



FACULTY OF COMMUNITY HEALTH SCIENCES

DEPARTMENT OF PHYSIOTHERAPY

**EXPERIENCES OF PARENTS REGARDING REHABILITATION OF THEIR  
CHILDREN WITH CEREBRAL PALSY IN KHAYELITSHA, CAPE TOWN, SOUTH  
AFRICA**

By  
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in the department of physiotherapy, University of Western Cape.**

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## ABSTRACT

Cerebral Palsy (CP) is a disorder that affects movement and posture and lasts throughout one's life span. It is often accompanied by disturbances of sensation, perception, cognition, and communication behaviours as well as musculoskeletal problems that lead to activity limitation and participation restrictions. Rehabilitation is recommended in the management and improvement of functions, promoting independence in CP cases. However, CP management brings about different experiences and challenges to children and families affected by the condition. The aim of this study was to explore the experiences of parents regarding rehabilitation of their children with CP in Khayelitsha Township, Cape Town, South Africa. The objectives of this study were to explore the positive and negative experiences of parents of children with CP encountered in rehabilitation management and explore their coping strategies. Permission to conduct the study was obtained from all relevant stakeholders and all ethics were observed. The study was conducted at Site B and Nolungile CHC in Khayelitsha. The researcher used an explorative qualitative study design an approach that seeks to understand social challenges of individuals and groups that experience a common problem. Purposeful sampling technique was used to recruit participants. Semi-structured interview guide and probes were utilized for interviews. The interviews were conducted by a research assistant due to the language barrier, interviews were audio taped and data were collected until saturation was reached. Data were transcribed verbatim, translated from Isi Xhosa to English, coded and analysed using thematic content analysis. The researcher applied the process of confirmability, transferability and credibility. The results showed that parents had experienced both negative and positive challenges. Negative challenges included socioeconomic, emotional, marital, wrong and delayed diagnosis and lack of hope and support structures. Positive challenges included rehabilitation and family support. The parents coping strategies included sharing groups and self-motivation.

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## ABBREVIATIONS

CHC	Community Health Centre
CP	Cerebral Palsy
FCA	Family centred Approach
IC	International Classification of Functions
NCPPDSA	National Council for Persons with Physical Disabilities in South Africa
WHO	World Health Organisations
UN	United Nations
UNDP	United Nations Development Program
UNICEF	United Nations Children's Fund
UWC	University of Western Cape



## APPENDICES

- A Ethical clearance letter from UWC
- B Approval letter from department of health South Africa
- C Consent form for participants in (Isi Xhosa)
- D Interview guide (Isi Xhosa)
- E Interview guide (English)
- F Information sheet (Isi Xhosa)
- G Information sheet (English)



## DECLARATIONS

I declare that “Experiences of parents regarding rehabilitation of their children with Cerebral Palsy in Khayelitsha Cape Town” is my work, and has not been submitted for any other degree or examination in any other University. Complete referencing has been made and acknowledged all sources used and or quoted.

Janet Modenyi Thoya



## DEDICATIONS

With very profound gratitude and appreciation, I dedicate this thesis to my husband Jackson Thoya and our three sons Jerry, Jesse and our 'special' Jimmy, without whom I would not have been in this profession today.

And to all families struggling with disabilities. Despite all the challenges they face, they still love and take care of their loved ones.



KEYWORDS

Challenges

Cerebral palsy

Disability

Experiences

Khayelitsha

Management

Parents

Rehabilitation



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## OUTLINE OF THE THESIS

**Chapter one** is a general description of Cerebral Palsy that includes the definition and its contribution to physical disability. It further contextualizes the importance of this study, problem statement, the significance of the study and the aims, objectives of the study.

**Chapter two** the literature review highlights all the essential issues that inform the current study, prevalence, causes, diagnosis and management of Cerebral Palsy. It further highlights both the negative and positive experiences of parents regarding rehabilitation and reviews the perceptions on Cerebral Palsy in paediatrics.

**Chapter three** discusses the methodology used in this study that includes; study setting, population and sampling, study design and instruments used, data collections methods and all procedures utilized to complete this study. It further discusses the data analysis and the ethical considerations in this study.

**Chapter four** presents a brief description of the main results of the study and the discussion. The demographic data and information on the parents at the three CHC facilities, their negative and positive experiences and coping strategies regarding the rehabilitation management of their children with CP. An interpretation of the current study is presented and compared with similar studies as per the current reviewed literature.

**Chapter Five** summarizes the study findings and presents conclusive information about the study. It further discusses strengths of the study and ends with study limitations and recommendations from the study. The chapter provides suggestions for further research in this area of the current study.

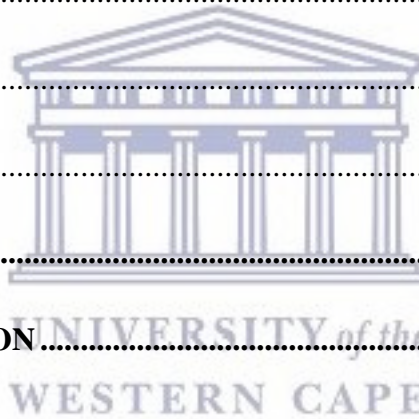
## TABLE OF CONTENTS

.....	i
<b>ABSTRACT</b> .....	<b>i</b>
<b>ACKNOWLEDGMENTS</b> .....	<b>ii</b>
<b>ABBREVIATIONS</b> .....	<b>iii</b>
<b>APPENDICES</b> .....	<b>iv</b>
<b>DECLARATIONS</b> .....	<b>v</b>
<b>DEDICATIONS</b> .....	<b>vi</b>
<b>CHAPTER ONE</b> .....	<b>1</b>
1.0 Introduction.....	1
1.1 Background.....	1
1.2 Problem statement.....	6
1.3 Rationale of the study.....	7
1.4 Research Question.....	7
1.5 Aims of the study.....	7
1.6 Objectives of the study.....	8
1.7 Definition of terms.....	8
<b>CHAPTER TWO</b> .....	<b>10</b>
<b>LITERATURE REVIEW</b> .....	<b>10</b>
2.0 Introduction.....	10
2.2 Classification of Cerebral Palsy.....	10
2.1 Aetiology of Cerebral Palsy.....	11

2.3	Clinical manifestation of Cerebral Palsy.....	12
2.4	Prevalence of Cerebral Palsy.....	13
2.5	Diagnosis of Cerebral Palsy .....	14
2.6	Management of Cerebral Palsy .....	15
2.6.1	Rehabilitation Management.....	16
2.6.2	Role of Physiotherapy.....	19
2.7	Experiences of parents .....	21
2.7.1	Effects of CP on the family.....	23
2.7.2	Accepting, coping and adaptation.....	24
2.7.3	Psychological challenges .....	24
2.7.4	Social – economic challenges .....	25
2.7.5	Rehabilitation challenges .....	26
2.7.6	Poverty levels in South Africa .....	27
2.8	Summary .....	27
<b>CHAPTER THREE .....</b>		<b>29</b>
<b>METHODOLOGY .....</b>		<b>29</b>
3.0	Introduction .....	29
3.1	Research setting.....	29
3.2	Research Methodology.....	30
3.3	Research Design.....	31
3.4	Population and sampling .....	31



3.4.1	Study population .....	31
3.4.2	Sampling frame .....	31
3.4.3	Sample size .....	32
3.4.5	Exclusion criteria .....	33
3.5	Data collection.....	33
3.5.1	Procedure .....	33
3.5.2	Trustworthiness.....	34
3.6	Focus Group Discussion (FGD).....	35
3.7	Data analysis .....	36
3.8	Ethics Consideration .....	37
3.9	Summary .....	37
<b>CHAPTER FOUR</b>	.....	<b>39</b>
<b>RESULTS AND DISCUSSION</b>	.....	<b>39</b>
4.0	Introduction .....	39
4.1	Table 1 Themes and Categories .....	39
4.2	Table 2: Demographic data details of Participants.....	40
4.2.1	Socio-Demographic data of participants.....	42
4.3	Theme 1: Negative experiences of the parents.....	46
4.3.1	Reactions of parents to CP diagnosis.....	46
4.3.2	Emotional challenges .....	48
4.3.3	Socio-economic challenges.....	55



4.4	Theme 2 Positive experiences of parents .....	63
4.4.1	Rehabilitation support.....	63
4.4.2	Family support .....	65
4.5	Theme 3 Coping strategies for the parents both positive and negative.....	67
4.5.1	Sharing groups and self-motivation.....	67
4.6.	Theme 4 Lack of hope and support structures .....	68
4.7	Summary .....	70
<b>CHAPTER FIVE .....</b>		<b>72</b>
<b>SUMMARY, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS.....</b>		<b>72</b>
5.0	Introduction .....	72
5.1	Summary .....	72
5.2	Conclusion.....	73
5.3	Significance of the study.....	73
5.5	Further Research .....	74
5.4	Recommendations .....	74
5.6	Limitations of the study.....	76
<b>REFERENCES .....</b>		<b>78</b>



## CHAPTER ONE

### 1.0 Introduction

This chapter includes the background of the study and aims at providing contextual information on the perception of parents regarding rehabilitation management of their children with Cerebral Palsy. It further presents the global experiences and challenges of parents of children with Cerebral Palsy and the rehabilitation management. The problem statement, research questions, aim and objectives of the study are presented.

### 1.1 Background

According to Pirani, et al, (2009) most childhood disability remains a challenge in developed and developing countries. There is an increase of infants born with disabilities and CP cases are on the rise further increasing the prevalence (Matthew, Dobbs, Nunley & Shoenecker, 2006). Cerebral Palsy is a disabling condition familiar to most social and health service professionals as well as members of the public. According to Bax, et al, (2006), Cerebral Palsy is defined as a group of non-progressive often changing motor impairment syndrome, and also as a disorder that affects movement and posture that lasts throughout one's life span. The writer further states that this condition is often accompanied by disturbances of sensation, perception, cognition, and communication as well as musculoskeletal problems that lead to activity limitation (Bax, et al, 2006). Cerebral Palsy definition remains elusive because it is not just a single diagnosis but an umbrella term used to describe the condition (Zeldin, Bazzono & Rotanawogsan, 2007). Rosenbaum, Paneth, Leviton, Goldstein & Bax (2006) defines Cerebral Palsy as a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement, muscle coordination, and balance. Cerebral Palsy affects the part of the brain that controls muscle movements causing activity

limitations that are attributed to non-progressive disturbances that occur in developing foetal or infant brain. The motor disorders of Cerebral Palsy are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour and by secondary musculoskeletal problems.

The current estimated incidence of CP is 2.0 –2.5 per 1000 live births worldwide (US Census Bureau, 2004). Impaired motor function is the climax of Cerebral Palsy. Many children have limitations in activities of daily life such as mobility, dressing, feeding and bathing and may also experience intellectual and sensory impairments. Other impairments secondary to CP could include seizure, communication, cognitive and perception disorders. Learning difficulties and behavioural problems are evident in most CP cases (Paneth, 2006). According to United Nations (2002), Cerebral Palsy accounts for 80% of disabilities in developing countries. In South Africa, CP accounts for 6.7% of the population living with disabilities (Census, 2011).

CP is known to have no cure, however, management of children with CP is very crucial to help them gain functions and promote independence. World Health Organization (WHO) model of health focusses on function and preventing secondary impairments while increasing the development capacity of a child (WHO, 2005). WHO (2005) further recommends the use of adaptive equipment e.g. walking aids, wheelchairs, sitting chairs, standing frames and many others to enhance independence in children with CP. The United Nations convention on human rights (2006) recognises the rights of children living with disabilities, advocates and promotes human rights and inclusion across all board in all sectors of the society including political, cultural, religious, and economic set ups. According to Rosebaum (2003) parents of children with CP undergo challenges of managing, adapting and adjusting to their children's condition, therefore, rehabilitation of children with CP requires an approach not limited to motor disorders but to include a developmental orientated approach that takes into consideration functional

assets. The writer further states that preventing secondary disabilities, promoting compensatory adaptations and principles of rehabilitation are a distinguished concept but interrelated in practice in the rehabilitation management process. For successful management of CP, the team should be of interdisciplinary approach (Murphy, 2003). This team may consist of the family members, rehabilitation specialist and other contributing professionals who have to develop a clear understanding of attainable goals. Early intervention promotes easy family adaptation and helps to attain development goals the writer further states.

According to Rosenbaum (2003), parental values and goals can form an important component of the management programme for their children with disabilities. The writer further suggests that management goals should be a combined effort between parents and health care providers. Developmental perspectives of parents go along with treatment and recommended goals which have so far been proven to be efficient and effective, the writer further states. Parents will likely follow the recommendations and treatment goals and needs of their children with CP. According to Becher (2005), CP is a long term condition that brings along challenges that parents and families need to resolve throughout their lives hence the need for a continued relationship between the parents and professionals as well as trusted counsellors responsible for the management process of children with CP.

The main challenge facing parents with children with CP is striking a balance between managing their children and other activities of their daily lives. In some cases, caring for children with disabilities can affect both physical health and the psychological well-being of the parents and have an impact on family income, sibling coping and acceptance, adjustment and family functionality (Shillitoe & Christie, 1990). Health care systems are leaning towards community and home-based settings, which in turn increases the burden of care to parents and caregivers (Talley & Crews, 2007). According to Gona, Munga'la-Odera, Newton & Hartley (2010), the task of caring for a child with disabilities exposes the parents to complex challenges.



Parents of children with CP experience various challenges which may include psychological, socioeconomic and environmental challenges. Other challenges may include marital problems, lack of hope and support structures regarding children with CP and delays or misdiagnosis of the condition of CP on the children (Borst, 2010; Tonga & Duger, 2008). Evidence suggests that caring for children with disabilities such as Cerebral Palsy, can lead to psychological distress (Resch, et al, 2010; Plant & Sanders, 2005 & Yurtsever, 2007). For instance, depression, stress and anxiety have been indicated as some of the psychological problems experienced by the parents of children with disabilities (Edward, 2009). Parenting children with disabilities is a demanding task which requires a significant amount of time. It can disrupt the social relationships of families and affect the chances of parent's employment (Borst, 2010; Brannen & Heflinger, 2006). In a similar way, parents taking care of children with disabilities are at risk of physical health challenges (Talley & Crews, 2007). Other effects of caregiving may include distress that affects the general health of parents. Distress is often associated with lack of sleep, poor dietary habits, risky health habits, and sedentary lifestyles (Ones, Yilmaz & Centinkaya, 2007).

The socioeconomic challenges arise from poor support structures. Parents have no support in terms of caring for their children with CP and have difficulties enrolling their children in regular day-care centers as most of these centers are not willing to accommodate children with disabilities, thus one parent especially the mother may be compelled to quit her job to take care of their child (Thyn, et al, 1999). Some of the parents have poor educational backgrounds which limits their chances of being employed leading to difficulties in finances and resources (Parish, et al, 2008). According to Eker & Tuzan (2004) mobility is the ability to move safely and independently and constitutes a fundamental part of activities of daily life of human beings, however, most of the mothers of children with CP face challenges often associated with a lack of environmental receptivity. CP leads to neurological consequences that result in a limitation

of mobility leading to dependency in the performance of activities of daily living in some children (Patla & Shumway-cook, 1998). Architectural structures within the built and non-built environments in most cases are not conducive for mobility of CP children, especially those using assistive devices (Verbrugge & Jette, 2004).

Another challenge faced by the parents of children with CP could be marital relationships. Marital challenges are on the rise due to both parents not meeting their marital obligations as expected (United Nations Development Plan (UNDP), 2007). The parents need extra time for their children with disabilities and are socially withdrawn often not having enough time for themselves, other siblings or their spouses (Emerson, 2003; Lawton, 2001). Moreover, parents of children with CP have little or no support from Government due to lack of good implementing policies for childhood disabilities (Camerot & Tveit, 2011; Flem & Keller, 2001). Another challenge is the safety of the children. Most parents neglect their children and expose them to abuse by relatives and neighbours. The children are exposed to harsh psychological and physical abuse (Paulucci & Violanto, 2004; Grocan, 2000).

Management of children with CP requires an interdisciplinary approach that includes physiotherapists, occupational therapist, speech therapists, orthotic experts, medical team and social workers (Patel, 2004). Physiotherapist work on the improvement of joint range, muscle strengthening, balance training to promote activities and prevent further disabilities (Signhi, 2004). Parents need support from the rehabilitation team and require their corporation and collaboration for a successful management of children with CP. Physiotherapists promote child-parent interaction programs that put parents at the centre of the rehabilitation process, guiding and promoting their response in the understanding of their children's needs, behaviour, and interests (Novac, Cusik & Lannin, 2009).

## 1.2 Problem statement

Cerebral Palsy has been classified as the most common sources of childhood physical disability and known to affect different people all over the world and the number keeps increasing annually (Erkin, 2008). CP diagnosis is a very devastating and traumatic experience to parents and can destroy a family set up. The news is shocking and often devastating especially when not properly communicated to an individual concerned, often leads to untold pain and suffering to the entire family. In African family set up, there are also a lot of cultural beliefs and people have all kinds of theories justifying why one has a child with CP or any other disabling condition for that matter. The parents and family face a lot of stigmas which increases their challenges in accepting, coping and adjusting to accommodate and care for children with CP. Psychologically, parents are affected and families need to adjust and cope with the situation. They face an increase in the burden of care that leads to an increase in parental stress and brings about depressive symptoms and decreased psychological well-being as well as anxiety disorders. Caring for a child with special needs poses challenges that include economical as these children need extra care, special diets, an extra care giver where both parents are working, specialised devices and equipment. Children with CP are often on long term medication and have to go through rehabilitation processes to assist them to achieve the delayed milestones. They go through grief in the process of accepting the disability status of their children and the burden of health care (Whittingham, 2010). When mothers give birth to their children they get news about complications that they experienced during birth and subsequent information that their children have a disability, they experience sadness, shock, and confusion. Parents are often referred to tertiary children's hospitals for further assessment and to confirm the diagnosis. These parents tend to have many unanswered questions and have difficulties adapting to the situation hence it is important that coping strategies are developed to help parents of children with CP manage their situation.

### **1.3 Rationale of the study**

The motivation for this study was due to the fact that the researcher has a child with Cerebral Palsy and her family went through challenges in accepting, adjusting, adapting and coping with their child's condition. The researcher also worked at Beit Cure children's hospital in Lusaka, Zambia and came across parents who had varied experiences in the rehabilitation process of their children with CP. The gaps identified were both negative and positive challenges parents faced, coping mechanism, emotional stress, and sustainability of the rehabilitation program, economic hardships and regular attendance. The rehabilitation processes are tailored to meet the needs of the children while the parents who bear the biggest burden of care are left unattended. In South Africa, children with disabilities are referred to different health care institutions for the management of their disabilities. Some parents get referred to community health care centres where they get follow up rehabilitation services for their children with CP. The transition of being referred from tertiary institutions to community health centres might have its own challenges due to the difference in management styles. There is less literature to prove that a similar kind of study has been conducted in Cape Town, South Africa, hence this motivated the researcher to conduct this study focusing on experiences of parents regarding rehabilitation of their CP children in Khayelitsha Community Health Centers in Cape Town in South Africa.

### **1.4 Research Question**

What are the experiences of parents on rehabilitation of their children with Cerebral Palsy in Khayelitsha, Cape Town?

### **1.5 Aims of the study**

To explore the experiences of parents regarding rehabilitation of their children with Cerebral Palsy in Khayelitsha.

## **1.6 Objectives of the study**

1. To explore the positive experiences of parents regarding rehabilitation of their children with CP in Khayelitsha.
2. To explore the negative challenges parents of CP children are facing regarding rehabilitation of their children in Khayelitsha.
3. To explore the coping strategies of parents of children with CP in Khayelitsha.

## **1.7 Definition of terms**

In this study entitled Parents experiences on rehabilitation of their children with Cerebral Palsy in Khayelitsha, Cape Town the terminologies utilized are defined below.

### **Cerebral Palsy**

Cerebral Palsy is a group of non-progressive but often changing motor impairment syndrome, a disorder that affects movement and posture and lasts throughout one's life span (Bax et al, 2005).

### **Challenges**

This term refers to a situation one is facing and requires great mental or physical effort to overcome (Online dictionary 2016). **Disability**

This an umbrella term defining activity limitation, participation restriction, impairments caused by an injury or disease influenced by both personal and environmental factors (WHO 2001).

### **Discrimination**

This term refers to treating people differently or bias against a person due to their circumstances or conditions (Online dictionary 2016).

### **Experience**

This is a general concept that combines skills and knowledge gained through involvement or exposure to a specific activity or an event and may be positive or negative (The Picker Institute, 2008).

### **Health Care Professionals**

In this study, the term 'Health Care Professionals' refers to all categories of health workers who are involved in the management of Cerebral Palsy at the health care facilities. According to online dictionary (2016), health care professionals are individuals who provide, preventive, curative, promotional, rehabilitative health care services in a systematic way to people, families and communities. These include; orthopaedic surgeons, neuro surgeons, medical doctors, physiotherapists, occupational therapist, speech therapists, counsellors and other community health workers.

### **Rehabilitation**

Refers to all actions and activities geared towards minimizing the influence of disability to an individual, facilitating social inclusions, independence, and improving the quality of life. Rehabilitation may include programs to re-establish functions, reduce functional restriction and improve function (World Health Organization, 2002).

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.0 Introduction

This literature review seeks to expand on the positive and negative experiences of parents regarding rehabilitation of their children with Cerebral Palsy. Studies drawn international and local will be used to support the arguments on the challenges and experiences facing the parents of CP and an evaluation of the rehabilitation process.

#### 2.2 Classification of Cerebral Palsy

Classification of CP is done according to the nature and type of motor disorder. According to Krigger (2005), the main type of CP is spastic that accounts for 80% and 20% between ataxia and athetoid. Spastic CP presents with increased deep tendon reflexes, tremors, muscular weakness, muscular hyper tonicity, toe walking and scissor gait (Ashwal, et al, & 2004). According to Flett (2003), dysfunction of spastic CP includes neuromuscular, musculoskeletal problems and abnormal movement patterns. There is evidence of neuromuscular problems, spasticity, dystonia, lack of coordination, loss of motor control and muscle weakness. Spastic CP manifests in hemiplegia, triplegia, monoplegia, diplegia, and quadriplegia. According to Bass (1999), ataxia is a rare type of CP estimated to affect 5-10% of all CP cases. This type impairs coordination and balance. It presents with a wide base gait and tremors, decreased muscle tone, inability to maintain stable postural position, head and neck muscle weakness (Taylor, 2005). Athetoid accounts for 10-25% of CP cases. It is characterized by slow writhing facial and all limbs movements but absent during sleep (Taylor, 2005). The tone fluctuates constantly between spasticity and flaccidity making positioning and postural control difficult.



According to National Council for Persons with Physical Disabilities in South Africa (NCBDDD), the most common type of CP in South Africa is spastic, it accounts for 77.4%, ataxia 13.5%, athetoid CP 5% and mixed CP accounts for 5%.

## **2.1 Aetiology of Cerebral Palsy**

The aetiology of CP is diverse, but the major causes may include congenital, genetic, inflammatory, traumatic and metabolic. According to Shankar & Mundukur (2006), 75% to 80% cases are due to prenatal injury and 20% due to birth trauma. These are common especially where mothers are not educated on the delivery process, hence it is important for both parents to have prenatal classes for information about growth and development of the foetus and be educated on possible dangers that they may be exposed to during this period. Premature births and low birth weights increase risks of CP as well as a decrease in gestational age and birth weight.

CP causes may remain unknown but there are certain factors that may predispose the incidents and occurrences. Some of the factors may include asphyxia or distress, premature births and new born babies that do not cry immediately after birth (Koman, Smith & Shilt, 2004). According to Lynch, Turner & Godwin (2007), prolonged use of recreational drugs by pregnant mothers may lead to damage of the central nervous and circulatory system of the foetus thereby predisposing them to CP. Premature births occur as a result of timing and body mass weight of the new born babies. Those that have a birth weight below 1500g are more predisposed to CP as compared to the ones born with 2000g birth weight and more (Nelson & Chang, 2008). The writer further states that maternal cigarette smoking is a known factor that leads to low birth-weight and may contribute to CP occurrences. However, Rosenbaum, Paneth & Levington (2007) states that the given factors do not necessarily translate to CP and further argues that even among the prematurely born babies have less than 90% chance of developing CP. There are other factors that are known to lead to CP like obstructed labour, prolapsed cord, and brain



malfunctions. According to Stanley, et al, (2000) post, neonatal challenges are often associated with injuries and accident and cerebrovascular accidents after surgery and other diseases e.g. malaria and meningitis. According to Croen, et al, (2001) congenital brain and cortical malfunctions that occur during the 1<sup>st</sup> and 2<sup>nd</sup> trimester of pregnancy often leads to central nervous and brain malfunctions. In a study done in Bosnia, Hegosvinia by Karabeg (2015) in Una Santa Hospital showed that 36 out of 56 children born with cord strangulation presented with different disabilities among them Cerebral Palsy. In South Africa, the incidents of CP are very high although there is no formal register/statistics available. However, a project was undertaken by Couper (2002) in Kwa-Zulu Natal reported that 10 out of 1000 children under the age of 10 years had Cerebral Palsy. World Health Organisation (WHO, 2005) report indicates that out of 18 million children in South Africa, 10% are diagnosed with significant neurogenic disabilities.

### **2.3 Clinical manifestation of Cerebral Palsy**

According to Thorogood (2001) classification of CP is mainly motor characteristic and the pattern of limb movements. Classification of CP provides nature of disability, severity details of the individual, and informs health care providers of the services and needs of an individual. It allows for comparison of different CP individuals in different places and monitors progress of these individuals (Bax, et al, 2004). CP has two major divisions, extrapyramidal and pyramidal. Pyramidal also known as Spastic occurs due to damage to the corticospinal pathways or upper motor neuro lesion and accounts for 70% to 80% of all CP cases. Spastic CP leads to cognitive impairments, increased muscle tone, hyperreflexia and persistent primitive reflexes (Thorogood, 2001). Extrapyramidal type of CP is damage to the nerve cells in the basal ganglia or the cerebellum and it presents with abnormal tone regulation and postural control and coordination challenge's and is further divided into Athetoid and Ataxia (Dorman & Pelligio, 1998). Athetoid accounts for 15% to 20% and

dystonia accounting for 5% of all CP cases (Rosenbaum, 2003). This is further categorized into motor characteristic that includes spastic, hypotonic, athetonia, dystonic and ataxia and limb pattern includes monoplegia, hemiplegia, diplegia, and tetraplegia and quadriplegia.

CP term may be used to describe a variety of motor and neurological disorders that can range from an individual with a single limb impairment to a wheel chair bound individual unable to perform activities of daily life such as bathing, feeding self, and dressing (Brehaut et al, 2004; Eunson, 2012). Children with CP usually present with other impairments which interfere with their daily lives functions which may cause them activity restriction and limitations more than the motor impairments usually associated with CP (Bax, et al, 2005). Other abnormalities associated with CP could be intellectual impairments which account for two-thirds of CP patients, and epilepsy which is common in about 50% of the CP children, severity varies from child to child (Ashwal, et al, 2004). There are other conditions like hyperactive disorder, learning difficulties, mental disorders, attention deficiencies present in CP children (Kriger, 2005). Neurological problems such as abnormal sensations, impaired hearing, hydrocephaly, swallowing difficulties, constipation have also been reported (Taylor, 2005). CP predisposes to conditions such as oral and dental decay, scoliosis, respiration infections and hip dislocation (Smith & Kurian, 2012). Co-pathologies in CP are common though not all of them are associated with specific brain injury, but are linked to neurological dysfunction (Taylor, 2005).

#### **2.4 Prevalence of Cerebral Palsy**

World Health Organization (2003) estimated that 12% and 10% of the population live with disabilities in developing and developed world respectively. Approximately 12% of children aged between 5-17 years are living with disabilities (Rogers & Avery, 1997). Another estimated 6.6 million children in the year 2000 were living with disabilities in the World (US Census Bureau, 2010). In a newsletter published in (June, 2014) from the “National Council for Persons with Physical Disabilities in South Africa, (NCPDPSA), children living with CP

come from rural, poor areas of South Africa and underserved and neglected groups. NCPPDSA, (2014) rates global incidents of CP between 0.2% and 0.3% and differ between developed and developing countries. Studies from South African have shown high incidents of CP between 1% and 8%. It is estimated that in Western nations, the prevalence of CP ranges from 1.5 to 2.5 per 1000 live births with minimal variations among these countries (Paneth, 2006). It is also estimated that out of the half a billion people are living with disabilities worldwide, 80% are from developing countries (United Nations, 2002). South Africa has 6.7 Million children living with CP (Census, March 2013). The prevalence of disabilities in children appear higher than for adults which further suggest that the 2001 census and the 2009 community survey under estimated the prevalences of children with disabilities in South Africa. Hence, available statistics show that 28% of children aged between 0 to 4 years, living with disabilities reside mostly in low-income set ups (Smith, 2000). According to Statistics South Africa (SA, 2003), the total population for children below 8 years is 17 million translating to about 1 million children living with disabilities.

## **2.5 Diagnosis of Cerebral Palsy**

CP diagnosis is a complex process, it takes time and there are no neonatal tests that can be done to confirm or rule out this condition (Sankar & Mundkur, 2005). The writer further states in severe cases of CP, diagnosis can be made soon after birth while in mild cases the diagnosis can take up to the first 2 years of the child life. In children with mild CP, diagnosis can only be done after 3 to 5 years of their birth when their brain is fully developed (Bax, et al, 2005). An early and timely diagnosis combined with management of CP is very crucial and it impacts the progress of the child greatly. However, a systematic approach of maternal, obstetric, prenatal and postnatal history is required as well as evidence of delayed developmental milestones accompanied by thorough neurological tests, examinations and observations (Sankar & Mukundur 2005). There may be a need for repeated tests and examinations and observations

over a period of time to confirm the diagnosis the writer further suggests. Parents of children with CP are often relieved when they are given a diagnosis of their children and have some hope and expectations as they begin treatment and rehabilitation process for their children (George, et al, 2007). However, Graungaard & Skov (2006) argues that CP diagnosis brings about new concerns and fears rather than certainty among parents of children with CP. Misdiagnosis of CP can be dangerous as it can lead to wrong treatment and interventions that may not be necessary exposing the parents to different challenges that they were not prepared for causing them confusion in understanding their children's condition (Tattersal & Young, 2006).

When parents are informed of their child's disability their reaction may be catastrophic (Hatton, et al, 2003). Parent's reaction vary but may be common, shock is usually the first reaction expected as all the parents' desire and expectations is to have a healthy and normal child (Skov 2006; Ho & Keiley, 2003). Some parents also experience anger, denial, guilt, unpredictable future and fear of the unknown (George, et al, 2007). Other emotional reactions for the parents may be applicable to other illnesses and disabilities and may be cross cultural and could be equated with the experience of mourning or grieving for a loved one (Huang, Ursula, Kellet & St John, 2010).

## **2.6 Management of Cerebral Palsy**

Cerebral Palsy cannot be treated but can be managed and use of interventions can help improve participation, integrations back to society, functional abilities and quality of life. The most successful management approach of CP is one that uses interdisciplinary approach drawing different expertise from various disciplines, family focus, and early intervention strategies (Liptack, 2005). A modern team approach gives focus to a total patient development as opposed to the improvement of single patient's presentations and symptoms (O'Connor, 2009). Treatment programs include physical, behavioural, pharmacology, surgical,

assistive technology and devices can be used to promote independence, improve the quality of life, and promote inclusion and participation in the society (Michaud, 2009). Such interventions can be made inclusive to involve the whole family (Kearney & Griffins, 2001). Rehabilitation is designed to improve the quality of life, improve adaptations, and increase participation of children with disabilities (Abdigoul & Gumuccii, 2000).

### **2.6.1 Rehabilitation Management**

Rehabilitation management of CP includes occupational therapy, physiotherapy, speech therapy, assistive devices and use of orthosis, corrective surgeries and medication (Kerem, 2009). The writer further states that recreational activities combined with comprehensive rehabilitation results into the improvement of the quality of life of children with CP and their families. Children with CP and their parents or caregivers benefit from family support, parental education, promotion of developmental and motor skills, interactions and supply resources (Mayston, 2005). They may also benefit from individual home programs and activities necessary to further improve the child's condition. Physiotherapist gives more focus on gross motor skills which aims to improve mobility functions that include walking, positioning, balance, posture control and seating with or without assistive devices (Kerem, 2009). Surgical interventions are recommended to prevent secondary disabilities, improve already existing milestones and promote further gains (Mayston, 2009). Surgical interventions in Cerebral Palsy may be necessary. A common surgical intervention widely used in CP management is dorsal rhizotomy that helps to reduce spasticity (Hordkinson 2001).

Nasogastric feeding tubes are part of the rehabilitation management of CP children. They are mainly used to manage children presenting with secondary conditions such as precipitation hypoxemia, severe vomiting temporomandibular joint contractures and pneumonia (Butler & O'Donnel, 2003).

Botulinum A (Botox) is a toxin based injection treatment with a formulation of botulinum that produces a protein that blocks the release of acetylcholine that relaxes the muscle and administered through ultrasound guide (Nelson, 2003). This injection is used in conjunction with physiotherapy to assist with the spastic limbs for CP children. Studies have shown that it helps reduce spasticity although it may have many side effects that are not clearly investigated (Kriger, 2006). Botox botulinum an intramuscular injection and bilateral tendon releases done surgically are widely used in the management of CP to improve function and increase mobility (Nelson, 2003).

Occupational, speech and language therapy are other interventions used in Cerebral Palsy management. Children presenting with the spastic type of CP and dyskinesia often suffer from complications such as drooling, dysphagia and dysarthria. According Schlaug, Marchina, & Norton, (2009) speech therapy improves swallowing and stimulates speech which in turn helps reduce feeding difficulties which are common in some children with CP. Combined with physiotherapy, occupational therapy helps promote independence and assist in improving functions such as independent sitting, walking, and general self-perceptions (Hayes, Lukas, & Schoendorf, 2008).

World Health Organization (WHO) model of international classification of disability and health (ICF) states that use of assistive devices helps to change the disabled person's perspective, improves their ability to perform tasks and helps in improving the society attitude towards that individual and facilitates inclusion (Hsu, Micheal & Fisk, 2008). Use of assistive devices often helps to facilitate function, compensates for impairments, manipulate and control the surrounding environment, increase independence and increase the ability to participate in activities. Orthoses devices are important in early stages of Cerebral Palsy rehabilitation management. These devices assist with the stability of the body. They can reduce the physical



disability which impairs mobility and improves gait and allows participation in activities of daily life.

Splinting and casting help to reduce muscle tone, improve joint range, positioning and specifically help to prevent the formation of contractures. This is done by a physiotherapist to help correct, improve and prevent secondary disabilities as well as maintain joint range.

Family centred approach is derived from Rogers (1940s) and is considered the best approach in early intervention of paediatrics rehabilitation in Community Based Rehabilitation (CBR), Clinics and Hospitals and is increasingly being adopted in many countries including North America, Asia and Australia (King, 2004). This approach is built on three principles, parents want the best for their children, families are unique and different and optimal functioning in a child occurs in a supportive family and community set up and acknowledges the importance of family (King, 2004). Bailey, Raspa, & Fox (2012) states that Family Centred Approach (FCA) utilises appropriate approaches that include set of value and attitudes. Therefore, rehabilitation of children with CP requires a developmental oriented approach that is not limited to the care of motor disorders only but takes advantage of functional assets. Rosenbaum (2003) states that parental values and goals should form an important component of the management programme for their children. The result of this approach in broad terms enhances the quality of life enhances community participation of children with CP and goes beyond just the emotional, cognitive and social physical functionality of these children (King 2000).

According to Health Care of Western Cape (2030) patient centred approach care includes the perception of the patient instead of processes in an organisational structure. This approach advocates for patients to be treated with dignity and respect, listened to and provided with information on their individual understanding and empowered to make informed choices and determine their treatment options. It further states that clinical staff manages their patients holistically by broadening personal care, family and community context considering their socio

economic status and addressing the patients concerns. This approach helps builds up a relationship of trust, increased compliance, improves the quality of care and brings out better health outcomes (Western Cape 2030).

### **2.6.2 Role of Physiotherapy**

Physiotherapy plays a key role in the management of Cerebral Palsy. It uses a child's potential and focusses on functional movements (Rosenbaum, et al, 2007). Physiotherapy utilises physical approach in maintenance and restoration of psychological social and physical well-being of children with CP (Bax, et al, 2005). Physiotherapy improves overall joint range of motion, improves muscle strength, and endurance, prevents secondary deformities, stimulates sensory organs thereby improving the well-being of children with CP (Patel, 2005). This is an important service in supporting families living with children with disabilities and empowers the family members in managing their daily lives and caring for their family member living with a disability. Physiotherapy can be incorporated in many aspects to be effective in the management of children with CP. The recommended approach is multidisciplinary team approach that has clear evidence based studies (Backheit, 2004).

### **2.6.3 Rehabilitation in South Africa**

South Africa is a developing country with more or less the same approach of Cerebral Palsy management as many of the African countries. The services are offered through a multidisciplinary team approach. The team mainly comprises of physiotherapists, occupational therapists, speech therapist, neuro surgeons, orthopaedic surgeons, psychologists, and paediatrician and other health care professionals. According to Levin (2005), this approach brings together different members of the rehabilitation team who work together for the benefit of the patient. The team members are a specialist in different areas addressing the different needs of the child with CP, but all promoting the well-being of the



child. This team of professional work in conjunction with the child family taking into considerations their concerns and priorities in the rehabilitation process. This approach has proven to be effective as it addresses the ‘patients’ needs holistically. According to Patel (2005), rehabilitation team members should come up with strategies that can help the children attain potential independence both at home and at the community level. The rehabilitation influence should not be restricted to the centre, but extended to the child’s home and school environment.

In most developing countries as well as in South Africa, patient centred approach is used to manage CP cases, according to health care (2030) of Western Cape patient care which includes the perception instead of processes in an organisational structure. This approach advocates for patients to be treated with dignity, respect, to be listened to and provided with information on their individual understanding and empowered to make informed choices and determine their treatment options, however not all rehabilitation service have adopted the above approach.

In family centred approach, therapist work with caregivers and parents to provide environmental support by establishing support groups in the communities (McConachie, 2000). South Africa is more advanced as compared to other African countries in the management of disabilities. According to Micheal & Ray (2008) the country has advanced technology in equipment’s such as voice output communication devices (VODC), powered wheelchairs, and another state of the art rehabilitative equipment’s in their state of art rehabilitation centres that help in promoting functionality and independence of the patients thereby improving their quality of life and reduces dependability on their families for basic function. This may boost the patient’s confidence and improve social interactions with other community members and general participation in other life activities.

## 2.7 Experiences of parents

Caring for children with disabilities at home can be very stressful and difficult as society expects these children to be cared for by their parents at home rather than in rehabilitation institutions (Chan & Sigafos, 2001). The writer further states that nurturing children with CP within home environment takes a major toll on the parents and may also have functional limitations to the children and impact on their quality of their life. A lot of emphasis is given to the quality of life and care for children with CP but less attention is given to the well-being of the parents. Brenahut (2004) states that parents of children with CP reported emotional distress, well-being, physical, emotional, health, marital stress and economic stress. The severity of a child's disability may determine the level of stress parents go through (Knusser & sloper, 1992).

Parents of children with CP experience shock immediately they learn of their child's condition, followed by denial, anger, guilt, indecision, shame, depression before they finally begin to accept and adapt to their status (Abdoglu & Gumuscu, Kearney & Griffin, 2001).

These mixed emotions and reactions often require professional handling and support. Parents of children with disabilities often report feeling isolated, lonely and depressed and not able to cope with their day-to-day challenges, and may have limited access to support services, such as peer support groups, counselling services and social networks (Mccubbin & Mccubbin, 2014).

When parents receive a diagnosis of their children's disability, the reaction is often catastrophic (Hatton, 2003). Every parent desire to have a healthy and normal child, hence the shock reaction (George, et al, 2007). Having a child with a disability often translates to parents shattered dreams of their 'ideal' child, the pain experiences may equal the loss of a loved one (Schmitke & Schlomann, 2002). Shock and disbelief is a commonly expected initial reaction after a CP diagnosis accompanied by crying moments, feelings of helplessness

and lack of response. In a study by Özsenol (2003) in Turkey, parents frequently experienced shock, disappointment, helplessness and hopelessness after receiving news of their children diagnosed with CP. Families suffer emotionally in the process of accepting their child's disability and experience depressive symptoms due to lack of strength to face the huge responsibility that comes with caring for a child with a disability and other related challenges (Abidoglu & Gumuscu, 2000; Wittert, 2002).

Denial is a manifestation of early stages of grieving and rejection of the diagnosis that leaves the parents seeking for a different or a better diagnosis for their children. It is viewed as a defence mechanism meant to look for inner strength and will power to accept and move on and buying time to be able to handle the harsh reality that disability brings along (Abdoglu & Gumuscu, 2007). Bargaining or 'fantasy thinking' is a period for parents with children with disabilities where they bargain with God and make promises or bargaining with clinicians if they can be assured of a significant improvement of their children's condition (Abidoglu & Gumuscu, 2007). Guilt is the theory that parents make up to justify the cause of their children's disability. It could be a belief that the disability is a form of punishment for past mistakes in their lives and they feel they 'deserve' the punishment of their children's disability (Schmitke & Schlomann, 2002). Studies done have shown that most of the parents feel responsible for their children's disability as they try to come to terms with the diagnosis as well as other emotional challenges (Foster, O'Brien, & McAllister, 2004; Godress, Ozgul, Owen, & Foley-Evans, 2005; Pelchat & Lefebvre, 2004).

Anger represents grieving and many parents of children with disabilities go through this phase with some of them wishing for the death of their children so they can overcome their present predicament and move on with their lives (Abidoglu & Gumuscu, 2007). Anger contributes to lack of acceptance of disability especially by parents, could be directed to someone who is not necessarily the source of their problem or could be in terms of asking

questions like ‘why us’ or sometimes directed to the child with disabilities (Abidoglu & Gumuscu, 2000; Schmitke & Schlomann, 2002). When most parents receive news of their child’s diagnosis with CP, they have difficulties accepting the diagnosis. They go through moments of anger, disappointment, and feeling of despair in the initial stages but managed to overcome the challenges through psychological support. Families of children with CP family have to make numerous adjustments to care for their child as well as adjust their general ways of life to accommodate and make their child comfortable.

In South Africa, the government has a policy that is aimed at supporting and assisting parents with children living with disabilities by providing them with a grant “Care Dependency Grants”. These grants are meant to assist families in meeting the needs of their children with disabilities but in most cases end up being the only source of income for the families and thus goes into many other uses. NCPPDSA (2014) is aware of the fact that caring for children with CP is an expensive venture due to their special needs that include special meals, visits rehabilitation centres, special devices, medical care, disposable diapers, hiring of nannies and other additional costs associated with caring for children with disabilities. According to NCPPDSA (2014) parents of children with CP have to contend with the challenges arising and provide care for their children’s activities of daily life. In studies conducted in South Africa previously, results have shown that less than 30% of children who need rehabilitation end up accessing the service. Despite the fact that rehabilitation services are offered for free many parents still experience economic challenges and are not able to afford transport costs to attend rehabilitation sessions, buy specialised equipment and devices for their children, and provide decent meals and other demands which arise in the process of rehabilitation.

### **2.7.1 Effects of CP on the family**

The birth of a child with disabilities changes family function as it's often accompanied by an unsuitable coping mechanism that leads to marital conflicts, family relationships and

professional relationships that lead to anxiety to families (Krstic, et al, 2012). When a child is born and diagnosed with a disability, the parents have to make numerous adjustments in order to provide appropriate care for their children (Ketelaar, 2008). Evidence available suggests that there is a variation on how parents and caregivers perceive their children's disability (Raina et al, 2004). While some parent's perceptions are stressful others are positive and are able to adapt and cope, some factors may contribute i.e. the number of siblings, occupation status of parents, and the age of the parents contribute and determine the level of parental stress (Wiegner & Donders, 2000). Studies have shown that mothers and fathers have different levels of stress with mothers exhibiting more parent related stress and fathers exhibiting child related stress (Wanamaker & Glenwick, 1998). Siblings of children with disabilities may react in different ways but mainly they show love, support, empathy, guilt, anger, embarrassments and resentment, and some may require counselling to accept and be able to cope (Burke, 2004).

### **2.7.2 Accepting, coping and adaptation**

Adaptation is not a single event but a multifactorial process that happens over time. At different stages of life, parents with CP children will have specific questions, worries as the burden of care increases. There's need for professional management on the coping adaptation capabilities to help identify the parental burdens, parental coping abilities and identify the risks of adaptation challenges. There is need to scrutinise the daily life experiences of the parents as they keep changing over time (Rentinck, et al, 2006).

### **2.7.3 Psychological challenges**

Several studies have shown that parents with children with intellectual disabilities experience higher levels of stress than those of normally developing children (Warfield, et al, 1999). Caring for these children exposes the parents to stress and depression related symptoms as compared to families with normal developing children (Hoare, et al, 1998). According to Blacher & Hatton (2001) parental stress, their interpersonal relations and negative

neighbourhood may impact the rehabilitation process of their children with disabilities hence the need to manage their stress levels and provide support structures for better functioning of families with children with CP.

#### **2.7.4 Social – economic challenges**

As it is with all disability cases, there's social stigma that continues to face families with children with CP especially in the African set up where people have justifications and explanations of disabilities. Many are advanced about how and why the child was born with disabilities, the family face discrimination and are isolated in the communities often viewed as a bad omen. Majority of the parents had an experience in this respect as some of the extended family members believed that there was something they did wrong to God and that someone had cast an evil eye on their child hence reason for presenting with challenges that CP brings about often suggesting traditional solutions as opposed to the recommended rehabilitation management. The social aspects of parents and families are compromised since there is no clear set out time for family interactions and themselves as a couple (Raina, et al, 2005; Mutla et al, 2003).

According to Rosebaum (2003), Cerebral Palsy is a long term condition that requires a continuing relationship between the parents and trusted professionals and counsellors tasked with the management process (Becher, 2005). Every child comes with a burden of care, education, and general support but a child with Cerebral Palsy brings along much more challenges, often accompanied by loss of income in cases where one parent has to quit employment to look after the child full time leading to loss of an income at a critical point (Fujiura & Yamaki, 2000). Generally, parents with children with disabilities face an extra burden of care especially in cases where long term and round the clock care is required and the parents have to offer or have to hire a nanny to care for their children. In addition to this, the children require physiotherapy services to, medical care, special education centres, specialised



equipment's e.g. wheel chairs, special seats and much more to help make their lives more comfortable and to help in milestone achievements. Families with children with CP often have financial difficulties, most of them living below poverty levels and can meet bare minimum requirements let alone care for a special needs child (Bailing & MccCubbin, 2001).

The situation in South Africa is not different. Disability is socially unacceptable and people have traditional beliefs that disability is a form of punishment from angered ancestors to the affected families (Levin, 2005). Society shuns families living with disabilities, mock them treat them as outcasts and avoid interactions with them. The writer further states that many families have broken up due to having a child with disabilities. The mothers of CP children are accused of causing their children's disability by their husbands and family members. The socio-economic status of the family plays a key role in increasing the incidents of CP since most of the mothers cannot afford prenatal care and proper nutrition, clean running water, sanitary access and generally inaccessibility of health care (Levin, 2005).

#### **2.7.5 Rehabilitation challenges**

People living with disabilities have long term intellectual, sensory, mental and face barriers that may hinder their full participation in the society hence the need for effective prevention interventions, treatment and rehabilitation that includes cost reduction interventions (Tomlison, 2009). These are challenges arising often in terms of accessing rehabilitation centres. These could be distance related or even affordability since not all centres provide free services and sometimes parents live far from the centres. Transportation can also pose challenges since most of these families live in the densely populated areas and wheelchair access may be limited. Public transport in most African countries is not designed for people with special needs or even wheel chair bound thereby becoming a great challenge. In a study conducted by Saloojee (2006) in South Africa, it established that out of 92% of the children in need of physiotherapy, only 26% got access to the services and out of the 85% in need of social grants, only 45% got

the funds. In the same study, parents reported a lack of money, lack of awareness and right knowledge and bureaucracy hindered access to rehabilitative services.

### **2.7.6 Poverty levels in South Africa**

A report by STATS SA (2011) indicate a drop in poverty rates but several reports indicate that many people are still affected by poverty especially people living with disabilities. The South African Constitution guarantees children and adults living with disabilities the right to free health care and basic education and a dependency grant of R 1600 approximately (120 USD) for all children with disabilities under the age of 18 years but unfortunately this is not being fully implemented due to lack of governments commitment (G. Saloojee, 2006). In a study by Barratt & Penn (2009) in Nkomazi municipality of Mpumalanga province of South Africa, poverty predisposes neonatal to disabilities. Mothers don't get access to prenatal care, lack of health literacy, good nutrition which exposes them to diseases that leads to disabilities in their children (Levin, 2000; Nutbeam, 2000). Other factors include lack of clean water, good schools, effective sanitation, housing conditions, access to health vaccinations, adolescence and childhood nurturing and adequate nutrition hence children from poor families are at a higher risk acquiring disabilities and chronic health conditions thereby imposing a burden of care on these families (Brorat et al, 2006; Hutcherson 1991).

### **2.8 Summary**

Based on the literature reviewed there is evidence that parents of children with CP face immense challenges. Right from diagnosis, the parents face challenges accepting, adjusting and coping with their children's condition and this leads them to experience anger, shock, denial and depression. However, with time, these parents learned to accept, cope, adapt and move on but other challenges come along such as psychological due to the increase of burden of care for their children. Parents faced social economic challenges due to the cultural beliefs in the society they lived in and lack of sufficient income to take care of their children needs.



Other challenges were rehabilitation related as the parents were not able to attend the clinics regularly due to lack of transport and sometimes affordability. Poverty restricted the parents from affording assistive devices that could have improved their children's condition and promote the delayed milestones.



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## CHAPTER THREE

### METHODOLOGY

#### 3.0 Introduction

In this chapter, the methodology of the study is described. The researcher utilized a qualitative study method to explore the challenges experienced by the parents of Khayelitsha, Cape Town South Africa regarding the rehabilitation process of their children with CP. The research setting, study design, sampling method, inclusion and exclusion criteria, data collection methods and analysis of the data are presented here. The conclusion of this chapter outlines the ethical considerations in the study.



#### 3.1 Research setting

This study was conducted at Khayelitsha, a township that has a build-up of brick houses and informal housing (so-called shack dwellings). It is described as an area that includes rapid urbanisation of the population from rural areas with an increase of youth mobility, widespread poverty, with a severe housing shortage (Johannes, 2002). Khayelitsha started when the apartheid government planned to move all Africans living near Cape Town city centre to areas further away from the city and suburbs. Khayelitsha is located approximately 26 kilometres from Cape Town city centre with a rapid population growth. It is estimated that in Khayelitsha, the population increase is 8.5% per year. Census (2009) estimated that Khayelitsha has approximately 300,000- 400,000 people. The population of this area is mainly the young urban dweller's Xhosa speaking people. Khayelitsha area has one government owned district hospital which was opened in 2012 with 24 hours' services. There are three Community Health Centres (CHCs), Site B, Michael Mapongwana, and Nolungile providing different services including

rehabilitation and some donor funded rehabilitation that support the needy especially children with special needs. The CHC offers a wide variety of services including, dental services, outpatient services, accidents and emergency units, HIV and AIDS clinics, well baby clinic, rehabilitation services, maternity service complete with a 24 hrs service to expectant mothers. These centres are government owned and managed by a medical officer of health with a competent team of medical personnel in every department. This study was conducted at the two of CHCs where rehabilitation services were provided namely Site C and Micheal Mapongwana. The rehabilitation departments were managed by a team of physiotherapists, occupational therapist, orthotic technicians and social workers. Services offered included rehabilitation therapy, counselling for mothers and home based training therapy, and the making of splints. The children were seen once a month on appointment and they were divided into groups of 6 mothers each session. The health team attended to the children and taught the mothers some of the exercises to take home and extend the rehabilitation services. The services offered here are free since this is a government policy to all its citizens.

### **3.2 Research Methodology**

According to Creswell (2003), a qualitative research method is an approach that seeks to understand social challenges of individuals and groups that experience a common problem. It is a process involving data analysis, emerging questions and procedures that build around general themes and interpretation of data.

This study used an explorative design through qualitative methods of data collection. The explorative design addresses a subject that is not well understood and often ignored such as negative and positive experiences of parents regarding the rehabilitation process of their children with CP. This study method is informal and flexible and seeks to identify environmental boundaries which bring about challenges and explores opportunities and salient factors which are relevant to the subject (Wyk, 2012).

### **3.3 Research Design**

The explorative study design was appropriate for this study as it took into consideration the positive and negative experiences and coping strategies of parents with CP children regarding rehabilitation of their children. In this study, the set up was informal and facilitated a relaxed environment for the parents and their children allowed a free interaction between researcher and the respondents. This allowed the parents to speak openly about their experience and enabled them to tell their story in their own style and language. Qualitative research has the ability to provide textual descriptions of people's experiences and provide information and gives a human perspective of the issues being addressed and expands on the emotions, opinions, behaviours, and individuals' relationship (Bless & Higson-Smith, 2000). This study design allowed participants to openly display their emotions and some of them broke down as they recounted their negative experiences and challenges they face in managing their children with CP. It provided an atmosphere that allowed free interactions between the researcher and participants thereby creating a conducive environment for the study. The researcher was able to achieve a greater depth and breadth of understanding the participant's experiences and views.

### **3.4 Population and sampling**

#### **3.4.1 Study population**

The population target for this study were all parents of CP children from Khayelitsha area attending the three CHCs rehabilitation centres for the management of their children in the past 3 months prior to the study. The parents had been seen at the tertiary hospitals and referred to these centres for rehabilitation services.

#### **3.4.2 Sampling frame**

Participant's details were obtained from the CHC registry department and the researcher planned to contact the parents via telephone. However, this method proved to be difficult since

parents were not willing to speak on the phone about their children. The researcher had to make a further appointment with the head of physiotherapy department in the three centres to meet the parents during their clinic days. With permission, the researcher explained the purpose of the study to the mothers and made an arrangement for the focus group discussions. Researcher targeted the clinic day to conduct the focus group discussions. All parents that were available on the clinic day and willing to participate on the clinic day participated in the study.

### **3.4.3 Sample size**

Based on purposeful sampling, 21 parents were selected to participate in the study. The selected parents were between the ages of 23 years to 60 years. The children ages varied between 1 year and 12 years. The focus group consisted of two groups with 8 mothers and one with 5 each picked randomly from the group. The research assistant explained to the participants the purpose of the study and was given the information sheet to read and familiarise with the conditions of the study. They were given the consent forms to sign and informed of their right to withdraw from the study at any point without any consequence, and that the information gathered was solely for the study purpose.

### **3.4.4 Inclusion criteria**

The sample included parents who were either married or single, employed and non-employed who resided in Khayelitsha, whose children were presenting with CP, and had been referred from the tertiary institutions to the CHC. The parents should have joined the CHC's CP rehabilitation programme and attended clinic regularly for a period of not less than 3 months or more prior to the study and their children were below 12 years of age and were willing to participate in the study.

### **3.4.5 Exclusion criteria**

The study excluded all parents married or single, employed and non-employed who had children presenting with other disabilities other than CP, children older than 12 years, those that resided out of Khayelitsha area, those who did not attend rehabilitation clinics regularly and those who were not willing to participate in the study.

## **3.5 Data collection**

### **3.5.1 Procedure**

The researcher was granted ethical clearance from the University of Western Cape and from the Department of Health in Western Cape before visiting the CHC to meet the head of the Physiotherapy departments explained the purpose of the study and sought permission to access patient's records. After accessing the records the researcher made telephone contacts with the parents but most of them were not willing to discuss anything about their children with a stranger on phone. This prompted the researcher to go back to the clinic and seek further permission to meet the parents during their clinic visits. Permission was granted for that and the researcher attended the next clinic and met the parents after the clinic session. The researcher recruited a research assistant to assist with the process of data collection due to the language barrier. The assistant was trained on how to conduct the focus group discussions and was familiarized with the study subject. She was taken through the interview guide and the researcher highlighted all the key aspects of the study. The research assistant explained to the parents the purpose and intentions of the study and got consent from all the parents who were interested to participate in the study and met her selection criteria. A venue was identified within the CHC premises and the focus group discussions were held there. Before the discussion started the parents were given the binding consent forms already translated and information sheets explaining the details of the study and given time to read and understand

the terms and conditions of participating in the study. The research assistant informed them of the use of the tape recorder during the discussion to store the conversation.

### **3.5.2 Trustworthiness**

Trustworthiness is the only way of establishing the truth in a natural, consistent and applicable manner in a qualitative research (Guba & Lincoln 1985). In this study, the process of credibility, dependability, transferability, triangulation and confirmability were followed. Below is a brief of the processes.

- Credibility was ensured through triangulation, peer debriefing, and member checking of collected data and by giving a rich description of the context (Morrow, 2004). Familiarity was developed by involving participants who were willing to genuinely take part in the FGD and probes were used during the interviews to ensure honesty from participants (Julien & Pecoskie, 2000). In this study, the researcher gathered information until saturation was reached. Member checking was ensured by taking back the transcripts and read the information collected to the participants to re-confirm if those were the true meanings of their expressions and feelings. The researcher involved a postgraduate student in the same department to assist in the data analysis process to further confirm the credibility of the study.
- Dependability is the reliability of data collected and seeks to address the changes in the data during the analysis process, a way of checking should the process be repeated would the responses and results be the same (Babbie & Mouton, 2007). This was achieved by giving adequate information on the participants and use of their verbatim quotes. All the data sources used in the study were from reputable authors and credible websites to further confirm the dependability of the study.
- Confirmability is the level of the finding of the study as being a product of the inquiry and not based on researchers biases (Babbie & Mouton, 2007). This process helps to



determine the interpretation, recommendations and conclusions are traceable and supported by the study (Baumgartner, Strong & Hensley, 2002). The raw data in the audio recorder was reviewed by the research assistant, then translated by two different language expert from Xhosa to English and back to Xhosa to reconfirm that the data was expressing the same meaning. The researcher read the translated transcript over and over again to familiarise and understand the content of the data. Data analysis process started by coding the quotes from participants and grouping the codes into the pre-existing themes and emerging themes.

- Triangulation; is the process of validating data through a process of verification from at least 2 independent sources (Bogdan, 2006). The researcher asked a colleague to assist with an independent analysis of the data for comparison and their results were almost similar further reconfirming the process.

### **3.6 Focus Group Discussion (FGD)**

Focus groups are small structured groups with selected participants, led by a moderator. The aim of FGD is to allow participants to share their positive and negative experiences as well as their coping strategies through group interaction. Groups had to be of standard composition in terms of size and purpose (Krueger, 1994). This method was recommended because it eliminates reluctant participants, and reduces discrimination of the illiterate participants, as well as the unresponsive ones too. A guide for the FGD was developed prior to the study based on the objectives of the study and literature review. The researcher used an assistant to assist in data collection (conduct the focus group discussions) due to the language barrier. The FGD had 8 participants in two groups and 5 in the third group. The venue of the study was organised at the CHC as they were suitable for the participants. Participants were provided with refreshments for them and their children before the discussion as they volunteered to participate in the study after a 2-hour session of the clinic. Prior to conducting the FGD, participants were

given information sheets that explained the study purpose in detail and were given binding consent forms to sign as a protective measure of information shared and as per the ethics requirements. Data collection was done using the tape recorder during the focus group discussions and notes were taken where clarity was sought. Permission to use tape recorder was sought from all participants and it was explained to the participants the process of keeping information in the tape recorders. The research assistant used an interview guide that was designed from the content of the literature available regarding the negative and positive challenges parents of CP children and their coping strategies with rehabilitation services. The questionnaire was translated in Isi Xhosa which is the predominant spoken language in Khayelitsha. The interview guide consisted of open ended questions covering all areas of the study as stated by Morris, et al (2007). The parents talked freely and told their story in their own way and style but the research assistant used prompts to keep them on track on the subject matter.

### **3.7 Data analysis**

The data analysis began with verbatim transcriptions after the interviews, the researcher engaged a fluent Isi Xhosa and English speaker to listen to the audio tapes and transcribed information verbatim from Isi Xhosa. Transcripts were then translated to English and back to Isi Xhosa by another professional translator then researcher went through the English transcripts several times to familiarise, understand the findings and context discussions. To ensure trustworthiness the transcripts were taken back to participants and read out to them for member checking and they confirmed the content as their true expressions and opinions. The researcher used an independent reviewer to go through the transcripts and analyse the themes independently. The results were then compared to researchers and they were similar thereby confirming the recommended process was followed. The data were analysed using thematic content analysis that is based on predetermined themes and emerging themes (Creswell &

Miller, 2000). Categories were used to refer to content, and codes were highlighted in different colours and then grouped together based on similar colours to form common themes. These pre-existing themes were then put together in line with the aims and objectives of the study and the emerging ones were grouped and established a pattern of presenting the emerging themes.

### **3.8 Ethics Consideration**

Ethics approval for this study was obtained from the University of Western Cape (UWC) Senate Higher Degrees and Research Committee. Further permission was granted by the Department of Health in the Western Cape Province. The Researcher was also granted permission by all the three CHCs where the study was conducted. The parents were given a detailed explanation of the study, given an information sheet to read that was translated into Isi Xhosa and binding consent forms that they signed before participating in the study. They were informed that the participation in the study was voluntary and informed about the use of a tape recorder during the discussions. The parents were assured of anonymity and were given codes as identification during the discussion and confidentiality was observed. The parents were informed of their rights to withdraw at any point of the study without any consequences and that information obtained from them was for the sole purpose of the study only. The parents who showed signs of emotional distress were referred to the social and counselling departments for further management. Results of this study will be shared with the relevant departments at the three CHCs as well as participating parents. The audio records were stored in a safe locker at the University and were only accessed by the researcher and the supervisor.

### **3.9 Summary**

The chapter described the research setting where the study was conducted and examined the approach utilized for data collection. The study design, study population, sampling method, study sample and instruments were well described together with the motivation for using these methods. The procedure for data collection and analysis were also explained. In conclusion,

ethical issues relating to the study were given before briefly touching on the reflexivity of the researcher.



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## CHAPTER FOUR

### RESULTS AND DISCUSSION

#### 4.0 Introduction

In this chapter, the results of the study will be presented and discussion of the results will be presented based on available literature. Demographic data table with a brief summary of the participants is also presented. The results seek to give the comprehensive findings in literature and narrative form. The data was analysed thematically into predetermined themes and emerging themes. The results and discussion sought to answer the aim of the study which was to explore the parent's positive experiences, negative experiences and their coping strategies regarding the rehabilitation process of their children with CP in the three CHC namely Site B, Micheal Mapongwana and Nolungile in Khayelitsha, Cape Town, South Africa. Identified quotes from the interviews with parents were extracted and presented in italics and inverted commas to separate them from the literature, and irrelevant material was omitted by use of (...).

#### 4.1 Table 1 Themes and Categories

The Table below will present the pre-existing themes and its categories, emerging themes and its categories arrived after thematically analysing the data.

Pre-determined themes	Categories
Negative experiences	Parents reaction to CP diagnosis,  Socio economic factors  Emotional factors  Environmental factors
Positive experiences	Rehabilitation support, Emotional support,
Coping strategies	Negative strategies  Positive strategies
Emerging themes	Categories
Lack of hope and support structures to parents with children with CP.	Lack of hope and support structures.

#### 4.2 Table 2: Demographic data details of Participants

The table below provides details of the participants in the study that includes their ages, gender, marital status, educational background, employment status, their children's ages and the respective clinic (CHC) attended for rehabilitation service.

Participants	Gender	Age	Marital status	Education level	Employment status	Childs age (years)	Childs age (months)	Clinics Name
M 1	F	37	Divorced	Grade 11	Working	4	0	Site B
M 2	F	34	Single	Grade 9	Not working	3	1	Site B
M 3	F	35	Married	Grade 11	Not working	4	0	Site B
M 4	F	29	Single	Grade 11	Not working	1	5	Site B
M 5	F	25	Single	Grade 10	Not working	5	0	Site B
M 6	F	35	Married	Grade 9	Not working	5	1	Site B
M 7	F	60	Divorced	Grade 5	Not working	5	1	Site B
M 8	F	23	Divorced	Grade 10	Not working	5	0	Site B
M 9	F	48	Divorced	Grade 12	Working	7	0	Nolungile
M 10	F	34	Married	Grade 10	Not working	8	0	Nolungile
M 11	F	26	Single	Grade 12	Not working	1.	9	Nolungile
M 12	F	29	Married	Grade 11	Not working	2	5	Nolungile
M 13	F	25	Single	Grade 9	Not working	7	0	Nolungile
M 14	F	36	Married	Grade 12	Working	3	2	Nolungile
M 15	F	45	Married	Grade 11	Not working	2	0	Nolungile
M 16	F	50	Divorced	Grade 10	Not working	7	8	Micheal
M 17	F	28	Single	Grade 9	Not working	7	0	Micheal
M 18	F	32	Single	Grade 11	Working	8	0	Micheal
M 19	F	38	Married	Grade 12	Not working	5	0	Micheal
M 20	F	40	Divorced	Grade 9	Not working	1.	5	Micheal
M 21	M	45	Married	Grade 12	Working	4	0	Micheal

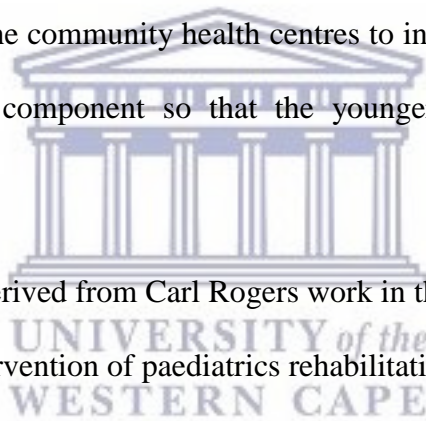


#### 4.2.1 Socio-Demographic data of participants

Table 2 above tabulates the socio-demographic data of the participant's characteristics as obtained from the respective CHC registries. This includes the participants, gender, age, occupation, marital status, the age of their children and the respective CHC attended. The CHC registries had no data available of fathers who attended or brought their children with CP for rehabilitation or even accompanying the mothers for moral support. There was only one father who on the day of the focus group discussion (FGD) discussion had attended clinic due to his wife being unwell, who fortunately agreed to participate in the study. He shared that ordinarily, he does not participate in the rehabilitation process but due to circumstances, he was forced to accompany his daughter to the clinic that day.

The sample size of the participants was  $n = 21$ . The parents were aged between 23 years and 60 years, therefore, their mean age of the parents was 35.9 years. Studies done by several authors present evidence suggesting that mothers can have children with Cerebral Palsy irrespective of their ages, levels of education and socio economic status (Resch, et al, 2010; Gona, Mugala, Odera, Newton & Hartley, 2010). According to Cohen (2010) between the parents, mothers bear the burden of care for their children with CP. Sen & Yertserver (2007) states that mothers of children with CP usually takes a leading role right from the time of diagnosis always relaying information to the fathers. This sets precedence for the fathers to feel less of experts in managing and participating in the rehabilitation process of their children with CP, thereby resorting to a secondary role. The mothers are forced to assume the sole responsibility of caring for their children, managing their rehabilitation process as well as taking care of other family responsibilities. This study had a similar outcome, out of the 21 participants in the study, only one was a father and who confessed that he brought the child to the rehabilitation clinic that day because the mother's child was not feeling well.

The experiences of the parents vary with age and studies have shown that younger mothers tend to worry not just about their children but also about their own challenges such as an opportunity to get married, advancing their education and career while the older mothers were more concerned with their children's physical conditions, focusing on the progress they were making and establishing financial independence (Sen & Yertserver 2007). In a study by Gona et al (2010) they used a wider age group (18 to 54) and the results indicated that the younger mothers faced more psychological challenges especially in peer acceptance as compared to the older ones who were more mature and had different focus and priorities. That was the case in the current study as the younger mothers were the most affected psychologically while the older ones tended to be more stable and settled often guiding and advising the younger ones. Therefore it is important for the community health centres to include a psychological support system in the rehabilitation component so that the younger mothers can be supported emotionally.



Family centred approach is derived from Carl Rogers work in the 1940s and is considered the best approach in early intervention of paediatrics rehabilitation in Community Based Rehabilitation, clinics and hospitals and is increasingly being adopted in many countries including North America, Asia and Australia (King, 2004). The writer further states that this approach is built on three principles, parents want the best for their children, families are unique and different and optimal functioning in a child occurs in a supportive family and community set up and acknowledges the importance of family (King, 2004). When both parents are involved in the rehabilitation process they will be able to accept the prognosis of their child with CP will have realistic expectations. The rehabilitation process empowers parents with knowledge, increases their resilience and master better-coping strategies.

In the current study, only the mothers were involved in the rehabilitation process. Most of the fathers had no connection and were not willing to participate in the rehabilitation process thereby placing a heavy burden of care on the mothers. It is therefore important to sensitize families on the importance of participating in the rehabilitation management of their children with CP for better outcomes.

The children ages varied between 1 year and 12 years, therefore, the mean age was 4.6 years. In this study, the children ages ranged between 1 and 12 years and they presented with different types of CP. According to Purgin (2007) challenges faced by parents with CP children vary with the age of the child and it's therefore difficult to compare their challenges generally. The writer further states that parents face different challenges at different stages of their children's development. At the early stages of CP diagnosis, parents face challenges of accepting, adapting and coping, and as the child grows and develops physically, other challenges set in including increase in the burden of care due to delayed milestones and the child's physical development making it more cumbersome to handle (Abidoglu & Gumuscu 2007). According to Burst (2010), parents view disability differently and this depended on the age of their children as this influenced their challenges. Such was the case in this study, as it was evident that the mothers with younger children had fewer challenges regarding the burden of care as opposed to the parents with older children. On the other hand, the parents with older children had fewer challenges in adaptation and coping processes since with time they had learnt to accept and cope with their children's disabilities. While it was easier for the mothers with younger children to carry them on their backs the mothers with older children were not able to carry their children on their back and often require use a wheelchair to facilitate their movements thereby exposing them to the transportation and weather challenges. This further emphasizes that indeed parents will experience different challenges according to their children's developmental stage and age.

In this study, it was evident that majority of the participants had no formal employment due to their low level of education and those that were employed had low paying jobs. This made it difficult for parents to meet the economic demands of their children and families in the process affecting their quality of life and that of their children and families. In a study by Resch et al (2010) results revealed that majority of the parents had not completed high school and those that had, did not have professional training and were from low income earning class with an income less than \$25,000 annually. Similar studies done by Parish, et al (2008); Murphy, et al, (2006); Ong, et al, (2005), all concluded that low level of education among parents with children with CP predisposed them to lack of employment and limits their employment chances and exposes the parents to lack of access to medical resources as well as socio education which could help improve their coping mechanism as they raise their children with CP (Ong, et al, 2005). Gona, et al, (2010) reported similar results in a study in Kilifi, Kenya that addressed the same topic. Singogo (2012) reported similar outcomes in a study done in Zambia with results revealing that mothers of children with CP reported poor education background as a key factor that contributed to the lack of employment opportunities.

In the current study, all the parents had less than high school education some citing poor family background that lead to their parents not affording to educate them and some reported dropping out of school due to teenage pregnancies. It is very challenging to get a well-paying job with low education levels. The few parents in the study who were employed worked as casual staff in low paying jobs and were unable to meet all the needs of their children's and families.

Poverty is a major factor in the areas of Khayelitsha where all the participants of the study resided. Coupled with the informal setup, the majority of people there are unemployed and were not able to afford the basic needs such as food, clean water, clothing and transportation, sanitation and specialized medical care. The results of this study showed that all the mothers

lived in poor conditions and were not able to afford good shelter and sanitation thus unable to meet the basic needs of their children. Most of them were unemployed and few of them had partners who either working in low paying jobs or unemployed were making it difficult for them to afford the basics of life. The single parents were most affected. Many had to depend on the government grant to cover the needs of their children with CP. In some cases, this grant was the only source of financial support which was hardly enough to sustain the child's needs let alone the family needs. In a study by Young (2004) most mothers of CP children in developed countries were supported by the government unlike their counterparts in developing countries who had to depend on their family support or the little grants offered by the governments. Sigongo (2012) highlighted in her study that mothers with children with CP were reported walking long distances to rehabilitation centres due to lack of cash for transport and often stayed away from rehabilitation due to financial difficulties. She further revealed that even the parents who worked received salaries that were not enough to sustain their needs, equally those who were self-employed were not able to sustain their business ventures due to insufficient funds and lack of access to bank loans. The unemployed parents were unable to meet the basic needs of their children as well provision of assistive devices which required financial means to acquire.

### **4.3 Theme 1: Negative experiences of the parents**

This section will highlight the negative experiences encountered by parents of children with CP in the rehabilitation management process.

#### **4.3.1 Reactions of parents to CP diagnosis**

When the participants were asked to share how they found out about their children's condition most of them reported that the health care professionals did not inform them of their children's

condition. They reported noticing on their own that their children had challenges while attending to them and observed that they were not developing as other children would normally do. A few were informed of their children's 'problems' but were given scanty information or vague information regarding their children's condition. The mothers expressed disappointment in the quality of health workers and felt that they were delayed to timely access rehabilitation for their children. Below are the responses from the participants:

*"I was told the baby had brain damage but will be fine with time and that he was going to develop slowly and may start walking at 4 years "* M 8.

*"I noticed on my own that my child was not sitting properly... they told me his muscles were very weak... He had water in the stomach and on his right side of the brain, and there was a gap on top of his skull."* M 6.

*"I was told by a doctor at maternity wing that my child had brain damage ... It didn't mean he was down and out and that I must be patient"* M 7.

An early diagnosis of CP combined with timely rehabilitation management is very crucial as it can impact the development progress of the child greatly. However, a systematic approach of maternal, obstetric, prenatal and postnatal history is required as well as evidence of delayed developmental milestones accompanied by thorough neurological tests, examinations and observations are required to effectively come up with CP diagnosis. There may be a need for repeated tests and examinations and observations over a period of time to confirm the diagnosis (Sankar & Mukundur 2005). Several studies indicated that some health physicians fail to give the correct diagnosis to their patients (Huang, Kellet, and St John, 2010; George, Vickerd, Wilkes & Barton, 2007). The writers' further states in cases where medical personnel choose



to give information it is not detailed enough for the family members to comprehend and understand the condition.

Some of the participants in this study shared the similar experience of not being given all details about their children's condition. According to Rannard, et al, (2005) parents of children with disabilities want to be given hope and certainty in the future of their children and commencement of rehabilitation and treatment. One study showed that “delays in effective diagnosis not only increased the parent's mistrust and dissatisfaction in medical personnel knowledge and skills but also aggravates their hopelessness and anger” (Ashwal, et al, 2004, pg. 255). This was the case in the current study. Most of the participants shared their negative challenges of medical personnel giving them a vague description or a wrong diagnosis regarding their children's conditions. It is therefore very important for the health care professionals to explain to the parents in details the process of CP diagnosis and help them understand and refer them to the necessary departments for further support and management.

Most of the mothers felt that it was the duty of the medical personnel to inform them of the correct diagnosis of their children and recommend further management. As a result of this misdiagnosis, the mothers had little faith in the competence of the medical personnel and some of them felt that their children were delayed in accessing the appropriate treatments and timely interventions. Some of the parents felt that the medical personnel were not fair to them because they did not disclose the true diagnosis and they were not adequately prepared for the 'bad' news and not given support to help them to accept and cope with the fact that their children had a disability.

#### **4.3.2 Emotional challenges**

All the participants in this study had experienced emotional challenges at some point that were related to stress, depression and anxiety. A few of them broke down during the discussion due



to various factors described below. Such participants were promptly referred to a social worker for further management.

#### **4.3.2.1 Depression Related Challenges**

Some of the participants exhibited signs relating to depression through regret, sorrow, self-pity, devastation, and loneliness, feeling sad all the time, and resorting to crying claiming it made them feel better. Some blamed themselves for their children's disabilities while others were not sure what the future held for their children and themselves. Below are the responses of the participants:

*"I was very sad, crying and asking myself why must this happen to me? What have I done to deserve this?" M 4.*

*"I cried a lot when I was told in future he was going to have problems ...it was bad news" M 2.*

*"Whenever I look at my child I feel sad and break down ...I can't imagine how her life will be like in the future" M 19.*

In studies done by Burning, et al, (2008) & Vijesh & Sukumaran (2007) mothers of children with CP had shown depressive symptoms. A study was done by Barlow (2006) in a developed country revealed similar results as most mothers in developing the world have no financial difficulties, therefore, focused on their children's development uninterrupted while mothers in developing nations cited depression due to the burden of care and socioeconomic factors (Mbugua, Kuria & Ndeti, 2011). A depressed mother will not strive to make any effort to improve the life of her child with a disability, leading to delays in the rehabilitation process or no rehabilitation at all (Cohen, 2010). The writer further states that these types of mothers vent

anger and resentment towards their children and may harm them and even wish death upon them. Researchers argue that some of the depressive symptoms exhibited by the mothers have no direct link to their children conditions or child to parent interactions (Mbugua, Kuria, & Ndeti 2011).

Results of this study showed that some of the participating parents had experienced depressive symptoms. They expressed sadness, self-pity, crying all the time and sorrow. They obviously lacked psychological support which was essential at this stage of acceptance and coping. Lack of sufficient knowledge of CP and its causes may have contributed to their self-blame since they were not aware of the actual causes. Some of them shared being left by the husbands to care for their children single handedly. Some of the participants shared their husbands left them due to the myth that they could have caused their children's disability. Mothers living with children with disabilities ought to be provided with rehabilitation support services that are all inclusive so they can benefit from services from all the team members support. The rehabilitation programs should include counselling and family support components to ensure the emotional stability of the mothers as they take full responsibility for caring for their children with CP.

#### **4.3.2.2 Anxiety challenges**

Most of the participants exhibited anxiety related symptoms. They were conscious of other people's reaction and comments towards their children and this brought them embarrassments. Some of the parents expressed having fear of the unknown as their children grew up not knowing what the future held for them. Some were scared of entrusting other people with their children fearing for their children safety. This is how the participants shared:

*“I cannot leave my child with anyone when I go out I wish I could go with him everywhere. I don't trust other people with him. He likes beating other children so other people won't understand him” M 6.*

*“I don't like the way people stare at us when we go out ...many times I have to cover my child so they don't see her ... the neighbour's gossip about us and I don't like it ” M 15.*

*“I don't know what the future hold for my son ... I'm not sure if he will ever walk or talk ...this makes me very sad ” M 11.*

In a study by Abdoglu & Gumuscu (2007) in Turkey, results showed that mothers of children with CP lived in isolation and were forced to abandon their other roles and concentrate on taking care of their children with disabilities. They feared reactions of community when out of their home environment with their children. Their interaction with the community was limited because people shun them and do not readily accept and support them. Anxiety leads to psychotic disorders, mental health problems and poor quality of life for the mothers if not treated (Quinn & Gordon, 2011). In the current study, some participants displayed anxiety related symptoms through worrying about their children's safety whenever they left them with other people. A study by Donovan, Vanleit, Crowe, & Keefe (2005), showed that the mothers with children with CP did not go for social functions, family members did not keep in touch with them and did not have time to go out with their spouse and children. Some of the participants shared similar challenges with experiences of neighbours talking about their children and avoiding to interact with them. They seemed not to trust anyone else and were worried that their children could be hurt while under other people's care. Some of the parents worried about the future of their children, especially the prognosis and education aspects, what the future holds for their children.

This study exposed the challenges participants faced that included lack of social interactions, community support, family support that can predispose them to anxiety related symptoms. There is need to have rehabilitation support systems that incorporate support systems for parents who exhibit anxiety symptoms and a system to refer them to the relevant professional for further management. There is need to sensitize the communities and extended family members on the need to accept, support and embrace families and the children living with disabilities.

#### 4.3.2.3 Perceived Stress by the parents

When the parents were asked how they were coping with the challenges of having a child with CP, some of the parents described stress related symptoms that included lack of sleep, anger, embarrassment, self-blame and being overwhelmed by their children's conditions.

Below are the responses from the participants:

*"Whenever someone visited, I would take my child to the bedroom and hide him... I even went at night to pick the wheel chair to avoid people seeing me ... I chose to live my life alone."* M

4

*"Having a child with a disability is painful, I blame myself and feel bitter that I may have done something that caused my child's disability"* M 1.

*"I always lock my child in the house and avoid questions from the neighbours and friends regarding his condition"* M 17

Studies have shown that mothers with children with disabilities experience high levels of anger unlike mothers with normal children. This is due to the pressure that comes with the high demand of caregiving responsibility for their children as well as taking care of other family roles (Cohen, 2010; Barbra, Chaud & Gomes, 2008, & Baker, et al, 2003). Most of the

participating mothers expressed undergoing pressure and were not able to cope with the stigma related reactions from family and friends. According to Vitaliano, et al, (2003), high-stress levels in mothers leads to psychological problems and may have an impact on their general health. In this current study all the participants were from a low-income bracket, therefore their stress levels would naturally be high due to their economic status and in addition to that, they had to deal with the harsh reality of their children disabilities that made their stress level worse. Results from studies in the developed world where parents of children with disabilities have free medical access, free assistive devices, good road network and social security grants proved that not all mothers with children with disabilities experienced stress related symptoms (Eisenhower, et al, 2005). A good number of the mothers participating in the study had challenges that increased their stress levels such embarrassment, denial, self-blame, and rejection.

There is a need for proper support systems for parents of children with disabilities that need to be included in the rehabilitation process such as counselling services, the formation of support groups, community workers who can reach out to these families in the communities. Community sensitization should be promoted to create awareness of people living with disabilities and the need to accept them as part of the community.

#### **4.3.3.3 Increased Burden of care**

Participants shared their experiences and challenges of combining the daily care of their children with CP, their siblings and other family responsibilities. Most of them shared having no time of their own, their other children and for their partners or spouses. Below are responses from the participants:

*“My child takes all the time I have. My other children don’t get any attention from me at all ... The only time I speak to them is instructing them to go to school, church, and eating ” M 6.*

*“My child takes all my time, I have no friends and I don’t visit any of my family members too ... we have limited conversation with my husband ” M 12.*

*“My child cannot be left alone cause of her condition. I can hardly get a chance for anything else I do all most of my work at night while she is sleeping ” M 17.*

According to Bumin, et al, (2008), Ones, et al, (2005) caregivers’ burden, chronic fatigue, negative social attitudes, social environmental issue and lack of implementation of policies on childhood disabilities cause high anxiety among mothers with children with disabilities. The above findings indicate the need to support parents in the task of caring for their children with CP to improve their quality of life as they execute the difficult task they are faced with. Talley & Crew (2007) state that if parents (mothers) are healthy and satisfied then the children will also experience better care and improved health. Caring for children with disabilities can be very stressful and difficult as society expects these children to be cared for by the parents at home rather than in rehabilitation institutions (Chan & Sigafos, 2001). The writer further states that nurturing children with CP within home environment takes a major toll on the parents and may also have functional limitations to the children and impact on their quality of their life. A lot of emphasis is given to the quality of life and care for children with CP but less attention or no attention is given to the well-being of the parents. Brenahut (2004) states that parents of children with CP reported emotional distress, well-being, physical, emotional, health, marital stress and economic stress. The severity of the child’s disability may determine the level of stress parents go through (Knusser & sloper, 1992). The writer further states the more severe the disability the more the burden of care.

In the current study results show that the parents were not coping with the demands of their children's care due to lack of support systems in the rehabilitation programs as well as extended family support. Some of the participant's challenges included lack of social interactions, community support, and family support. Some of the participants shared challenges with the severe conditions of their children making it difficult for them to leave them under the care of others thereby overwhelming the mothers with the burden of care. Therefore it's very important that rehabilitation programmes be made all-inclusive to increase support to the parents and families of children with CP helping them to cope and adjust to their predicament. Community sensitization should be incorporated to create awareness of the needs of families living with children with disabilities and structures to be put in place to support these families. The Government should establish a mechanism that can consider such parents for extra economic support since some of the children's conditions cannot allow the mothers to leave them unattended.

#### **4.3.3 Socio-economic challenges**

All participants in the study had gone through the socio economic challenges, some were due to lack of education, employment opportunities, high costs of living and poverty. Most of the mothers had high school education levels and none of them had a college qualification, a few had basic skills training, therefore, making it difficult for them to secure good and well-paying job.

##### **4.3.3.1 Lack of employment**

Lack of employment made it impossible for the parents to provide for their children needs. This was aggravated by the lack of family support to the parents in caring for their children with CP. Most of the participants in this study had experienced challenges in securing employment. Below are responses from some of the participants:



*“My child takes all my time. I cannot do anything when she is around... I cannot go out to look for work ... I’m struggling because I don’t have someone to leave her with” M 4.*

*“It’s not easy at all. I have no income yet I need a helper because, besides my child, I have to care for my aged mother. They both need my attention and sometimes I have to lock up my mother in the house to take my baby to the clinic” M 5.*

*“I had to quit my job because my sister whom I was living with refused to continue looking after my child ... now I have no money to take care of my needs ’ M3.*

Most of the parents in this study were unemployed due to lack of support from family members to look after their children as they went out to look for work and lack of support and acceptance from education centres where they could leave the children for daytime care. In developing and developed countries, education levels determine the chances of employment (Sen & Yurtserver, 2007). According to Gray & Edward (2009) parents were not able to combine employment with care giving responsibilities due to lack of support and understanding by their family members as well as employers. Lack of income impacts good health, therefore, there is need to empower these parents to be able to provide economically for their children with CP. Extended family members should offer these parents support in caring for their children so they can be able to engage in employment and other recreational activities. Governments should come up with day care centres where these mothers can leave their children under safe care as they go to work and attend to their other needs. This will empower the parents economically and can be able to meet their children needs and demands.

#### **4.3.3.2 Marital challenges**

Some of the married participants had gone through separation and divorce due to marital conflicts arising from challenges of having a child with CP and being blamed for causing their

children's disability. They shared their experiences and attitudes from their spouses and family members and being blamed for having the child with a disability. The participants exposed the lack of spousal support, denial and lack of coping mechanism. Below are the responses of the participants:

*"My Husband was most affected. He did not want to accept the situation ... He did not want anything to do with the child... he cried bitterly" M 7.*

*"My family supports me but his father did not accept that our child had a disability so he left me with the baby and I now live with my sister" M 5.*

*"My husband left as soon as he discovered our child had a disability. He blamed me for causing our child's disability" M 9.*

Studies have shown that there is a direct link between marital status, accepting, coping and adaptations of families with children with disabilities (McCubbing & McCubbing 1996). The writer further states resilience model of coping and adaptation assesses the stress levels in a family, coping mechanisms and family disruptions brought about by the responsibilities of having a child with disabilities. According to Hansson (2001), married parents were able to cope with the challenges better by utilizing spousal support, building the strength of each other, adapting to stressors in a positive and manageable way. The writer further states that economic stability, open communication, shared spiritual beliefs and flexibility are strengths that make coping easier for families. According to Doucette & Pinelli (2004), failed family relations make coping difficult for the parents faced with the disabilities. In a similar study by Martz & Livneh (2007) the findings indicated that unmarried and divorced mothers had difficulties coping and adjusting to the challenges as opposed to the married mothers.

In this study, the parents who were either divorced or separated had more difficulties in coping with their children disability than the married ones. The married participants shared that their husbands listened to them if they were feeling overwhelmed and offered emotional support while the divorced ones shared bitterness for being left by their partners and blamed for their children's disability. There is a need for creating awareness with in marital and family set up through counselling and creating awareness and educating couples on the causes of CP and other disabilities to help them accept and cope with their children conditions.

#### 4.3.4 Environmental challenge

All the participants in this study expressed their negative environmental challenge that included social, physical and attitudinal.

##### 4.3.4.1 Environmental Attitudinal Challenges

The majority of the participants in the study expressed some social and physical environmental challenges that included lack of family and friends support, isolation from society, and community. Below are responses from participants:

*“My Husband and his family support me but my sisters are hostile ...when we last visited them I overheard them say the cripple is occupying the space because he cannot sit on the floor” M 2.*

*“My family is judgmental more than the community by the way they treat us and the things they say... families are completely wrong most of the time.” M 6.*

*“I get support from my husband and family, but my neighbours don't treat us well. They fear to be associated with us” M 3.*

Most of the parents in this study had experienced negative attitudes from family, relatives and neighbours. These mothers reported hostility and ill treatment and negative reactions from the society towards them and their children with CP. Most of the negative attitude and reactions were from partners and families blaming the mothers and accusing them of being the cause of the disability. African cultural beliefs laid blame to the mothers of children with CP, families and society discriminates against the mothers and their children. In studies by Rosenweig & Huffstutter (2000) & Corrigan, et al, (2003) attitudes towards children with disabilities are always negative due to cultural beliefs. In the African context, mothers go through a lot of maltreatment in the name of cultural beliefs and shoulder the blame in cases of children born with disabilities. The accusation varies from mothers who were not in line with the traditional beliefs of having committed some 'sins' and beliefs that having a child with disabilities translates to punishment from the "cultural gods." Studies that were done in some African countries that include Uganda, Zimbabwe, Zambia, and Ghana all reported negative attitudes in the communities towards the children and families living with disabilities.

There is a need for the community members to be educated on the causes of disabilities and be sensitized on offering support, accepting and integrating the families living with disabilities as opposed to mocking them and treating them as outcasts.

Some of the participants shared their experience of negative attitude challenges from the health care professionals. Below are participant's responses:

*"They did not give me hope ... the doctor said if the child will live for 3 days it was a miracle, ... Later the doctor said if the child survived for the next hour he will know God is great ... after 3 weeks we were discharged from hospital "* M 4.

*“I stopped attending clinic because each time we attended clinic the nurses will say here comes the woman who has a child with a lot of problems... they kept us for long without attending to my child” M 11.*

*“She was not very nice to us at all, she didn't treat us well ... she was angry most of the time making therapy very unpleasant ... It is because of this reason I moved to this clinic.” M 7.*

Matziuo, et al, (2009) investigated health care professional attitudes towards children with disabilities, results indicated that nurses were insensitive and gave poor nursing services to children with disabilities. Another study that compared the attitudes of different health professional results showed that nurses had the least positive attitudes and that occupational therapist exhibited the most positive attitudes towards children with disabilities (Dorgi & Salom, (2009) & Tervo & Palmer, (2004)). In the current study, some of the participants had experienced negative attitudes towards their children by the health professionals. These challenges included lack of support, hostility and lack of empathy. This was displayed through the attitudes of the health care professional in the way the treated and handled the parents and their children with CP. Therefore there is a need for the rehabilitation team to show empathy, support and exhibit professionalism as they manage the rehabilitation programs of children with disabilities. The health care professionals should be equipped with the necessary skills including short term training in different management skills to enable them to offer the much-needed support to these parents. Efforts should be put in place to create a good atmosphere within the rehabilitation institutions to make the experience pleasant so as to encourage these parents to continue bringing their children for rehabilitation.

#### 4.3.4.2 Physical Environmental challenges

Most of the participants expressed challenges with the physical environment they lived in. These included lack of good access roads, changing weather patterns, poor structural patterns in their homes including narrow doorways, lack of sidewalks and wheel chair ramps. Their experiences included difficulties in using the wheel chairs, rude and inconsiderate public transporters and lack of appropriate transport means to accommodate their children needs. Below are responses from participants:

*“We struggle when it comes to transport ... I have been carrying him on my back taking him to catch his school transport on the road since he was 3 years... the passages in between the shacks are narrow the wheel chairs do not fit so I cannot push it through to the transport ” M 8.*

*“Last week I stopped a taxi on my way to the clinic when I was about to board it ... the driver started yelling that I should not damage the car seats with our wheelchair ... yet we have to pay for transporting the wheelchair ” M 10.*

*“Health net promised to give us transport to and from the clinics whenever we had appointments, been calling but no one picks the calls ... they should honour the promise they made to us” M 16.*

This study revealed that participant’s experiences negative experience brought about by geographical and architectural shortcomings in the environments they lived in. These shortcomings made movements difficult due to lack of proper road access, the presence of kerbs, no clear defined walk path for wheelchairs and narrow pathways. In this study transport was a common challenge, participants talked about the lack of public transport systems that could accommodate their children and the wheelchairs, lack of finances to acquire appropriate



assistive devices that conform to public transport like foldable wheelchairs. Moving to and from rehabilitation centres was a challenge as most of the public transporters were not willing to carry the wheelchairs since most of them were not foldable hence making it cumbersome to transport. A study by Donovan, Vanleit, Crowe, & Keefe (2005), the results showed that the mothers with children with CP couldn't move freely and rarely went out due to challenges brought about by transport systems and the environment not being wheelchair friendly. According to Palisano, et al, (2003) architectural restrictions which may be part of buildings, pathways, landscaping, ramps, narrow sidewalks, doorways, and heavy doors, debris on walk ways causing obstructions and may hinder movements. Geographical challenges faced by the mothers included difficulties in accessing rehabilitation centres due to transport challenges and affordability. The public transportation systems were not designed to accommodate people with disabilities thereby posing difficulties in mobility. In a study done in Kenya by Kormardjaja, (2000) mothers lacked moral and financial support, and had difficulties in accessing rehabilitation centres. The mothers in this study had difficulties accessing the rehabilitation department in the main hospital that was on the second floor due to non-functional elevators and no ramps were available. In a study by Grut & Ingstad (2006), the finding reported that in most developing countries, the majority of parents live in poor housing structures surrounded by uneven surfaces, rocky terrain, slopes that hinder the free movement of persons with disabilities especially those on wheel chairs. Some of the physical challenges the mothers reported were a lack of proper housing since most of them lived in shack dwellings, the structures were not friendly especially to those that used wheel chairs and the houses are small and they had big families thereby experiencing congestion and risk of contracting communicable diseases.

It is therefore important the sector responsible for road maintenance ensure that the access roads within these shack residential areas be upgraded to accommodate the wheelchair users.



Public transporters need to be sensitized about the existence of people with disabilities and need for supporting them to be able to access public places. The government need to intervene by ensuring that all the public transport are wheel chair compliant to accommodate the people living with disabilities.

#### **4.4 Theme 2 Positive experiences of parents**

Some of the participants shared positive experiences which they encountered during the rehabilitation of their children with CP. Among their positive experiences were the rehabilitation team, some family members, spouses and the governments support in form of a monthly grant given to families to support their children with disabilities.

##### **4.4.1 Rehabilitation support**

The majority of the participants reported that the health care professionals running the rehabilitation clinics were very supportive. They had positive experiences on the support the physiotherapist and occupational therapists offered them. The support included teaching them exercises to carry on rehabilitation process at home, nutritional advice, counselling services and encouraging them to attend clinic regularly. The parents were also happy with the progress their children were making and were able to appreciate the role of rehabilitation in improving the lives of their children with CP. Below are some responses from the participants:

*“My child has been helped since we started attending clinic here and I can say he is improving ... I’m impressed by the service ” M 3.*

*“The therapist teaches us how to conduct exercises on our children, corrects us where we go wrong and asks us to write down the procedure ” M 2.*

*“I felt very happy when I came to this clinic they have, physiotherapist, speech therapist, occupation therapist, and they advise us on the type of food to give to our children ” M 14.*

Rehabilitation management of CP includes occupational therapy, physiotherapy, speech therapy, assistive devices and use of orthosis (Kerem, 2009). The writer further states that recreational activities combined with comprehensive rehabilitation results into the improvement of the quality of life of children with CP and their families. Children with CP and their parents or caregivers benefit from family interactions, support provision of parental education, promotion of developmental and motor skills and resources supply promote motor and developmental skills (Mayston, 2005). These families may also benefit from individual home programs and activities necessary to improve and help in the child’s development. The recommended approach is multidisciplinary team approach that has clear evidence based studies (Backheit, 2004). The rehabilitation team may comprise of physiotherapists, occupational therapists, speech therapists, orthosis experts, doctors, nurses, dieticians and psychologists. This approach puts the needs of the patient first and directly work with the children and their families.

This was the case at the three CHS where this study was conducted. The rehabilitation team worked in conjunction with the parents of the children with CP. They involved them in drawing realistic goals in the rehabilitation programme and empowered them with the knowledge to support the rehabilitation process and to manage the home programs for their children.

Therefore, rehabilitation of children with CP requires a developmental oriented approach that is not limited to the care of motor disorders only but takes advantage of functional assets. Rosenbaum (2003) states that parental values and goals should form an important component of the management programme for their children. The result of this approach in broad terms

enhances the quality of life, enhances community participation of children with CP and goes beyond just the emotional, cognitive and social physical functionality of these children (King, 2000).

In this study, the parents who attended were rehabilitation services at all the three CHS had to access to more service that included physiotherapy, occupational therapy, speech therapy, orthotic, medical management and counselling services. They were empowered with skills that assisted them to take charge of their children's home therapy. The participants who attended rehabilitation services regularly reported improvement in their children's conditions. The medical team played their role by providing the necessary service required and empowered the parents to carry on the rehabilitation process at home. This further proves the theory of studies done by different writers that advocate for a multidisciplinary team approach. Therefore it is advisable to use a multidisciplinary approach in the rehabilitation management of children with CP.



#### **4.4.2 Family support**

Some of the participants shared how supportive their families and spouses were to them and accepted their children's condition helping them cope better with their situation. This gave them hope and encouraged them to hold on despite the challenges that disability brings along. Below are responses from the participants:

*"I get a lot of support from her father although he lives in Eastern Cape. It feels very nice when he calls to ask about the child especially when she is not well. I cope better because of his love and support" M 9.*

*“My family supports me and even offers to help with our child and my husband is very supportive he listens to me especially when I’m feeling depressed ... He provides for us financially too” M 20.*

*“My boyfriend supports me with our baby ...he can feed the baby, change the diapers and takes the baby outside” M 6.*

The family centred approach is considered the best approach in early intervention of paediatrics rehabilitation in Community Based Rehabilitation (CBR), clinics and hospitals and is increasingly being adopted in many countries worldwide. This approach is built on three principles, parents want the best for their children, families are unique and different and optimal functioning in a child occurs in a supportive family and community set up and acknowledges the importance of family (King, 2004). Bailey, Raspa & Fox (2012) states that Family Centred Approach (FCA) utilises appropriate approaches that include set of values and attitudes. Many studies have shown that despite the difficulties that parents and families with children with disabilities encounter many of them have accepted the conditions of their children (McCubbin, 2000; Patterson & Grawick 1994). In the effort of understanding family adoption and coping strategies McCubbin & McCubbin, 2004 introduced a model of family stress adjustment, adaptation and coping. This model was developed to explain the variations of resilience in different families dealing with CP explaining how one family may cope better than the other. In the current study, some of the parents reported that they were able to adjust and cope with their children’s disabilities due to various reasons while others found it difficult to cope thereby proving that the above-explained model can be used to support the parents and families living with children with CP.

In the current study, the participants who had spousal and family support were able to adjust and cope with their children’s disabilities better than the ones who had no family support. There

is need of the rehabilitation to utilize the family centred approach for better rehabilitation outcomes and in support of the parents of children with CP.

#### **4.5 Theme 3 Coping strategies for the parents both positive and negative**

##### **4.5.1 Sharing groups and self-motivation.**

Some parents shared how despite the social stigma associated with a disability they still managed to get on with their lives. In this study, some of the parents practised self-motivation and some formed sharing groups and met regularly after the clinic sessions to share their experiences, challenges and encourage one another. Below are responses from the participants:

*“I simply tell myself that she is my child, my burden and nobody can carry it for me ... I just stay strong and feel good ... an elephant doesn't leave its trunk behind because its heavy” M3.*

*“I keep on praying that God will allow my child to live long ... he kneads dough and bakes the bread” M 18.*

*“We are like sisters, we advise one another how to deal with our issues, encourage, listen, and learn from each other ” M 17.*

Disability is socially unacceptable and people have traditional beliefs that disability is a form of punishment from angered ancestors to the affected families (Levin, 2005). The writer further states that many families have broken up due to having a child with disabilities. This study exposed the challenges participants faced that included lack of social interactions, community support, family support. Most mothers reported experiences with social stigma, from some community members that were not supportive and would throw harsh comments and mock them regarding their children's conditions further aggravating their negative challenges. Social stigma remains a huge challenge for people living with disabilities, there is a tendency to judge and label families of children with CP. Society tends to judge and blame these parents for

having children with disabilities. Despite all these challenges and more, there are some of the participants decided to use self-motivation to help themselves cope with their children disabilities. Some of them used their religious beliefs while others used their vernacular proverbs for self-motivation thereby developing their own coping mechanisms.

In this study, the participants used their own initiative to form sharing groups that were managed and regulated by themselves. This initiative acted as a unity against their challenges bringing the participants closer and being able to relate with one another well. Despite their low education level, lack of support structures these parents managed to developed their own self-sharing groups where they shared their experiences, encouraged one another promoting a support system for one another and were able to develop coping strategies individually and as a group. This shows that there is a level of awareness and acceptance by the parents living with children with CP that they can be able to develop and manage their own coping strategies.

#### **4.6. Theme 4 Lack of hope and support structures**

Some of the participants in this study had experienced a lack of support structures from the rehabilitation programs that left the parents of children with CP with little or no hope at all. This made most of them lose hope for a good future for their children with CP. Below are some of the responses from the participants:

*“My son was allocated a child grant instead of a full disability grant, efforts to have it adjusted have are fruitless ... the grant is not sufficient to support all his needs” M 21.*

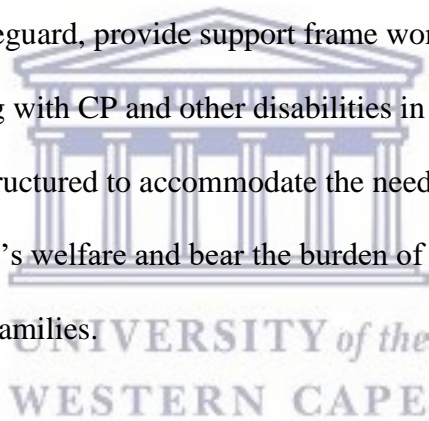
*“I’m requesting our government to give us small loans to start-up businesses so we can support our children and ourselves, our education level is low, we can’t find decent jobs, and we have no one to help take care of the children” M 9.*

*“I’m grateful for the grant offered by the government but I would like it to be increased ... it’s not enough for all the needs of my child” M 13.*

Parent’s experiences included lack of good support structures that included lack of sufficient grants, lack of provision of assistive devices, lack of suitable transportation systems, and lack of enough vacancies in the special schools and distance to the special schools. Some participants complained of discrimination in crèches that offered day care for children with disabilities and lack of acceptance or delays in being accepted. It is common practice that whenever a couple is blessed with a child with disability one of the parents have to quit employment to take care of the child thereby interfering with the economic stability of the family which is very crucial in the caring for the special needs children. UN (2005) convention for children with disabilities rights states that “the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms”. In a report by Human Rights Watch, ( 2015) an estimated five million children living with disabilities in South Africa, were locked out of learning institutions thereby contravening the policy on ‘complicit and inclusion’. South African government has failed to protect the rights of children living with disabilities due to widespread discrimination during the enrollment stage. Statistics have shown that in five out of the nine provinces, children living with disabilities faced physical discrimination and attitudes barriers by being classified according to their disabilities. According to UNICEF (2012), there are numerous policies in place to support people living with disabilities but the constant linking of the policies to national and provisional government planning process hinders the implementation.



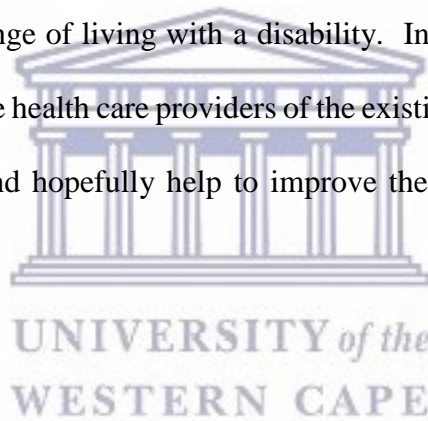
In the current study, there was an inadequate support to families of children with disabilities, the grants offered by the government meant were not sufficient to cater for their needs and provide for the required assistive devices which parent have to acquire privately. Some of the participants complained of discrimination in crèches that offered day care for children with disabilities through lack of acceptance or delays in being accepted. UNICEF report for (2012) has given guidelines regarding rights of children with disabilities but the South African government has not implemented most of the policies due to budget constraints and lack of priorities and proper planning and implementation. The report further suggests that South African government just like another African country has no structures in place that supports the parents of children living with disabilities there is a need for the government to come up with policies that safeguard, provide support frame work and provide equal opportunities to children living with CP and other disabilities in general. Rehabilitation management should also be structured to accommodate the needs of the parents as they are the back bone of their children's welfare and bear the burden of care, and charged with providing for their needs and families.



#### **4.7 Summary**

The results of this study elaborate the challenges that parents with children with CP encounter which varies from physical, emotional, marital, environmental, lack of policy implementation of policies regarding children with CP and diagnosis challenges. The parents worried about the future of their children and battled with the fear of the unknown for not being sure of what the future holds for their children. The parents suffered from stress, depression and anxiety related challenges. Most of them experienced economic challenges because they are unemployed hence not able to meet basic needs for their children with CP. Some of the parents suffered

from isolation and loneliness, had no support from extended family members and spouses, and were discriminated by the community due to their children disabilities. Some mothers experienced environment challenges especially the lack of access to buildings, roads and access to rehabilitations centres due to lack of proper roads and access and affordability of public transport to and from CHC. It was also evident that the South African government has failed in implementing the existing policies that were developed for people living with disabilities thereby making it difficult for families with children with CP. There were many cases of wrong diagnosis or delayed diagnosis, which could have led to an early ambulatory of the CP children and prevented secondary disabilities. The parents were not psychologically prepared for the news on their children's condition and were not given adequate support to enable them to adjust and cope with the new challenge of living with a disability. Information emerging from this study will be used to update the health care providers of the existing challenges and experiences of the parent's Information and hopefully help to improve the rehabilitation services in the identified gaps in this study.



## CHAPTER FIVE

### SUMMARY, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

#### 5.0 Introduction

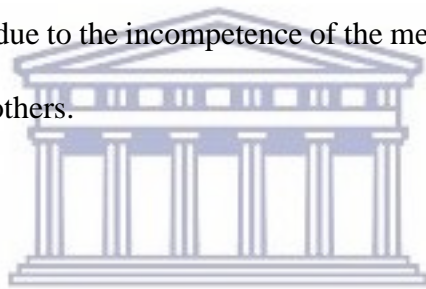
This chapter presents a summary of the study, in conclusion, recommendations, possible future studies and limitations of the study.

#### 5.1 Summary

This study sought to explore the challenges experienced by mothers in relation to the rehabilitation process of their children with CP at the CHC's in Khayelitsha, Cape Town in South Africa. The aim of the study was to explore the positive and negative challenges and the coping strategies for the mothers with children with CP. The areas covered by this study included physical, emotional, health, socio-economic, CP diagnosis, marital challenges and lack of implementation of government policies on disabilities. The researcher was motivated to conduct this study by the lack of evidence of studies in Cape Town regarding the challenges of parents with CP children and the fact that she is a parent of a child with CP. Hence, being aware of some of the challenges and the need to educate the concerned sectors of the said challenges in order to give parents of CP children more support.

The researcher used focus group discussion following a qualitative methodology. Participants were selected through purposeful sampling and 21 parents were identified and formed focus group discussions. The ages of the participants ranged between 22 years to 60 years, which gave a good variety of challenges faced at different ages. The children's ages ranged between 1 and 12 years, which gave the study an opportunity to explore the experiences at different ages. The study employed a thematic content analysis to analyze the data.

The results from this study identified the most common challenges experienced by the parents of children with CP included marital, socio-economical, environment, psychological, parent's reaction to CP, lack of government commitment. The socio- economic challenges arose from the lack of employment due to mothers having poor educational backgrounds and lack of financial support from families and the relevant authorities. The environmental challenges were due to discrimination, stigma, and rejection due to cultural and traditional beliefs and the geographical set ups that made it difficult for movements for the children. The psychological challenges included stress, anxiety and depression. Marital challenges were mainly due to separations and divorces, conflicts and misunderstandings among the couples. The lack of good support structures for families with children with disabilities exposed the mothers to financial challenges. Misdiagnosis was due to the incompetence of the medical personnel and partly due to lack of awareness by the mothers.



## **5.2 Conclusion**

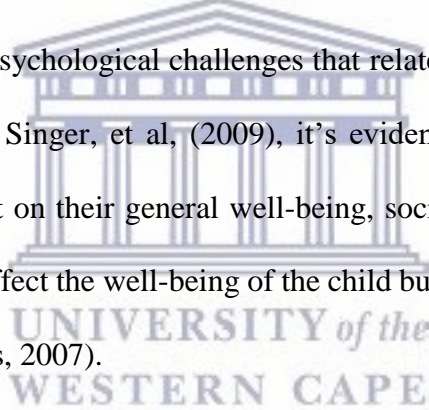
The study findings showed mothers are taking full responsibilities of caring for the children and that the fathers were not involved in the daily management of their children thereby increasing the mother's burden of care. The mothers struggled with social stigma from family members and community members and health care professionals. The mothers lacked support from their families, spouses and community members predisposing them to emotional challenges. Despite all the challenges, the mothers were able to care for their children and families at large, adapt and cope with their children conditions.

## **5.3 Significance of the study**

The aim of rehabilitation in CP management is to promote activity, independence, prevent secondary disabilities and improve participation amongst children with CP. The results of this

study will be used to facilitate an increase in the awareness on the management of CP amongst the service providers, at the three community health centres in Khayelitsha and the country at large. The results of the study will be used to enlighten the medical service providers and rehabilitation team on the different experiences of the parents that may help in improving their services. The parents will be enlightened on the importance of compliance with treatment requirements and may also be used in health care organizations in the execution of awareness programs at the community level about CP and its management in Khayelitsha and in the country as a whole. Finally, the results could be of value to other researchers intending to take up additional studies on CP management.

Results from this study demonstrate that mothers of children with CP experienced high levels of stress both physically and psychological challenges that relate to the burden of caring for a child with CP. In a study by Singer, et al, (2009), it's evident that caregivers and parents experienced a negative impact on their general well-being, socially, physical and emotional. These challenges do not just affect the well-being of the child but have a general impact on the whole family (Plant & Sanders, 2007).



## **5.5 Further Research**

1. Study policies and related concepts and effects of specific policy initiatives.
2. Identify needs of families with CP children and understand the challenges they encounter accessing rehabilitation services and health care.

## **5.4 Recommendations**

In developed countries, the well-being and health of the parents and caregivers of children with disabilities are a public concern and it is becoming increasingly important to provide family

support as a public health priority (Singer, et al, 2009). However, this is not reflected in the developing countries and particularly in South Africa, the study area. The government, medical professional, and the society, in general, do not seem to recognize the challenges families and especially the parents of children living with disabilities encounter. Based on the results of this study, the researcher would like to recommend the following:

1. Rehabilitation teams should introduce the family centred approach in CP management since the approach has been proven to be more inclusive. The rehabilitation process should be tailored to the family needs in consideration, address the family concerns and goals, provide support and build the capacity of the family in their child's management thereby reducing stress and anxiety. Therefore, it is recommended that family centred approach is used in all rehabilitation programs in South Africa in general.
2. Social support groups for families should also be initiated at the rehabilitation centres for families with CP children where they can meet other affected families and share experiences, interact and exchange ideas.
3. The South African government should implement the support grants and increase the amount they provide monthly and empower these families financially through small loans to start some income generating projects to promote their financial stability.
4. Professional counselling services should be incorporated to provide coping mechanisms since most of the parents had experiences with depression, stress and anxiety.
5. Sensitization and creating awareness of the causes of CP to the mothers, families and the public, in general, should be incorporated in the antenatal care and educate them on the risks that predispose them to CP and other childhood disabilities.
6. The South African government should make special provision for the day care centres that will accommodate children with CP and provide inclusive programs such as

education, rehabilitation and care for the children to allow time for their mothers to attend to other duties either social or economic.

7. The South Africa government should strive to implement the policies on children with disabilities as recommended and proposed in the National Disability Policy (NDP) Vision 2030 which states that:

- Persons with disabilities should be accorded equitable social rights that enable them to participate in the society. These include the right to education, social development services, healthcare, housing, sports, transport, recreation, food security, culture, and family life.
- Persons with disabilities must be accorded the right to exercise their economic rights among them access to resources such as capital infrastructure, finance, decent work.
- Children with disabilities are provided with a government grant that is not less than R1600 a month to support their daily needs.
- Persons with disabilities must enjoy the right to culture component in equality, dignity, nondiscriminatory and humanity.

## **5.6 Limitations of the study**

1. The study had projected to engage both parents of children with CP but unfortunately, only one father was available for this study thereby not able to give the perspective of the fathers.

2. The challenges experienced by parents in the low-income bracket, and with low education may not be similar with those of parents who are within the upper or middle earning bracket and well educated were not explored.





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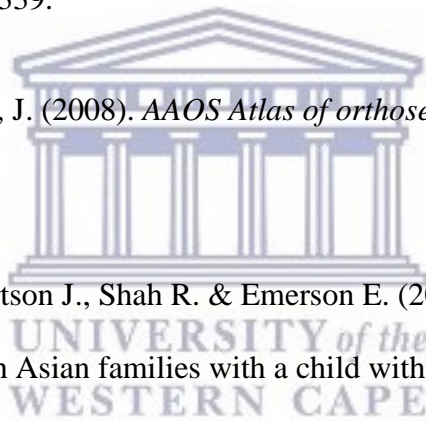
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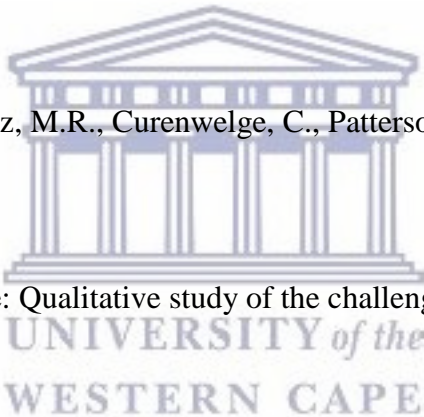
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16 August 2016

Mrs J Thoya  
Physiotherapy  
Faculty of Community and Health Sciences

**Ethics Reference Number** HS/16/3/28

**Project Title:** Experiences of parents regarding rehabilitation of their children with cerebral palsy in Khayelitsha, Cape Town.

**Approval Period:** 10 May 2016 – 10 May 2017

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

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

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

**PROVISIONAL REC NUMBER - 130416-049**



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ENQUIRIES: Ms Charlene  
Roderick

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University of Western Cape  
Robert Sobukwe Road  
Bellville  
Cape Town

For attention: Mrs Janet Thoya

Re: Experiences of parents regarding rehabilitation of their children with cerebral palsy in  
Khoyelitsho, Cape Town.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased  
to inform you that the department has granted you approval for your research.

Please contact following people to assist you with any further enquiries in accessing the following  
sites:

Khoyelitsho (Site B) CHC

Dovid Binzo

021 360 5207

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (annexure 9) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator



In the event where the research project goes beyond the estimated completion date  
which was submitted, researchers are expected to complete and submit a progress report  
(Annexure 6) to the provincial Research Co coordinator

3. The reference number above should be quoted in all future correspondence.

Yours sincerely



DU A HAWKRIDGE

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 31/10/2016.

CC:

M PHILLIPS

DIRECTOR: KESS





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Title: **EXPERIENCES OF PARENTS REGARDING REHABILITATION OF THEIR CHILDREN WITH CEREBRAL PALSY IN KHAYELITSHA, CAPE TOWN.**

### INTERVIEW GUIDE

1. When you were informed by the doctors that your child is having cerebral palsy, what was your reaction?
2. What is your understanding of cerebral palsy?
3. Explain to me the challenges that you experienced as a parent of a child with cerebral palsy.  
Probe: at home, within the family, in community, in a health centre
4. Tell me about challenges that you have regarding transport to go to CHC for your child's appointments.
5. Tell me about your experiences with rehabilitation at the CHCs visited.  
Probe: positive experiences and negative experiences
6. When you visited the CHCs how was the reception at the rehabilitation department?  
Probes: Welcomed, given appointment, waiting time to be attended
7. Explain to me how were you engaged in the process of rehabilitation of your child.  
Probes: shown handling techniques, shown exercises, given time to demonstrate techniques, spent time with the therapist, home programme



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### UMGAQO WOKUBUZA IMIBUZO

1. Ngethuba wawuchazelwa ngalo ngoogqirha ukuba umntwana wakho ukhubazekile ngokwasengqondweni okubona ngokungasebenzi komzimba (CP), waziva njani?
2. Khawundichazele ngokolwazi lwakho yintoni ukukhubazeka ngengqondo kubonakale ngokungasebenzi komzimba(CP)?
3. Khawundichazele ngeengxaki othe wanamava ngazo njengomzali onomntwana okhubazeke ngengqondo okubona ngokungasebenzi komzimba.  
Umkhombandlela: ekhaya, kumalungu osapho ngokubanzi, ekuhlaleni, kwiziko lezempilo.
4. Khawudixelele ngeengxaki zezothuthoothe wadibana nazo xa unedinga kufuneka uye ekliniki.
5. Ndixelele malunga namava akho onyango lokukubuyisela kwisimo sakho kwikliniki owawuyihambe.  
Umkhombandlela: amava amahle namava amabi
6. Ngethuba wawuhambe ikliniki wamkeleka njani kwicandelo lonyango lokukubuyisela kwisimo sakho?  
Umkhombandlela: Wawamkelekile, wanikwa imini omawuze ngayo, walindiswa uzakuhoywa kwangoko
7. Khawundicacisele wabandakanywa njani kwindlela yonyango lokukubuyisela umntwana wakho kwisimo sakhe.  
Umkhombandlela: waboniswa indlela zokuphatha umntwana, waboniswa imithambo, walinikwa ithuba lokunonisa imithambo yenziwa njani, walichitha ixesha nomnyangi, inkqubo yasekhaya



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Revised: December 2015

### IPHEPHA ELINENKCAZELO

**Igama loluphando lwenziwayo:** Amava abazali malunga nonyango olukubuyisela kwisimo sakho lwabantwana babo abanokhubazeko lwengqondo olubonakala emzimbeni eKhayelitsha, eKapa.

#### **Ingaba lungantoni oluphando?**

Olu luphando oluzakuqhutywa ngu Janet Mondeyi Thoya kwi Dyunivesithi ye Ntshona Koloni. Siyakumema ukuba uthathe inxaxheba koluphando ngoba unendima ebalulekileyo kwindima yokunyanga umntwana onokhubazeko lwengqondo olubonakala emzimbeni abuyiselwe kwisimo sakhe. Injongo yoluphando kukujonga amava abazali malunga nonyango olukubuyisela kwisimo sakho lwabantwana babo abanokhubazeko lwengqondo olubonakala emzimbeni.

#### **Yintoni endizocelwa ukuba ndiyenze ukuba ndiyavuma ukuba yinxalenye yalento?**

Uzakucelwa ukuba uthathe inxaxheba kwiqumrhu labantu abazakuthatha inxaxheba kuphando. Oluphando lwequmrhu luyathi lwenzeke ngexesha nakwindawo elungelene nawe. Ngexesha lolophando lwequmrhu ukuqoda kwakho neembono zakho zokukhuliswa kwezempilo luyakuthi luphandwe nzulu. Uphando lwequmrhu liyakuthi lishicilelwe.

#### **Ingaba unxulumana lwam noluphando luzakuba yimfihlelo na?**

Abaphandi bathathela kubo ukukhusela kwesazisi sakho nobume bolwazi olunikezeleyo. Sizakwenza konke okusemandleni ethi ukuze zonke inkcukacha zakho zibeyimfihlo. Ukunceda ukukhusela inkcukacha zakho asizolifuna igama lakho. Yonke inkoazelo oyakuthi uyichaze izakukhutshwa okanye igcinwe ecaleni kwindawo ekhuselekileyo. Onke amaphepha anemibuzo azakuthi agcinwe kakuhle kwikhabhathi etixwayo. Iyakuba ngumphandi nomlawuli phando abayakuthi babanelungelo kolu lwazi luqokelelweyo. Siyathembisa ukuba olu lwazi luyakusetyenziselwa olu phando kuphela. Xa lugqityiwe uphando lonke ulwazi luyakutshatyalaliswa kungabikho nenye into efanekayo malunga nophando. Ukuba kuye kwenzeka ukuba sibhale inkcazelo ngoluphando, inkcukacha zakho ziyakuthi zikhuselwe kangangoko. Ukuba abomthetho okanye aboqeqesho lwabucala bafuna olu lwazi, sizakubanika ukuba bayalufuna ulwazi ngakumbi ukuba lubhekiselele eluxhaphazweni lwabantwana okanye ukungakhathali okanye ukonzakalisa ngenjongo kuwe okanye kwabanye. Ngokwesihlo siyakuthi sikwazise ukuba saphule isivumelwano semfihlelo ukuzalisekisa inkxaxheba yomthetho sazise abomthetho. Esi sifundo siyakusebenzisa iqumrhu kufanelekile ngoko ubuwena buhlale bukhuselekile ngamaxesha onke.

#### **Bobuphi ubungozi obukhoyo koluphando?**

Bungaba khona ubungozi obuthile xa uzibandakanya koluphando. Xa usebenza ngabantu yaye uthetha ngawe okanye abanye abantu bungakhona ubungozi. Ukuba awuziva ukhululekile



sizakuzama ngandlela zonke ukukunceda ngokukhawuleza. Apho kufuneka uncedwe ngabanye abantu sakukuthumela kwabantu abafanele ukuba bayakunceda.

#### **Yeyiphi inzuzo ekhoyo koluphando?**

Inzuzo kuwe ibandakanya oku: olu phando lwenzelwe ukuncedisana nomphandi ukuvelisa indlela enokuthi yakhe kwindawo yokwazisa ngezempilo banzi nabafundisayo. Olu phando alwakhiwanga ukuze uzuze nto wena, kodwa iziphumo zalo zinganceda umphandi lo ukuba afunde nzulu ngamava abazali malunga nonyango olukubuyisela kwisimo sakho lwabantwana babo abanokhubazeko lwengqondo olubonakala emzimbeni. Sinethemba lokuba kwixesha elizayo, abanye abantu bangaxhamla kwesisifundo ngokuphucula ukuqonda ngokhubazeko lwengqondo olubonakala emzimbeni.

#### **Ndinyanzelekile ukuba ndibe koluphando kwaye ndingakwazi ukulandula ukulwenza nangaliphi na ixesha?**

Ukuzibandakanya kwakho koluphando kuxhomekeke kuwe. Ungakhetha ukungathathi nxaxheba kulo xa ungafuni. Ukuba uye wenza isigqibo sokuba uzakuzibandakanya koluphando, ungakwazi ukuphuma kulo nangeliphi ixesha ufuna. Ukuba wenze isigqibo sokuba awuzokuzibandakanya noluphando okanye ufuna ukuyeka, awuzokugwetywa okanye aphulukane nanto ubuzakuyifumana.

#### **Kungathini ukuba ndinemibuzo?**

Olu phando lwenziwa ngu Janet Mondeyi Thoya kwi Dyunivesithi yase Ntshona Koloni. Ukuba unemibuzo ngoluphando, ungaxhulumana no Dr Nondwe Mlenzana kwinombolo yakhe u 021-9592542 Private Bag x17 Bellville 7535 okanye [nmlenzana@uwc.ac.za](mailto:nmlenzana@uwc.ac.za)

Ukuba unemibuzo exhulumene noluphando okanye amalugelo akho njengomntu othathe inxaxheba koluphando okanye ukuba unqwenela ukubika ingxaki oye wadibana naye echaphazela oluphando, sicela uxhulumane no:

Head of Department: Dr Nondwe Mlenzana  
University of the Western Cape  
Private Bag X17  
Bellville 7535

Dean of the Faculty of Community and Health Sciences: Prof Jose Frantz  
University of the Western Cape  
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Olu phando lunikezwe imvume yikomiti ye Yunivesithi yase Ntshona Koloni necandelo lophando kunye nekomiti yokuqonda ukuba wonke umntu uphatheke kakuhle.



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## INFORMATION SHEET

**Project Title: Factors influencing the educational experience of international students at the University of the Western Cape**

### **What is this study about?**

This is a research project being conducted by Prof Julie Phillips at the University of the Western Cape. We are inviting you to participate in this research project because you are an international student at the University of the Western Cape. The main aim of this study is to investigate the factors influencing the educational experiences of international students at the University of the Western Cape (UWC). Understanding international student experiences from an institutional perspective is critical for improving your overall satisfaction and positive experience at UWC and possible enrollment of others from your country.

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

You will be asked to complete a survey. This survey will ask you to report on information such as age, gender, year of study and country of origin. In addition, you will be asked to report on interpersonal closeness you experience, perceived discrimination, homesickness, stress due to change, guilt, and your self-reported fluency of English, etc. The survey will take approximately 30 minutes to complete. You may also be invited to participate in a focus group discussion. These discussions will be conducted to further explore the factors influencing your educational/academic experience at the University. Issues to be explored will include amongst others difficulty in reading and writing in English at the postgraduate level; difficulty in adapting to an independent learning environment; pressures on academic staff; and your expectations of yourself. The group discussion will last approximately 45 minutes.

<http://etd.uwc.ac.za/>

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

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, the surveys are anonymous and will contain no information that may personally identify you. Participants joining the discussions will all sign confidentially forms to ensure that the information shared in the group discussions will be kept confidential too. Details of any information provided will be kept strictly confidential. Data collected will be kept in a pass worded computer and other saving devices. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

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

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?** Understanding international student experiences from an institutional perspective is critical for improving their satisfaction and ensuring their retention as well as enrollment of others from their country. International students frequently share their experiences and levels of satisfaction with peers in their home country, influencing the latter's decision about whether to study abroad. It is therefore important for the university to understand the issues that could influence the academic experience of students to establish measures to assist international students.

### **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 Prof Julie Phillips from the Department of Physiotherapy at the University of the Western Cape. If you have any questions about the research study itself, please contact me at Department of Physiotherapy, University of the Western Cape, Private Bag X17, Bellville 7535, South Africa or (021) 959 2542, email: [jphillips@uwc.ac.za](mailto:jphillips@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:

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



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