of daily living (Taub et al, 2004). Mothers find it very challenging as their children with cerebral palsy cannot meet the demands of the environment which leads to a compromise in independence and disability results. Architectural structures within and outside their home environments in most cases are not conducive for mobility of their children and especially those using assistive devices (Verbrugge & Jette, 2004). Most CP children live in poor housing structures and are surrounded by terrains, slopes, curbs and uneven surfaces which

hinder their mobility especially when using assistive devices. In a study conducted in Yemen by Grut and Ingstad (2006), it was reported that the design of the houses was a challenge to children with physical disabilities. In developed countries, most houses are quite large, providing space for a large family. The only challenge is stairs in the houses for people with disabilities. However, houses for the poor in developing nations are much smaller and more crowded which makes mobility for children more challenging. Grut and Ingstad (2006) also reported architectural features on buildings and roads are not friendly to wheelchair users and suggests that more needs to be done to have environments that are accessible to the disabled.

A study in Iran also reported that in most cases children and adults with disabilities do not participate in social activities as features in the environment are not accommodating to them (Lancioni et al, 2009). Another study reported that “the physical environment of developed countries has changed over the years which they attributed to the changed infrastructure of the countries. Skyscrapers, fascinating interior, ultra-modern usage of machines amongst others have made the lives of individuals more convenient, even though it has made the lives of individuals with disability difficult” (Newton et al, 2002: P.286). The progress in infrastructure has not added any freedom for people with disabilities, as built environments have added inaccessibility, uncertainties, anxieties and dangers.

Due to the unfriendly physical environments, mothers of children with CP closely monitor/supervise their children throughout the day affecting their other roles of motherhood. Because of infrastructures that are not wheelchair friendly, mothers physically lift their children when going to places leading to their musculoskeletal health problem and in most instances they prefer to stay at home leading to their social seclusion. However, these challenges are mostly experienced by mothers in developing nations as most homes and

infrastructure in developed countries have been modified to suit the condition of children with cerebral palsy (Osteonsjo, Carlberg and Vollestad, 2005).

2.9.5 Marital challenges

Marriage is an institution in which interpersonal relationships usually intimate and sexual are acknowledged through traditional ceremonies or weddings (Duran, 1997). People get married for various reasons including procreation, however problems may arise in marriage when the couple bears a child with disabilities (Risidalle & Singer, 2004). A study by Wade et al (2006) found that parents of children with disabilities are twice likely to divorce by the time the child is eight years old. The study reported that unresolved grief, disruptive child behaviour combined with demands associated with raising a child with disabilities results in extremely higher levels of stress which in turn produces conflicts, dysfunctional marriages and high rates of divorce. Another study that looked into marriages of parents of children with disabilities reported that couples raising children with disabilities are at great risk of divorce and have poorer marital quality (Rodrigues & Patterson, 2007). Griffin (2000) in his study in Canada found that there was an 80% divorce rate among parents raising children with disabilities compared with a national divorce rate that was a little less than 50%. Other causes of divorce among parents according to Morrod (2004) include; feelings of low self-esteem, helplessness, resentment, excessive demand of time and financial burdens which increases the risk for marital breakdowns. Research in this area is marked with a long standing and almost pervasive belief that the birth of a child with a disability is a tragedy entailing lifelong hardships for families (Singhi, 2004).

Although much has been written suggesting that stress, grief and other factors lead to marital discord, dissatisfaction and divorce among parents of children with disabilities, this notion is poorly supported by research (Sobbey, 2004). In 2003, researchers asked parents of children

with disabilities how the condition of their children had affected their marriages. Out of 275 participants 44.1% reported that having a child with a disability strengthened their marriages, 34.9% felt the condition of their children neither weakened or strengthened their marriages and a smaller percentage of parents 6.8% had already divorced (St John, Pai, Belfer & Mullikeni, 2003). Stoneman and Gavidia-Payne (2006) in their study noted that the high divorce rates and failure to adjust among parents of children with disabilities was due to a discrepancy in methodology and operational definitions. They suggested that further research must be done to establish why a minority of families do poorly while the majority of families function well.

It is therefore safe to say that research reporting on marital dysfunction and divorce among parents of children with disabilities has produced inadequate evidence to conclude that childhood disability is associated with any reliable increase in marital problems.

2.9.6 Challenges with implementation of policies

A policy is a principle or rule to guide decisions in trying to achieve rational outcomes (John & Menizabal, 2009). Policy implementation is a stage of policy making which lies between the stage of policy making and the consequence of the policy for the people whom it affects (Hunter & Marks, 2002). Implementation involves translating the goals and objectives of a policy into an operating, on-going program. However, it has been observed that policy implementation is one of the major problems confronting developing nations (Makinde, 2005). Implementation problems occur when the desired results on the target beneficiaries are not achieved and this normally happens when critical factors crucial to implementation are missing (Cameron & Tveit, 2011). Critical factors may include communication, dispositions, attitudes and bureaucratic structures.

Faleya (1999) pointed out that these factors could arise from the policy itself, policy makers or the environment in which the policy has been made. In most instances where policies are made in a top-bottom manner without including the views of the target group, policies fail to meet their goals (Khosa, 2003). Similarly policy makers fail to take into consideration the social, political, economic and administrative variables when formulating policies. In developing nations, serious implementation problems are those of bribery and corruption (UNPD, 2007).

Zambia has ratified International Labor Organization (ILO) convention act no. 159 regarding persons with disability. In 1996, Zambia adopted the disability act prohibiting discrimination on the grounds of disability and created a state of agency to look into disability issues. The amended constitution included article 112 (f) which state that the state shall endeavor to provide persons with disability social benefits and amenities which are suitable to the needs of persons with disabilities and are just and equitable. Disability Act Article 19 also states that assistive devices and reasonable accommodation shall be provided to every person with any restriction resulting from impairments or inability to perform any activity in a manner or within the range considered normal for a human being. The objectives of the national policy on disability are to promote awareness of disability issues, to facilitate the provision of rehabilitation and other services to people with disabilities, to promote equal rights and opportunities for and to eliminate all forms of discrimination against people with disabilities and to create an enabling environment for the full participation of people with disabilities. The national policy on education recognizes the right to education for each individual regardless of personal circumstances or capacity. The policy contains a section on special needs education, which states: *“The Ministry of Education will ensure equality of educational opportunity for children with disabilities and special needs”*. The policy aims to

include children with disabilities in the mainstream education system. The Ministry of Community Development and Social Services (MCDSS) has the overall responsibility for disability issues. It is responsible for alleviating the suffering of poor and disadvantaged groups, including women, children, youth and people with disabilities, through facilitation and provision of survival community development skills and direct social support.

A report by the Zambia Federation of Disability (ZAFOD) (2006), read that the Persons with Disabilities Act (1996) has not been enforced and its violations are rarely recognized mainly due to ignorance, among the various stakeholders, of what it entails. The same is said about the provisions on disability in the general policy documents. Flem and Keller (2001) reported that policies for children with disabilities were not implemented. Mothers of children with disabilities in their studies reported a lack of support by government as they lacked in many areas especially in care giving. Many more studies have found that most countries both in developed and developing nations had good policies regarding childhood disability, but they are not implemented (Camerot & Tveit, 2011; Solli, 2008; Flem & Keller, 2001).

In a study by the Inter Network for Education Emercienced (INEE) (2005) which reviewed policies regarding education of children with disabilities reported that the policies were inadequate and were poorly implemented. Camerot and Tveit (2011) had similar findings and added that policies that guided the implementation of school inclusion were not being effected.

2.9.7 Challenges with diagnosis of the condition of CP

The diagnosis of the condition of CP on children is a complex issue. Sankar and Mundkur (2005) in their study found that the diagnosis of CP takes time as there are no tests in neonates that confirms or rules out the condition. In severe cases, the child may be diagnosed soon after birth, but for the majority diagnosis can be made in the first 2 years of a child's

life. Another study has shown that for children with milder symptoms, a diagnosis cannot be made until the brain is fully developed at 3-5 years of age (Bax et al, 2005). However, issues pertaining to misdiagnosed, delayed diagnosis and wrong diagnosis may occur. Misdiagnosing any condition can be harmful to a child and can lead to inappropriate treatment such as unnecessary medications, surgery and expenses and this can be difficult to parents who already know there is something different about their child (Tattersal & Young, 2006). According to Seltezer (2001), a wrong, delayed or misdiagnosis of CP will cause severe symptoms of spasticity, abnormal postures contractures and deformities.

In a study by Huang, Kellett and St John (2010), mothers of children with CP felt hopeless when physicians disclosed their children's diagnosis and prognosis as very severe, without giving any positive information. Some researchers pointed out that disclosure without positive information leads to dissatisfaction with a physician's insensitive attitude, caring and support (George et al. 2007).

Literature has shown that in most cases CP is misdiagnosed (Dagenais et al. 2006, Graungaard & Skov 2006). These findings are echoed in studies on the experiences of mothers with disabled children that found that mothers were dissatisfied with the diagnosing process of their children (Tattersall & Young 2006; Rannard et al. 2005). According to Graungaard and Skov (2006), a delayed or wrong diagnosis makes mothers hopeless and in most cases they start pushing health professionals for a diagnosis which they expect in time. Because of the delayed diagnosis, mothers end up mistrusting healthcare professionals and accuse them of failing to confirm their suspicions and concerns. The mothers also fail to trust the treatments administered on their children (Fitzpatrick et al, 2007). Research has found that a delay in effective diagnosis not only increases mothers' mistrust and dissatisfaction with physicians' knowledge and skills, but fuels their hopelessness about receiving a better

prognosis (Graungaard & Skov 2006). These findings echo previous research relating to a loss of trust in healthcare professionals and the resulting loss of hope for future treatment and possibilities for children with CP (Rannard et al, 2005)

In a study it was reported that mothers are relieved when they receive a diagnosis. Their hopes are raised and knowing they could begin treatment for their children gives them satisfaction (George et al. 2007). Graungaard and Skov (2006) however argued that knowing a diagnosis creates new images rather than certainty and creates fears among mothers of children with CP.

2.10 Summary

In light of the literature reviewed, it is evident that mothers of children with CP experience many challenges associated with raising their children with CP. On discovering the diagnosis of CP on their children, mothers react in different ways and go through many emotional stages which include shock and disbelief, anger, bargaining, sadness and denial. These emotional stages disappear with time as they accept the conditions of their children, but mothers face many other challenges including psychological, physical health, socio-economic and environmental, marital, policy misdiagnosis and safety challenges. The psychological challenges which include depression, stress and anxiety are as a result of the characteristics of the child with CP, lack of support structures and the caregiver strain. The physical health challenges experienced by the mothers emanate from activities such as lifting, bending, pushing during bathing, feeding, carrying and ambulation. Elevated levels of stress hormones also lead to physical health problems suffered by the mothers. The lack of employment opportunities, poor educational backgrounds and people to help look after their children with CP whilst the mothers work, lead to the socio-economic challenges experienced by the mothers of children with CP. Mothers equally face environmental challenges in form of

social problems such as social isolation and lack of social support structures. Mothers also face negative attitudes from families, friends and the community at large. Architectural features in the built environment that limits mobility of their children with CP lead to physical environmental challenges experienced by the mothers. Marital problems arise from conflicts between parents who may be stressed and vent anger on each other. Sometimes it is a lack of implementation of policies regarding childhood disabilities that are challenging to the mothers. The diagnosis of the condition of CP becomes an issue at times as it results in misdiagnosis or delayed diagnosis becoming an issue to the mothers.



CHAPTER THREE

METHODOLOGY

3 Introduction

This chapter describes the methodology used in this study. Qualitative design was employed to explore the challenges experienced by mothers of children with CP in Ndola, Zambia. The research setting, the study design, the sampling method, inclusion and exclusion criteria, methods of data collection and analysis are presented in this chapter. Finally the chapter ends with an outline of the ethical considerations as applied to the current study.

3.1 Research Setting

The study was conducted in Mushili and Twapia townships of Ndola district. The district is one of the ten districts on the Copper Belt that has a population of 37,299 from 6312 households; of these 2.2% are persons with disabilities and among these are children with cerebral palsy (Loeb, 2008). Due to the closure of companies in Ndola, there is a very high unemployment rate (60%) and people live in abject poverty. Although most of the houses in Ndola town have electricity, more than half of the houses in Mushili and Twapia are old, small, very close to each other and are dilapidated. There is no water supply in most households and there is poor sanitation as most people in the areas use pit latrines for their toilets which are very close to their houses (Central Statistics Office, 2002). Both rehabilitation centres are accessible, but the road leading to Twapia rehabilitation centre was impassable as the researcher could not drive through due to potholes, drenches and uneven surfaces accentuated by stagnation of rain water, the researcher had to walk 2km from the main road to get to the rehabilitation centre in Twapia.

The Catholic Diocese of Ndola has six (6) rehabilitation catchment area of which Ndola district is one of them with four community based rehabilitation centres (CBR). These centres

provide rehabilitation services to the public. The program receives its clientele through referrals from 18 primary health care centres (PHCC), the hospitals and rehabilitation workers from the community. Initially, the researcher had applied to conduct the research in three of the rehabilitation centres (Chifubu, Mushili and Twapia), but was informed by the CBR coordinator that there were no longer children with cerebral palsy in the Chifubu rehabilitation centre as it was currently housing only adults with severe physical disabilities. Therefore only the two settings (Twapia and Mushili) were used in the research. The researcher used the two settings for easy identification of participants as mothers of children with CP accessed services from the said centres. The two centres are located in different townships, but provided convenient venues to meet mothers of children with cerebral palsy needed for the study sample. The centres are managed by trained paramedical personnel such as Clinical Officers (COs), nurses and health assistants. Mushili rehabilitation centre has three COs and 20 nurses, two COs and 13 nurses for Twapia rehabilitation centre. Mushili rehabilitation centre sees about a 100 new cerebral palsy cases in a year and Mushili sees only about 60 new cases of cerebral palsy per year (Personal communication with the Physiotherapists in the two centres).

The CBR program is monitored by a coordinator at a provincial level, however every centre is run by specialized personnel who are assisted by volunteers. Other services that are provided at rehabilitation centers include physiotherapy, day care, special education, pre-vocational training and home-based care programs.

3.2 Research Design

This study used a qualitative research design. Qualitative research involves the gathering of data that reflect experiences, focusing on perceptions and opinions of individuals taking part in the research or as observed on the scene (Todres & Holloway, 2004). According to McMillan and Schumacher (2001) qualitative research takes place in natural settings employing a combination of observations, interviews and document reviews. While there are several research strategies, the researcher used the qualitative approach because the approach aims to describe rather than explain, it seeks to bring out the experiences and perceptions from an individual's own perspective and therefore challenging structural or normative assumptions enabling it to be used as a basis for theory. It also allows to inform, support or challenge policy and action as alluded to by Denzin and Lincoln (2000). The use of qualitative research is advocated when the researcher seeks to understand meanings people attach to actions, decisions, beliefs and values. According to Babbie and Mouton (2007), experiences of daily living are a series of common sense constructs that individuals have preselected and pre-interpreted.

The researcher chose to use the qualitative research method as it was an appropriate method to use in achieving the aim and objective of the study which was to explore the challenges experienced by mothers of children with CP. Qualitative research allows greater spontaneity and adaptation of the interaction between the researcher and the study participants asking "open-ended" questions which have an ability to evoke responses that are meaningful and culturally salient to the participant, unanticipated by the researcher and are rich and explanatory in nature. Also participants have the opportunity to respond more elaborately and in greater detail than is typically the case with quantitative methods as indicated by Mouton (2001).

The strength of qualitative research is its ability to provide complex textual descriptions of how people experience a given research issue. It provides information about the “human” side of an issue and these often include behaviours, beliefs, opinions, emotions, and relationships of individuals (Bless & Higson-Smith, 2000).

3.3 Population and Sampling

3.3.1 Study population

The target population has been described as a group of persons, organisations or communities at which an intervention is directed (Fouche, De Jager & Crafford, 2004). The target population for this study were all mothers of children with CP who responded to the call, were either receiving services from the two rehabilitation centres or not and were residents in Ndola township of Zambia.

3.3.2 Sampling Frame

The administrators and physiotherapist contacted the mothers that they had in their records telephonically to inform them about the study. These mothers were then asked to inform other mothers whom they knew had a child with CP about the study. The sampling frame for the study consisted all mothers of children with CP who responded to the call to participate in the study. All in all forty (40) mothers of children with CP responded to the call, However, purposive sampling was used to group participants according to preselected criteria relevant to the research question (Babbie & Mouton, 2007). Babbie and Mouton (2007) defines purposive sampling as one where the researcher targets a group with certain characteristics representative of the population on key variables. The variables used in selecting the mothers included age, educational level, employment and marital status and the age of the child.

These variables were considered as they would influence the challenges experienced by the mothers when they cared for their children with CP (Wanburg, Welsh & Hezlet, 2003).

3.3.3 Sample

Following purposive sampling, twenty (20) mothers of children with CP were selected. Among the selected mothers were married, unmarried, employed, unemployed and mothers of different ages ranging from 18 to 50 years of age. The ages of the children ranged between 8 months and 14 years of age. Apart from the mothers that were either married or unmarried, the other mothers were selected irrespective of their marital or employment status. Twenty (20) mothers of children with CP were included in the sample all together. The mothers were categorized into subgroups and the researcher interviewed mothers from each subgroups. Once a mother from each group was interviewed the process was repeated. Sixteen mothers were interviewed before theoretical saturation was reached. By the thirteenth interview, there was no new data emerging from the participants, but the researcher had to interview three more mothers to ensure that theoretical saturation was reached. Extensive review of literature regarding challenges experienced by mothers of children with CP and repetition of challenges as perceived by participants made the researcher decide to stop the interviews after the sixteenth mother was interviewed. According to Charmaz (2006), theoretical saturation is reached when new data no longer bring additional insight to the research question.

Inclusion Criteria

The sample included mothers of children with cerebral palsy who reside in Ndola town of Zambia. These included mothers who were able to communicate in either the “Bemba”, “Nyanja” or “English” languages and are the birth mothers of their children with cerebral palsy.

Exclusion Criteria

The study excluded all mothers of children with any other disabilities other than cerebral palsy and all persons that were not birth mothers of the children with cerebral palsy. Mothers from other regions rather than Ndola town were also excluded.

3.4 Data Collection

3.4.1 Interviews

The qualitative data collection was conducted using face-to-face semi structured interviews. Lindlof and Taylor (2002) describes semi-structured interviews as a conversation with a purpose. In these interviews, the researcher knows the topics to be covered in the interviews, but allows the participants to tell the experience in their own ways even if they drift from the topic, the researcher then uses prompts to bring them back to the subject under discussion (Kvale & Brinkman, 2008). The researcher used an interview guide (Appendix J) which was designed after an extensive review of literature regarding challenges experienced by mothers of children with CP. A move supported by Morris et al (2007). The interview guide contained questions that defined the areas to be covered consisting of open ended questions which were thought of well in advance as stated in the above paragraph. Lindlof and Taylor (2002) supports the use of interview guides prepared with informal grouping of topics and questions that the interviewer can ask in different ways for different participants. The researcher asked a general question to all the participating mothers even though not part of the objectives. The question was *“How did you feel when you were told that your child had CP?”* It was relevant to ask this question as the researcher wanted to know from the mothers’ perspectives what having a child with CP entailed thereby allowing the mothers to open up and telling the

challenges faced. The participating mothers were allowed to speak in their own way in a language they were comfortable with (English, Bemba or Nyanja).

3.4.2 Procedure

With permission obtained from all relevant committees, the researcher met with the CBR Coordinator at the Catholic Diocese of Ndola in Zambia, who wrote introductory letters and made personal calls telephonically to the administrators of the two rehabilitation centers. The researcher met with the administrators where the purpose of the research was explained. The Centre administrators with the help of the physiotherapists of the two rehabilitation centres called the mothers of children with cerebral palsy telephonically for a meeting in one rehabilitation centre. Over a hundred caregivers of children with CP attended the meetings. The researcher explained the aim and purpose of the research and clarified that only birth mothers of children with CP and resided in Ndola were eligible to participate in the study. Forty birth mothers came forward and were willing to participate in the study, however using stratified purposive sampling as reiterated in 3.4.2; twenty (20) mothers from both centres who met the sampling criteria were selected (12 from Mushili and 8 from Twapia). The researcher explained to all the other caregivers and mothers why only a few participants were selected and assured them that the few that were selected were representative of all the mothers of children with CP in Ndola. Before dismissing the other caregivers and mothers, Lunch and transport (Bus fares) was provided to all the mothers that attended the meeting. Information sheets and consent forms were issued to the remaining 20 mothers. Appointments and actual interview dates were made for all the selected mothers. At least four (4) mothers were interviewed on alternate days in each rehabilitation centre. The interviews were done in Nyanja , Bemba or English languages depending on which one the participants were comfortable with. Each interview lasted between 45 minutes to an hour and were audio

recorded. After each interview, the audio recorder was played back to the participants so as to confirm or make any necessary adjustments to clarify what was said and any new ideas that may have developed. The tape play back and participants' listening also served as member checking (Eisner 1991). Any changes that arose were written in the note book together with field notes and later incorporated into the transcripts. The researcher made a summary of the transcribed data with themes and sub-themes. The researcher also gave explanations for the interpretations and early conclusions made. These were presented to the first four participating mothers and they were in agreement that the items were reflective of the interviews. Transport and lunch was once again provided to the participating mothers.

3.4.3 Trustworthiness

According to Guba and Lincoln (1985), trustworthiness is the only way to establish the truth value in a naturalistic, applicable and consistent manner in qualitative research. To ensure trustworthiness in the present study, credibility, transferability, dependability and confirmability and triangulation were done. Below is a description of how trustworthiness in this study was achieved.

Credibility: This asks the question as to how congruent the findings are with reality (Guba & Lincoln, 2004). In this study this was achieved through extensive review of literature regarding challenges experienced to establish the extent to which the findings correlate with past studies. Member checking as described in 3.5.2 was equally done and verification of the researcher's theories and inferences was done by the participants (Also described in 3.4.2). Peer debriefing was done by engaging colleagues (physiotherapists) that understand the study, but were outside the study who questioned the working hypothesis of the study at different stages. This process brought fresh perspectives and challenged the researcher whose closeness to the project was detachable. The researcher also had frequent debriefing with the

local supervisor and the supervisor at the university. Finally to ensure honesty among participants', tactics such as asking them to participate in the study only at free will without being constrained in any way and allowing them to feel free to withdraw at any point of the interview ensured that the participants were willing to participate and provide genuine information freely (Eisner, 1991).

Transferability: This has been described as the extent to which the findings of the research can be applied to other contexts or with other respondents (Babbie & Mouton, 2007). This was achieved through thick descriptions of the data with sufficient detail and precision that would enable other readers to pass judgment and to consider applicability to other settings. Stratified sampling was also used which maximizes the range of information by having informants with different characteristics. By so doing, findings of the study can be used in other contexts or on other respondents in similar positions, but are not part of the study population (Patton, 2002).

Dependability: This seeks to inform on the reliability of the gathered data. If the inquiry was to be repeated with the same respondents, would the responses be the same? (Babbie and Mouton, 2007). This was achieved by clearly outlining the processes used in the study. The research design and how it was implemented, methods of data collection and through evaluation of the effectiveness of the inquiry undertaken were done. Evaluation was done through an advisor at the University of Western Cape who examined the data, findings and interpretations that attest the coherence between the findings and the data collected through code, recording of the sessions-data auditing (Guba and Lincoln, 2004).

Confirmability: According to Babbie & Mouton (2007), confirmability refers to the degree to which the findings are the product of the inquiry and not the researcher's biases. The

researcher ensured that the findings are products of the focus of the study and not the biases of the researcher. This determines if the conclusion, interpretations and recommendations can be traced to their sources and are supported by the study. This was done by reviewing the raw data (audio recorder, field notes, documents and survey results), the data analysis criteria and through triangulation (Baumgartner, Strong & Hensley, 2002).

Triangulation: Bogdan (2006) described triangulation as a useful technique that facilitates validation of data through cross verification from at least more than two sources. Following data collection, the researcher using thematic analysis, analyzed the data collected into themes. The researcher gave the transcripts to a colleague who equally analyzed the data and came up with his own themes. The researcher and the colleague met to discuss the themes and realized that we both had the same themes.

3.5 Data Analysis

Data analysis began with verbatim transcriptions immediately after all the interviews. The researcher sat in a quiet place to listen to the voice recordings and transcribed word for word in the language the participant said it (Bemba/English). This allowed the researcher to detect and recognize recurrent ideas and patterns. After transcribing in Bemba, the researcher gave the audio recordings to a professional translator. The professional translator translated the Bemba transcripts to English and another independent translator read the English transcripts and translated them back to Bemba and compared them to the original Bemba transcripts to ensure accuracy (Gibbs, 2007). There were no major differences between the two Bemba transcripts.

The data was organized by putting together the field notes and the transcribed data in form of a dialogue with the participants labeled by number codes (e.g. M1, M2... M16). This was

done in order to maintain anonymity of the participants. After all the transcriptions and translations were completed, the researcher explored the transcripts carefully by reading them several times to get a general sense of the information and to reflect on the overall meaning of the participants' words and to understand the contents as an experience a move supported by Cresswell (2009). The data was coded by inserting a code or label into the margins of the transcripts. This was done by analyzing key words in contexts, word repetitions, indigenous terms and through careful reading of larger blocks of texts as advocated for by Patton (1990). Strauss (1992) reported that words that occur repeatedly are seen as being salient in the minds of respondents henceforth by reading through the long stretches of the data, it is easy to identify how people circle through the same data. The themes were identified by sorting the codes into similar meanings. This was done by cutting the similar codes and pasting them into one file ensuring that the quotes maintained the context in which they occurred and labeling their source. The data was then sorted into the pre-determined themes as indicated in section 1.6. The familiarity and differences of the themes were compared using the constant comparative method described by Charmaz (2006). Themes that did not fit into any of the pre-determined categories stood on their own as emerging themes. Local terms that sounded familiar within themes were categorized into sub-themes (Patton, 1990). A physiotherapist colleague with a second degree in clinical psychology assisted in the analysis of psychological challenges of the mothers. Finally the data was interpreted by identifying the core meaning of the data remaining faithful to the responses of the participants but presented with a wider social and theoretical relevance (Kohlbacher, 2005). Discussions with three colleagues and peers, helped to critique and review the process of coding, categorizing and arranging of the data into appropriate themes. This is supported by Guba and Lincoln (2004).

3.6 Ethical consideration

Ethical clearance from the University of the Western Cape Ethics Committee was granted. Permission from the Ministry of Health (MoH) in Zambia, the Tropical Diseases Research Centre's Scientific and Ethical Committee (TDRC-SEC) and the Catholic Diocese to conduct the research at the different rehabilitation centers under the CBR program in Ndola was sought. The mothers of children with cerebral palsy were met at the two rehabilitation centers upon being called by the administrators of the two centers. The study was explained clearly to the mothers. Information sheets and consent forms were supplied to the mothers. Married mothers were encouraged to seek permission from their spouses before signing the consent forms. It was explained to the mothers that participation was clearly on voluntary basis. Permission to use an audio recorder was also sought from the mothers. The mothers were assured that the study would not harm them in any way (physically, psychologically and morally) as anonymity and confidentiality were observed. Participating mothers had a clear understanding of the study and were not pushed into supplying information. Mothers were also informed that they have a right to withdraw at any point of the study without bearing any consequences. Referral structures such as physiotherapists and counselors were in place to handle participants whose physical and emotional wounds would be triggered. The results of the study will be made available to participating mothers as well as to the relevant authorities and institutions. The voice recorder containing the data has been locked away ensuring that only the researcher has access to them. The consent forms and information sheets were translated to a language that was understood by the participating mothers which were Ichi-Bemba or Nyanja.

CHAPTER FOUR

RESULTS

4 Introduction

The demographic data of the participating mothers and their children is presented in table (4.1) and a brief summary of the data is followed thereafter. The relationship between the demographic characteristics of the participants and the challenges experienced are outlined in section 4.3. The data was analyzed thematically into pre-determined themes. Other themes emerged from the transcripts and they have also been enlisted:

- i. Emotional challenges
- ii. Physical health challenges
- iii. Socio-economic challenges
- iv. Environmental challenges
- v. Marital challenges
- vi. Challenges with implementation of policies regarding children with CP
- vii. Challenges with diagnosis of the condition of CP and



These themes sought to answer the aim and objective of the study which was to explore challenges experienced by mothers of children with CP in Ndola, Zambia. The themes and sub-themes are presented in a table in the appendix section (Appendix K).

The quotes are presented verbatim in a narrative writing style. The participants' responses are quoted (“”) and presented in *italics*. The precise meaning and phrases used by the participating mothers are by all means preserved. However, for smooth flow of information and clarity, slight grammatical changes owing to translations have been made. Some information not related to specific quotes provided have been omitted and replaced with three ellipsis points (...). Anonymity and confidentiality was observed for ethical reasons, therefore transcribed quotation of the data from the interviews will be presented using codes (e.g. M1, M2..., M16).

TABLE 4.1**Demographic data for participants and their children with CP**

Participant Code	Age of Participant	Marital Status	Level of Education	Status of Employment	Age of Child (Yrs)	Sex of Child	Type of CP	Child Scholastic	Other Siblings
M1	42	Married	Tertiary	Employed	7	M	Spastic diplegia	Nil	2
M2	37	Divorced	Primary	Unemployed	8	F	Spastic quadriplegia	Nil	1
M3	33	Married	Tertiary	Self Employed	3	F	Diplegia	Nil	None
M4	37	Married	None	Unemployed	4	M	Spastic diplegia	Nil	1
M5	21	Single	Secondary	Self Employed	2	F	Athetoid	Nil	None
M6	50	Married	None	Unemployed	17	M	Triplegia	Nil	1
M7	25	Single	Primary	Unemployed	11 months	M	Spastic diplegia	Nil	None
M8	35	Divorced	None	Unemployed	13	M	Spastic Quadriplegia	Nil	2
M9	18	Married	Secondary	Unemployed	2	F	Diplegia	Nil	None
M10	38	Widow	None	Self Employed	6	F	Hemiplegia	Nil	None
M11	42	Divorced	Primary	Employed	7	F	Ataxia	Nil	None
M12	22	Single	Secondary	Unemployed	5	F	Spastic diplegia	Nil	1
M13	27	Married	None	Unemployed	7	M	Athetoid	Nil	2
M14	43	Married	None	Unemployed	10	M	Spastic quadriplegia	Nil	4
M15	31	Divorced	Secondary	Unemployed	3	F	Spastic diplegia	Nil	1
M16	39	Married	None	Unemployed	14	M	Quadriplegia	Nil	3

4.1 Summary of Demographic Data of Participants

The sample size for this study was n=16 which comprised mothers of children with cerebral palsy. The mothers' ages ranged between 18 and 50 years of age. The ages of the children ranged between 11 months and 17 years with different types of CP. The mothers' level of education, marital and employment status are indicated in table 4.1.

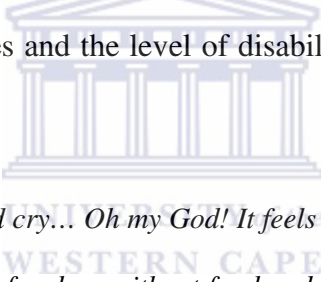
4.2 Emotional challenges

Nearly all the mothers in this study had experienced some emotional challenges as a result of having children with CP. These challenges included depression (31.25%), stress (56.25%) and anxiety (12.5%). This was due to many factors as described under the sub-themes.

4.2.1 Perceived depressive Symptoms

Less than half of the mothers in this study may have been suffering from depression. Symptoms such as feelings of loneliness, sorrow, regret, loss of appetite, self pity, insomnia, devastation and feeling suicidal suggested that the mothers could have been suffering from depression.

One of the mother's perceived depression was due to loss of appetite, living an isolated life, attitudes of her husband's relatives and the level of disability of her child with CP as shown in the quote below.



“... I lock myself indoors and cry... Oh my God! It feels so bad. My husband's relatives laugh at me, so I cry. At times I go for days without food and I have chosen not to visit or socialize with them... It is a huge burden to have a child with CP as their lives revolve around where the child is sitting, they have to be fed, washed, they mess themselves and my child cannot talk at all. It is stressful”. M13

Another mothers' source of perceived depressive symptoms included feelings of loneliness, self pity, hopelessness and feelings of committing suicide. This is illustrated in the quote below.

“...I feel very lonely and I pity myself. When my husband left me because of the child, I was hopeless. Life became meaningless; it was not worth living...” M2

The researcher found that one of the participating mothers had a permanent and reoccurring experience of pervasive sadness and loss which may have led her to suffer from depression.

“...I can’t shake this sorrow off. I cry a lot especially when I pass through hard times. My sisters in-law really laugh at me, they say ‘even if I take this child for physiotherapy, the child will not get better’. It hurts so I cry”. “...Another thing that bothers me is that I am educated. I have finished my grade 12. I really want to do something about my life, find a job or go to college. I would like my child to walk fast as I need to do something about my life”. M9

4.2.2 Perceived stress

More than half of the participating mothers (56.25%) had perceived stress symptoms. The symptoms described included persistent worry, constant headaches, perceiving their situation to be extremely difficult and having a burdensome feeling.

One of the mothers’ perceived stress was the unemployment situation of her and her spouse, failure to afford basic needs of life, assistive devices and transportation for the child to and from rehabilitation centres. This is demonstrated below.

“I am extremely worried as my husband and I do not work. We cannot afford most of the things for our child; clothes, assistive devices, nutritious food and transportation to and from physiotherapy. It is better to suffer alone, not with a child like this”. M14

For one of the mother, her perceived stress was due to the care giving roles which she thought were difficult for her especially that there was a lack of communication between her and her child with CP. Depending on her other daughter for survival made her feel like a burden.

“...The fact that I cannot do anything else apart from looking after this child is stressful in every way. The work of taking care of him especially that he does not talk makes the work

more complicated... I am happy that my daughter supports us financially, but I feel like I put too much pressure on her, it stresses me..." M16

Another one of the mothers' stress levels were so high she fell sick and had to be admitted at the hospital.

"I was admitted at once at Ndola Central Hospital for symptoms of stress. My husband's relatives did not accept my child. They said a lot of bad things that were slowly eating me up. I developed this constant headache, I went to the hospital and they said I had symptoms of stress..." M10

4.2.3 Perceived anxiety

Only 2 of the mothers (12.5%) may have been suffering from anxiety disorders. This was because they were afraid of the reactions of others towards their children with CP, they were afraid of the future of their children and they dreaded the unknown. The mothers panicked about many things and the condition of their children overwhelmed them.

One of the employed mothers with a tertiary education was afraid of many things including the young age of the care giver for her child with CP who was only 13 years old and may not be able to cope if the child had a seizure. She was also afraid of losing her job as it was their only means for survival. This is what she said:

"I have this constant fear that does not go away... I am afraid of many things. Firstly because the girl that looks after my child is very young, she is 13years old and my child with CP is 9. My child suffers from fit... I am afraid as she does not know what to do in most cases... The fits and the fear give me sleepless nights... I am constantly tired it is beginning to affect my work. I want to stop working, but I am afraid of how we will survive... Secondly I am afraid of what people say about my child". M11

A 35 years old mother suffered from perceived anxiety attacks as she worried about what would happen to her child with CP should she die. This was because her health was not okay and the only other person that has accepted her child is her old and ailing grandmother.

“...I suffer from panic attacks and anxiety disorders. I fear what will happen to my child when I die considering I am not well and my grandmother, the only one that has fully accepted my child is ailing and old. I worry about too many things and the fact that it is not every day we afford a meal bothers me...” M8

Another 50 years old mother lives in constant fear as people in her community are violent towards her children with CP and mainly because they think she is a witch.

“I live in fear. People stone my children saying ‘there goes mad people. When I let this one with CP go out to play, young people beat him up... People accuse me of practicing witchcraft...” M6

4.3 Physical Health Challenges

The task of taking care of the children with functional limitations who need assistance with ADLs leaves mothers with musculoskeletal and physiological problems. The mothers complained of symptoms such as chest pains, neck pain, back pain, headaches and hypertensive symptoms. Approximately 70% of the mothers were suffering from musculoskeletal problems, 25% had physiological problems and only one mother reported not to suffer from either physiological or musculoskeletal disorders.

4.3.1 Musculoskeletal Disorders

Among the mothers who were experiencing musculoskeletal disorders, activities such as lifting, carrying, transferring and pushing of their children with CP which are repeated

several times a day subject the musculoskeletal structures of the mothers into stress causing injury.

A 43 year old mother was suffering from shoulder chest and neck pains as she does everything for her 7 years old child with spastic quadriplegia including carrying him on her back and walking long distances. This is shown in the statement below.

“The child has problems with feeding, he cannot sit on his own and he cannot crawl. His muscles are very stiff and at 10 years he still soils his nappies. I do everything for him, bathing, feeding, lifting, clothing him, everything! He is very heavy as you can see, I am very tired lifting him, I always carry him on my back when going to church, it is not easy, I always have shoulder, chest and neck pain...” M14

Some musculoskeletal pain experienced by a 27 year old mother are as a result of walking very long distances on foot to and from the rehabilitation centre nearly every day carrying her 7 years old child on her back. Her constant assistance in activities of daily living for her child, leaves her with aches and pains.

“... He cannot walk, you have to lift him all the time to go to the toilet, to bath and for every activity... I walk a very long distance to and from the rehabilitation centre on foot carrying him on my back. My I have generalized aches and pains all the time.” M13

A single 22 year old mother reported having back pains and feeling restless after constantly lifting her 5 year old child with spastic diplegia who is only beginning to shuffle, but cannot sit or communicate.

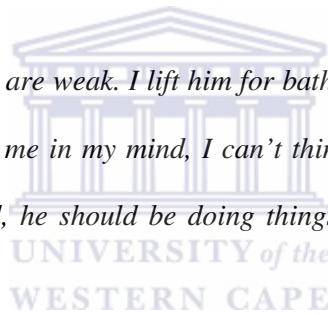
“...She does not talk, she cannot even sit, her leg muscles are very stiff, she is starting to shuffle herself around but I still have to do everything for her. I lift her a lot. It gives me a lot of back pains. My body is so tired, it needs to rest”. M12

4.3.2 Physiological Disorders

About 25% of the mothers were suffering from physiological disorders that result from elevated stress hormones stimulating further physiological activities that might have led to negative health outcomes.

A 35 year old divorced mother was very affected by the condition of her 13 years child such that she struggles to make decisions as she does not think straight and from time to time she suffers from amnesia. Atleast she does not perceive the condition of her child to be severe as the child can communicate and even feed himself though he has weak lower limbs, cannot walk on his own and depends on her mother for ADLs. The mothe expects the child to be independent given the age.

“...He cannot walk, his legs are weak. I lift him for bathing and to the toilet. At least he talks and feeds himself. It affects me in my mind, I can't think straight and I suffer from memory losses... He is 13 years old, he should be doing things for himself, but I have to do it for him...” M8



One 39 years old mother suffers from constant headaches as she struggles to divide attention between her 14 year old child who is incontinent with quadriplegia and her other younger children. Her roles as a mother and caregiver for her disabled child which includes cleaning after him when he soils his napkins were overwhelming and tiring causing the condition that she suffers. The statement below illustrates this.

“...The child has stiff muscles all over the body he cannot move. He does not sit or move. Everything is done for him. You have to feed him, wash him, lift him a lot and clean him after he soils his nappies. That is too much for me to handle considering I have other small kids now. I am constantly tired and have these headaches that don't go away”. M16

One of the mothers' physiological problems of fatigue was due to her lack of rest as her 4 year old spastic diplegic child struggles to sleep and cries a lot at night. The mother is always awake assisting her child especially in changing napkins. The mother is hypertensive and due to lack of rest, her blood pressure is constantly elevated.

"I am fatigued all the time, sleeping during the day does not even help. My BP is constantly raised due to lack of rest. The child is paralyzed from his waist going downwards. He cannot control his bowels. He is able to sit on his own, but he cannot crawl or walk. He has to be lifted for all activities. He cries a lot during the night and I cannot sleep... I only rest when my mother visits." M4

Only one (6.25%) of the mothers reported not suffering from any anatomical or physiological problems as her child was still very young and mimicked demands that are normal with a normal growing child. This is shown in the following quote.

"I have not experienced any physical problems as my child is only 11 months. He is just like a normal child. I think I will only worry when he starts getting bigger and he is not able to do things like standing or crawling."M7

4.4 Socio-economical challenges

Nearly all the participating mothers were experiencing socio-economic challenges. For some mothers it was due to their poor educational backgrounds, lack of employment opportunities for others and high poverty levels for some.

4.4.1 Education

The level of education of the mothers as indicated in the demographic data was as follows. Only two (12.5%) of the mothers had a tertiary education, four (25%) had a secondary education, three (18.75%) had only attained their primary education and the remaining seven (43.75%) had no form of education.

A 37 year old mother without any form of education blamed her lack of education to be the cause of her inability to get a good paying job and opted to stay at home to look after her child as jobs for people without education are generally low paying. This was making her struggle to raise her child with CP.

“The upbringing of my child has not been an easy one because I am not employed. Even if I found work, what sort of job would it be and how much could I get considering that I am not educated? I would rather stay at home and look after my child”.M4

Another 37 year old divorced mother blamed her parents for her low level of education which she believed was hindering her from looking for a job. She also felt like if she had a job, she would have bought the much needed assistive devices for her child with CP.

“...If it were not for my poor education, I would not be struggling to raise my child like this. I would have looked for a job and my child would be much better now... She is not okay as she does not have any of the assistive devices which I could have bought if I had a job... I blame my parents for not educating me”. M2

Another divorced mother blamed her low level of education to be attracting minimal income which was not sustaining her and her child. She could not even afford to pay for her child's CT scan when it was recommended some years back at a specially hospital. Four years down

the line, she has not managed to have the scan done but has continued with physiotherapy. This is shown in the quote below.

“Sustainability is not there. I earn so little working as a cleaner and office orderly. I could be earning much better if I had a trade.... I even explained to the health personnel 4 years ago who said the child needed to have a CT scan in Lusaka that I could not afford it. It costs K1.2 Million Kwacha. Where can I get such money from? We will just continue with physiotherapy”. M11

4.4.2 Employment

The demographic data shows that only two ((12.5%) were employed, three (18.75%) were self-employed and the rest of the mothers (68.75%) were not employed. The mothers that were employed reported that their salaries were not enough to sustain them and their children with CP and those who were self-employed reported that from time to time they ran out of business and the unemployed mothers reported to be suffering from financial hardships.

One of the unemployed mothers was eager to look for a job at the factories, but the condition of her child could not allow. She was hoping that the child could start walking so that she would be able to look for a job and be able to buy the recommended assistive devices which she has not been able to afford as her husband was also unemployed.

“At the moment I do not work, it is difficult as my husband does not work either. We could not even afford the chair that the physiotherapist suggested that we buy for the child... I was earnestly hoping that the child walks fast so I can go and look for a job at the factories. I am eager to look for employment”. M9

A 31 year old divorced mother was facing financial crises due to lack of employment. Her lack of finances had forced her to attend rehabilitation sessions only occasionally as she could not afford to. This is shown in the quote below.

“...I am not working. I stay at home to look after my child with CP. It is very expensive to care for a child with this condition. Due to financial crises, I cannot even afford to take this child for physiotherapy, so I just do it once in a while...” M15

Another unemployed mother stays at home to look after her child with CP reported not coping financially as the money the husband brings home is not sufficient. This she said was even worse in the rain season when her husband could not do any business, then she would struggle to transport her child to and from the rehabilitation centre. This is demonstrated below.

“I do not work; I stay at home to look after the child. My husband sells different commodities in a makeshift shop. We do not manage financially with the money he gets from the sales. We struggle especially during the rainy season when he cannot do any business... Transportation to and from rehabilitation is a huge burden as we do not afford. M9

4.4.3 Poverty

More than 50% of the mothers reported living in poverty as they could not afford the basic necessities of life such as food, clothing, sanitation, clean running water and even a roof on their heads.

One 50 year old mother reported surviving by selling vegetables in particular wild okra picked from the bushes. She did not manage to feed her family on a daily basis and had to buy food on credit at times just to feed her children and old husband.

“... It’s only God who knows. My husband doesn’t do anything, he is old and I go around selling wild vegetables picked from the bushes from door to door, by the end of the day whatever cash I have, I buy small quantities of maize meal and maybe eggs for the sick child who doesn’t walk. Sometimes I get food on credit and pay later even for charcoal. General living is not up to the standard, we struggle to find food, the roof in our house is leaking and we have no blankets and clothes. There is nothing right”. M6

Another 39 year old mother reported to be living in poverty as her husband disowned her child and did not offer any financial support. The mother would beg from house to house for food and used her other children’s old clothes for her child with quadriplegia.

“My husband disowned this child. He does not offer any financial support and never bought any clothes or special food for this child. It was difficult. I was using his other siblings’ old clothes and would beg from house to house for food”. M16

A 38 years old widow has been living in poverty since her business failed as she had no one to help look after her child with CP whilst she went about doing her business. Since stopping, she cannot afford anything including food for her child with CP as stated below.

“My husband died when the child was 10 months old. It was the most difficult time of my life; I had to move out of the house as I could not afford to pay the rent. I started a small restaurant at the main market, but it did not thrive as I had no one to look after my child whilst I ran the business. Since stopping, life has been difficulty. I struggle to get anything. My main worry is food especially for the sick child...” M10

4.5 Environmental challenges

Nearly all the mothers were experiencing some form of the social, attitudinal and physical environmental challenges due to having children with CP.

4.5.1 Social environmental challenges

The social environmental challenges experienced by the mothers were due to living in social isolation, lack of support from family and friends and lack of support from the community. Fifty percent of the mothers were living in social isolation, 31.25% of the mothers were lacking support from their families and friends and 18.75% of the mothers lacked community support.

A 31 year old divorced mother was living in isolation for fear of people not accepting the condition of her child. She was equally afraid that people will blame her for the condition of her child as stated below.

“...I have not had so much contact with my friends and neighbors as I stay indoors with my child most of the time. I am afraid of being laughed at or other people not accepting my child the way she is, it would hurt. I also don't want anyone to blame me for the condition”. M15

Another 22 year old single mother was living in isolation after losing her friends whom she believes have been bad mouthing her. Due to the child's behavior in public places, the mother has also decided not to have any social interaction except when her mother helps her to look after her child. This is shown in the quote below.

“...My friends laugh at me, in fact they are not even my friends anymore because they were telling everyone in the community that the baby is sick because of my promiscuous ways ‘She sobs’... He is a very difficult child, if I go with him to church, we spend the whole time outside so I have stopped going to church, not even town. Unless I'm in dire need then I ask my mother to help look after him...” M12

Another 25 year old mother does not receive any support from her mother who had re-married after the death of her father. The mother to the participant has isolated herself fearing

that her new family might not accept her if they knew she had a disabled grandchild. She could not even let her daughter with her disabled child to visit her as demonstrated in the quote.

“My mother re-married after the death of my father. She does not support me at all as she is afraid that her new husband and his relatives might not accept her if they knew I had a disabled child... We are not even allowed to visit her”.M7

4.5.2 Attitudinal environmental challenges

This study found that the mothers were experiencing negative attitudes from families and friends, from the community and from healthcare professionals. At least 37.5% of the mothers were experiencing negative attitudes from family and friends, 50% from the community and 12.5% received negative attitudes from healthcare professionals.

One of the married mothers was experiencing negative attitudes from her husband and his family who do not like her and blamed her for the condition of her child. They go to an extent of forcing her husband to leave her and marry someone else. As if that is not enough, her friends laugh at her and refer to her child as mentally challenged. This is shown in the quote below.

“...My husband’s family does not like me and the fact that I have a child with CP. They have been trying to force my husband to leave me and marry someone else...I struggle and the fact that my husband and his family accused me of being the cause of the condition it is difficult... My friends say all sorts of things and refer to my child as a mentally ill child and that my husband wants to leave me because of that, they are big snakes in the grass”. M4

A 38 year old widow trying to run her restaurant business experienced negative attitudes from the community who accused her of bewitching her child for her own gain. This is shown in the quote below.

“... They say I have bewitched my child to enrich myself... I used to take him before and people shunned my restaurant saying I was using my child with CP to pull customers to myself”. M10

One of the mothers who is employed but divorced experienced negative attitudes from healthcare professionals. This was after a misunderstanding with one of the nurses who urged her to report her (nurse) if she was not happy with the services. The nurse was nearly fired after she was reported, this made the other nurses to give her negative attitudes whenever she needed help.

“...the nurse I found on duty gave me a very bad attitude and said the only way she would help me was if my child had TB. I tried to reason with her, but she would not listen and told me to report her to the district health board if she wasn't happy with the services. Desperate for help, I reported her to the district board which did not turn out well as she was nearly fired. Equally this did not work well for me as now all the nurses started giving me negative attitudes”. M11

4.5.3 Physical environmental challenges

Nearly all the mothers were experiencing physical environmental challenges. More than 50% of the mothers experienced physical environmental challenges due to architectural features in the built environment which included narrow or no side walks, only stair cases in tall buildings, narrow doorways and lack of ramps. 43.75% of the mothers were experiencing poor geographical features in their environment which included terrains, slopes, curbs, hills and uneven surfaces which were all making mobility for their children with CP difficult.

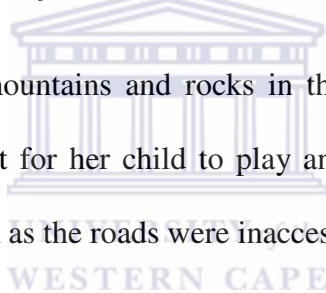
For one 42 year old employed mother, the architectural features in shops and other public buildings are restrictive as there are no ramps for wheelchairs and either the lifts in tall buildings do not work or the buildings do not have any.

“...When we go to town, it is a problem as most shops do not have ramps for wheelchairs. Hardly any of the lifts on the tall buildings work. That is the same at the big hospitals. The lifts don’t work most of the time...” M1

Another mother’s physical environmental challenge was due to lack of space in her 2 roomed house as there is nowhere for her child to play let alone use a wheelchair.

“...We stay in a very small 2 roomed house, there is no space in the house for the child to play, a wheel chair cannot even fit in the house... M9

Geographical features such as mountains and rocks in the environment of a 35 years old divorced mother made it difficult for her child to play and for transport to get to her area especially when the child fell sick as the roads were inaccessible.



“... The roads are inaccessible, it is difficult when she gets sick, my house is in a mountainous region with a lot of rocks. I am only renting a room. Taxis cannot get to this area... Because of the rocks, it is not safe for my child to play.” M8

4.6 Marital Problems

The study shows that some of the mothers were having conflicts with their spouses because of having a child with CP. Some of them were divorced as a result. This was mainly due to lack of acceptance of the child with CP especially by the male spouses, influence from relatives, poor spousal support and poor coping mechanisms. Of the 16 mothers, 3 were single, 3 were happily married, 4 were divorced and 6 were having conflicts with their spouses.

A 33 year old married mother reported to having conflicts with her husband as she could not agree with him when he wanted to keep the condition of the child a secret as he was embarrassed about it. This is what she said:

“... He was too embarrassed about the condition of the child and did not want others to know about it and sympathize with us. He wanted us to keep the condition of the child a secret, I could not. This put a strain on our relationship as we were always fighting...” M3

One husband of a 37 year old unemployed mother left her upon discovering the condition of their child. The mother has no idea where her husband is except for rumors that say he is married to someone else.

“... Since he discovered that the child had CP that is how he disappeared. I have not seen him since, I just hear from other people that he is now married to someone else...” M2

This is not different from the experiences of another mother 31 years old divorced mother whose husband equally left her upon discovering the child had CP. Her former husband's relatives do not assist her financially arguing that if the father of the child does not support his child why should they. This makes the mother think that her former husband's relatives have equally not accepted the child

“The father ran away upon discovering the child had CP... His relatives have not accepted the condition of the child because when I ask for financial support, they say ‘if the father is not responsible over the child, don't expect us to be’. It shows that they have not accepted the child”.M10

4.7 Lack of implementation of policies regarding children with CP in Zambia

All the participating mothers in this study reported that the government was not implementing policies regarding their children with CP. Policies regarding inclusion of

children with CP into mainstream education were not effected as there were no schools enrolling their children with CP, let alone teachers trained to handle such children. Most of the mothers failed to undertake specialized procedures recommended for their children as they could not afford them and the government did not assist them in any way. The government could not assist them with transport and assistive devices which they much needed and yet policies on disability states so. The government has equally done nothing to ensure safe environments for these children. None of the mothers were receiving disability grants and any other kind of financial assistance from the government.

One of the employed mothers of a 7 years old spastic diplegic child did not know what to do except wait on God as all her child wanted was to go to school after seeing his sisters go and come from school. There are currently no schools that enroll children with CP in Ndola, Zambia. The only school she could think of trying was Dagama School which is mainly a secondary school for the physically disabled which could not enroll him for his young age.

“... All that he wants is going to school as he sees his sisters go and come back. He’s been asking me when he will start going to school. He is 7 years and that has not been easy, we have no special schools here in Zambia where this child can be taken too. Last time I tried Dagama School just to be told he was too young, they could not accept him. I am only waiting for God to give me direction”. M1

A 31 year old divorced mother reported her disappointment with the government. She blamed her suffering and inability to purchase assistive devices on the government whom she thought should have been there to help them. Below is what she said:

“If the government cared, we would not be suffering the way we do. I have failed to purchase any of the assistive devices I was advised to buy. I don’t even have enough money to take my child for physiotherapy. Do policies exist?”M15

Another 42 year old divorced, but employed mother wished CP Africa could extend its help to mothers of children with CP in Ndola as it did with mothers in Lusaka. The mother reported struggling with transportation and wished for the government to assist them with transport. She also wished children with CP to be included in the feeding program by a non-governmental organization.

“In Lusaka, mothers are transported to and from the rehabilitation centers under the sponsorship of CP Africa, if there is no transport, the mothers are reimbursed with their bus fares. Why can’t they extend the same help to us or the government should at least provide transport for us. We struggle a lot where transport is concerned... There is an organization that feeds children with HIV/AIDS. I wish our children could be included in that program...”M11

4.8 Challenges with diagnosis of the condition of CP

The mothers in this study reported that they got a wrong diagnosis or a delayed diagnosis or the right diagnosis. About 37.5% of the mothers got a right diagnosis, 12.5% had a delayed diagnosis and 50% had a wrong diagnosis. The mothers with delayed or wrong diagnosis were frustrated and thought if they had the right diagnosis, maybe the appropriate measures would have reduced the impact of disability on their children.

One 42 year old mother despite noticing that there was something wrong with her child, the medical professional kept assuring that her child was okay. This was despite the fact that the child was being able to perform activities that children his age could perform. This is illustrated in the quote below

“I was told the child was okay. ‘You are just anxious to see change fast’, as the baby was looking healthy and was very fat. I was assured that it was because of his weight. I should expect some differences from my two girls... months down the line there was no improvement I thought of going back”. “He was 18 months and I went back when he was almost two and a

half years after seeing no change, he couldn't even call papa not even perform any activity a child his age does. Still they assured me that the child was fine, 'he's just too fat' and they claimed he will be fine, 'give him time'... I went back home". M1

A 38 year old widow could not get a diagnosis for her child from the medical professionals who suspected a lot of other diseases on her child. Medication was administered for the other suspected conditions, but no changes were noticed until she was advised to take the child for rehabilitation where the physiotherapist diagnosed the child with CP.

"... The doctors could not diagnose my child. They were suspecting a lot of diseases. At one time they thought she had malaria, one of them thought it was tetanus and another thought it was tuberculosis of the brain, she was prescribed a lot of medication which did not help her at all. One of the neighbors suggested that I take her to the Catholic Church, this is where the physiotherapist told me that my child had CP..." M10

A 22 year old single mother of a 5 years old diplegic child noticed that there was something wrong with her child after she had suffered from meningitis at 2. Upon visiting a clinic, the mother was told the legs of her child were dead and she was referred to a children's hospital where she was given herpes complex a nutritional supplement for malnourished children and discharged thereafter.

"My child was 2 years old when she suffered from meningitis. After that she could not sit and each time I tried to lift her, her head was always lagging behind. I decided to take her to the clinic where they said that the legs of my child were dead so we were referred to Yengwe Children's Hospital where herpes complex was given to my child for a week and we were discharged". M12

4.9 Summary

The results of this study shows that mothers of children with CP, may experience emotional, physical, socio-economic, environmental and marital challenges. Other challenges experienced by mothers include lack of implementation of policies regarding their children with CP and challenges with diagnosis of the condition of CP. Among emotional challenges, mothers had perceived stress, depression and anxiety. They worry much about the futures of their children with CP and the fact that most of them are not employed and they do not cope financially. Care giving demands placed on the mothers superseded their expectations making them to suffer from perceived anxiety disorders. Nearly all the mothers except for one had experienced either physiological or anatomical physical health challenges. Some mothers experienced headaches, back/neck pains, chest pains and were tired. Most of the mothers in this study were not employed. The ones that were employed complained that their salaries were not sufficient for them and their children. Environmental challenges included the social, attitudinal and physical environments. Socially, some mothers were living isolated lives and lacked support from friends, relatives and in some cases support from their spouses. Some of the negative attitudes faced by the mothers included stigmatization, discrimination and lack of acceptance by their families, the community and in some cases health care professionals. Cited by the mothers as physical environmental challenges were poor architectural designs of buildings which were inaccessible for their children with CP and geographical features such as terrains, slopes and rocky surfaces. Marital challenges for some mothers included conflicts and divorce emanating from spouses not accepting the condition of the child, influence from relatives, poor spousal support and partners blaming each other for the condition of their child. All the mothers reported that the Zambian government was not implementing policies for their children especially the education policies as they were no schools for their children. The mothers were not getting any support from the government in terms of finances,

transport and assistive devices. Finally some of the participating mothers experienced challenges with the diagnosis of their children with CP as some mothers experienced delayed or wrong diagnosis.



CHAPTER FIVE

DISCUSSION

5 Introduction

In this chapter, the relationship between the demographic characteristics and the challenges experienced by the mothers are discussed. The major findings of the current study are summarized and discussed in comparison with findings of other studies. The relevance of the study with regard to challenges experienced by mothers of children with CP in relation to the aim and objectives of the study will finally be discussed.

5.1 Relationship between demographic characteristics and challenges experienced

The demographic characteristics to be discussed will include; the ages of the mothers, ages of the children with CP, level of education and employment status of the mothers, marital status of the mothers and the level of function of the children.

5.1.1 Ages of the mothers

The ages of the mothers ranged between 18 and 50 years with a mean age of 34.8 years. Most studies on challenges experienced by mothers of children with CP use mothers of a wide age group (Resch et al, 2010; Gona, mun'gala-Odera, Newton & Hartley, 2010). This is because challenges experienced by younger mothers may not necessarily be the same as challenges experienced by older mothers. Younger mothers worry not only about the condition of their children, but also about their future in terms of marriage, education and employment whereas older mothers worry about financial and mostly physical health challenges (Sen & Yurtsever, 2007). Gona et al (2010) in their study regarding challenges experienced by mothers of children with disabilities in Kalifi, Kenya recruited mothers of a wider age group 18-54 years

old mothers and were of different ethnic groups. The authors reported that mothers of younger ages face a lot of psychological challenges as they worry about acceptance issues compared to mothers of an older age. It has also been reported that mothers of different age groups view disability differently (Borst, 2010). The findings of the current study are similar to those of previous studies as the younger mothers mainly worried about education and finding employment compared to the psychological problems experienced by the older mothers.

5.1.2 Ages of the children with CP

In this study, the ages of the children with CP ranged between 11 months and 17 years with a mean age of 7.1 years and the children had different types of CP. In this study, 8 mothers of children below 7 years old and 8 mothers of children from 7 years old and above were recruited. A study that looked at challenges experienced by mothers of children with CP recruited mothers of children whose ages were similar to those of the current study (Sen & Yurtsever, 2007). Many of the studies cited in the literature used samples with very wide age ranges. Similar to the age range used in this study, Manuel et al (2006) also used subjects whose children ranged between the ages of 8 months and 18 years. It has been reported that challenges faced by parents raising children at different ages can be very different and unique and it is thus arguably very difficult and unreliable to compare challenges amongst parents of children whose ages are vastly varied. Purgin (2007) reported that mothers face different challenges in different phases of the child's life. The child's diagnosis of cerebral palsy which usually takes place at about one or two years of age is a particularly stressful time for the mothers. This is also evident at different times associated with various developmental milestones in the child's life such as when the child reaches school going or school leaving age. Also worth noting is that in the absence of major feeding difficulties, the burden of

caring for a baby or toddler with cerebral palsy is in fact very similar to caring for a child of a similar age with no disability since both are completely dependent on the parent for all needs and as such there is less of a discrepancy between normative expectations and actual events. For this reason, Failla and Jones (1991) in their study decided to exclude younger children from their study and only included children between the ages of six and 12 years. Mothers with older children in this study experienced more challenges than mothers of younger children. One of the mothers with an 11 months old baby reported not experiencing some of the challenges that the other mothers were experiencing.

5.1.3 Level of education and employment of the mothers

In this study, the level of education among the participating mothers ranged between uneducated and tertiary education. Seven (7) of the participating mothers had no form of education, 4 of the mothers had their primary education, 3 had their secondary education and only 2 had their tertiary education. From the above data it is evident that the majority of the participating mothers had no form of education. Regarding employment, 2 of the mothers were in formal employment, 3 were self-employed whereas 11 of the participating mothers were unemployed. A study by Resch et al (2010) regarding challenges experienced by mothers of children with disabilities, revealed that majority of the mothers in their study were from low income class as they earned less than \$25,000 per annum. In the same study, majority of the mothers had less than high school education, only 3 of out of a sample of 20 mothers had high school education and another 3 had a college education. Sen and Yurtsever (2007) in their study on challenges experienced by mothers of children with CP showed that among 40 participants, 7 mothers were illiterate, 23 had a primary education, 11 had secondary education, 9 had a high school education and only 1 mother had university education. Only 4 mothers were employed and 47 were unemployed. Another study in Kalifi,

Kenya showed similar findings on mothers of children with CP who had poor education and were not in employment (Gona, Mung'ala-Odera, Newton & Hartley, 2010).

Literature has shown that having care giving roles for mothers of children with CP reduces the probability of employment (Borst, 2010; Gary and Edward, 2009; Carmichael and Charles, 2003). The level of education among most mothers of children with CP has been found to be very low and tending towards low income (Ong et al, 2005). The mothers in this study that had low levels of education and were not in employment had financial hardships and failed to afford important equipment for the rehabilitation of their children with CP. The progress in the rehabilitation of their children was slow and physical limitations were eminent. However, it is also important to note that there was no difference in financial challenges between mothers with low levels of education and those with tertiary education and were in employment.

5.1.4 Marital Status of the mothers

Marital status has a direct relationship with accepting, coping and adaptation of families with a disabled child as illustrated by the resilience model of family stress, coping and adaptation (McCubbing & McCubbing, 1996). Friedman, Bowden and Johns (2003) describes the model as a way to assess the stress brought about by a child with disabilities in a family, the coping strategies and how the crisis has disrupted the family. Childhood disabilities can influence many aspects of the family including health, roles and responsibilities (Sen & Yurtsever, 2007). However married mothers find it easy to cope with stressors utilizing family resources such as support and spouses building on the strength of each other and adapting to the stressful situation in a manageable and positive way (Hanson, 2001) as was the result in this study. The researcher further reported reported that economic stability, flexibility, hardiness, shared spiritual beliefs and open communication are critical family resources that enable

families to cope. According to Martz and Livneh (2007), failure for some mothers to adjust and cope is as a result of being unmarried or divorced. Another researcher elaborated more that the challenges faced by mothers of children with disabilities are accentuated by failed family relationships (Doucette & Pinelli, 2004).

5.2 Emotional challenges

In this study the results show that mothers experience many emotional challenges including depression, stress and anxiety. It is very common for mothers of children with disabilities to experience psychological problem due to different factors (Bayat, Salehi, Bozognezhad & Asghari 2011). The psychological problems experienced by the mothers will be discussed under the depression, stress and anxiety headings.

5.2.1 Perceived depressive Symptoms

Most studies on the psychological status of mothers of children with CP have found that most mothers had depressive symptoms (Buming et al, 2008; Vijesh & Sukumaran, 2007:).The results of this study show that almost 50% of the mothers may have been suffering from depressive symptoms. They complained of feeling empty, had sleep disturbances, were restless, they felt sad, were irritable and some of them had intense sorrow which made them cry from time to time. Other reasons cited by the mothers as causes of their depressive symptoms were; lack of finances for transportation to and from rehabilitation centres, lack of finances for general upkeep of their children with CP and for purchasing required assistive devices for their children. In most cases their husbands failed to accept the condition of their children and accused the mothers as being the cause of their children's condition and they decided to leave their wives who in most cases were unemployed and worried about the prognosis and future of their children with CP. Many studies have shown that mothers of children with CP are at risk of suffering from depression (Sajedi et al, 2010; Glasscoe,

Lancaster, Smyth & Hill, 2007). One study that looked into challenges experienced by mothers of children with CP correlated the high depression levels of mothers to the level of disability of their children (Dagenais et al, 2006). However, some researchers argue that the depressive symptoms observed in mothers of children with CP are not meaningfully related to a child's developmental status or parent child interaction behaviors (Mbugua et al, 2011; Press et al, 2001). This was a similar finding in the current study that the depressive symptoms experienced by the mothers may have not been directly related to the level of disability of their children, but other reasons for their perceived depression were cited. This is not surprising as most mothers in developed countries do not worry much about financial hardships therefore they focus on the child's development as a source of their depression (Barlow, 2006) whereas mothers in developing nations suffer from depressive symptoms due to mostly the caregiver burden and socio-economic factors (Mbugua, Kuria & Ndeti 2011). One of the consequences of depression is that affected persons lose interest in activities that are meaningful to daily situations. Research has proved that mothers are the core of a child's rehabilitation process, if mothers are depressed, they will not strive to better the lives of their children with CP leading to delays in the rehabilitation process (Cohen, 2010). Also the mothers may have resentment and vent anger towards their children with CP, they may harm their children and even have death wishes towards them. In light of the above findings, effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviews which not only offer information on the children's disabilities but also psychological support for the mothers.

5.2.2 Perceived stress

More than 50% of the mothers that participated in this study reported experiencing symptoms of stress. Some of the stressors reported by the mothers included lack of sleep, lack of

finances, lack of employment, demands of care giving and lack of clarity of roles and responsibilities. The dependency of their children with CP for activities of daily living (ADLs) also increases the stress levels on mothers. Some mothers reported that involvement in the rehabilitation process was an additional stressor to that of caring for their children. Studies have shown that mothers of children with CP experience great levels of stress and emotional demands than do mothers of normal children (Cohen, 2010; Barbra, Chaud & Gomes 2008; Baker et al, 2003). In most studies, stressors of mothers are similar to those in the current study. Some researchers agree that it is normal for mothers to have high levels of stress, but it must not be assumed that all mothers of children with CP are stressed as stress is not inevitable (Eisenhower et al, 2005). It is not surprising to note the findings in the above study as the study was based on mothers in developed countries with good social supports, free assistive devices, social security grants, good transportation, road networks and medical insurance. According to the demographic data of the participants in this study, the stress experienced could be due to the fact that most of the mothers were uneducated, did not have jobs and were living in poverty. This was also concluded by Zhou (2010) that mothers do not receive any social or security grants are likely to experience stress. According to Vitaliano et al (2003), sustained levels of stress in the mothers could further impact on the physiological processes of the mothers leading to negative health outcomes. Hence rehabilitation processes must include programs that teach mothers how to cope under stressful situations and involve other family members who will offer support to the mothers in their stressful times.

5.2.3 Perceived anxiety

The results of this study show that some of the mothers were experiencing perceived symptoms of anxiety disorders. Mothers in this study were anxious about the future of their children with CP. The mothers worried about the changes in family dynamics and education

for their children with CP. The mothers also reported fear of their spouses leaving them because of traditional/cultural beliefs and they wondered how they will cope with the condition knowing it was chronic in nature. These findings are similar in many aspects to findings of other studies regarding anxiety levels in mothers of children with CP. Literature has cited many reasons for high anxiety levels among mothers and these include; acceptability on the social environment, negative attitudes on the social grounds, lack of implementation of policies regarding childhood disabilities, caregiver burden and chronic fatigue (Bumin et al, 2008; Ones et al, 2005; Rudolph, Rosanowski, Eysholdt & Kummer, 2003). The poor educational backgrounds and lack of income and support from the Zambian government has led to the perception that mothers of children with CP experience anxiety. A report by the Zambia Federation of Disability (ZAFOD) (2006) indicated that the Persons with Disabilities Act (1996) have not been enforced and the same is said about the provisions on disability in general policy documents. Another study reported that policies regarding children with disabilities in Zambia were not effected (Flem & Keller, 2001). Anxiety if not treated may lead to poor quality of life (QOL) and may lead the mothers to suffer from psychosomatic disorders including neurosis which is associated with impaired mental health (Quinn & Gordon, 2011). Mothers suspected to be suffering from anxiety disorders must be referred to the relevant professionals for evaluation and treatment.

5.3 Physical Health Challenges

In this study, most mothers of children with CP had problems with their physical health and there was a direct relationship between the mothers' health status and having a child with CP. The results show that some mothers had physical health problems with their body structure (anatomy) and others with their body systems (physiology). The results of the physical health challenges are discussed under musculoskeletal and physiological challenges.

5.3.1 Musculoskeletal challenges

Close to 70% of the mothers in this study reported experiencing musculoskeletal problems. . It was reported that the joints, ligaments, muscles, tendons and nerves were affected in these mothers and most of the mothers said they has neck pain, back pain, shoulder pain and chest pains. This could have been because of the activities of lifting, carrying, transferring and pushing of their children with CP, performed several times leading to repeated and overuse injuries of the musculoskeletal structures. Other factors that caused mothers in this study to end up with musculoskeletal problems could be the negative social and economic conditions of mothers, lack of equipment and assistive devices or architectural features that restrict activities inside or outside the home which directly affects the independence of children with CP. Many studies have shown that due to the dependence of children with CP for ADLs, mothers offer increased level of assistance causing them to suffer from musculoskeletal problems (Tonga & Duger, 2008; Duger et al, 2008). These challenges are mostly seen among mothers of children with CP in developing countries due to the poverty situations, mothers cannot afford especially assistive devices which could prevent over-involvement in care giving and constant assistant to their children. According to Osteonsjo, Carlberg and Vollestad (2005), this is not the situation in developed nations as the use of advanced assistive devices has lessened the care burden on mothers Musculoskeletal pain if unattended to, persists and become chronic. Chronic pain often causes feelings of helplessness, anger and frustration. Difficulty in sleeping is also very common which in addition to anatomical pain leads to irritability, worry, anxiety and ultimately depression. Consequently, if mothers of children with CP experience anatomical pains, they may not institute the rehabilitation home programs and will not leave their homes (Ones et al, 2005). This will cause significant delays in the rehabilitation program of their children with CP. Physiotherapist treating children with

CP must examine mothers from time to time and give the necessary treatment to prevent chronicity of any condition.

5.3.2 Physiological health challenges

Any changes in the normal mechanical, physical and biomechanical factors either caused by disease, injury or abnormal syndrome leads to physiological disorders (Brehaut et al, 2009). Some of the mothers in this study were experiencing physiological health challenges that they reported were a result of having children with CP. Some of the causes for their physiological challenges included conditions which emanated from restlessness, lack of sleep and heightened levels of stress. The heightened stress levels associated with raising a child with CP, if prolonged lead to negative physiological health impacts (Singer et al, 2009). Mothers also reported not having enough time for themselves, hence they engaged in negative health practices such as not exercising or watching their diets. This coupled with high levels of stress can lead to negative health outcomes such as hyperglycemia, hyperinsulinemia, higher blood pressure and poorer immune functions (Talley & Crews, 2007). Some of the physiological conditions suffered by the mothers included migraines and high blood pressure.

There is strong evidence that the work of caring for a child with disabilities has a substantial impact on health and well-being of mothers (Vitaliano et al, 2003). MacDonald and Callery (2007) in their study of mothers of children with disabilities on the effects of care giving in the US found that more than 50% of the mothers in their study had physiological health problems. The findings of the previous study are almost similar to those of this study except the mothers had a spectrum of diseases compared to the mothers in the current study. This may be due to the fact that healthcare services are readily available for mothers in the US who may be exposed to numerous medical tests unlike the mothers in Zambia who do not manage to afford even rehabilitation services for their children with CP. It is important that

mothers are tested for different diseases especially those associated with high levels of stress and chronic diseases of lifestyle so that the right treatment may be provided for the mothers. Physiological conditions such as those reported by the mothers (migrains and hypertension), in this study may lead to conditions such as stroke and diabetes if not properly treated. It is important that rehabilitation personnel are conversant with such conditions so that appropriate measures are taken to prevent deterioration of the conditions.

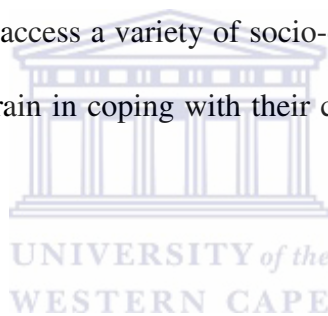
5.4 Socio-economic challenges

Most of the mothers were facing socio-economic challenges due to their poor educational backgrounds, lack of employment and the poverty situation in Zambia.

5.4.1 Poor educational background

Education is a means of achieving basic skills, knowledge and qualifications. It is a process by which society deliberately transmits values from one generation to another. Some of the mothers in this study had not attained any form of education and some had poor or low levels of education. Some mothers reported that their poor educational backgrounds were a result of their parents failing to pay for their education or the mothers themselves dropped out of school due to various reasons including falling pregnant before completing their education. Poor education fails to equip mothers of children with CP with the coping skills required to deal with the added difficulties imposed on them by their children's disabilities. Parents with low education levels struggle to find employment, if they do they only attract low income which may have a multiplier effect on the degree of parenting stress experienced (Purgin, 2007). Studies that have looked into the education of mothers of children with CP have found that the level of education among most mothers of children with CP is very low (Parish et al, 2008; Murphy et al, 2006; Ong et al, 2005).

The education system in Zambia has suffered a decline over the past two decades as a result of a drop in national revenue, linked to the low copper prices and substantial increase in fuel costs. Despite the Government recognizing the newly created Fifth National Development Plan (FNDP) and the role of education in poverty reduction, education has not adequately been invested in. Only 27% of Zambians are literate, but the dropout rate at schools is very high. In rural areas, the standard of education is hampered by lack of facilities, transport and teachers (USAID/Zambia, 2007). This has led to poor or lack of education among most Zambian populations leaving some of the mothers uninformed and lacking information and knowledge about the diagnosis and prognosis of their children. Poor education not only limits employment and financial opportunities for mothers of children with CP outside their homes, but leaves them less equipped to access a variety of socio-educational and medical resources which could help alleviate the strain in coping with their children with disability (Ong et al, 2005).



5.4.2 Lack of employment

Most of the mothers in this study were unemployed. The high unemployment rates among the mothers of children with CP are due to their poor education background, lack of employment opportunities and lack of support structures such that should they be employed, who would look after their children with CP considering that most day care facilities and schools do not recruit children with CP. Educational attainment is strongly related to employment and earnings across both the developed and developing nations (Sen & Yurtsever, 2007). Unemployment rate in Zambia is generally very high. Only 35% of 11 million people, are in formal employment. The closure of industries in the various provinces due to the open market economy and privatization as well as economic decline due to lowering copper prices on international markets has reduced formal employment opportunities (International Labor

Organization (ILO), 2008). Studies have shown that most mothers of children with CP are not in employment (Borst, 2010; Gary and Edward, 2009; Talley and Crews, 2007). Other reasons cited in literature for lack of employment among mothers include; Failure of mothers to combine employment and their care giving roles, poor health, duration of caring episodes and willingness of employers to accommodate mothers' caring needs(Gray & Edward, 2009). These findings are different from those of the mothers in this study as they were not employed mainly due to their low education levels and the lack of employment opportunities in Zambia. Unemployment deprives mothers of an income and sound financial standing in societies. When families do not have enough income, fundamental prerequisites for good health are difficult to obtain. It is therefore important to empower mothers with skills that will enable them to be self sufficient.

5.4.3 Poverty

The results of this study show that majority of the mothers were living in poverty. Most of the mothers reported failing to afford basic needs like food, clothing, shelter and good sanitation. Some of the mothers walked long distances to and from the rehabilitation centres due to lack of transport money and others opted not to attend the physiotherapy sessions as they stayed too far from the rehabilitation centres and could not afford the transportation. The mothers that were employed reported that their salaries were not enough to sustain theirs and the needs of their children with CP. The mothers that were self-employed claimed to run out of business from time to time and did not have sufficient funds to sustain their lives. Most of the unemployed mothers were either single or they were married to partners who were equally not employed making them to live in poverty.

According to a report by the International Labour Organization, majority of Zambians are socially and economically disadvantaged. They have no adequate access to the basic

conditions required to develop and live primarily in poverty (ILO, 2008). The poor Zambian economy and the socio-economic status of Zambians especially women worsens the situation (Zhou, 2010). Where there is poverty there is inadequate shelter, hygiene and infections can easily be contracted and passed on. Furthermore, the presence of cockroaches, rodents and other allergens in low-income minority households aggravate chronic conditions and as a result of these factors, childhood disabilities are overrepresented among children living in poverty (Wise, Wampler, Chavkin & Romeo, 2002). A study in Turkey on the poverty levels of mothers of children with CP found that most mothers do not have access to prenatal care, are exposed to the spread of infectious diseases such as tuberculosis, and do not take in sufficient nutrition due to living in poverty (Levin, 2005). A study has shown that most of these poor mothers are mainly in developing nations as most mothers in developed countries are fully supported by the systems socially and economically (Young, 2004).

5.5 Environmental Challenges

The environmental challenges experienced by the mothers of children with CP that participated in this study encompassed the social, attitudinal and the physical environments.

5.5.1 Social environmental challenges

The social lives of most of the mothers were affected. The study revealed that the mothers lacked social interaction, they lacked family and community support and they lacked support from healthcare practitioners and the government. Most of the mothers lacked social interaction as they were afraid that others in the community may not accept their children, the volume of daily care giving activities, physical and emotional exhaustion, social stigma due to child's perceived inappropriate behavior in public places and practical concerns related to transporting the child. A study that investigated the reasons for social isolation among mothers of children with CP in Turkey found that mothers were living in isolation due to

abandoning other roles and responsibilities of motherhood and concentrating on their child with disabilities, fear of the reaction of others to their children and environmental factors that are restrictive to mobility of their children outside and within their home environments (Abidoglu & Gumuscu, 2007). Some mothers also reported a lack in social support from their friends, family and the community. In most cases their friends and family members failed to accept the condition of the children with cerebral palsy and due to traditional beliefs, many choose not to associate themselves with a child with disabilities for fear of having a disabled child themselves. A study revealed that mothers of children with CP lack family time, they do not go on outings with their kids or spouses, they do not stay in touch with friends and extended family members and they rarely get together with friends (Donovan, VanLeit, Crowe & Keefe, 2005). Lack of social support increases the magnitude and reaction to stress which is considerably less for individuals with good social support from close friends and family members than for individuals with inadequate social support. Some of the mothers also experienced lack of support from healthcare providers whom they believed had the knowledge to take them through the different stages of the condition of their children. The importance of healthcare support for mothers of children with CP has been documented in literature (Olson & Huang, 2001). Most of the mothers reported that the government did not offer them any support or assistance with their children. In most cases, they failed to afford many things especially transport to and from rehabilitation centres. Similar findings on the lack of government support for children with disabilities were reported in Zimbabwe. The Zimbabwean government took no deliberate effort to improve the lives of children with disabilities despite numerous challenges faced by the mothers (UNICEF, 2007). Many studies in Zambia have shown government's efforts in trying to assist children with disabilities (Dando, 2011; UNICEF, 2007; WHO, 2005), yet none of the participating mothers has so far received any help from the government.

Social isolation and lack of social support is common among both developed and developing nations (Scott, 2007). Social support has long been regarded to avert stress and socializing has been seen as an important tool in mitigating psychological challenges experienced by mothers. Social support is a means of providing assistance and encouragement to individuals with physical or emotional problems in order that they may better cope. Some form of social support is provided for by churches, organizations and support groups (Uchino, 2009). Family and community support is important for mothers of children with CP as it increases resilience, multiplies joy, and softens sorrow as alluded to by Gallagher (2008). Because mothers in Zambia do not receive any respite services for their children with CP, it is important that rehabilitation services adopt family centred approaches to ensure constant support for mothers. Part of the reason as to why mothers live isolated lives is that families, friends and the community are not aware of the condition of CP. Creating awareness on CP might prevent mothers from living isolated lives.

5.5.2 Attitudinal Environments

Nearly all the mothers of children with CP were experiencing negative attitudinal environments. The negative attitudes experienced were from families, friends, the community and from healthcare providers. The mothers reported that society reacts with horror, fear, anxiety, distaste, hostility and patronising behaviour towards their children with disabilities. The negative attitudes were due to traditional and cultural beliefs and partners with or without their families blaming the mothers for the condition of their children. This leads to discrimination and prejudice against the mothers and their children. Studies have shown that attitudes towards children with disabilities are predominantly negative (Rosenzweig & Huffstutter, 2004; Corrigan et al, 2003). In most African cultures, pregnant women are subjected to a lot of taboos and rituals to prevent them from having children with disabilities.

A child born with any defect will be seen as a violation of such traditional belief systems and the family will often be maltreated and looked down upon by the rest of the community members and in turn the family ostracizes or discriminates against the mother. Families believe if a mother gives birth to a child with disabilities, they should be blamed as giving birth to a child with disabilities is seen as failure to follow traditional beliefs and cultures. It is also believed that pregnant women must not laugh at, look at or associate with children with disabilities or they will themselves give birth to children with disabilities (United Nations Development Plan (UNDP), 2007). A study in Zambia on attitudes of the community towards children with disabilities revealed that disability is associated with witchcraft, promiscuity of the mother during pregnancy, punishment by ancestral spirits or by God (Phiri, 2003). Once a mother has a child with disabilities, family members shun them. There has been little research done on negative attitudes towards mothers and their children with CP in Africa. The few studies done in Uganda, Ghana, Zimbabwe and Zambia had similar findings to that of the current study regarding negative attitudes of communities towards children with disabilities (Masasa, 2005; Hartley et al, 2004; Bwana and Kyohere, 2001; Chimedze, 1999).

The attitudes of healthcare professionals were not spared as a few of the mothers reported experiencing negative attitudes from them. For the mothers, this was disappointing as the last place they expected to experience such negative attitudes was with healthcare providers. A study that investigated attitudes of nurses towards children with disabilities reported that many nurses did not exhibit sensitive and appropriate attitudes towards the children with disabilities leading to poor quality of nursing care (Matziou et al, 2009). Other studies that compared attitudes of healthcare professionals across professions found that nursing professionals had the least positive attitude whilst occupational therapy showed the most

positive attitudes towards children with disabilities (Dorgi& Solom, 2009; Tervo & Palmer, 2004). The positive attitudes of occupational therapists was influenced by provision of accurate information concerning disability, frequent interaction with children and through humanistic and holistic philosophy embedded in the curriculum. The findings of this study show that the mothers of children with CP appreciated the services offered by physiotherapists and this could be because occupational therapy is not a profession that exists in Zambia.

Mothers of children with CP regard society's prejudices as more restrictive than the practical difficulties experienced as a direct consequence of their children's impairments. This increases stress levels among mothers which can lead to physical ailments, isolation, self-devaluation and may cause psychological disorders (Huffstutter et al, 2007). The International Classification of Function Disease and Disability (ICF) describe disability in terms of how individuals without disability views people with disabilities. The negative attitudes are the ones that disable individuals (WHO, 2001). The physical and social environments send the message to people with disabilities that their presence in society is not equivocally, welcome or vital. Mothers need all the necessary support they can get from their families, friends and the community to cope better with their situations. It is important to encourage mothers to maintain communication with friends, family and the community whilst raising awareness on CP.

5.5.3 Physical environmental challenges

The physical environmental challenges experienced by nearly all the participating mothers were due to architectural and geographical features in the environment. Architectural features which restrict mobility for children with CP may be parts of buildings, landscaping, walkways, or parking areas, and include high curbs, lack of curb cuts or ramps, gravel

walkways, narrow sidewalks, extreme variations in the grade of walkways, debris which interfere with passage along sidewalks, narrow doorways, heavy doors requiring excessive force to open, and insufficient parking (Palisano et al, 2003). The geographical features in the environment limited the mothers from accessing rehabilitation and health services which made most of the mothers to abandon the rehabilitation process or not attempting it at all. It has been reported that in many African countries, long waiting periods and transport costs, particularly for those in rural areas, make it difficult to access services and to obtain assistive devices (McLaren, Philpot & Hlophe, 1996). A study that looked into accessibility issues in Kenya found that mothers of children with CP have problems accessing rehabilitation services, information, moral or financial support (Komardjaja, 2001). The mothers in this study reported to have problems accessing the main hospital which is more than 10 kilometers from the township. It is an eight storey building, the lifts are rarely functional and there are no ramps. The physiotherapy department is on the second floor which makes it difficult for mothers to get their children to the department. Public transport is difficult to access as most of the vehicles are not designed to carry wheel chairs, most roads are impassable and the transport charges are too high for the mothers.

Literature has documented physical environmental challenges experiences by mothers of children with CP (Worcester et al, 2008; Lollar, 2008; Eker & Tuzan, 2004). Most children with CP in developing nations live in poor housing structures and are surrounded by rocky terrains, slopes, curbs and uneven surfaces which hinder their mobility. The houses are much smaller and more crowded which makes mobility for children with physical disabilities more challenging (Grut & Ingstad, 2006). The official buildings as well as designs of roads do not seem to be made accessible for wheelchair users and there seems to be much left to do in order to accommodate the needs of people with disabilities into physical planning. These

challenges are mostly experienced by mothers in developing nations as most homes and infrastructure in developed countries have been modified to suit the condition of children with CP even though some researchers argue that the progress in infrastructure in developing nations has not added any freedom for children with disabilities (Osteonsjo, Carlberg and Vollestad, 2005). The physical environments in most developing nations have not been modified due to lack of finances (Venter et al, 2004).

The failure of some mothers to access rehabilitation services, information or assistive devices leaves children with CP with more limitations and exclusion from mainstream activities. When environments are not receptive to mobility of children with CP, mothers are forced to manually lift their children most of the time for mobility to access different places. This leads to the musculoskeletal problems suffered by the mothers and some mothers will choose to live in social seclusion which leads to elevated levels of stress.

5.6 Marital challenges

Some of the mothers in this study reported experiencing marital challenges due to misunderstandings and conflicts. Some of the mothers reported that their husbands left them as soon as they discovered their children had CP. Others reported that they had constant fights with their husbands due to interference by relatives of their husbands and in many cases they ended up being divorced. Marital conflicts arose as partners blamed each other for the condition. Cultural beliefs in Zambia just like in many African countries dictate that physical disabilities on a child are caused by women as suggested by Skinner and Weisner, (2007). The fathers feel left out and are deprived of their conjugal rights as mothers spend all their time looking after their children with CP and have no time for their spouses. Some of the spouses engage in extra marital affairs, fights and divorce are common. Studies have shown that living with a child with disabilities can have profound effects on the entire family

and can affect all aspects of family functioning (Swaminathan, Cornman & Noonan 2005; Conman, Noonan & Reichman, 2005). A study in Canada that investigated marital relations among families of children with disabilities reported that relationships suffer unduly from the added stress of blame, guilt and anxiety (Sobsey, 2004). In a study, Vijesh and Sukumaran reported that the increased stress takes a toll on the mental and physical health of parents affecting decision making (Vijesh & Sukumaran, 2007). A child's disability attacks the fabric of marriage in different ways and excites powerful emotions in both parents which create fertile ground for conflicts and divorce. Stein (2005) indicated that factors that increase stress on a family have repercussions on the quality of relationship between the parents, their living arrangements, future relationship and family functioning.

A study suggested that conflicts between parents of children with CP may be extremely traumatizing given the difficulties experienced by children with CP (Portela, 2009). The yelling, misery, aggressive behavior between the parents, physical and verbal abuse affects the well-being of the children with CP. Conflicts between parents is considered a major life stressor for the mothers (Vijesh & Sukumaran, 2007). Divorce on the other hand leads to psychological and emotional problems suffered by the mothers as reported in a study by Bayat et al (2011).

5.7 Lack of implementation of policies regarding children with CP

All the mothers of children with CP in the current study reported the government as not implementing policies regarding their children with CP. The mothers lacked moral and financial support from the government in many aspects. They reported lacking many things including assistive devices. They had no proper transportation and the existing transport was very expensive for them. The mothers could not afford certain medical procedures including therapies such as physiotherapy (due to transport issues). The national policy on disability

states that the government will endeavor to provide rehabilitation and other services to people with disabilities and yet this was not the case. The mothers live in poor houses with several environments barriers, when the policy for children and adults with physical limitations states that the government will create an enabling environment for the full participation of people with disabilities. The mothers lack general funds for the upbringing of their children with CP and none of the children with CP was attending any school as they are currently no schools in Ndola, Zambia that takes children with CP. The policy aims to include children with disabilities in the mainstream education system. The Ministry of Community Development and Social Services (MCDSS) has the overall responsibility for disability issues. It is responsible for alleviating the suffering of poor and disadvantaged groups, including women, children, youth and people with disabilities, through facilitation and provision of survival community development skills and direct social support.

A report by the Zambia Federation of Disability (ZAFOD) (2006) read that the Persons with Disabilities Act (1996) has not been enforced and its violations are rarely recognized mainly due to ignorance, among the various stakeholders, of what it entails. The same is said about the provisions on disability in general policy documents. Other studies have reported similar findings regarding lack of implementations of policies regarding disability (Camerot & Tveit, 2011; Flem and Keller, 2001).

The lack of implementation of policies by the government leaves mothers lacking in many aspects. Their children's disabilities are overrepresented due to poverty levels among mothers as they cannot afford many things including assistive devices. This leads mostly to the psychological problems suffered by the mothers.

5.8 Challenges with diagnosis of the condition of CP

Some of the mothers in this study reported that the medical personnel who attended to them initially either gave them a wrong diagnosis for the condition of their children with CP or a correct one, but without explaining the condition of their children to the mothers. Some of the wrong diagnosis given to the mothers included malnutrition, malaria, tuberculosis of the brain, obesity being the cause for flaccid paralysis and mental retardation. This, the mothers thought delayed them in implementing the right treatment and therapies for their children. Most of the participating mothers claimed to have received a wrong diagnosis for their children with CP. The mothers that received correct diagnosis claimed that the medical practitioners did not explain the condition of their children to them.

Diagnosis of CP in severe cases can be made immediately after birth, but for some children diagnosis can only be made up to the second year of birth. Irrespective of the fact that mild cases of CP are difficult to diagnose in the first few months or years, some studies have shown that in most cases physicians fail to give the right diagnosis (Huang, Kellett and St John, 2010; George, Vickers, Wilkes & Barton, 2007). If they do, they fail to give adequate explanation to the affected individuals. In some instances, medical personnel disclosed children's diagnosis and prognosis as very severe, without giving any positive information (Graungaard & Skov, 2006). Some mothers are not happy with the way health professionals disclose the condition of CP on their children. What they want to hear is information that gives them hope, certainty, a possible picture of the future, and direction for commencing treatments and rehabilitation (Rannard et al, 2005).

A delayed diagnosis or wrong diagnostic makes the mothers despair. All they want to know is what is wrong with their children on time. In this study, some of the mothers failed to trust healthcare professionals as they failed to give a right diagnoses for their children. The

mothers felt alone as their suspicions and concerns were not confirmed and they felt that some of the treatments administered to their children were inappropriate and delayed the right treatment. A study that looked into the diagnosis of children with CP found that “delays in effective diagnosis not only increased mothers’ mistrust and dissatisfaction with physicians’ knowledge and skills, but fuels their hopelessness and aggravated anger about receiving a better prognosis” (Ashwal et al, 2004: P. 255). These findings are similar to those of the current study. It is a possibility that some of the mothers were not aware that the diagnosis of CP may take long. The healthcare professionals attending to mothers must explain to the mothers the complexities involved in diagnosis the condition of CP rather than sending them away without any explanation or diagnosis.

5.9 Significance of the study

No one influences the life of a child with a disability more than a mother. Mothers however experience a lot of challenges associated with raising their children with CP. Consequently, these challenges affect not only the well-being of a child, but affects the family as a whole (Plant & Sanders, 2007). The results of this study have demonstrated that the mothers of children with CP consistently experience higher levels of psychological and physical health problems related to having a child with CP and the complex task of caring for their children. Studies examining the complex effects of care work on physical, emotional and social health of caregivers found that mothers have negative impact on general well-being (Singer, et al., 2009).

These facts indicate that caregivers require support for their caregiving tasks. This supportive services could help the mothers to have a good quality of life and find balance in their lives. Literature suggests that if the caregivers/mothers are healthy, the children being cared for will experience much better care and health (Talley & Crews, 2007).

This information will be used to inform healthcare providers about the different challenges experienced by the mothers of children with CP. If they are not informed, they will not be able to help the mothers in anyway. The information will therefore help healthcare providers to offer the necessary support and information on where else mothers of children with CP can get help and in future source help from relevant government ministries and non-governmental organizations (NGOs) as regards to the mothers and their children's well-being.

The study will add to the scanty information in Zambia with regards to the challenges experienced by mothers of children with cerebral palsy. The results will also be used to inspire healthcare providers to adopt approaches that are family oriented in the rehabilitation program of children with CP. Mothers are at the centre of rehabilitation programs (Uchino, 2009), if they experience a myriad of problems which are never considered by healthcare professionals, rehabilitation programs will not be effective leading to further disability of children with CP. Our goal as healthcare professionals is to see to it the children get the necessary rehabilitation program. If rehabilitation programs are not effective because of the challenges experienced by the mothers, it is a failure on the part of healthcare providers.

CHAPTER SIX

SUMMARY, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

6 Introduction

This chapter presents a summary of the chapters, a conclusion, recommendations and proposed future research. The limitations of the study are also highlighted.

6.1 Summary

The study sought to explore the challenges experienced by mothers of children with CP in Ndola, Zambia. The areas that were explored included the emotional challenges, the physical health challenges, the socio-economic challenges, the environmental challenges, marital challenges, challenges with implementation of policies regarding children with CP and challenges with diagnosing the condition of CP. The environmental challenges according to the ICF included the social, attitudinal and the physical environments. The researcher adopted the study as there is scanty information in Zambia regarding challenges experienced by mothers of children with CP. Most studies done have concentrated on the challenges experienced by children with CP and the concerns of the mothers are not considered.

The researcher employed a qualitative research method using in-depth interviews. The mothers were selected using stratified sampling, though the mothers were interviewed till theoretical saturation was reached. All in all 16 mothers were interviewed and made the sample for the study. The ages of the mothers ranged between 18 and 50 years of age which was a good distribution of age as different mothers face different challenges at different ages. The ages of the children ranged between 11 months to 14 years which was equally a good age gap as children of different ages pose different challenges. The children presented with

different types of CP including athetosis, quadriplegia, diplegia, hemiplegia, triplegia, and ataxia.

The result of the study shows that mothers of children with CP experience psychological, physical health, socio-economic environmental and marital challenges. The mothers also experience a lack of implementation of policies by the Zambian government and misdiagnosis of the condition of CP by medical professionals. Psychological problems include depression, stress and anxiety. These problems emanate from lack of funding, poor spousal support, fear for the future of the child and the home care burden. The physical health problems suffered by mothers include the musculoskeletal which result from constant lifting, pushing and carrying of their children with CP and the physiological (systemic) which result from elevated stress levels and poor health habits such as lack of exercise and having unhealthy diets. The socio-economic challenges are as a result of poor educational backgrounds of the mothers, lack of employment and income and lack of financial support from the government. The environmental challenges included the social environments which saw the mothers with poor support networks and social isolation, the attitudinal environments which subjected the mothers to stigmatization, discrimination and rejection due to traditional and cultural beliefs or lack of awareness by the general population and physical environments including architectural and geographical environments which are usually inaccessible to children with disabilities. The marital challenges experienced included conflicts, misunderstandings and divorce. The challenges with implementation of policies arose as the government was not doing anything to assist and support the mothers morally and financially. Some mothers experienced delayed and misdiagnosis of the condition of CP on their children by medical personnel that attended to them.

6.2 Conclusion

The present study sought to explore the challenges experienced by mothers of children with CP. The results show that mothers experience many challenges raising their children as discussed in the preceding section (6.2). Mothers of children with CP, despite the challenges faced are known to be competent and effective Caregivers of their children. They offer an invaluable service to healthcare. If healthcare professionals and the government do not recognise the challenges experienced by the mothers, the physical, psychological and general well-being of the mothers will deteriorate and their children due to lack of financial assistance and assistance with assistive devices will have more physical limitations and disability will be over represented. Rehabilitation professionals should be aware of the factors that impact mothers both positively and negatively in order to implement effective rehabilitation programs.

6.3 Recommendations

The health and wellbeing of informal caregivers, such as mothers raising a child with a disability, has become a public health priority in developing nations and given the goals of policy initiatives such as providing support for families has become increasingly important (Singer et al, 2009). However, this is not the case in developing nations and in particular Zambia. Perhaps the government and healthcare professionals are not aware of the challenges experienced by mothers of children with CP and disability. Having highlighted some challenges as experienced and expressed by the mothers, the following are the recommendations:

1. Seeing that mothers of children with CP in Zambia struggle financially, policy makers should offer support in terms of childcare grants, tax relief incentives, credits to start small businesses, disability grants and pension benefits for the mothers.

2. Rehabilitation personnel in Zambia should adopt family centred approaches in the management of CP. The current management of CP focus on the impairments and the disability of the affected children. However, in family centred approaches, the child is considered within the context of the family. This means that interventions address needs and preferences of the family. This approach provides supports that increase and enhance the capacity of the family to better meet the child's needs and avert stress imposed on the mothers. This must therefore be emphasized among health care providers in Zambia.
3. Family support groups must be created where mothers or families of children with CP can interact, exchange information and share experiences. The mothers must be educated on key policies and how to source help from relevant organisations.
4. Considering mothers of children with CP in this study were experiencing psychological problems including depression, rehabilitation personnel must incorporate counselling sessions to mothers on a regular basis that will address various psychological problems experienced.
5. The Zambian government could also embark on the creation of day care centres for children with CP and respite care which could be essential in trying to support mothers and caregivers. Such services can provide time for rest and social activities for the caregivers.
6. The Zambian policy does not recognize mothers as partners in the rehabilitation process of children with CP. There is need to change policies and adopt those that will

include mothers in the planning of management for their children. There is also a need for support services that will meet the needs of the mothers.

7. Resource distribution between institutions and community-based care programs in Zambia are not equal. There is therefore a need for redistribution, so that care can become effective and accessible to many children with CP and their mothers. Such redistribution should include mostly rehabilitation professionals, who are currently concentrated in health institutions in urban areas at the expense of the majority in peri urban and rural populations.
8. The government with the help of healthcare providers must embark on training and providing information to mothers on numerous topics including, coping skills, counseling, disability and skills to help themselves in distressing times. This will at least enable the mothers to find solutions to most of the problems encountered. Such information will help the mothers to understand the permanence of disability and rule out some cultural beliefs and practices which create negative perceptions.
9. Education systems in Zambia must incorporate models of caregiver support in the curriculum of healthcare professionals so that models for best practice with respect to caregiver support are identified
10. The Zambian government must create partnership among existing organizations to identify existing resources for the mothers and how these resources can be accessed.

11. Policy makers should ensure the following human rights for children with CP in Zambia are met:

- Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child.
- Highlighting the fact that the majority of children with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on mothers and their children with disabilities
- Recognizing the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling children with disabilities to fully enjoy all human rights and fundamental freedoms.
- Implementing policies regarding education of children with CP and inclusion into mainstream educational systems. Training teachers with sign language and how to handle children with multiple disabilities. Can be beneficial.

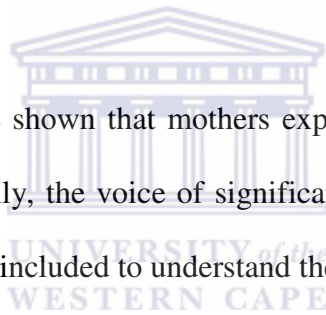
6.4 Further Research

1. Describe the presence/need for respite care across jurisdictions and examine the costs and benefits of respite care.

2. Study the hidden costs of lack of focus on caregiver health.
3. Identify the needs of caregivers and of children with CP and evaluate how mothers navigate the healthcare system and access services.
4. Study policy related concepts and examine the effects of specific policy initiatives.

6.5 Limitations of the study

1. The challenges experienced by mothers living in different localities which may be different (e.g. between mothers in urban, peri-urban and rural areas) were not explored as all the participating mothers came from peri-urban areas.
2. Even though studies have shown that mothers experience more challenges than any other member of the family, the voice of significant others like the father and other siblings should have been included to understand the phenomenon better.



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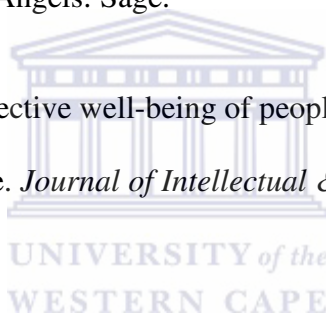
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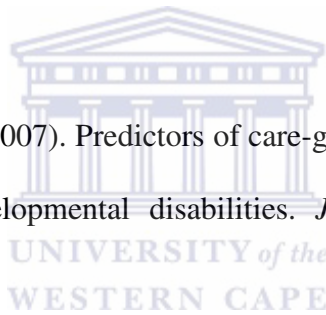
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APPENDIX A: Ethical clearance letter form UWC.



UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

21 October 2011

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Mrs C Singogo (Physiotherapy)

Research Project: Challenges experienced by mothers of children with cerebral palsy in Ndola townships of Zambia.

Registration no: 10/9/26

A handwritten signature in black ink, appearing to read 'Josias'.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*

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A place of quality,
a place to grow, from hope
to action through knowledge

APPENDIX B: Application letter to TDRC



The University of the Western Cape

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: 3080434@uwc.ac.za

THE COMMUNITY BASED REHABILITATION CO-ORDINATOR

CATHOLIC DIOCESE

NDOLA

Dear Sir/Madam

Ref: **PERMISSION TO CONDUCT RESEARCH IN THE CBR CENTRES OF NDOLA**

In reference to the above mentioned subject, I hereby apply to conduct research in the three (3) Rehabilitation Centers of Twapia, Chipulukusu and Mushili areas of Ndola under the CBR catchment area of the Catholic Diocese.

I am a Zambian citizen, who is currently studying towards my Master's Degree in Physiotherapy at the University of the Western Cape in South Africa. I have to conduct research (full thesis) in full fulfillment of the Master's program.

My research proposal is on:

“Challenges experienced by mothers of children with cerebral palsy in Ndola Township of Zambia”.

It is a qualitative study, using a phenomenological method and mothers of children with cerebral palsy will have to be selected from within the three rehabilitation centers using stratified sampling methods.

Participation of the mothers will purely be voluntary. Anonymity and confidentiality will be observed. All participating mothers will be supplied with information regarding the research and its aims and they will have to sign written consent form. All other ethics as set by your organization will be adhered to.

I would greatly appreciate an opportunity to conduct this research as exploring the challenges women face by having children with cerebral palsy will help expose the difficulties these mothers face and see where we, as health professionals can help. It is believed by wadding a mother's problems, one enhances the rehabilitation of a child. The research will also help us, as medical professionals to produce rehabilitation programs that are family oriented.

The research is scheduled to take place within December 2010 pending your permission as I have to return to the university mid of February 2011.

Yours Truly





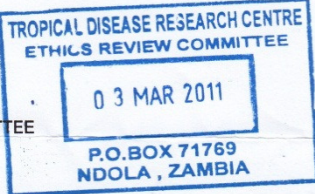
CAROL SINGOGO

STUDENT RESEARCHER

PROF ANTHEA RHODA

SUPERVISOR

APPENDIX C: Permission letter from TDRRC

TROPICAL DISEASES Tel/Fax 615444 tldr-ethics@tdrc.org.zm		RESEARCH CENTRE P O Box 71769 NDOLA, ZAMBIA
TDRRC ETHICS REVIEW COMMITTEE IRB REGISTRATION NUMBER: 00002911 FWA NUMBER: 00003729		
<hr/>		
TRC/C4/03/2011		
3 rd March 2011		
The principal Investigator Challenges experienced by mothers of Children with cerebral palsy in Ndola, Zambia University of the Western Cape Private Bag X17, Belville 7535 South Africa		
Dear Mrs. Carol Singogo		
RE: APPROVAL OF YOUR STUDY		
On behalf of the Chairman of the TDRRC Ethics Review Committee, I am pleased to inform you that your protocol entitled " Challenges experienced by mothers of children with cerebral palsy in Ndola, Zambia " was reviewed during a meeting held at TDRRC on 16 th February 2011.		
The protocol was approved with the following conditions/comments:		
<ul style="list-style-type: none">a. Whereas it is common in the context of Zambian culture for a mother to seek permission from the husband before participating in a study, it is not necessary for the spouse or other relatives to sign the consent form as well. However, where the mother is a minor i.e. less than 18 years of age, then her legal guardian can sign alongside the mother.b. You must include the contact details of the TDRRC Ethics Review Committee on the consent form in case the participants have any complaints or questions.		
This approval is valid until 2 nd March 2012. You will be required to apply for a renewal of your study at the end of this period, upon submission of a satisfactory progress report. The final report on the outcome of the study must be submitted to the Committee. You are required to seek ethical approval from the TDRRC Ethics Review Committee for any amendments to the approved protocol.		
We wish you every success in the implementation of the study.		
Yours faithfully TROPICAL DISEASES RESEARCH CENTRE		
 Dr Gershom Chongwe MD, MPH SECRETARY, TDRRC ETHICS REVIEW COMMITTEE		
cc: STC - Secretary		

APPENDIX D: Application letter to CBR



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959, Fax: 27 21-959

E-mail: 3080434@uwc.ac.za

15th November 2010.

The Community Based Rehabilitation Centers
(Twapia, Chipulukusu & Mushili)
Ndola, Zambia.

Dear Sir/Madam,

RE: APPLICATION TO USE YOUR BOOK RECORDS TO LOCATE PARTICIPANTS FOR MY STUDY.

Please refer to the heading above. I am a Zambian Citizen currently studying at the University of the Western Cape in South Africa, enrolled in Masters Degree in Physiotherapy. One of the requirements of this course is that I must conduct research which meets the criteria for full thesis. My research proposal is on **The challenges experienced by mothers of children with Cerebral Palsy in Ndola township of Zambia**. This study is set to take place in Twapia, Chipulukusu and Mushili townships under the Community Based Rehabilitation (CBR) catchment area. It is a qualitative study and the data collection will take place at the mentioned rehabilitation centers once the participating mothers have signed the informed consent forms. All other ethical rules including confidentiality and acting appropriately in case of emergencies happening during the study will be adhered to.

The period of data collection is two months (December 2010 and January 2011) as the university re-opens early February 2011. By this letter I am requesting your authorized office to allow me to use your client's records in order to allocate them geographically. Thank you in advance for all that will be done to make this request a success.

STUDENT:

Carol Singogo

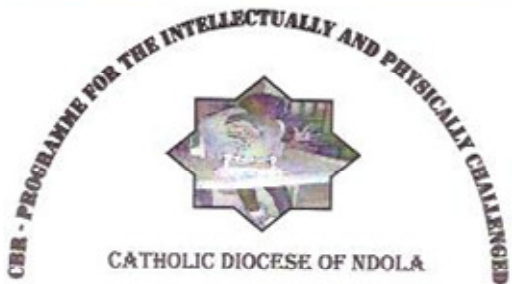
.....

SUPERVISOR:

Dr. Anthea Rhoda

.....

APPENDIX E: PERMISSION LETTER FROM CBR



P. O. BOX 70244, NDOLA, ZAMBIA
TELEPHONE: 621533, FAX: 613939/615884/620630
E-MAIL: cbrproj@yahoo.com

10th December 2010

Carol Singongo
University of the Western Cape
Physiotherapy Department
Private Bag X17
Bellville 7535
CAPE TOWN


RE: PERMISSION TO CONDUCT RESEARCH IN OUR CBR REHABILITATION CENTRES OF NDOLA

We acknowledge receipt of your letter a research in community based rehabilitation (CBR) programme. We are pleased to inform you that permission has been granted to conduct research entitled "Challenges experienced by mothers of children with cerebral palsy in Ndola Zambia"

You are free to do your research in any of our centres especially Chifubu and Mushili. For any further assistance you are free to call on our office.

We wish you all the best as you carry out this noble assignment.

Yours faithfully
CATHOLIC DIOCESE OF NDOLA


**MWANSA CHARLES
CBR COORDINATOR**

APPENDIX F: Consent form (English version)



The University of the Western Cape

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: 3080434@uwc.ac.za

CONSENT FORM

Title of Research Project:

Challenges experienced by mothers of children with cerebral palsy in Ndola township of Zambia.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Yes: I agree to be [videotaped/audio taped/photographed] during my participation in this study.

No: I do not agree to be [videotaped/audio taped/photographed] during my participation in this study. (Circle appropriately)

Participant's name.....

Participant's signature.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Dr. Anthea Rhoda

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-3647

Email: arhoda@uwc.ac.za



APPENDIX G: Consent form (Bemba version)



The University of the Western Cape

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: 3080434@uwc.ac.za

CONSENT FORM

Umutwe wa mulimo ukabombwa:

Ukufwailisha amafya yashingwana nabana mayo abakwata abana abalwala ubulwele bwakupona atemwa ubwikata bongo bongo (cerebral palsy) mwi town.

Aya masambililo nayalondololwa mu lulimi lwa cikaya, ning'ufwikisha elyo kabili amepusho yalimo ifyafyasuko nafipelwa icakuti nelyo nalabulamo ulubali nshakeshibikwe ku bantu, nalintu nafwaya ukuleka ndi muntungwa ukucita ico pa nshita ili yonse tacakandetele ubwafya iyo.

EE: Nasuminisha (ukukopwa pa fitunshi tunshi (television) / amashiwi/ifikope) pa nshita tulebulamo ulubali mukufwailisha.

AWE: Nshilesuminisha (ukukopwa pa fitunshi tunshi (television)/amashiwi/ifikope) panshita tulebulamo ulubali mukufwailisha.

Ishina lya uulebulamo Ulubali

Apakusaina uulebulamo Ulubali

Ubushiku

Nga namukwata amepusho ukullosha kuli uku kusambilila atemwa kuli amafya mupitilemo ayo mwingatwishibishako, twapapata tumineni kuli

Bakakondenkanya ba iyi milimo:

Study coordinator's Name: Dr Anthea Rhoda

University of Western Cape

Private Bag X17, Bellville 7535

Telephone: (021)959-3647

Email: arhoda@uwc.ac.za



INFORMATION SHEET



The University of the Western Cape

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 , Fax: 27 21-959 1217

E-mail: 3080434@uwc.ac.za

Project Title:

Challenges experienced by mothers of children with cerebral palsy in Ndola township of Zambia

What is this study about?

This is a research project being conducted by Carol Singogo at the University of the Western Cape. We are inviting you to participate in this research project because you have a child with cerebral palsy. The purpose of this research project is explore the challenges faced by mothers of children with cerebral palsy in the above mentioned townships which will help healthcare providers employ a family oriented approach in rehabilitation and offer the necessary support needed by the mothers as well as other referral structures where mothers can get help.

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

You will be asked to sign a consent form you will be asked to spare time to meet those carrying out the research at a time convenient to you. At the meeting you be asked to fill a form that seeks your socio-demographic information such as age, sex, relation to the stroke client. A general question will be put forward by the researcher, related to the challenges you face by having a child with cerebral palsy for which you will be expected to respond according to your experience. The researcher and/or research assistant will be available and ready to answer your questions should you have some, in a meeting that may last about 30 minutes- 1hour.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, we will not ask for or write your name on all papers related to this research. Instead identification codes using numbers will be used on data forms to ensure anonymity, and the researcher will personally collect all data collection forms and will ensure their storage in a locked and secure place. When we will finally write a report about this study your identity will remain protected and not displayed at any point.

What are the risks of this research?

There are no known risks associated with participating in this research project. However if you experience any problem in the course of the study such as mental or physical trauma, we will make sure you are referred to appropriate services such as counselling.

What are the benefits of this research?

The results of this research will help health care providers to incorporate you in their treatment plans and give you the necessary support and referral structures that might help you cope well with your child,s condition.

This research is not only help you as a person, but it will help highlight the problems faced by mothers of children with cerebral palsy and hopefully in future other people might benefit from this study through improved understanding of challenges faced and how they can be helped .

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify

What if I have questions?

This research is being conducted by *Carol Singogo* at the University of the Western Cape. If you have any questions about the research study itself, please contact __Carol Singogo at:

The Physiotherapy Department. University of the Western Cape, South Africa. Cell no. +27767391387; email; 3080434@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department:

Prof. J. Phillips at +277219592543; email- jphillips@uwc.ac.za

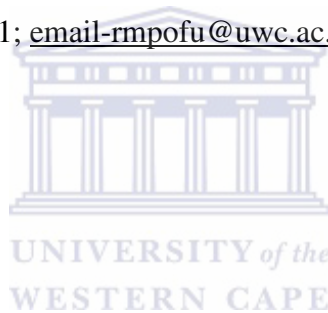
Dean of the Faculty of Community and Health Sciences:

Prof. R. Mporfu at +277219592631; email- rmpofu@uwc.ac.za

University of the Western Cape

Private Bag X17

Bellville 7535



This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

APPENDIX I: Information sheet (Bemba version)



The University of the Western Cape

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542 , Fax: 27 21-959

E-mail: 3080434@uwc.ac.za

INFORMATION SHEET

Umutwe wa mulimo ukabombwa:

Ukufwailisha amafya yashingwana nabana mayo abakwata abana abalwala ubulwele bwakupona atemwa ubwikata bongo bongo (cerebral palsy) mwi town Iya Ndola.

Amasambililo yali pali finshi?

Aya masambililo yalelekeshe no kufwailisha pa bulwele bwikata bongo bongo ubulekanya ukunfwana kwaba pa kati kamubili elyo na bongo bongo, yaletungululwa nab a Carol Singogo abali pesukulu likalamba (University of the Western Cape). Eco tulemwiita ukuti mubulemo ulubali nga abafyashi bakwata abana abalwele ku bongo bongo pakuti twafwane no kubombela capamo. Cikankala pa kufwailisha pali ubu ubulwele no kuceceeta bwino bwino pakuti twaishiba nangula ukusanga amafya bana mayo bapitamo ilyo balwalika aba bana nobu ubulwele bwikata bongo bongo mulili itauni Iya Ndola pakuti abo abalolekesha no kuceceeta pabumi bwa aba bana ba pela iyi milimo kuli balupwa nangula abafyashi pakuti baishiba inshila benga kushishamo no kubasambilishamo aba bana, no kufwailisha muli fimo fintu benga kabila elyo no nokubalangilila kufifulo uko benga sanga ubwafwilisho.

Nga nasumina ukubulamo ulubali, finshi bakanjipusha ukucita?

Bakamwipusha ukusaina ifipepala ifya kushininkisha ukuti namusumina, no kumipusha ukukumanya abo abalefwailisha pa bulwele munshita iya linga kuli imwe. Ilyo mwalongana bakamwipusha ukusaina, ukulemba imyaka muli nayo iya kufyalwa, nga muli banakashi nangula abaume, umulwele musunga mwaba nankwe shani? Elyo imbi eco bakamwipusha kufwaya ukwishiba amafya mupitamo pakukwata umwana uwalwala ubulwele bwikata bongo bongo atemwa ubwakupona, ici icipusho mufwile ukwasuka ukulingana nefyo

mwapitamo. Aba bakafwilisha bapali ubu bulwele pamo nabakafwa babo bakaba abaipekanya ukwasuka amepusho yamo ayo mukakwata elyo mukalongana. Uku kulongana kufwile kwaposafye ba mineti amakumi yatatu (30 minutes).

Bushe ukubulamo ulubali mu milimo yaku fwailikisha pa bulwele,bukasangwa munkama?.

Tukesho namaka yonse ukusungo ifipepala bwino bwino pakutilla ilyashi mukatolondolwela talifikile kumatwi yambi. Cimbi, pa kumwafwa ukusungo iyi inkama tatwakamwipushe ukulemba ishina lyenu pa mapepala tukalembapo ifyo tufwailishi. Ifyo tukacita tukalabonfya ama numbala pamapepala pakutilla ifyebo byonse mukatushimikilla tafyakeshibikwe uko fifumine, no kufikomona mu ncende fingasungwa bwino bwino. Napakulekelesha tukapitulukamo no kulemba fyonse ifyo tukasanga mukufwailisha kwesu ukwabula ukumishibisha nangu ukumisokolola kucintu bwingi.

Busanso nshi bwinga sangwa muli iyi milimo yakufwailisha?

Kwena tamuli ubusanso bwaishibikwa ubu kumine kuli uku kufwailisha. Lelo ngacakutilla mwakuntukilwa atemwa mwasangwa no busanso kumubili wenu tukashininkisha ukuti twa mwafwa ukumutwala ku benga mwafwilisha ukupwisha ubwafya ukupitilla mukulanshana (counselling).

Bononshi nshi buli muli uku kufwailisha?

Ifikafuma muli uku kufwailisha fikatwafwa ukubombela pamo na basungo babumi ukutupekanishisha ubundapishi elyo nokutulangililla uko twingasanga ubwafwilisho bwa pamisungile ya bana besu nobulwele bubacusha.

Uku kufwailisha takwaktwafwefye ngo muntu umo umo, lelo cikatwafwa ukwishiba no kuposako amino kumafya bana mayo bapitamo na bana bakwata ubulwele bwikata bongo bongo icakuti na bambi kuntanshi banonkelamo muli aya masambililo ukupitilla mukumfwikisha amafya bana mayo bapitamo nefyo bengafwilisha.

Bushe ndekabila ukuba mulimuku kufwailisha, nangula bushe kuti naleka inshita ili yonse?

Ukubulamo ulubali muli uku kufwailisha kufwile kwaba kwa kuipelesha mwebene, nga mulefwaya teti mubulemo ulubali. Lelo nga mwasalapo uku bulamo ulubali, kuti mwaleka inshita ili yonse. Nga cakuti mwaleka tamwakapelwe umulandu, nangu tabakakane uku mupako ifyo mulingile ukupoka.

Nga cakutula ninkwata ifipusho?

Apo uku kufwailisha kuletungululwa nab a Carol Singogo abali pe sukulu likalamba (University iya Western Cape). Nga namukwata ifipusho pa mulimo bakalabomba kuti mwa ba sanga pa University of Western Cape ku department ya physiotherapy, South Africa. Cell no +27767391387: email; 3080434@uwc.ac.za

Nga na mukwata ifipusho ifikumine imilimo iyi ne nsambu nga bamo aba bulilemo ulubali mukufwailisha, nangu pali ubwafya mwakwete elyo mwali muli uyu mulimo, kuti mwatumina ba

Head of department:

Pro.J.Phillips at

+277219592631;

email- jphillips@uwc.ac.za



Dean of faculty of community and Health Science:

Prof.R. Mpofu at +277219592631;

Email: rmpofu@uwc.ac.za

University of the Western Cape

Private bag X17

Bellville.

Uku kufwailisha kwalisuminishiwa na University of the Western Cape's Senate Research Committee Ethics Committee.

APPENDIX J: Interview guide

Opening question

How did you feel when you were told that your child had CP?

Psychological challenges

- i. How does it feel like being the mother of a child with CP?
- ii. Does the condition of the child affect you in any way?
- iii. In which way does it affect you?
- iv. If you are not affected in any way, could you please explain why?
- v. Have you accepted the condition of your child?
- vi. If yes, what made you accept the condition and if no, could you please explain why?

Physical health challenges

- i. What are some of the problems on your child with CP?
- ii. How would you describe the level of assistance you offer to your child because of his/her limitations?
- iii. Does assisting your child affect you in any way? If yes how are you affected?
- iv. Are there any parts of your body involved? If yes, please name the part of your body affected and explain how it gets affected

Socio-economic challenges

- i. What is the level of your education? If with a low level of education or without any form of education, what would be your reason for not attaining higher education?
- ii. Are you employed? If not how do you cope financial? If yes, how does the condition of your child affect your contribution to your family?

- iii. If you are employed does your salary sustain your needs and those of your child with CP?
- iv. Is your child on any social/disability grants? If not how do you cope financially?

Environmental challenges

- i. How would you describe your relationships with your friends, family and the community?
- ii. Do you get any support from your friends, family, the community and from healthcare providers?
- iii. How do others receive/react to the condition of your child?
- iv. What are some of the attitudes you experience from your friends family or the community?
- v. Have traditions or cultural beliefs affected you in any way?
- vi. How would you describe the environment that you live in?
- vii. Does your child move freely or is there anything in the environment where you live and elsewhere that affects the mobility of your child?
- viii. Is it easy for you to move your child from one place to another? If not, please explain why?
- ix. How does this affect you?

Marital challenges

- i. Has the condition of your child affected you relationship with your partner in any way? If yes, how has the condition of your child affected your relation?
- ii. Is your partner supportive? If not, how does this affect your relationship?

- iii. Do you find time to spend quality time with your partner? If not, does this affect your relationship in any way?
- iv. Have you and your partner accepted the condition of your child? If not, does this cause any conflicts between the two of you?

Lack of implementation of policies

- i. Does the government assist you in any way? If yes, in which way does the government assist you and if not, in what way would you like the government to assist you?
- ii. What do you understand by the term policy? Are there any policies regarding your children that the government is meeting? If not, which policies would you like the government to effect?



Challenges with the diagnosis of the condition of CP.

- i. How did you discover that your child had CP?
- ii. How old was your child when you discovered the condition of your child?
- iii. Where you immediately told the condition of your child or how long it did take before you were told of the condition of your child?
- iv. Was the condition properly explained to you and were you happy with the explanation given?
- v. How did you react to the diagnosis of CP on your child?

APPENDIX K: Table of themes and sub-themes

Themes	Sub-themes
Perceived psychological challenges	Perceived depression Perceived stress Perceived anxiety
Physical health challenges	Musculoskeletal challenges Physiological challenges
Socio-economic challenges	Low levels of education Unemployment Poverty
Environmental challenges	Social environmental challenges Attitudinal challenges Physical environmental challenges
Marital challenges	Conflicts Misunderstandings Divorce
Challenges with implementation of policy	Environmental policies Social policies Educational policies
Challenges with diagnosis of the condition of CP	Delayed diagnosis Misdiagnosis