PSYCHOSOCIAL CHALLENGES EXPERIENCED BY CHILDREN WITH CEREBRAL PALSY AND THEIR FAMILIES IN MOSES KOTANE HOSPITAL IN BOJANALA DISTRICT, SOUTH AFRICA

BY

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LIST OF KEY TERMS

Child

Psychological

Social

Cerebral palsy

Disability

Society

Community

Family

Parent

Challenge

Abstract

The goal of the study was to investigate describe the psychosocial problems experienced by children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.

The study had the following objectives, in order to get more insight about the nature and challenges of CP:

- To identify the psychological and social problems faced by children with cerebral palsy and their families.
- To find out the social and emotional effects of cerebral palsy on children with CP and their families.
- To find out if there are any programs in place to address the problems and needs of children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.
- To investigate social work services provided to children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.

The aim of the study was to determine the social and psychological challenges that children with cerebral palsy and their families go through on daily basis. In order to achieve this goal, a qualitative research approach was adopted to investigate these challenges and to make people aware of them, with the aim that they will come to an end.

To this end, the in depth interview sessions which comprised of open ended questionnaire guided this cerebral palsy study. Purposive sampling method was employed to identify potential participants, and resulted in the recruitment of 10 children with cerebral palsy. These children attend CP clinic in Moses Kotane Hospital on a monthly basis. Semi-structured interviews held on one-on-one basis guided by the open ended questions contained in the interview schedule were used as a method to collect data.

The findings of the study confirmed that children with cerebral palsy do experience problems on daily basis. The study further proved that problems that children with

CP go through on daily basis also have a negative and direct impact on their families, particularly their parents (mothers).

The ultimate goal of the study was definitely achieved as it revealed the social and psychological challenges that children with CP goes through on daily basis. The study recommended that education be given to the society, particularly in rural communities on the importance of acknowledgement and acceptance of people with disabilities as people of worth and dignity, and to accept them as, and for who they are.

1. CHAPTER ONE: INTRODUCTION

1.1. Introduction

There are many children living with different kinds of disabilities throughout the world. These disabilities affect their psychological and social functioning in general. Amongst other disabilities, cerebral palsy (CP) is one of the most common disabilities that many children throughout the world live with.

Cerebral palsy is caused by a problem in the parts of the brain which control muscles (Coulter, Kynman, Morling, Murray, Grayson & Wing, 2015: 23). Cerebral palsy is also said to emanate as a result of the brain lacking the ability to perform its normal daily functions such as sending messages to the relevant body cells. This delays the body's ability to respond to its intended movements or functions.

Cerebral palsy has been highly topical, being the main subject of many good scholarly contributions. Some of the very eminent minds of the greatest writers of all times such as (Little, Rosenbaum, Bjoklund, Brehaunt and Russel), always had interest in examining the phenomenon further, with the intension to elicit more understanding of it. Other authors such as (Stanton, Shorvon & Andersmann) began to contribute some useful perspectives about cerebral palsy at the end of the 19th century, and thereafter many researchers started gaining interest from the medical field, to explore this health condition in a broader sense.

From the mid-1940s, the founding fathers of the American Academy for Cerebral Palsy and Developmental Medicine (Carlson, Crothers, Deaver, Fay, Perlstein, and Phelps) in the United States, and Mac Keith, Polani, Bax and Ingram of the Little Club in the United Kingdom, were among the leaders who moved the concepts and descriptions of CP forward and caused this condition to become the focus of treatment services, advocacy, and research efforts.

It has always been a challenge to define 'cerebral palsy' (Rosenbaum, 2006:8). Cerebral palsy (CP) is defined by Shorvon, Andermann and Gueriri (2011: 382) as a group of permanent disorders of the development of movement and posture, causing

activity limitations that are attributed to non-progressive disturbances that occurred in the developing infant brain.

It is the researcher's observation that children with cerebral palsy experience other psychological and social problems such as (stigma and luck of support) than the general population due to the virtue of their disability. They are often labelled and mistreated. This is because CP still remains a less known disability despite its historical background, which makes it difficult for the society to relate to a person with CP.

In their research, Olawade, Deigh&Yadaar (2013:159) explained that psychological stress associated with cerebral palsy is known to be one of the most pressing conditions of families. In the traditional society, some peculiar factors may contribute to the stress. In the very same study respondents agreed that having adequate knowledge of CP would help them cope with the demands of taking care of children with CP.

Lyons & O'Connell (2010:1-4) emphasise that CP children experience much pain and they are more likely to have emotional and behavioural difficulties than children in the general population, and that they take part in fewer activities than other children of their age. In addition, young people with disabilities who experience harassment in secondary schools are at the risk of achieving their goal of successful employment. The occurrence of harassment of disabled learners in special education can be frequent and severe. If that is the case, the question to be asked is: why will these students in transition feel that their experiences of harassment in school situations would be any less happy adults in the work-place (Holzbauer & Conrad, 2004: 113).

Children with CP are defined and judged by what they lack rather than what they have. This is the view of the report by UNICEF (2013:3) which adds that, CP children are often excluded in many activities that other children undergo, which serves to render them uniquely vulnerable, denying them respect and dignity, their individuality and often their right to life. This simply means that children with CP are often the marginalized and excluded group experiencing prevalent violations of their rights (UNICEF, 2013: 3).

Discrimination against CP children arises as a result of lack of understanding and knowledge of its causes and implications, fear of difference, fear of contagion or contamination and cultural views on disability (UNICEF, 2013: 3). Many people in the society do not want their children to associate with CP children. This can be as a result of lack of acceptance of CP children for who they are, because other people in the society have personal tendency of not appreciating people with disability.

Children with cerebral palsy (CP) usually experience problems with motor skills, muscle tone, muscle weakness, reflexes and balance. They normally experience cognitive difficulties because the damage has affected multiple areas of the brain. Muscle tone and motor skill impairments can also affect cognitive development. If a child has trouble moving independently, it might be difficult to participate in some of the typical childhood activities that foster learning (Gillette, 2009:4).

Due to varying degrees of the condition, children with CP often require greater involvement from their caregivers, as they have certain care needs that extend beyond those of others of the same age who do not have the condition (Guillamon, Nieto, Pousada, Redolar, Munoz, Hernandez & Gome-Zuniga, 2013:10).

There is much information on the medical aspects of cerebral palsy, as much research has been conducted on the field. There is a need for research on cerebral palsy based on the psychological and the social challenges that CP children experience. The study therefore aims to identify the psychological and social problems that children with CP and their families experience on daily basis. The focus of the study is on CP in Bojanala District, Moses Kotane Hospital in the North-West Province. The study will help to get a better understanding and knowledge of the problems that these children go through on daily basis, both the perceived and the assumed.

1.2. Problem statement

In the United Kingdom the number of children born with disabilities is said to be 1 in every 400 births, and approximately 1800 children are diagnosed with cerebral palsy every year (PACE, 2012:1). There is high prevalence of cerebral palsy in the United Kingdom. Even though there is high prevalence of CP in UK, the United States of

America seems to be topping the statistics of children born with CP. Statistics shows that it has about 10, 000 babies born with cerebral palsy each year, which is very high as compared to other developed countries (Collingwood, 2016:1). Collingwood further noted that the condition is 20 to 80 times more common among infants born weighing less than 3.3 pounds (1500 grams) known as very low birth weight (VLBW).

Worldwide, there are a number of people living with CP. Developed countries with sophisticated medical services are also experiencing CP. In Malaysia people with disabilities (PWDs) can be considered as one of the most vulnerable of the minority group in the Malaysian population. WHO (2011) estimated that 15% of the world population has some form of disability. According to the statistics from the Department of Social Development South Africa, the registered number of disabled people is 197,519.

Total 359,203 disabled people were registered with the Department of Social Welfare in December 2012. Rashid, as noted by Donald, Samia, Kakooza-Mwesige, & Bearden (2014:9) mentioned that the total number of disabled people in Malaysia is 305640. Among them, 27,363 are visual, 39,303 hearing, 180 speech, 106,252 physical, 117,699 learning, 2,130 mental and 12,713 multiple disabled people. Donald *et al*. (2014:9) continued to say that in Africa CP rates have been found to be even higher, with an estimated prevalence of 2-10 cases per 1000 births.

South Africa as a country of focus lacks enough statistical data on the number of children with CP. According to Cooper (2002:14) South Africa as one of the developing countries with a high number of children born with CP has an estimated number of CPs which is between 1% and 8% with more prevalence in less developed communities and rural areas. Islam (2015:299) believes that the number of people with disabilities is expected to increase due to population ageing, rapid increase of chronic diseases and improvements in methodologies used to measure disability.

Coming to the specific focus of the study, North West Province also has a high number of children with CP. The statistics within the North West Province on cerebral palsy was collected from Moses Kotane Hospital and Job Shimangane Tabane Hospital in Rustenburg, Bophelong Hospital in Mafikeng and Klerksdorp

Hospital in Klerksdorp. The total number of CP patients from these four hospitals is 547, with a higher prevalence in male patients.

This statistics are a prove that as opposed to developing countries, developed countries can still maintain the fast growing number of CPs, which leaves the countries with less sophisticated medical services vulnerable to CP. It is also said that in developed countries, a significant proportion of children with cerebral palsy are those that are born prematurely, because in developing countries premature babies are not being exposed to the sophisticated medical intervention needed for them to grow, develop and to survive.

Despite this high numbers of patients with cerebral palsy, there are few organizations, specialised health institutions and schools for children with special needs in the district. The situation is of more concern particularly in the Bojanala District, because there are inadequate resources and services available to address the needs of children with disabilities, specifically those with cerebral palsy.

Children with CP are faced with many social and psychological problems such and (social exclusion and stigma) and their family members and significant others are also affected by their problems. It is because many CP children are incapable of doing things for themselves and rely mostly on people who live with them.

The respondents to the study conducted by Olawale *et al.* (2013:159) agreed that having adequate knowledge of CP would help them cope with the demands of taking care of children with CP. Thirty eight point five percent (38.5%) of respondents said that people in the society accused them of some wrong-doing that has made their children to have CP. Personal problems experienced include loss of job, lack of concentration at work, loss of family joy, and derangement of financial affairs of the family. Twenty six of the respondents, which make fifty percent (50%), resort to religious or spiritual intervention as an alternative mode of treatment for their children, while 28% said to depend on the extended family system for support.

Viscardis (1998:12) believes that these families are required to deal with an alteration in the family dynamic which requires a modification of their activities with the increased burden of caring for a child who cannot adequately care for himself.

They also experience considerable stress associated with their concern for their child's future potential and prognosis.

On the other hand, the families of children with CP experience financial challenges, for them to get necessary equipment that enable them to comply with the medical needs for the child. The burden of the child's disability on the family needs to be scrutinised to see as to what needs to be done, particularly the changes that needs to be put in place, with the effort to accommodate the child, and to make him/her feel welcomed and at comfort within the family.

As it is understood, disability is not a problem; the only problem is the negative treatment they get from the community. Some children do not want to associate with them because they are afraid to get close to them, as they look different from them. These children are also influenced by the stigma they get from the community towards CP children and those with other disabilities. As a result, they also discriminate against a child living with a disability. The parents of CP children are also at times called names. Some community members accuse them of having done bad things which are the reason why they gave birth to CP children.

Disability needs not be an obstacle to success. Professor Stephen Hawking quoted on the report by WHO (2011:9) outlined that he had a motor neurone disease for practically all his adult life. Yet it has not prevented him from having a prominent career in astrophysics and a happy family life. Reading the world report on disability, he finds much relevance to his own experience. He has benefitted from access to first class medical care.

The environment has a serious influence on the experiences that children with CP come across, and to his or her extent of the disability. This implies that when the environment is more enabling for the child to function, it becomes easier for the child with CP to learn and develop different and necessary basics.

Malamulele (2006:1) points out that caring for a child with CP comes with many challenges and expenses such as regular visits to the clinic and hospital as well as special food that they have to eat. Many of them rely on their mothers/care givers for feeding, bathing, toileting and other things. Moreover, Brehaunt, Kohen, Raina,

Walter, Russell, Swinton & Rosenbaum (2004: 18) posit that caring for a child with disability often requires substantial resources, such as time and money.

Most children from poor rural areas with CP are the ones who are extremely neglected and underserved by the government. The researcher further adds that they are underserved, particularly in public institutions such as medical institutions. Parents/caregivers often take the children on time for routine health treatment at government institutions, but they are often left queuing for a long period of time without being attended. At times they even go home unattended at all.

According to South African Social Security Agency (SASSA), children with cerebral palsy qualify for disability grant from the state. The money is due to an individual just by the virtue of being born with a disability. When they benefit from the grant, the money is not utilised for its intended need. Most parents/caregivers of children with CP are unable to look for employment to support their families, because they are always looking after their children, as they require much attention on daily basis.

All these problems relate to the story of the American motivational speaker born with CP. Fentom (2010:1) of Mlive News reported that, “the United States motivational speaker with CP was left out at the United States Airways flight after being told he was too disabled to fly alone”. A forty seven year old Jonnie Tuitel of Grand Rapids Township, Michigan, told the Grand Rapids Press that he has probably flown over 500 000 miles to give motivational speeches, but he missed a speech because of the incident at Palm Beach International Airport.

It is an indication that people with disabilities are often criticized and discriminated, not forgetting that acceptance is also a problem to other community members. Even though they are born disabled, disability does not mean they are useless, but children with CP and other disabilities go through many problems and they are mostly angered by these situations, because they are at times seen as hopeless and useless people. These challenges are the rational which led to the formulation of the following research questions:

- What are the psychological problems experienced by children with cerebral palsy?

- What are the social and emotional effects of cerebral palsy on children and their families?
- What are the reactions and perceptions of the society towards children with cerebral-palsy?
- What are social work services provided to children with cerebral palsy and their families?

1.3. AIM AND OBJECTIVES OF THE STUDY

1.3.1. Aim

The aim of the study was to investigate and identify the psychological and social problems experienced by children with cerebral palsy and their families in the North West Province in Bojanala District.

1.3.2. Objectives

The following objectives were applied to attain the aim of this study:

- To get more insight about the nature, and challenges of CP through:
- Identifying the psychological and social problems faced by children with cerebral palsy and their families.
- Figuring out the social and emotional effects of cerebral palsy in children with CP and their families.

- To investigate if there are any programs in place to address the problems and needs of children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.

- To investigate social work services provided to children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.

1.4. THE SIGNIFICANCE OF THE STUDY

The outcomes of this CP study will add to the pool of knowledge for professionals involved in the interventions for children with disabilities. These include social workers, psychologists, speech and audio therapists, occupational therapists and nurses among others. The outcomes could also be useful in the following respects:

1.4.1. Knowledge

The study could help to advance the already existing knowledge on cerebral palsy. The study will also educate people who do not know much about cerebral palsy to learn about it and the different aspects relating to it.

1.4.2. Practice

The study could also help to develop better intervention methods when attending to cases of children with disabilities and their families. They will also develop skills suitable to bring sustainable change and improvement in the lives of people living with disability. The study will open a door for more criticisms towards CP through undergoing academic investigations and research to develop more ideas on how to better address the issues faced by people living with disabilities.

1.4.3. Policy

It is viewed that the study will help the policy makers both in the government and private institutions to develop better policies that will favour people with disabilities. It will also help improve the already existing policies and to work on the limitations that active policies have.

1.5. DEMARCATION OF THE STUDY

This cerebral palsy study falls within the field of clinical/medical social work. It was conducted in Moses Kotane Hospital in the Bojanala District (North West). It covers both formal and informal areas of Rustenburg. The study focuses on the people

living with CP, their families by investigating the problems they are faced with in the society.

1.6. ASSUMPTIONS

The following assumptions were realised by the study:

1.6.1. Children with cerebral palsy experience psychological and social problems due to their disability.

1.6.2. Families of children with cerebral palsy are also affected by the problems that the children with cerebral palsy are affected with.

1.6.3. The society has a negative perception and treatment towards children with cerebral palsy and their families.

1. 7. DEFINITION OF CONCEPTS

- ***Child***

Children's Act No. 38 of 2005 defines a 'child' is a person below the age of eighteen (18) years.

- ***Psychosocial***

According to Frederick (2000:4), the term psychosocial means the influence of social factors on an individual's mind or behaviour, and to the interrelation of behavioural and social factors. Psychosocial also refers to anything that is socially related that can affect the mind or brain, the emotions, thoughts and feeling that can affect or be affected.

- ***Social***

This term refers to the relation between the person and the "external" world, such as the interactions in the family, at work and in general in the socio-cultural environment (UN Refugee agency, 2010:12). The term social can simply refer to anything relating

to the environment within which an individual function. It may be the community or the society that an individual lives in.

- ***Societies***

A human society is a group of people involved in persistent interpersonal relationships, or a large social grouping sharing the same geographical or social territory, typically subject to the same political authority and dominant cultural expectations. Human societies are characterised by patterns of relationships (social relations) between individuals who share a distinctive culture and institutions; a given society may be described as the sum total of such relationships among its constituent members. In social sciences, a larger society often evinces stratification or dominant patterns in subgroups, as defined by Cram101 Text Book Reviews (2016:17).

- ***Cerebral Palsy***

Cerebral palsy (CP) is described as a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing infant brain, (Shorvon, Anderson & Gueriri, 2011: 382). The motor disorders or cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems, (Shorvon, Anderson & Gueriri, 2011: 382). It can be better understood as failure of the brain to perform its normal duties, affecting different parts within the body, such as the muscles.

1.8. Research methodology and research design

The research is qualitative in nature as it provides an opportunity for participants to express the social and psychological challenges and experiences of living with a child born with cerebral palsy within the family. The strategy used in the study is defined by Fouche (2002: 273) as phenomenological as it “aimed at understanding and interpretation of participants’ meaning that subjects give in their everyday lives”.

This study is of exploratory nature. It gave the researcher an opportunity to interpret data, with the intension of providing an in depth understanding of the experiences by linking various data obtained. During the process of analysing data, the researcher linked data gathered from the participants and the literature reviewed on the phenomenon studied, and came to a conclusion that indeed children with cerebral palsy and their families are mistreated and the most excluded minority within the communities.

The sampling procedure used was purposive sampling which forms part of the non-probability sampling procedure. It involves the selection of a sample for observation that is known to have the potential of providing the most comprehensive understanding of the subject studied (Rubin & Babbie, 2010:46).

The sample size of 25 respondents was drawn from the parents and caregivers of children born with cerebral palsy, coming from all villages and townships in Moses Kotane Sub-district. These participants are children who attend CP lessons in Moses Kotane Hospital in Ledig Village. The sample size was adequate for the purpose and the nature of the study.

Out of a total of 25 participants, only 10 participants did not withdraw from participating in the study. Number of 15 participants withdrew from participating in the study. Some made mention of transport challenges to reach the venue agreed upon and arranged for the interview schedules. Some of the participants withdrew participation in the study, because of the reasons that they did not feel comfortable to disclose.

The 10 participants were then interviewed using the semi-structured interview schedules. This method of data collection helped the researcher in the interview sessions to collect information using a set of predetermined questions. The questions also enabled the researcher to ask follow-up questions which vary among the respondents in seeking in depth experiences, views and perceptions of the respondents. This method of data collection also enabled the participants to relate to their experiences and their thoughts.

During the process of data analysis, the researcher evaluated whether the data acquired provided an answer to the research question. De Vos (2005:339) is of the idea that one must “search for alternative explanations and linkages to identify and describe these linkages and demonstrate why the explanation offered is most plausible. This means that the researcher must support with relevant justification the explanation provided, as the one that makes sense in answering the research question.

1.9. Theoretical framework

A theoretical background on cerebral palsy is presented in detail later in this study. This study relied on two theories to guide and give meaning to this research. Systems theory and strengths perspective were the two relevant theories adopted by this cerebral palsy study.

Systems theory guided the study to understand everyday functioning of the child with cerebral palsy. It explains how the child is able to cope within an ever changing environment which is the community that he or she finds him or herself living at; and how the child is able to connect to the family as a system and how the family is able to function with the child born with cerebral palsy. This theory also enabled the study to look into how the family was able to cope with the changes that the family faced after the family had given birth to a child with cerebral palsy. Cerebral palsy is known to be a life changing medical condition, which comes with many challenges. Therefore systems theory also guided the study in understanding how the family managed to emerge out of those challenges and how they have also managed to accept and accommodate the child as one of their own.

This obviously comes with strength, therefore the study also adopted the strengths perspective as another theory that looked into the strengths that the family has. Strengths perspective theory believes that, no matter how the situation may be like or the environment, there are still strengths to be looked into. The study also focused on the strengths that the family had, in accepting and coping with the life changing situation that the family had. The study looked at the strengths and coping mechanisms the family of a child with CP are employing to keep the family strong and going, despite the challenges the family experience from the community on daily

basis. The study explained in detail the relevance of the strengths perspective theory and the systems theory in the study in the later chapters

1.10. Limitations of the study

The study has only one major limitation which is the following:

The major limitation of this study was time constraints as the participants to the study could only be interviewed on Wednesdays during their visits to the CP clinic and during office hours. These times were in conflict with their schedules. To try and address the this challenge, the researcher organised with the occupational therapists that they shorten their sessions for two conservative Wednesday in order to accommodate the study interview schedules. This was not hard to achieve because the management of Moses Kotane Hospital were the study was conducted were aware of the study and concurred with the agreement.

1.11. Outline of the research study

- **Chapter one**

The chapter outlines a detailed introduction to cerebral palsy by defining what it is and the statistics of cerebral palsy worldwide. CP was also defined and explained by different authors. The problem statement that resulted in the researcher undergoing this cerebral palsy study was also explained in detail. The research questions that were influenced by the problem statement were also outlined in the chapter. Aim and objectives of the study as well as the significance of the study were also outlined in detail. This chapter stated how the study was demarcated. The assumptions of the study were stated and at the end the key concepts that were used throughout the study were defined clearly.

- **Chapter two**

The chapter provides a review of relevant literature in relation to the study topic, the psychological challenges faced by children with cerebral palsy and their families. The chapter also makes a presentation on an overview of CP, its aetiology, violation of the rights of people with disabilities, different types of cerebral palsy, its causes,

family's reaction after discovery of the child's condition, the factors related to caring for a child with CP. Diagnosis of cerebral palsy, looking at CP worldwide, in the continent and in South Africa, and lastly the social impact of CP on the victim (a social work's perspective) is also presented.

- **Chapter three**

The chapter outlines the research methodology that was used in the research study. This includes the discussion of the research design, the approach that was followed to address the research questions. The chapter also describes the population of the study and the method used to select the population, the method of sampling used, the type of sampling, and the sampling size. The method used to collect data is outlined, as well as data analysis, the measuring instrument used to analyse data, and the ethical considerations of the study.

This chapter concludes by giving the theoretical framework and describe the theories used to guide and shape the study. Theories adopted by the study are the systems theory and the strengths perspective. It further provides a detailed outline of how these theories fit into the study and how they were used to guide the investigation on the experiences of children with cerebral palsy, their families and caregivers.

- **Chapter four**

The chapter presents in detail the results and key findings that emerged during the study. The main themes and subthemes that were adduced from the semi-structured interviews that were conducted are conveyed in this chapter.

- **Chapter five**

This last chapter outlines the discussion of key findings in relation to previous studies that are related to the topic of the current study. This chapter also incorporates the theoretical framework of the strengths perspective and the systems theory. The study concludes with an examination of its challenges and limitations, as well as the recommendations for future research on any topic related to the study.

1.12. Conclusion

This chapter introduced what cerebral palsy is as it is a phenomenon studied. A brief historical background of the phenomenon was outlined. A detailed outline of the problem statement was introduced in this chapter. It detailed how people with cerebral palsy and other disabilities experience challenges on daily basis. The research questions that the study responded to were outlined, together with the intended aims and objectives of the study. Just like any other research, the significance of the study and how it will be of benefit and contribute to the field of social science was presented. This chapter also went on to explain the study demarcation and the assumptions. Concepts that are repeatedly used within the study are explained, and a brief method and design of the study were also stated, as well as the limitations of the study as well. The chapter concluded by outlining the chapters of the study.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. Introduction

People with disability form an important minority within our society. Notwithstanding this, disability rights have been a concept long ignored throughout the world. Fortunately, a new awareness on disability issues and rights has started to emerge (Truter, 2000:75).

This chapter on literature review therefore aims to present relevant information gathered concerning the challenges experienced by people with disabilities, specifically those with cerebral palsy. Data for this study was collected from different sources such as books, journals, master and doctoral dissertations. The chapter attends to different aspects namely, the overview of cerebral palsy, diagnosis of cerebral palsy, classification of cerebral palsy, the challenges with cerebral palsy, the psycho-social interventions on cerebral palsy and the people's mind-set on cerebral palsy.

The chapter later on introduces the theoretical framework, explains what a theory is and how it is applied. The systems theory and the strengths perspective are also outlined in the chapter. What these theories are all about, their significance to the social work practice and their relevance in the study are also discussed later in the chapter.

2.2. An overview and challenges of CP

Cerebral palsy is defined by Shorvon, Anderson & Gueriri (2011:382) as a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances in the developing infant brain.

Kim, Lee, Yoon, Shin, Cho & Rhee (2015:89) in their research showed that the motor disturbances of CP are frequently associated with disturbances of sensations,

perception, cognition, communication and behaviour caused by epilepsy, or secondary musculoskeletal problems.

The number of people living with CP continues to grow largely due to increased survival of low-birth weight infants and improved life expectancy. Despite extensive research and impressive progress in medical care, there is still no intervention that can reverse the brain injury causing CP (Langerak & Fieggen, 2013:1). It can be assumed that the more the number of children born with low-birth weight (LBW), the more chances of increased number of children born with CP.

It clearly shows that much research has to be conducted in the medical field, so that these inconclusive decisions regarding the causes of CP can be dealt with or resolved. As a result of no intervention to cure the injury to the brain that leads to CP, researchers believe that there is a need for combining interventions by medical specialists to better the overall function and participation in the community in childhood.

Cerebral palsy is the most common physically disabling paediatric condition globally (Gagliardi, 2008: 35). The prevalence in Zimbabwe is estimated to be at 1.55 per 1000 in rural areas and 3.3 per 1000 in urban areas (Finkenflufel, 1996: 24). It is evident that urban areas are more likely attacked by CP that the rural areas. Rural areas could have been thought to be the ones mostly affected due to lack of health-care service delivery and the level of service delivery as compared to the urban areas, but this is not the case.

There are few opportunities to place young children in appropriate day care facilities, particularly those with severe disabilities from families with limited financial resources (Dambi, Jelsma & Mlambo, 2015:1). Most rehabilitation centres are state owned institutions and have limited resources and space to accommodate a larger number of people with disabilities. At other state institutions, the degree of service is very poor compared to that in private institutions. Parents or care-givers find themselves without any other means, besides using the little skill and knowledge they have to care for the child at home, leaving their work permanently and other commitments.

Moste *et al.,* & Raina *et al.,* as cited in Dambi *et al.* (2015:1) say that “even in contexts in which there may be more supportive care available, caring for a child with physical disabilities may have a negative impact on the health and well-being of care-givers”. A child with disability may come as a source of happiness in most families, particularly to their parents. Bu their special needs often lead to challenges that are financially oriented. This is mostly true with families that are poor, and under resourced.

Looking after a child with disability for a long period of time has an effect on the physical, social and emotional being of the care giver, which also affect the health of the child and his well-being. They end-up losing relationships they had with friends, as they no longer have much time to spend with them. They often suffer from stress, and only few resorts to counselling to help accept the physical condition of the child. People they used to spend time with usually tell them they are not the same people they used to be. It means their well-being is affected by the disability of the child.

Caring for a child with disability may also extend to caregiver losing their relationships. A woman in a relationship with a man who is not the biological father to the child is often the one experiencing that. The partner loses faith and patience in the relationship, because the woman is always looking after the child and does not have enough time to be with her partner.

“In the past 40 years a number of thoughtful clinicians, researchers and epidemiologists have contributed to an ever-improving understanding of CP, in part through collaborative efforts among CP registers that have enabled researchers to discern epidemiological patterns using the very large databases that such registers make possible” (Morris & Condie, 2008:35). An effort to undertake research with the intension to come up with a central understanding and interpretation of cerebral palsy has been of interest to many academics. Even so, today there is still little knowledge on the understanding of this endemic.

Morris & Condie (2008:35) argue further “that there have been important advances in understanding what CP looks like clinically, and how it can be defined and characterised. At the level of ‘treatment’ as will be described in this workshop, research developments are helping to identify the benefits (and limitations) of a host

of specific interventions, using increasingly thoughtful and methodologically sound study designs and tailor-made outcome measures".

2.3. The diagnosis of cerebral palsy

"Cerebral palsy as the most common physical disability of childhood is a clinical diagnosis encompassing a heterogeneous group of neuro-developmental disorders that cause impairments of movement and posture that persist throughout life. Despite being commonly attributed to a range of environmental factors, particularly births asphyxia, the specific cause of cerebral palsy remains unknown in most individuals" (Moreno-De-Luca, Ledbetter & Martin, 2012: 1).

According to O'Shea (2008:1), "the diagnosis of cerebral palsy is based on a clinical assessment, and not on laboratory or neuro-imaging. He adds that, while the underlying abnormality of the brain is presumed to be permanent and non-progressive, there is overwhelming evidence that clinical manifestation and functional impairments often changes over time".

"Physicians tend to be very cautious in their diagnosis of cerebral palsy and usually wait until the infant reaches at least 12 months of age before making a definitive diagnosis. When possible, neurologic testing and neuro-imaging studies are used to enhance the understanding of the infant's movement or lack of movement and the possible prognosis" (Tecklin, 2008:180-181).

Vykuntaraju (2014:79) on the other hand believe that, "the evaluation of a child with cerebral palsy requires a multidisciplinary approach with a team of professionals comprising of a paediatrician or paediatric neurologist, occupational therapist, a physiotherapist, child psychologist and a social worker. He says that the evaluation of a child with CP is necessary to confirm the diagnosis, determine the severity of the problem and its cause. The team of professionals, need to work together in close cooperation of parents and teachers to help the child reach his maximum potential".

An article written by an organization, My Child Without Limits (2016:1) points out that "parents are often the first to notice that their infant is not developing normally. Infants with cerebral palsy are often slow to roll over, sit, crawl, or walk. When an

infant develops more slowly than usual, it is called developmental delay. It further says that most children with cerebral palsy are diagnosed by the time they are two years old. But if a child's symptoms are mild, it can be hard for a doctor to make a true diagnosis before the child is four or five years old. If the doctor thinks a child has cerebral palsy, he or she will probably schedule an appointment to see the child and talk to the parents about their child's physical and behavioural development".

Parents are the ones who spend most of the time with their children, and therefore are able to notice if there is something odd they realise with the child. Even though the condition may not be familiar to the parents, they are able to explain to the medical personnel what they see an unlikely with their child. Doctors therefore have a challenge to explain to the parents the condition of their child, if the disability was not picked or noticed during birth.

Medical practitioners make diagnosis of cerebral palsy through gathering a child's medical history, relating to the development of the child, before examining the child. More attention when examining the child is put on the movements that the child makes. Basic movements and signs, such as minimal encouragers are being observed on the child to see if the child is able to respond like other children. In addition to checking for the most common symptoms such as slow development, abnormal muscle tone, and unusual posture a doctor also has to make sure the child doesn't have something else that could cause similar symptoms.

Some children have hypotonia, which means that their muscles are too relaxed. In this case, the baby may seem floppy. Other children have hypertonia which makes their muscles seems stiff. Sometimes a child can have hypotonia that later become hypertonia two to 24 months after birth. Children may also have unusual posture or favour one side of their body (My Child Without Limits, 2016:1).

On the other hand, Grandview Children Centre (2008:7) says that it is also common that your doctor or therapist is the first to notice differences in motor function. They say signs of Cerebral Palsy are present within the first 24 months of life and it is often suspected as early as 6 months. A firm diagnosis does not usually take place until 1 - 2 years of age. The doctor is the one who diagnoses Cerebral Palsy.

According to their experience with doctors, the centre often experienced the doctor listening to the child's medical and developmental history, especially the motor skills, and reviews all aspects of health and development.

"A physical examination determines whether there is tightness in the muscles (spasticity) or increased reflexes. Sometimes pictures of your child's brain are necessary to confirm a difference in one of the areas that controls motor function and this is called Magnetic Resonance Imaging (MRI). The decision to proceed with MRI can be discussed with the child's doctor and depends on the child's symptoms" (Grandview Children Centre, 2008:7). Putting all this together, along with information about risk factors and results from tests, allows for a diagnosis of Cerebral Palsy to be made.

2.4. Behaviour problems in children with CP

It is common that children with cerebral palsy have behaviour problems. They can be picked in the child more especially, when there is the presence of epilepsy in the child. It is therefore very important to identify those problems on the child and to address them accordingly. Most parents and caregivers are able to identify behaviour problems on the child, but their observations are often overlooked by medical personnel. The behaviour problems do not only affect the child but also the family.

Siguardardottir cited by Stanton (2012:85) concluded that "a large number of pre-school children with CP have behavioural and emotional difficulties". Colver, as in Stanton (2012:85), commented on the ways in which his study affected his practice in that his assessment pay more attention to the pain experienced by children with CP and also with focus on attention, sleep patterns, tantrums and how parents manage behaviour especially in pre-school years.

"Cause may differ from one individual to another and may not be connected to brain damage. The enormous pressures and stress put on the family and the child who has CP affected behaviour. There is often lack of adequate counselling, information sharing and practical assistance when immediately required in the early stages of discovering that a child has CP" (Stanton, 2012:85).

In Stanton's survey, the comments from carers suggested overwhelmingly that families feel unsupported and ill-informed by the helping professions. The child may understandably feel frustrated by lack of mobility and muscular movements which refuse to obey the child's intention. It is difficult for parents to know exactly how to introduce the normal disciplines appropriate in child rearing when they may be having difficulties in understanding their child's communication and be distressed to witness their child's frustration. All these things may contribute towards the development of behaviour disorders (Stanton, 2012:85).

A significant proportion of people with cerebral palsy also have learning challenges, which may mean they may not reason fairly or fully understand their environment within which they function. Behaviour problems most frequently happen within this group, especially where an individual cannot communicate effectively. Behaviour problems can, however, occur across the whole range of intelligence.

Most parents and caregivers may find some of the behaviour patterns displayed by children with CP as challenging, because they are not trained and prepared to expect some of the behaviour changes and the developments in their children. They therefore find it hard to cope with the changes and the developments experienced by their children.

2.5 Cerebral palsy in the World, in Africa and in South Africa

"Population-based studies from around the world report prevalence estimates of CP ranging from 1.5 to more than 4 per 1000 live births or children of a defined age range. About 1 in 323 children has been identified with CP according to estimates from CDCs Autism and Developmental Disabilities" (Centres for Disease Control and Prevention, 2016: 1).

In Africa, statistics shows that CP is the most common cause of physical disability in children worldwide. However, little is reported on this condition in the African context. "Doctors from 22 countries in Africa, and representatives from other 5 countries outside Africa, met to discuss the challenges in the evaluation and management of children with CP in Africa". The meeting was also to propose service needs and

further research (Donald, Kakooza, Wammanda, Mallewa, Samia, Babakir, Bearden, Majnemer, Fehlings, Sherell, Chugani & Wilmshurst, 2014:1).

South African as one of the developing countries indicates a high prevalence rate of CP, between 1% and 8% with prevalence in less developed communities and rural areas. This is a clear indication that CP exists in our communities.

2.6. Classification of Cerebral Palsy

More agreement has been reached on the classification of the term CP according to its functional severity. It is usually grouped according to “the way the condition affects a person’s movement or the way it affect a particular body part” (Bjorklund, 2006:21). Types of cerebral palsies are spastic, athetoid, ataxic and mixed cerebral palsy. The classification is as follows:

2.6.1. Spastic cerebral palsy

Spastic Cerebral Palsy is said to be the most common type of CP. The muscle of people affected with this type of CP feel stiff and their movements may look stiff and jerky (Cerebral Palsy Alliance, 2016:1). As the most common CP, many children are said to have the symptoms of this particular kind of cerebral palsy.

“Children with spastic cerebral palsy are identified by stiff muscles and awkward movements. It affects the arm and hand on one side of the body, but it can also include the leg. “Children with spastic cerebral palsy generally walk later and on tip-toe because of tight heel tendons” (National Institute of Neurological Disorders and Stroke, 2014:1).

2.6.2. Athetoid cerebral palsy

“Main motor characteristics are involuntary movements-athetosis. These are bizarre, purposeless movements which may be uncontrollable. The involuntary movements may be slow or fast; they may be jerky, tremor, scoping or rotator patterns or they may be unpatterned. They are present at rest in same children. The involuntary motion is increased by excitement, any form of insecurity and the effort to make a

voluntary movement or even to tackle a mental problem" (Levitt, 2013:8). He further posits that "factors which decrease dyskinesia (athetosis) are fatigue, drowsiness, sleep, fever, prone lying or the child's attention being deeply held".

2.6.3. Ataxic cerebral palsy

'Ataxic cerebral palsy' is clinically noticed about 5-10% of altogether instances of cerebral paralysis, creating it the minimum recurrent shape of cerebral paralysis identified. 'Ataxic cerebral palsy' is triggered by harm to cerebellar constructions, differentiating it as of the other 2 forms of cerebral paralysis, that are spastic cerebral paralysis (damage to cortical engine sections and fundamental white matter) and athetoid cerebral paralsysis (damage to primary ganglia) (Leonard, 2014:8).

Because of the harm to the cerebrallum, that is necessary for organising muscle moves and level, cases with ataxic cerebral paralysis encounter difficulties in organisation, especially in their weaponry, legs, and trunk. Ataxic cerebral paralysis is recognized to reduce muscle timbre. The nearly all compliance display of ataxic cerebral paralysis is aim (action) shudder that is particularly obvious once bearing out exact moves, such like binding footwear laces either authoring with a pen. This manifestation receives increasingly falling short of a standard as the motion perseveres, bringing about the hand to juggle (Leonard, 2014:8).

According to Gilman (2001:8), this is the least common type CP. Ataxia is the word used for unsteady, shaky movements or tremors. It can also mess with the persons' balance and depth perception.

2.6.4. Mixed cerebral palsy

Mixed CP is a situation whereby two types of cerebral palsy occur in one body at the same time. Usually it is the spastic cerebral palsy and the athetoid cerebral palsy, which combine to cause many disabilities in a child. Spasticity is visible at the beginning of life that is between nine months and three years. The child experiences a lot of involuntary movements (Chipulu, 2013:7).

Chipulu (2013:7) points out that there are three types of mixed cerebral palsy and they are:

- *Spastic hemiplegia,*

This is a type of mixed cerebral palsy which affects one side of the body.

- *Spastic diplegia*

With this type of mixed cerebral palsy, the lower part of the body is affected more than the upper part of the body; most people with this condition do eventually walk.

- *Spastic quadriplegia*

The whole body and the normal functioning of the digestive system should be monitored for persons affected by this condition.

All the three conditions affect the motor development and this may lead to disability. "The physical disability will vary from one person to another depending on the severity of the condition" (Chipulu, 2013:7).

2.7. Impact of Cerebral Palsy

"Cerebral palsy is rooted by damage to the motor control and cognitive centres of the developing brain and can occur during pregnancy (approximately 75 percent), during childhood (approximately 5 percent) or after birth (approximately 20 percent)" (Thorngren-Jerneck & Herbst, 2006:505).

According to Davis, Shelly, Waters, Boyd, Cook & Davern (2009:63), caring for a child with a disability can be difficult and stressful. They also argue that changes in health care systems and societal attitudes have resulted in almost all children remaining at home in the care of families, rather than in group homes or institutions. The continuing attitudes towards children with CP by communities' make these children and their families feel rejected by the society and therefore limit their networking with the members of the community, because they are afraid to be badly labelled.

Because of their developmental problems, people with CP face a number of medical complications during their growing years, such as gastrain testinal reflux, aspiration, syndromes, respiratory infections, seizures, and contractures. In addition, they are prone to suffer common age related conditions such as astherosclerosis, muscles wasting, osteoarthritis, bone loss, and low trauma fractures (Kim, Lee, Yoon, Shin, Cho & Rhee, 2015:91).

Although a nurturing home environment can maximize a child's capabilities and minimize the impact of impairment, providing the high-quality care that is required for a child with long-term functional limitations may impact on the health and quality of life (QOL) (Davis *et al.,* 2009:63).

The baby may not respond or react as other babies do. This may partly be due to "floppiness, stiffness, or lack of arm gestures, or control of face muscles. Also, the child may be slow in beginning to speak. Later some children develop unclear speech or other speaking difficulties. Although parents find it hard to know exactly what the child wants, they gradually find ways of understanding many of his needs. At first the child cries a lot to show what he wants, later he may point with his arm, foot or eyes" (Gupte, 2008:477).

It becomes clear that the more time parents spend with their children, the more chances of getting to know better the needs of their children, especially children with cerebral palsy, because other children are unable to communicate their needs or wants verbally, but they elicit certain gestures in a way of communicating their needs at the particular moment. It is therefore the responsibility of the parent/caregiver of the child to spend much time with the child so that they can know them better.

2.8. Problems experienced by the cerebral palsied and other disabilities

People with disability are still experiencing problems and challenges of different kinds on a daily basis. They form the minority within the population but they are the most excluded group, and the vulnerable. Among others, the following are the problems that people with disability experience in their livelihood:

2.8.1 Discrimination against the cerebral palsied and other disabilities

The history of discrimination against disability by the society has a rich ancient history. It began during the times of our great-great grandmothers, and the society continues with it even today. Even though the level of discrimination is not in the same level as that of the ancient times, it still exists. Due to the extent of developments in the legal systems of different countries, people with disabilities are no longer killed, but the hatred against them still persists in our societies.

Coleridge (1993) as cited by Kisanji (no date: 1) traces through history the killing of people with disabilities, beginning with the Spartans who killed disabled persons as a matter of law; the endorsement by Martin Luther to kill disabled babies because they were incarnation of the devil, the English eugenicists who eliminated disabled people under the Darwinian evolution theory of the 'survival of the fittest' and the Nazi Euthanasia. There was also a programme under Hitler to exterminate disabled people as they could not make any contribution to society. These persecutions recorded in western cultures are still evident today.

“History is replete with examples of disabled people worldwide being ridiculed, killed, and abandoned to die or condemned to permanent exclusion in asylums and ridiculed”, Pritchard, (1963) as cited in (Kisanji, no date :1).

“The Greek abandoned their disabled babies on hillsides to die, while early Chinese left their disabled people to drown in rivers. In Europe, Nero Commodus is said to have targeted bow and arrows on physically disabled individuals and the Church in the 15th century sanctioned the extermination of disabled persons”, Anang (1992) as cited in Kisanji (no date : 1).

Even today people living with cerebral palsy and other disabilities are often affected by the stigma of acceptance by the society, despite the awareness that people living with this disability and others deserve to be treated with respect and to live harmoniously in the society like any other human beings.

Overcoming rejection of disability is still a problem that the society finds difficult to withdraw from. Cerebral palsy is a well-known disability by the society, but people find it interesting to label and discriminate against people who have it.

Marumoagae (2012:3) concurring with the latter statement believes that "discrimination against people with disabilities is one of the worst social stigmas that the society has not been able to overcome. She adds that women, men, and children with disabilities are often amongst the most marginalised in all societies and face unique challenges in the enjoyment of their human rights".

Section nine (9) paragraph (a-c) of The Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 states clearly that, no one may unfairly discriminate against any person on the ground of disability, including:

(a) Denying or removing any person who has a disability, any supporting or enabling facility necessary for their functioning in the society.

(b) Contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility; and

(c) Failing to eliminate obstacles that unfairly limit or restrict persons with disabilities from enjoying equal opportunities or failing to take steps to reasonably accommodate the need of such persons.

Despite the clear and friendly policies and legislations that prohibit the discrimination of persons with disabilities; the society continues to discriminate against them. This is a problem that still needs a serious address.

2.8.2. Medical problems

"There is no cure for the brain damage caused by CP and the same is not continuous or progressive. However, the effects of brain damage may become more pronounced as the child grows. Therefore, the best strategy for doctors is a combination of methods that consist of clinical treatment and physical therapy. Without these treatments, the permanent tightening of joints is very common. Doctors can avoid such scenarios by ensuring treatment use. The problems of CP

management differ from patient to patient. In some patients, the problems may be severe soon after birth while in other patients; they are not visible until early childhood" (Alshehri & Bach, 2014:1).

There are many cases reported on the poor medical treatment that children with cerebral palsy receive in the public medical institutions in South Africa. Most reported medical problems extend to pregnant women who get bad medical treatment which later results to birth of children with cerebral palsy. North West Division Mafikeng presented a case of a minor female born on the 2 July 1995. The applicants claimed damages in consequence of professional negligence of a medical doctor who delivered the baby at Tshepong Hospital.

As a result of the reported negligence by the medical doctor, the child was reported to be born with spastic quadriplegia with severe permanent deficits in cognitive ability and growth (cerebral palsy). There are other reported poor medical treatment cases which resulted in highly alarming results. This proves that many medical personnel do not offer quality medical services to many pregnant women, which later results in them giving children with cerebral palsy.

The cases reported by the North West Division Mafikeng, presented only the cases that were heard in the North West High Court in Mafikeng. This therefore means that there can still be more occurring problems than the actual or the presented ones in the North West Province.

2.8.3 Exclusion and lack of access towards disabled people

There are many places and areas where people living with disabilities do not have easy access to facilities compared to non-disabled people. Some institutions, organisations and other places do not allow easy access for people living with disabilities; the buildings do not have wheel chair ramps, and escalators. They are therefore forced by the situation to send their fellows to consult and do things they regard important for them.

The blind find themselves attending conferences and meetings where hand outs are given and there are no sacrifices for them with regard to documents written in Braille

system. They often feel excluded, because they find themselves listening to the presenter and not reading for themselves like people who are not blind. This is also a world experienced, because even in developed countries, people with disabilities feel excluded in many ways.

According to Islam & Cojocaru (2015:38), “disability historically, remained as one of the most neglected and forgotten development agenda by both the State and the non-state actors. They have always been considered as recipients of charity and welfare. By the late 90’s, almost all donors in the development field started changing their support from a service-delivery approach to a rights-based approach. He says that from the 1970s onwards, academic discussions on disability and disabled people have moved away from a notion of impairment or handicap, and the concept of a social model of disability has been introduced”.

Islam & Cojocaru (2015:38) say the “most important thing is that a large numbers of disabled people are socially excluded in Malysia and they are now out of the main development stream. There is no complete statistics on this number, but this process is very influential. Disability in one hand, and social exclusion in another, intensifies the lives of disabled people so challenging. Persons with disabilities are usually the nation’s largest minority and they tend to be marginalized in all aspects of life. They usually experience substantially poorer quality of life and are more likely to be unemployed due to institutional discrimination”.

In the institutions of higher learning, there are such challenges but an attempt to address them is continuing. Research report by FOTIM (2011:17) outlined that the higher education system in South Africa is one that has been moulded by various historic, social and political factors. Taking the degree of racial inequality that existed in the past, it is not surprising that there has been a large focus over the last few years on increasing the participation of black students in the higher education system. Some attention has also been directed at the position of women.

Parallel to equity issues, Foundation of Tertiary Institution of the Northern Metropolis (FOTIM), (2011:17) noted that the government has embarked on a process of restructuring the institutional landscape by merging and consolidating different universities and technikons into the 23 tertiary institutions that currently exist in

South Africa. Within all of these developments and changes that have taken place over the last couple of years, limited attention has been placed on addressing issues of access, retention and participation of students with disabilities. This is notwithstanding the fact that they have been identified in various governmental policy documents as being historically disadvantaged and deserving of special attention.

2.9. THEORETICAL FRAMEWORK

This chapter introduces the theoretical framework and describes the theories that were used to shape and guide this cerebral palsy study. The theories are the systems theory and the strengths perspective. The chapter further provides a detailed outline of how these two theories fit into the study, their significance to social work profession and how they were used to guide the investigation on the experiences of children with cerebral palsy, caregivers and their families, particularly their parents.

2.9.1. Systems theory explained

In general it is essential for one to start by understanding what a theory means, before attempt to use it. A theory is a statement backed by evidence gathered through the scientific method intended to explain something (Nguyen, 2015:3). There are a number of theories that can be used in the assessment and interaction process with children and families to contribute toward the improvement of their lives using a developmental approach. The developmental assessment tool is meant to “assess the developmental needs and strengths of the child. In other instances the assessment are conducted in relation to risk, need, and potential change” (Adams, Dominelli, & Payne, 2009: 222).

Systems theory may be applied to understand the role played by the family of a child with cerebral palsy. It may also be applied to understand the family of origin and social networks, and how they contribute to his or her frame of reference (Parrish, 2014:3). Organizations necessary to the child are also considered when applying the systems theory in trying to understand the holistically.

Theoretical approaches for social work are often used to explain human behaviour and intend to give guideline in coming up with appropriate models for specific treatment methods. A theory is also understood and used as a token that paves ways; it is used to understand certain phenomenon not just people, but many other things.

Brandell (2011:3) regards systems theory as a “theory that elaborates increasingly complex systems across a continuum that encompasses the person-in-environment. He believes that bio-psychosocial assessment and development of appropriate intervention strategies for a particular client requires consideration of the individual in relation to a larger social context”.

The researcher believes that a systems theory is aimed to guide an individual in trying to understand a particular thing and its operations or functions. This particular thing may be an individual viewed as a system or an institution such as churches and schools. To be regarded or recognised as a system is because this particular system has subsystems which operate out of a larger system. A practical example would be that a church as a system has its own congregants whom together form a church. A church cannot just be regarded as a church without its congregants; instead it would be regarded as a structure, or a building. More on what systems theory is and its relevance to the study is given below.

The bio-psychosocial assessment and development of appropriate intervention strategies for a particular client requires consideration of the individual in relation to a larger social context (Brandell, 2011:3). The researcher uses the systems theory to analyse the general functioning of the child with cerebral palsy and the family functioning of the child.

2.9.2. The relevance of systems theory in social work

In their view Evans & Keating 2016:17) say the systems theory relied heavily on the assessment expertise of the practitioner. They strongly believe that family members are seen as being involved in constant processes of reciprocal, interactive communication which impacts in complex fashion. Each individual was conceived of

as a system, as was the family as a whole, this also included the parents and also their children as whom together form a system.

Other external systems were also interacted with, impacted upon and had effect. Rather than assuming that a client was behaving in a particular manner because this was some manifestation of individual self-character or temperament, problematic situations or actions were seen as developing out of the interaction between various 'sub-system' within a wider system (Evans & Keating, 2016:17).

Basically each and every subsystem and system do not exist in isolation; it has to belong to a larger system. Even a system does not exist in exclusivity, for it to be regarded a system it is made up of subsystems. Therefore, practitioners in their interventions with individuals should go an extra mile and extend their services to the family. The aim is to make an assessment to understand how the subsystem's problem affects the family as a whole, and how it affects also day to day living of the family.

All the subsystems within the system are related. The systems theory also emphasises the equilibrium, which is the balance within the systems. Other theorists and practitioners may explore this theory to an extent that they relate it to the principle of "an injury to one is an injury to all," Meaning when one family member has a problem, it will automatically affect other members of the family, be it siblings or dear and near family members.

The systems (families) also have a level whereby they are regarded as subsystems of a larger system (community) in which they exist. Family members as subsystems also have interactions with external subsystems, which are the members of the community.

2.9.3. The relevance of the systems theory to the study

A child with cerebral palsy is also regarded as a subsystem of a system which is the family. The family of this child is a system belonging to a larger system which is the community. The whole family belongs to the community and have the right, just like any member of the community to enjoy socialising with friends and people who are

dear and near to them. But instead they are often excluded in a way that they are discriminated and often not accommodated in their communities as people with special needs.

It is the researcher's observation that many institutions within the larger system (community) such as churches and clinics are not accommodative to them. Most buildings of these institutions within the community are not accommodative to them because they are not engineered to allow for wheel chair ramps. They do not enjoy the feeling of belonging to their communities, because they are often called names and criticised therefore end up living indoors to avoid this challenge. Other members of the community see a child with cerebral palsy as a curse, burden to the community and a disgrace to human kind. The family automatically get affected by the community treatment, because the child is a member of their family.

The researcher is of the view that practitioners in their interventions should therefore include the whole family when working with the child with a disability, because they do not exist in isolation. The family will also need the practitioner's intervention, because they have to be helped to accept, cope and adjust to the changes that the family is faced with. Firstly the family was not expecting a child born with a disability; it is therefore a new experience to them.

They need to accommodate the new member of the system and therefore, have to try by all means to create an environment that suits his special needs. If the environment is accommodative and conducive to the child, the family will also have peace, knowing each and every member of the system is welcome. Doing so will also help the system to maintain its balance. This equilibrium will help the system to function to its intended needs.

2.9.4. What is strengths perspective?

The strengths perspective theory as explained by Khoza (2011:20) uses the same premise as systems theory to guide intervention with individuals where they are viewed as active agents within their environment, because they have strengths. It is further described by Saleebey (2006:10) as capacity, possibilities and resources that can be tapped into to create change.

Some principles of strengths perspective theory that are central in the interaction with clients are the individual, group, family or community, has the strengths that must be acknowledged by respecting them as individuals as well as respecting their potential. The use of these principles in the practice may direct the social worker's intervention to identify strengths in individuals that can be used to contribute towards facilitating change in their lives (Saleebey; 2006:19).

The strengths perspective theory according to Du Bois v Milesy (2014:24) is aimed at eliciting the strengths in people, or rather making them aware of the strengths that they never thought they have. According to this theory, each and every individual is born with the innate talent and it is always waiting to be identified and utilised accordingly. It is therefore important to see each individual not as useless, but as people born with different talents. As people we are born as different and therefore our skills, strengths and potentials will therefore be different. It is thus important to respect people as they are and acknowledge their strengths and weaknesses. No matter how useless they may seem in one's eyes they definitely are not useless.

2.9.5. Relevance of strengths perspective to social work

According to Zastrow (2016: 67), social work practice emphasizes empowerment and a strengths perspective rather than a focus on pathology in working with individuals, groups, families, organisations, and communities. It is essential that social workers include clients' strengths in the assessment process. In working with client, social workers focus on the strengths and resources of clients to help them resolve their difficulties. To utilise clients' strengths effectively, social workers must first identify those strengths.

There is a danger that a primary focus on weaknesses will impair a worker's capacity to identify a client's growth potential. Social workers strongly believe that clients have the right and should be encouraged to develop their potentialities fully. Focusing on pathologies and weaknesses often undermines this value commitment. Social workers in their interventions do not focus on what the client lacks, but rather on what the client has, and to help the client utilise the strength that he or she has to achieve what he want to achieve.

2.9.6. Relevance of strengths perspective to the study

Beside every challenge and the problems that families and children with cerebral palsy have experienced, they can support each other towards the challenges that they encounter on daily basis. This simply proves that these families and children are capable of believing in each other, and having a positive mentality towards their children despite their medical conditions.

It is clear that other families have the strengths, or that they have gained the strengths to handle the situation which they first regarded traumatic. According to Yip (2008:5), “trauma, and abuse, illness and struggle may be injurious but they may also be sources of challenge and opportunity”. The study uses strengths perspective to identify the strengths that CP children and their families have that helps them to grow and develop from the problems that they come across.

Through the abuse the trauma faced by the child and the family, and labelling character from individuals, and the community, the families of children with cerebral palsy can still set aside those disturbing and demoralising spirit and focus on the strengths that they have. The fact of the family and the child being able to accept and cope with this cerebral palsy condition, it is a true significance of the strength of support and dedication towards seeing to it that the family stays together despite the day to day medical challenges and criticism from the community. This on its own is what can be considered or seen as strength.

The researcher chose this theory because it emphasises clearly in its principles that every individual, group, family, and community has strengths, (Zastrow, 2010:77). No matter disabled or not, children with cerebral palsy may have the strengths which one of them is simply the ability to keep the family united through working together and supporting each other.

Despite being born with a disability, a person has the ability, capability and the potential to do or perform certain tasks and engage in activities that people without disabilities can. The only thing needed is for the community to accept them together with their needs and to give them an opportunity to showcase their strengths and their abilities.

If there are no resources within the communities that can accommodate people with disability, it is the very same responsibility of the community to open a room for development through the establishment of those resources that will help uncap and establish the strengths of people with disability. No one is born incapable, despite their special needs, people have disability have strengths. The community should therefore stop labelling and calling them negative names that belittle and discredit them, and to start creating for them an environment that is allowing for them to make associations that will be of benefit to themselves and their family, and for their communities as well.

The community should adopt the equality method of life, whereby people with disability will benefit equally to those without disability. If given the opportunity they can also be the active instead of passive participant to the growth and development of their lives and to the community.

2.10. Conclusion

This chapter presented an overview of cerebral palsy and its challenges, to give a clear understanding of what it is the phenomenon all about, and the challenges that people living with disability experience on daily basis. An outline of how cerebral palsy is diagnosed is given, so that there can be awareness and differentiation of how it is diagnosed as opposed to other disabilities. The behaviour problems that are displayed by children with CP have been discussed. It is very important to understand that children with CP have certain problems as compared to other children.

Cerebral palsy was also classified in this chapter, because CP comes in different forms. It is mostly classified according to how it has affected the child, particularly the areas of the body that have been attacked, and also the impact it has made on the child. The chapter also gave the problems that children with cerebral palsy encounter on daily basis. Discrimination, medical problems and social exclusion are amongst those challenges explained by the chapter.

The chapter also presented the theoretical framework. It firstly gave a brief description of what a theory is, why, how, and when it is used. The general

description of the systems theory was explained and its relevance to the social work practice and how it fit to the study. The strengths perspective theory was also discussed as well as its significance, what it is all about and also its relevance to the study. It was important to discuss the strengths perspective in relation to the study so that there can be collaboration and to show that the strengths can be used and identified in different ways.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1. Introduction

This chapter adduces a detailed description of the research design and the methodology used to achieve the intended aim and objectives of the study. It provides some important aspects of the research, like the population, sampling procedure utilised, method used to collect data, research instrumentation, data analysis, and lastly it makes reference to the ethical research considerations.

3.2. Aim and objectives of the study

The aim of the study was to investigate and identify the psychological and social problems experienced by children with cerebral palsy and their families, in the Bojanala District North West Province.

The following objectives were employed by the study to achieve its intended aim:

The study sought to get more insight about the nature and the challenges of cerebral palsy. The objectives set to achieve this are:

- To identify the social and the psychological problems experienced by children with cerebral palsy and their families.
- To identify the social and emotional effects of cerebral palsy on children and their families.
- To figure out if there are any programs in place to address the problems and need of children with CP and their families in Moses Kotane Hospital, Bojanala District.
- To explore the social emotional and psychological services provided to children with CP and their families in Moses Kotane Hospital, Bojanala District.

3.3. Research methodology

The nature of the topic chosen for the study required a qualitative research method to be used to collect data that would give a thorough understanding of the experiences that the participants go through on daily basis. The study aimed to gather in depth data that would supply answers to the research questions. The method was used due to its effectiveness, as it enabled the researcher to collect the information that captured the experiences, and perceptions of the participants.

3.4. Research design

The qualitative research design which was used is phenomenological in nature. The aforementioned research questions of the study sought a detailed description of the participants' lived experiences, therefore the phenomenological research design was deemed the most appropriate for this study.

As explained by Hicks (2016:29), "the purpose of the phenomenological research is to describe the lived experiences of participants as authentically and accurately as possible. Therefore a phenomenological research design is seemed the most appropriate when investigating the problems that children with cerebral palsy and their families experiences".

The study design also enabled the researcher to understand the meaning and perspective of the participants. "It refers to the overall strategy that you choose to integrate the different components of the study in a coherent and logical way, thereby, the researcher ensuring that he or she will be effective in addressing the research problem, collection of data and its measurement and the analysis of data" (Labaree, 2009:1).

3.5. Population

Children with cerebral palsy are the population that the study sought to investigate. Population is "a set of all individuals, items, or data of interest about which scientists will generalise" (Privitera, 2016:27). The research study was conducted at Moses Kotane Hospital in Bojanala District. The study's target population were the parents

and caregivers of children born and living with cerebral palsy. Twenty five (25) participants agreed to participate in the study, nineteen (19) of them were boys and six (6) were girls. Out of the total number of twenty five (25) participants, only ten (10) were able to start and complete the study. The other fifteen (15) participants decided to withdraw from participating in the study due to various reasons. Some had transport challenges to arrive to the agreed upon venue and some had other challenges which they felt uncomfortable to disclose.

The rationale behind the number of participants selected was to get enough information regarding their experiences, to understand their challenges in a broader way. When recruiting the participants, the researcher selected the parents and caregivers of children born with CP from a group of children with CP who attend CP-clinic in Moses Kotane Hospital in the Bojanala District.

3.6. Sampling procedure

3.6.1. Sampling method

A purposive sampling technique was used to select a group of parents and caregivers of children with cerebral palsy who participated in the study. It is a form of sampling that is based entirely on the judgement of the researcher. The sample is composed of elements that contain the most characteristic, representative or typical attributes of the population, that is according to De Vos, (2005:302). Rubin & Babbie (2005:153) further say “purposive sampling involves the selection of a sample for observation that is known to have the potential of providing the most suitable information for the study”.

3.6.2. Sampling type

Non-probability sampling was used in the study to select the sample. It is relevant in essence that selection of the participants is based on non-random means. According to Richie, Lewis, Nicholls & Ormston (2013:113), “non-probability sampling refers to units deliberately selected to reflect particular characteristics of individuals or groups within the sampled population”.

The study followed a non-probability sampling type which is called reliance on available subjects, sometimes called availability sampling. Rubin & Babbie (2010:146) say “it is a frequently used sampling method in social work since 1994, because it is less expensive than other methods, and has been reported in the majority of research articles”.

As already mentioned, the participants of the study were children with cerebral palsy. They were represented by their parents and caregivers because they cannot speak for themselves. The children attend cerebral lessons in Moses Kotane Hospital. Twenty five (25) people were invited to participate in the study. They are parents and caregivers of children with cerebral palsy. These children are severely challenged by cerebral palsy; hence the study opted to work with their parents and caregivers because they cannot represent themselves. This is because all these children are unable to talk, some are able to make sounds trying to talk but you cannot make sense out of what they are saying.

3.6.3 Sampling size

The sample of twenty five (25) participants which comprised of parents and caregivers of children with cerebral palsy were selected in the study. The sample was chosen from a total of two hundred (256) children who form a database of Moses Kotane Hospital cerebral palsy clinic. According to Fouche (2002:273), “there are no rules for sample size in qualitative enquiry”. Patton (2015:1) extends that the “sample size depends on what you want to know, the purpose of the inquiry, what is at stake and what is it you want to achieve”.

In achieving the sample size, the researcher selected the participants who suited the characteristics of the study. Most participants were interested in forming part of the study and all of them met the characteristics of the participants needed by the study. Therefore the researcher selected twenty five (25) participants who were of the same characteristics, which were parents of children who are severely impaired with cerebral palsy. Even though the study started with 25 participants, only 10 of them were able to successfully complete all the sessions. As already mentioned, other participants could not conclude the study because of various reasons.

3.7. Data collection

The study employed one method for data collection namely, semi-structured and open ended interviews. This was said to be relevant in terms of establishing a good rapport with the participants, through one on one contact (Leedy & Omrod, 2010:156). The researcher used open ended questionnaires and gained an advantage from that as they did not limit the answers of the participants, it opened a room for follow up questions and clarification on their statement of answers.

According to Babbie, Mouton, Vorster & Prozesky (2008:47), “semi-structured interviews consist of standard questions while leaving a room for follow-up questions that were designed for probing or gaining clarity on given answers”. Questions were structured to afford the researcher to explore the experiences that every participant who is either a biological mother or a caregiver of a child with cerebral palsy.

In the view of Weyers (2011:169), “interviews are useful when you require more in-depth answers or target the participants who have difficulty in reading or using printed materials”. The information was gathered in a form of asking questions, and also the participants had printed copies of their own questions so that they could follow or be in line with what is being asked in the interview session.

The researcher made an effort to clarify the questions in a way that suited the participants’ level of understanding in each question asked. The interviews were conducted in the participants’ preferred language to enhance easy communication. There was no need to compile a Setswana questionnaire because most of the participants could understand the questions. The researcher only unpacked the question in Setswana were the participants were not easy to interpret the questions.

As a method of building rapport, the participants were asked to tell when did they join Moses Kotane Hospital CP-clinic, and how has the experience been. They were also asked of the changes or developments they had seen since. These questions built a solid foundation on other questions to ask, including whether or not it was easy to accept and live with the child’s condition.

The answers that most participants gave helped them betray their denial of not feeling at ease opening up to such questions. Each participant unfolded her side of story from the minute she heard that the child has CP. Other parents knew of their children's condition before birth and others late after birth. Those who knew before birth were told by their medical practitioners, being considerate of the child's development. Further questions explored whether they feel their life would have been different should there be no child with a disability within the family.

Permission was asked from the participants, and after it was given interview sessions were recorded and lasted between thirty and forty minutes (30-40minutes). Although interviews did not take long, the researcher was able to acquire adequate information that was required. All interviews were arranged at the time suitable for the participants. The participants never at any time withdrew from the study due to time constraints.

All interviews were conducted in Moses Kotane Hospital in the Bojanala District in the multi-disciplinary boardroom. That is the place where participants were able to gather together in one place, when they had attended cerebral palsy clinic every first Wednesday of the month. That was the venue recommended by the interviewer, as it was considered the quietest and private. All the participants were not familiar to the venue, but they assured the interviewer that they are safe and comfortable. Proper arrangements were made in advance; the venue was always available at the time of all scheduled interviews.

3.8. Research instruments

"A research instrument is pretty much anything the researcher use to get data to be analysed" (Hofstee, 2015:15). The data collection instrument used were interviews, with semi-structure questionnaire. Before the full-scale data collection, the semi-structured questionnaire used by the study was pre-tested.

Five parents of children with cerebral palsy looking after their children on daily basis were questioned. They did not form part of their final study. The pre-testing of the research instrument assisted the researcher to ascertain the exact time he would spend for interview sessions with the final research participants of the study. It also

helped the researcher to enhance the reliability and the validity of the research tools. The researcher pre-tested only the interview questions.

According to Colton & Covert (2015:86), “when testing the research instruments, you want to know the items and the instructions make sense, are ambiguous, and are understandable by those who will complete them, for example, pre-testing can determine whether items are complex, are wordy, or incorporate inappropriate language”. They further say that “once you determine how long it takes respondents to complete your instrument, you can make decisions about its length and format. That pre-testing also produces data you can use to demonstrate the validity and reliability, which ultimately helps you, ascertain whether the instrument is producing the desired information”.

3.9. Data analysis

The study employed thematic analysis for the purpose of data analysis. Thematic analysis “is probably the most common qualitative data analysis method; it is often employed in the social, behavioural, and health sciences”. Guest, MacQueen, & Namey as noted by Baran (2016:10) say “the process of this method of analysing data consists of reading data through textual data, identifying themes in the data, coding themes and then interpreting the structure and content of the themes”.

The researcher went through the recorded data, tried to pick and organise the information that is important for the study in terms of answering the research questions. The researcher started to draw the main themes in the data collected, which was the grouping of statements, words and phrases that assisted in answering the research questions. This helped the researcher to make use of the process called familiarization and immersion whereby data collected is read over and over to become familiar with the content.

Thematic analysis also assisted the researcher to minimally organise and describe data set in rich details. It also went on to interpret various aspects of the research topic. Data from the tape recordings obtained during the interview sessions was transcribed for interpretation. This provided the researcher with an alternative to engage with and be familiar with the data as well. De Vos (2002:344) maintains that

this process provides an opportunity of heightened awareness of data and openness to messages that are central to identifying and organising data into themes, categories, and patterns.

3.10. Limitations of the study

The study was analysed using qualitative method. One of the advantages and strengths of qualitative method is working with a small sample, as it provides rich and detailed information. But given the nature of the qualitative study, the sample size was relatively limited. The study did not have 25 willing participants as it envisaged. The study had 17 participants and some of them were forced to withdraw from the study due to difficulties of transport to reach the meeting venue, and some of them had personal commitments which they did not feel comfortable to tell. Most of the participants were willing to form part of the study until the end, but they were forced by circumstances stop participating into the study. There is limited transport to Moses Kotane Hospital which is where the researcher met with the participants. The study had to rely on 10 participants whom the study was left with. Therefore due to this effect, it may be that the study does not represent the total number of the study population. As a result, the research results could not be generalized within the population identified for the research study. However the study was qualitative in nature, therefore the aim was not to make any generalisation, but explorations.

Another limitation is that the trustfulness of the answers given by the participants cannot be guaranteed as the participants could have given desirable answers to protect themselves from being attacked by their communities. In order to minimise this situation, the researcher tried to clearly explain to the participants that there would be no consequences arising from the answers they have given in the study. He further assured the participants that there is no link between the study and the Department of Health, more specifically Moses Kotane Hospital, so their participation in the study will not anyhow lead to termination of the services they benefit from in the hospital.

Even though the researcher drew on a semi-structured interview as a guide during the process of the interviews with participants, spontaneous probing and the use of

different wording on the part of the researcher may have negatively affected the consistency of the finding across interviews and elicited information in a way that confirmed his pre-conceived assumptions on the topic.

3.11. Ethical considerations

The North West University has a strict process whereby ethical approval must be obtained before the study can commence. The research proposal for this study was analysed and reviewed by a panel of supervisors, and research co-ordinators, in the Faculty of Human and Social Sciences, and thereafter ethical clearance was granted. The management of Moses Kotane Hospital was presented with the ethical clearance obtained, and therefore permission to undertake the study was also granted.

“Ethics concerns the morality of human conduct, and they refer to moral deliberation, choice and accountability on the part of the researchers throughout the research process” (Miller, Birch, Mauthner & Jessop, 2014:14). The researcher maintains that ethics also indicate the manner in which the researchers are to conduct themselves throughout the study.

The study also acknowledged the code of ethics prescribed for research. Code of ethics considered when undertaking the study includes confidentiality, voluntary participation, avoidance of harm and debriefing.

3.11.1. Confidentiality

The participants were well informed that their identity will not be revealed. They were further assured that all the tape recorders, books and the laptops that were used to save the information will be kept save and will be deleted once the study is completed. De Vos, Strydom, Fouche & Delport (2011:119) believe that “every individual has the right to privacy that it is his or her right to decide when, where, to whom and to what extend his or her attitude, beliefs and behaviour will be revealed. The interview sessions were even conducted in a private space”.

3.11.2. Voluntary participation

According to Rubin & Babbie (2010:257) “major tenet of research ethics is that participation must be voluntary, that no one should be forced to participate in the study”. The researcher therefore made the participants aware that participation in the study in voluntary that they can withdraw from the study at any time without fear that their withdrawal will not have any negative impact or jeopardise the relationship they have or the services they receive from the hospital.

3.11.3. Avoidance of harm

Avoidance of talking about highly sensitive topics that could harm the participants was always noted and avoided in the study. The questions were also set in a manner that avoids harm to the participants, and provision was granted to the participants who were emotionally affected when participating in the study and professional assistance was offered.

3.11.4. Debriefing

Debriefing session was held at the end of the interview sessions to help the participants who were affected by the sessions held. The session helped the participants to deal with some anxiety and stress encountered during the interview to relax. The social workers at Moses Kotane Hospital were asked to avail themselves, and they accepted and confirmed their availability whenever needed to assist conduct counselling sessions with the participants.

3.12. Conclusion

The chapter started by introducing the aspects to be discussed within the chapter. The chapter presented the intended aim and the objectives of the study. The method employed to shape and give direction of the study. The research method that the study employed to understand the lived experiences of the participants was given, together with the research method of design used by the study. The study population was given and the specific number of the participants who formed part of the study.

The sampling procedure was outlined in detail to give direction of the study. The method used to collect data was given as well as the type of research instrument used. The method in which data was analysed was clearly outlined. There are always challenges that the researcher face when undertaking the study. The chapter therefore outlined the challenges, and named the limitations of the study. The ethics are very important in research, therefore the chapter presented lastly how they were adhered to.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF RESEARCH FINDINGS

4.1. Introduction

This chapter has two sections of which both discuss the findings of the research study. Section A of the chapter starts by presenting the demographical information and the profile of the participants who formed part of the study. Section B of the chapter provides a discussion of the research findings that the study achieved. The findings are given according to the main themes and sub-themes that were formulated. Quotes from the interview sessions held with the participants were used to substantiate the findings of the study, and also to give more meaning and understanding on the challenges faced by children with cerebral palsy and their families.

The chapter starts by providing the demographic information and the profile of the participants. The aim of this chapter is to respond to the research aim and objectives of the study. The study's intended objectives were to identify the psychological and social problems faced by children with cerebral palsy and their families, to find out the social and emotional effects of cerebral palsy on children with CP and their families. It also aimed at identifying the programmes in place in order to address the problems and needs of children with cerebral palsy and their families in Moses Kotane Hospital. To investigate social work services provided to children with cerebral palsy and their families in Moses Kotane Hospital.

4.2. SECTION A: Biographical information and Profiles

4.2.1 Biographic information

The study had a great diversity in demographics of the participants who took part in the study. The study consisted of a total number of 10 participants who comprised of the biological parents and the caregivers of the children with CP who are the main focus of the study. The researcher also interviewed 2 social workers who work in

Moses Kotane Hospital. From the total number of 10 children who are the main focus of the study, 7 of them were boys and 3 of them were girls. Majority of them which is 9, were black and 1 coloured. Majority (4) of them came from Setswana speaking families, 2 came from Sotho speaking families, 3 came from Zulu speaking families and only 1 came from Afrikaans speaking family.

4.2.1.1 Biographic analysis

• *Age*

The ages of all participants were recorded. They range between 1 and 11 years. It was the researcher's observation that the parents to the older children have accepted their children's condition. They seemed to have coped better with the situation in the family. It may be because they have been living with their children for a very long time and have found it in their hearts to accept the child's condition and to live with it.

• *Race and Gender*

Many of the participants, which is nine over ten, came from the same racial backgrounds. All of them were black, beside one participant who was coloured. Even though they are black, they do not belong to the same tribe, and therefore do not speak the same language. They speak Isizulu, Sesotho, Afrikaans, and the majority speaks Setswana. Their differences did not create any language barrier, because they could all hear the questions clearly when clarified in Setswana, more especially were they could not interpret what exactly was required of them by the question.

• *Gender*

Most of the children who participated in the study were males. There were 7 males and only 3 females. Moses Kotane Hospital as a focus area of the study has a high volume of males born and diagnosed with cerebral palsy, and it may be the reason why the study had a high number of males who participated in the study as compared to females.

4.2.1.2 Table 1: Demographic Information

Demographic factor	Sub-category	Number
Age	1-3 years	03
	4-7 years	05
	8-11 years	02
Race	Black	09
	White	01
Gender	Males	07
	Females	03
Home Language	Zulu	03
	Pedi	0
	Sotho	02
	Tswana	04
	English	0
	Afrikaans	01
Religion	Christian	09
	Muslim	0
	Hindu	0
Non-religion	-	0

A total of 25 participants were selected using the non-probability sampling. Out of 25 participants, only 10 participants were able to remain and take part in the study. Only 2 of the participants were not represented by their biological mothers. One was represented by her sister and the other one was represented by his aunt. Both of them are the day to day carers of these children. These 2 cannot be with their mothers on daily basis due to their day to day work commitments.

All the children who formed part of the study are severely attacked by cerebral palsy and they cannot talk properly. That is the reason that led to the researcher choosing to talk to day to day carers of these children, because they are their immediate family members, and therefore spend most of their time with them. Most of the children who

formed part of the study have mixed type of CP. This is a type of CP whereby two types of CP exists in the same child.

4.2.2. Table 2: Profile of participants' representative

Representative	Profile
Representative 1	The respondent stays in rural area where she occupies a 4 roomed shack. She is single and has 2 children, one is attending school and the other one is not. She is unemployed, she was employed at a local clinic as a cleaner, but had to leave her job to take care of her child. The father to the child is not supportive to them, either financially or emotionally. She relies on her mother and her siblings for support. Disability grant of the child is also the main source of income within the family. She said that her religion was very useful, as it was a source of comfort and a pillar that gave her strength during difficult times. She indicated that she believe God is the creator and one has to accept whatever that is created by God.
Representative 2	Respondent number 2 stays in a rural area in a 6 roomed brick house. She is married and blessed with 4 children. 2 of them are of school going age, and the one is working and the last born has CP. She is an Extended Public Works Programme (EPWP) employee, and also a day to day carer of the child. The father to children does not support them financially and emotionally. They are

	separated but not divorced. She has a partner; he is the one who support them financially and emotionally. Her main source of income is her salary, the child's disability grant and the little she get from the partner.
Representative 3	Respondent number 3 stays in a rural area in a 6 roomed brick house. She is married and has 3 children. She is unemployed and stays home full-time. Being at home full-time enables her to continue to take care of the disabled child. The father to the child does not support them financially and emotionally. The husband is a pastor and he is always supportive. The main source of income is the husband's salary, the child's disability grant, and the money they get from their children. Church is one of the things that she relies on for support and courage.
Representative 4	Respondent number 4 stays in a rural area in a brick house. She is single and has 1 child aged 4 years. She is unemployed and it enables her to continue to care for her child. The father to the child does not support them financially and emotionally. She gets support from her mother, father and her siblings. She stays full-time with her parents at their home. The child's disability grant is also a source of income within the family. She indicated that

	religion was very useful as it came as a source of comfort during difficult times. Church still plays a vital role even today.
Representative 5	Respondent number 5 stays in a rural area in a 6 roomed brick house. She is single and has no child. She is a day to day carer of her younger brother who has CP. The mother to the child is working as a cleaner at a local clinic and does not have time to look after the child due to work commitments. The family is supportive towards the child. The father is a pensioner; he is supportive emotionally and financially. He still has money he got of his pension funds. The family members are not regular church attendants, but regard church as important and powerful to their lives.
Representative 6	Respondent number 6 stays in a 4 roomed mud-house. She stays with her mother and her 3 children. The father is not emotionally and financially supportive. She relies on the child support grants, and the disability grant of the child who has CP. She is a full-time church attendant and regard church as a source of comfort during hard times.
Representative 7	Respondent number 7 stays in a rural area in a brick house. She was married and got divorced to the father of her children. She is unemployed and blessed with 4 children. The father to the children is supportive financially due to

	maintenance of his 2 children, and continuously visits them. The other source of income within the family is the child's disability grant and the salary of 2 children who are working at the mines.
Representative 8	Respondent number 8 stays in an informal settlement in a 6 roomed shack. She is unemployed and single. She has 5 children, and depends on their child support grant and 1 disability grant of her child who has CP. She is not a Christian and said she does not attend church as she does not believe in God. All her children have different fathers, and they are all not supportive emotionally and financially.
Representative 9	Respondent number 9 stays in a rural area in a brick house. She is single and has 2 children. They are school going age, but the one who has CP is not at school. She stays full-time at home, and is a full-time career of her child. Both her children have different fathers and all of them are not supportive emotionally and financially. She relies on the child support grant and the disability grant for survival. She also has a small business, selling vegetables to have a sustainable income.
Representative 10	Respondent number 10 is unemployed and has only one child. She is not the biological mother to the child with CP, but is a day to day carer of the child. The

	mother to the child is working as a clerk at a government department and does not have time to look after the child due to work commitments. The mother to the child is married and is blessed with 4 children. Both the husband and the wife are support to the child, the carer and the entire family, emotionally and financially. They regard the role of church in their life as significant. She said church moulds their behaviour and is their source of strength.

4.3 SECTION B: Discussion of the research findings

This last section of the chapter is comprised of the findings and interpretations based on the results from the empirical investigation with the parents and day to day carers of children with cerebral palsy in Moses Kotane Hospital in the Bojanala District. In this section, the themes and the sub-themes that were generated will be discussed. Direct quotes from the interviews that were held with the participants' representatives were used to reflect these themes:

4.3.1 SUMMARY OF IDENTIFIED THEMES AND SUB-THEMES

Themes	**Sub-themes**
The psychological challenges experienced by children with cerebral palsy and their families	• Feelings and experiences of children with CP, parents and carers. • Stress. • Feelings and experiences seen on the child with CP by parents/carers. • Coping mechanisms with CP. • Labelling and its effects.

The social and emotional effects of cerebral palsy on the children and their families.	• Community Stigma. • Unemployment. • Educational challenges. • Sense of belonging. • Social security. • Support structure. • Availability of resources
Programs in place to address problems and needs of children with cerebral palsy and their families in Moses Kotane Hospital.	• Physiotherapy • Occupational Therapy • Community outreach programmes
Social Work services to children with cerebral palsy in Moses Kotane Hospital.	• Counselling • Outreach programmes • The impact provided by the social work services in Moses Kotane Hospital to children with cerebral palsy and their families.

4.3.2. PSYCHOLOGICAL CHALLENGES EXPERIENCED BY CHILDREN WITH CP AND THEIR FAMILIES

- **Feelings and experiences of the participants and the children**

All the participants indicated that they were psychologically disturbed because of the conditions of their children. As one of the important wishes in life, having a child who is born without disability is a wish of every parent. They indicated that it always comes with great sadness when coming to think of the future of their children with cerebral palsy. They feel like their children will never find any happiness in their lives as they will never have families of their own because they cannot do anything for themselves.

Some of the participants summarised their experiences and feelings in these words:

- *"I had mixed feelings when I started to realise that I have a child with CP. I was sad and angry. I once imagined that life is unfair and that God does not like me. On the other hand, I at times say to myself; whatever that is happening is the wheel of God and I should accept, even though it is hard at times to cope with the condition".*

- *"At times I cry when I look at my child. I sometimes feel like I have done something wrong, or offended God which is why he ensured that I have a child like this. I cannot talk to her, when I do, she does not respond. She does not give me any reason to make me feel like I am a mother, or blessed with a babe girl".*

- *"At times I feel like listening to her crying and calling my name or it would satisfy my heart to just hear her say mum to me. Though I cannot deny or not admit that it is God's wheel, such creation often feels like a burden. But I have no choice but to be there for her, give her the love and raise her with dignity".*

- *"I was stressed and I cried a lot. Most of the times I feel devastated and feel like God has given me a heavy punishment for the mistake I do not know I committed. My self-esteem as a parent is affected, I do not feel confident to walk the streets of my village with confidence. My child is still young; I always ensure that I cover her, so to avoid people asking to see him. I feel like God is forcing me to love the child I did not ask for".*

- *"I wanted a child who I could be able to pride myself with, I wanted a child who I could walk the streets of my community without any fear of shame or embarrassment. At first I wanted nothing to do with the child, but for some time nothing went well with my life, and I have no choice but to love this child. He is my child yes, I learned to love him, but he is definitely not what I asked for from God. I am always home based, because of him".*

- *At first it was hard for me to accept that I have a child with disability. I was planning to give the babe for adoption after I was told by the medical personnel that I have a child with CP. It is hard for me to have another child, because I always have a feeling that haunts me. I am even afraid to have another child. The fear I always have, is what if I give birth to a child with CP again, what will I do with two kids with disability if I cannot manage with one. At times I feel like my child is a burden. I love my child, but I cannot deny the fact that he is a burden.*

➢ **Stress**

The participants admitted that stress is one of the condition that will never disappear as long as one has child with disability and particularly cerebral palsy in life. They said that it does not only exist after finding out about the child's medical condition because it is a feeling that repeatedly present itself even if not always, but the feeling do not end. Watts (2014:14) defines stress "as a physiological and psychological response to events that upset our personal balance in some way. These events or demands are known as stressors that lead us to feeling pressured and tensed".

Seeing a child of another woman, same age as of the one you are having doing things that you know your child is unable to do is one of the things that trigger stress, said the parents. They said one would feel sad and wish it was her own child doing that. One parent concluded that, one of the things that contribute to stress is when she wants to go out with friends and not get someone who can help look after the child while away.

One participant who is still in her youthful ages voiced the following concerning the issue of stress:

"I do not feel comfortable being approached by guys for love. I often turn them down, because I know that should we agree on starting a relationship, I will not have time to give it attention because my child take all the time I have. I am single and I am not married. It is my wish to find a guy who can love me with my child, because most of the guys I dated did not take well the fact that I have a child with disability".

The comments that the parents expressed and their feelings tell that they have much load of mixed feelings, which some of them had no enough chance to talk about. It really felt like a platform of true expression of inner feelings toward the situation faced with.

- **Labelling and its effect on children with CP and their family**

"Human beings have a predisposition for categorizing, for labelling, and have done so since the beginning of time. Labelling human beings according to an ever-changing set of general characteristics has brought into existence an apparatus for human to behave at their worst: to enslave, so to sell as chattel, to abuse, or to murder en masse their fellow human being" (Benedict, Schmidt, Spruce & Woodford, 2015: 191).

Labelling comes in many forms. There is negative and positive. Positive labelling can be that in which people are classified according to their specific speciality, or the work they do. This allows people to know you better and be able to differentiate you from others. Negative labelling intends to cause harm or pain to one's emotions and leave them hurt and looking down to themselves.

Children with cerebral palsy are amongst the most labelled people we have in our communities. Participants explained that they are called names and they are categorized by the way they look or who they are. They admitted that negative labelling affect many things in a person such as self-confidence.

Below is what some participants had to say concerning labelling:

"I remember my child was called (seritsa) and I was addressed as (mmage seritsa), which means a cripple, someone who cannot do anything by himself. Even though the child is disabled, it does not permit a right for anyone to call a person like that. Everyone has a right to a name, and deserves to be called with his or her name. I believe the child would not be happy to hear being called in that name if he could hear and understand what it means.

I see this labelling thing as disrespect and inhumaneness at its best. It was a norm in my community for most of the people to address me with that name, more especially when I had a disagreement and exchange of words with them. It was a way to hurt me, and one has to believe when I say it really hurts. It makes me feel down, hopeless and useless at times. Labelling really is a bad thing ever that one would want to experience".

"You know I really know what you are talking about when you talk about labelling. The name that the community used to call my child with rings a bell when you talk about it. I do not even want to say the name, because it makes me sad and angry. I started threatening those who used to call my child with that name.

You know at times I used to feel like life is unfair, simply because when a mother is raising a child with disability alone, there are many good and courageous names that she can be called with for the job well done, so that she can continue to have the strength and courage to keep doing good. Instead of people doing that, they rather call you names that belittles you and that will make you feel discourage at times".

Benedict *et al.,* (2015: 191) believe that "negative labelling can be very painful and can even lead to a person deciding to commit suicide, or deciding to kill the person who is labelling you". Knowing and understanding each other's indifferences as humans is very important as it allows for accepting the individual strengths and weaknesses.

- **Coping mechanisms with CP**

From the participants' point of view and the live experience of the researcher, children with CP find it hard to communicate their needs. They are children, everything is decided for by their day to day careers. They cannot express their felt needs, and therefore most of the times, they cry. It may be because they feel hurt that their needs cannot be felt and met when they try to express them. At times they do not get the attention whenever is needed. Some of the children who participated in the study can talk but you cannot understand or make sense out of what they say.

The researcher asked the representatives of the children as participants how they know what the child needs or want when trying to communicate. These were some of the responses:

- *I try by all means to pay attention to whatever sound the child makes, in order to understand what he is trying to say to me or the other person. After hearing the sounds, I would try to come with something to the child and try to understand if he was asking for that particular thing. If he shows a sad or bored face, I know it is not what he wants. Truly speaking it is frustrating to the child if you do not follow what he is trying to say or what he wants. Even if he is crying, he does not cry like normal, I would see tears coming from his eyes then I would notice he is not happy.*

- *"My daughter is 7 years now, I have been looking after her on daily basis, but even today I still find it hard to understand her methods of communications. She cries like any other babe when she needs something and does not get it, or when you give her the opposite of what she want, she cries like nobody's business. At times you would think she want a certain thing and give it to her, she would just stop crying and take it, but you see that it is not what she wanted, but because it is a child she would just accept it".*

- *"My son is more severe on physical parts, but he can hear understand when you talk to him. He can respond, but words coming from his mouth are not clear. He is 9 years; I have learned to understand how he communicates. To other people it is difficult to understand what he says when he talks. When someone keeps asking him to repeat what he said, because of not getting the message clear. He gets angry and throws whatever he sees around him to that person. He has temper issues, I took him for sessions with the psychologist, in Moses Kotane Hospital but there is no change. I am planning to take him to a private psychologist, because this anger issues is seriously affecting him.*

Anger issues in children with cerebral palsy are common (Health Boards, 2010:1). Logangage a single parent (father) to a 10 year old agree with the report by Health Boards, and has written this on their webside:

"*Hi. I am brand new to these forums and really need help with my oldest child. He is 10 years old and has mild CP. He is a pretty normal looking child, but has had CP all his life and has speech and physical delays. He can do most of what other kids can do, but has trouble with certain things. The main problem I have is his anger issues. He gets very frustrated and hits things or people when he cannot accomplish a goal or yells in a very angry fashion".*

This is a clear indication that children with cerebral palsy have anger issues more especially when they cannot get what they need or want.

4.3.3 SOCIAL CHALLENGES EXPERIENCED BY CHILDREN WITH CP AND THEIR FAMILIES

- **Stigma**

Stigma is one of the leading factors amongst most of our communities. Patel, Woodward, Feigin, Quah & Heggenhougen (2010:484) regard stigma as a "pervasive social force that has powerful; consequences for those who are stigmatized and society itself. They believe that stigma acts to decrease life opportunities among those that it affects by reducing among other things social contacts".

Same as it is viewed by the authors above, participants said that the community has a very negative image about them, the child, and also their families. Though others admitted that not all community members have a negative attitude towards them, but a handful of people within the community do have a tendency of stigmatising them.

Following, are some of the words expressed by the participants:

- *"In my community especially people of the same street I live and some in my neighbourhood used to call my mother a witch. It was a well-known thing in my community that my mother is a witch. The time people find out that I gave birth to a child with disability, they started saying that I am paying for my mother's sins. They regard my child as a punishment. To them my son is paying for the sins committed by my mother. There is nothing wrong that my*

mother did to all these people, but they are confident enough to say whatever they say about her.

- *At first it was frustrating to believe that the community regards my son as a punishment. But through support from some of my friends and family, I have come to terms with the fact that they hate my mother so is my son. I am no longer participative in some of the activities or rather the ceremonies in my community such as weddings, and funerals because when I try to assist, I get side lined at times, because people do not feel safe and comfortable to eat the food that were prepared through my assistance".*

- *"In my community some of the words I hear about my daughter are not said to me directly. I hear them from my friends and other people I associate with around the community. They accuse me of having slept with multiple partners, which is why I gave birth to a child with disability. They accuse me of taking other people's partners, and therefore my daughter came as a form of punishment. At first these words used to hurt me, but I have learned to come to terms with them.*

- *I decided not to care anymore as to who says what about me, my family and more especially my child. People use to stare through the windows when I walked with my child. I believe the aim was to confirm whether it is true I have a child with disability or not. I will not allow anyone to turn me into a joke in the community, and I will definitely not allow whatever they say to haunt me anymore".*

- *"My child is wheel chair bound. Wherever I go I am with him. He cannot talk, he cannot do anything. I am not working, I am self-employed. I make enough profit out of the business that I run. People who are running the same business that I do in my community do not progress faster than I do. When we are together they always say I am lucky and that the luck I have comes from my child. They often say if it was not of having a child who is disabled I would not be where I am.*

- *At first I could not take offence because I thought whatever being said was just a joke. This joke as I used to see it started developing; it was a routine and started to get into my nerve. I started to take offence when one said i use my child as a "muti" to run my business. We were fighting with words over something, immediately she said that everyone was laughing and I started realising that all this has always been a topic behind my back. Even today when I look at my child and think of those words I become angry and sad"*

- **Unemployment**

Unemployment is another significant and evident factor that most of the parents to children with CP are faced with. Those who are not biological parents, but day to day carers of children cannot regard looking after the child as employment because they are earning any cent from the work they do. One is a family member and another one is a sister, the rest are biological parents the children with CP. Those who are not biological parents have not agreed with the parents of these children of the payment for looking after the child, they do it voluntarily.

The parents said it is hard for them to go look for work, because they have no one to look after the child, should they work. Boland & Griffin (2015: 209) argue that "one of the most significant ways we know unemployment is through the production; they further say that it is joblessness, the absence of paid employment".

The status of being unemployed has caused most families to be one of the victims of poverty. Most of these families rely on the child support grant and the disability grant of the child as the main source of income. Most of the parents said that, just like other parents, they have dreams of working and earning their own salaries, but they are forced by the circumstances facing them to remain at home and look after the child.

- **Education**

All the children who took part in the study do not attend school. All participants admitted that school is very important in the child's life. Most of them said, they have

not bothered to make an effort to look for school for the child. Their reason differs and this is what some of the participants had to say:

- *"I have never thought of taking my child to a special school. I am afraid that I am going to give teachers a challenge with my child. The last thing I need if for my child to be regarded a burden. I believe I am the one who understand his need better than anyone. I have learned to understand him. Even his siblings and his father do not understand him, so I will not risk giving my child to other people, while it is not easy for those who live with him on daily basis to understand him and his needs".*

- *"My friend had a child with disability. Her child's condition was severe as that of mine. She took the child to a special school but nothing was changing. The teachers also did not treat her well as compared to those who were not severely disabled. They would leave him for a long time without asking the helper to change her nappies. When I think of taking my child to a special school, I always think of what happened to my friend's child and seriously I will not bare the pain of experiencing that with my child, because I believe she has suffered enough with her condition to let her suffer even more".*

Most of the participants had almost same feelings about special schools. The services offered by the special schools need to be marketed and explained to the parent of children with disabilities. Because most of these children live in deep rural areas and do not know about some of the schools, and the service or roles these schools can play in their lives. There is a need to also monitor the service level or performance of those schools so to change the mind set of parents about these schools, which make them not to trust these schools with their children.

- **Sense of belonging**

According to Videbeck (2010:123), sense of belonging is the feeling of connectedness with or involvement in a social system or environment of which a person feels an integral part. He noted Abraham Maslow when he described a sense of belonging as a basic human psychosocial need that involves feelings of both value and fit.

“Value- refers to feelings of being needed and accepted. Fit – refers to feeling that one meshes or fits in with the system or environment. This means that when a person belongs to system or group, he or she feels valued and worthwhile within that support system”.

Each and every individual has a longing to belong somewhere. It is everyone’s wish to be involved in some of the activities that are happening within the environment which we live. Same as with friends, we all have the wish to have friends that we can keep for a long time and also grow with if possible. Unlike any other person, it is different with most of the participants who took part in the study.

Most of the participants admitted that, there have been a lot of changes in their lives since the birth of the child with disability. They admitted that they have lost touch with the society, because they have a duty that they fulfil on daily basis. Touch in the society in a sense that they are no longer able to socialise like they used to before.

This was an outcry to most of the parents of children with CP who are still in their early stages in life. The responses were the answers to the question of how their lives have changed since giving a birth to a child with cerebral palsy. Most of them said that they had friend who they are no longer closed to since the child’s birth. They said it is not because the friends are excluding them but it is because they do not have enough chance to visit them because they have to look after the child on daily basis. They admitted that they used to visit when their children were still young, but now that they are a bit old it is heavy to always go to friends with the child.

Others said that they are afraid to even visit institutions like their churches, because most of them do not have environments that are not accommodative to the child’s condition. The church is built without making the environment friendly to those who are wheel chair bound. There are no wheel chair ramps at most of the churches of which makes it not easy for them to go to church regularly.

One of the participants had this to say:

“Most of the kids around my community do not see a need to come at my place to play with my child because she cannot talk and she cannot play. If you see kids at

my place coming to play with my boy, know that I called them to come and play with him. Even though I cannot get an answer from my child when I ask, I can see often that he also has a wish to have friends, and to always play with them. He has that special sense of belonging somewhere as well, being able to socialise and to play with friends. It is true every being has a sense of belonging".

- **Social security**

All the participants identified some social security challenges such as poverty as one of the main challenges that makes them look desperate and vulnerable. Though they admitted that the child's disability grant is active, they said it is not sufficient to accommodate the entire family. They admitted that the money is not always utilized for the things is intends to achieve, which is caring for the child.

Most of the kids are said not to have enough clothes that afford them a chance to change clothes after every bath. All the parents and carers said they always ensure that the child bath twice a day on daily basis. Most of the children have problems eating the food that are prepared for the whole family on daily basis. They have a problem swallowing some of the food. They should always be special meal prepared for them on daily basis. They eat soft meals such as soup, soft porridge and fine potatoes.

The parents and carers admitted that raising a child with cerebral palsy needs a huge commitment. They said that is expensive to raise the child, because it comes with a lot of expenses to most of the child's daily needs and also the health needs. "The child needs to be taken for routine check-up at the clinic, and at the hospital at times. The disability grants the children receive is not enough; it also forces the family to use its budget to accommodate also the child's needs. This situation leaves the family leaving a very difficult live, being unable to meet their daily needs. They further said that it is not easy to compromise the day to day needs of the child".

Intensive research undergone by Nimbalkar, Raithata, Shah & Panchal (2014:3) pointed out that according to many parents, money played an important role in the upbringing of the child. These costs ranged from the doctor's consultation and medicines to transports of the child. In some cases, as the child was more disabled,

parents had to hire a separate vehicle each time in order to bring the child to and from the hospital.

- **Support structure**

In most cases, it is usual that the mother to the child with cerebral palsy is the one blamed by the paternal family to have given birth to a child who is disabled. This is more common in Africa and this negative judgement creates a negative impression within families which often results in hatred and exclusion towards the child and her mother by the paternal family. The support is always there before the family becomes aware of the child's condition. The maternal family is the one always being supportive towards the child and the mother. These incidents lead to the child growing without a father figure, and not knowing the presence of the father, because their fathers do not make an effort to visit them. This is viewed to be a common practice with African Men.

Most women end up separating from their husbands who are unable and not willing to come to terms with the disability of their child. They do this because they cannot handle the pressure being given by the husbands' family. This is a clear indication that many families tend to blame the mother to the child if it happens that she give birth to a disabled child". Many children who were represented by their mothers and caregivers in this study do not know their fathers. Since they were born they have not seen them, because their biological fathers do not make any effort to help the mothers raising them. Their fathers are no longer in a relationship with their mothers. Participants admitted that raising a child with disability as a single parent is *not a simple thing to do.*

Some of the participants echoed the following comments:

"Everything was fine before and when I was still pregnant. I have another child who is the first born, between me and my ex-boyfriend, also the father to the second child who has disability. After giving birth to the second born who has cerebral palsy, things started getting tough at home. The maternal family started talking some nonsense to the mind of the child to say that I am not the right woman for him,

because I will always give him children who are disabled, and it is not what they want in their family. He had the guards to tell me what his family said about me.

At first he did not take serious what his family was saying about me, but after we months, he started to act in a strange way. He never wanted to hold the child; he would lift and play with the first born alone. When I asked him why he is doing that he said the child is not his, that he can feel it in his veins. I was angry at him, because I know very well that it is his child. I felt like he was indirectly accusing me of having multiple partners whom I was having sexual intercourse with. I felt angry, bitter and that I was belittled, because he was influenced by his family. After saying that to me, I shouted him out of anger, and by so doing I did not know that I was giving him a reason to break up with me".

"I am still married to my husband, but we are not staying together. After he find out that we have a child with disability, he started being distant. We were not staying together full-time, because of his work commitments. He was working for from home and would only come home twice a month. He started not coming home, when I ask him why he would give excuses that he is busy working even on weekends that I knew he was off.

He came for one weekend with a car and he did not have a car by then. He did not spend a night at home, he was moody. He came to fetch his clothes without saying anything, when I asked him where he was going, he just asked me to leave him alone. I was afraid to ask him more questions. Two days after he left, he sent me a message with his pone, in which he said he cannot be made a fool anymore, the child is not his and that I should be happy that he is gone. He accused me of cheating him because there is not one in his family who is disabled and there is no way the child could be his. He thanked me for wasting his time his time and said, I should forget about him".

The feelings that participants showed and the answers they gave to the questions, are a true significance of the fact that children with CP get negative treatment from other members of their family. They do not only get bad treatment from community members but also from who are closely related to them. Majority of them do not know the feeling of having their fathers by their side in life, let alone issue of support.

Only two parents declared their husbands to be supportive and caring to their children.

According to Lamb (2010:9), “a second source of influence in a child’s life stems from the father’s role as a source of emotional and instrumental support to the other people, principally mothers, involved in the direct care of the child. The provision of emotional support from the father is continuously important to enable the child to grow knowing the warmth, love and the support of the father in life. Lamb further believes that the father’s function as a source of emotional support tends to enhance the quality of mother child relationship and thus facilitate positive adjustment by children”.

Mothers to the children with cerebral palsy would also not lose the courage and the strengths to continue with maximum care and support to their children, if they had support from their children’s fathers from the onset a lot would have been different to the way they are currently.

- **Availability of resources**

There are many resources for children with disability in South Africa. The South African government is trying by all means to cater for people with disabilities, to make them not feel excluded and not cared for. Most participants fully agree that there are services and resources for children with disabilities in South Africa. But the participants believe and agree that most of them do not reach those people who are living in rural areas like themselves. The participants said the government is doing good to deliver these services in urban areas and townships, but there are no such resources in rural areas.

They over emphasised lack of resources such as the health care services in their rural communities. They said it takes them a long time to access services such as those of an occupational therapist, and physiotherapist. Their local clinics do not have sufficient resources for the government to employ people of such qualities full time, so to better the conditions of their children.

They believe the conditions of their children would have been better if they had full time physiotherapist and occupational therapist in their clinics. But due to lack of resources, they find themselves going for treatment only once in a month. They also over emphasised also the need for day care centres for children with special needs, so that they can take them there for them to socialize with other kids similar to them. They believe availability of such institutions will enable them to look for jobs, because they will be assured of their children's safety during the day.

They said that there are many places and areas where people living with disabilities do not have access to many services as compared to normal people. They said many buildings even today in their communities still do not have wheel chair ramps, and in particular those in their communities.

- **The impact provided by the social work services in Moses Kotane Hospital to children with cerebral palsy and their families.**

"Social workers in a hospital setting help patients and their families understand a particular illness, work through the emotions of a diagnosis, and provide counselling about the decisions that need to be made" (NASW, 2011:1). Social workers working in Moses Kotane Hospital also ensure that they help the parents of children with cerebral palsy to understand CP and also to learn to accept the child's condition. They admitted that their role is not easy but they make sure that they handle the situation effectively. They said they find themselves without any choice but to control their emotions. Intervening social workers said they do the following:

"We help patients to deal with the emotions of a diagnosis, and give counselling. Experience has taught us that our services are very important to the patient, particularly to parents of children with CP. After having counselling sessions, most of them start to accept the child's condition, though it is always not easy for them to accept the condition and at time the child itself. CP is a life changing condition to each and every family. We therefore help them address their social, psychological and financial needs, so to accommodate the child's special needs which are related to the condition itself.

“We make this possible through screening and evaluation of the patients’ families during the initial meeting of the referral. We make a psychosocial assessment of the child, but also to their parents”.

Social workers in the hospital apply the family systems theory, as they know and understand that, when a part of the system which is a member of the family is affected, the entire system is affected as well.

The social workers in the hospital further alluded that they believe that finding out of the diagnosis of CP comes as a shock to most parents and to the family in general. They further said the diagnosis can be traumatic to other parents and families, and therefore, when necessary they offer in depth counselling to avoid trauma from happening. They said to give them emotional support, hope and to make them accept and recognised that despite the child’s physical condition, he or she deserves to the love and support from the family.

They partner with private and public institutions to ensure that the parents and families receive continued care and support, even beyond the borders of the hospital. They do so because once the child has been discharged their powers to further take charge of the case are not easy, given the policies of the hospital. They therefore refer to other institution for further management and support, because change, acceptance and adaptation are not an event but a process.

- **Occupational Therapy**

“Occupational therapists aim to assist children with cerebral palsy with normalisation of their muscle tone, maintaining range in the muscle of the upper limb, development of play, functional and fine motor skills” (Therapies for Kids, 2016: 1). Occupational therapy sessions are very important in the life of the child born with cerebral palsy, the sessions helps better the muscles of development and posture so as the child can be able to perform certain functions as the normal child.

In the interview sessions with occupational therapists at Moses Kotane Hospital, they pointed out that it takes perseverance and commitment to continue participating on the cerebral palsy sessions that are held within the hospital. They said they try by all

means to ensure that they invest most of their time thinking of better strategies to arrange more sessions with them so that they can bring change in the physicality.

According to the Cerebral Palsy Guide (2016:1), “occupational therapists helps children with CP develop or recover the skills needed to lead independent, satisfying lives. Paediatric occupational therapy focuses on improving the child’s ability to play and learn, which are important for development and becoming independent”.

“Occupational therapy has a very important role it plays, in the physical and mental fitness of a CP child”. When combined with occupational therapy, “Botulium toxin-A injections are relatively safe and effective treatment for arm spasticity for children” (Cerebral Palsy Alliance, 2016:1).

Occupational Therapists in Moses Kotane Hospital admitted the challenges that are faced by children with cerebral palsy. They said it is not simple as it is thought for all the children to come for sessions because of monetary problems. All these children are the beneficiaries of disability grant, but not all of them are budgeted the money to travel every twice a month to the hospital for cerebral palsy lessons. The money is used to look after the whole family for a living. Most of these children come from disadvantaged families.

They try by all means to avoid a situation where months pass without children getting occupational therapy sessions. Occupational therapists do community outreach programmes, whereby they go to central villages and children with cerebral palsy from nearby villages comes to them and receive their services. OTs does this as part of one of their community outreach programs that they do in collaboration with multi-disciplinary team to ensure maximum treatment and support by the hospital to its patients. The hospital multi-disciplinary team does this rough giving people living with cerebral palsy social, psychological and health support that they need.

Most of the children attending cerebral palsy sessions regularly can be seen though physical developments in their body. Most of them are able to do basic bodily functions such as holding things for themselves and being able to play with other children.

4.3.4. CONCLUSION

Chapter four has presented detailed demographic information of the participants who formed part of the study. This included detailed background information of the participants. The research findings were discussed in line with the research themes and sub-themes that were formulated by the study. The themes and the sub-themes have covered both the social and psychological challenges suffered by children with cerebral palsy on daily basis, which were the main challenges that the study aimed to reveal.

CHAPTER FIVE

KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter concludes the research report with an outline of everything that has been covered by this cerebral palsy study. It provides a summary of the research interviews that were held with the participants, it also aim to re-look at the ultimate aim and objectives of the study and to determine whether they were achieved as it was intended by the study. This concluding chapter also draws attention on the conclusions that reached by the study. The chapter also gives recommendations to be considered by different relevant departments, agencies and organisations that aim to see to it that the well-being of children with disabilities, particularly cerebral palsy are realised and enhanced.

5.2 Key findings of the study

Many children are born with cerebral palsy on daily basis. South Africa as one of the fast growing and developing countries also has a high number of children living with cerebral palsy. The researcher took note of the growing statistics which triggered the interest in undertaking this cerebral palsy study. The aim of the researcher was to be specific, focusing mainly on the psychological and social challenges that children with cerebral palsy go through on their everyday lives.

The reason to focus specifically on the social and psychological challenges that these children go through, was mainly because many studies have been conducted regarding cerebral palsy as a phenomenon within the medical sector. On the other hand less attention has being put on the social and environmental challenges facing children with cerebral palsy and their families. The problems lead to psychological challenges such as stress, depression and other psychological ills and they affect the well-being of these minority and their families.

All these challenges led to the aim of this cerebral palsy study, which was to explore and describe the psychosocial problems experienced by children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.

The ultimate goal of the study was achieved. Thus the following findings can be made:

- An investigation on the social and psychological challenges affecting children with cerebral palsy on daily basis were identified.
- The participants were able and willing to open up about everything they go through on daily basis.
- Among other things, the participants who are parents and caregivers to children with cerebral palsy, noted social exclusion by their communities as one of the main issue they face on their life endeavours.
- They said their children are not recognised and identified as people of worth and dignity within the society.
- Most parents discourage their children to associate with children who have CP, because they are unable to talk. They feel that a child with CP delays the developmental ability of their children and limits their role to interact with other children and they are unable to learn from them as compared to children without disabilities.
- They identified labelling as another dominating issue within their communities. They are being called names that belittle them and their children. They said at times it is better because as parents of these children they are the ones to take and feel those hurtful words and names instead of their children themselves. They said it hurts, but it would hurt much, if those children were able to hear, understand and draw sense out of these words.
- Being unemployed is a serious issue in the families of these children, and has a negative impact on them. Their parents are unemployed and their families do not have any other source of income, beside a disability grant given to the child as the main source of income. Therefore instead of the money being used to meet the child's health needs, it is used to support the family and leave the child even more vulnerable. This poor and heart rending feelings leads to stress and depression.

- Participants said that stress is a routine for them. It hurts to see a child who has not done any wrong to anyone being treated like non-human beings
- They said the child may be disabled, but it does not mean he or she can be treated equally to a non-living organism. They have feelings and they can feel pain.
- The stigma of the community towards their children does not treat them well at all. All these experiences outlined by the participants are a true indication that the aim of the study was attained.
- The study has revealed that indeed children with cerebral palsy and their families, particularly their parents are faced with many challenges, which are socially and psychologically oriented.
- The support system from the fathers of CP children has been revealed to be very poor. The support system from other family members from the maternal and paternal families of CP children has proven to be inadequate.
- The study has revealed that support from communities to children with CP and their families is still low. There is a need for communities to gain a greater consciousness and awareness about CP as a medical condition and what it is about so to ensure that communities do not find them as a burden and passive members of the community.
- The study has also noticed lack of adequate support in relation to academic literacy to children with cerebral palsy.
- There is a shortage of day-care centres for children with disabilities, particularly in rural areas. The participants admit that the schools for children with disabilities are mostly situated in urban areas and they do not have money to take their children to those schools, so that they can learn. This leads to day to day caregivers of children with cerebral palsy taking it to their own hands to give basic education to their own children with disabilities.
- There is a need recognising that children with CP have inadequate resources that enables them to grow and develop better like other children.

- Also lack of resources and skills in rural health centres should be given attention so to ensure that enough resources are put in place to assist children with disabilities.

- There is a need for acceleration of provision of services.

There is also an on-going stigma towards children with CP, according the community they act as a source of luck to their families. Their parents are seen as sinners which resulted in giving birth to children with CP. The general attitude of the community towards children with CP is not a good one at all.

There is a need for more support systems towards children with CP and their families, so to ensure that they do not feel as burdens to the society. These support systems should also include building of more facilities that will see to it that there are more day to day centres for children with CP and other special needs in rural areas. This will help ensure that parents, particularly mothers of CP children are able to look for employment, so to better their lives and to look after their children, instead of depending only on the government disability grant. These will reduce dependency syndrome on the state, parents will be able to work for themselves with the aim to better their lives. The rate of unemployment and poverty in families of children with disabilities will also be reduced.

Most children with CP are raised by single a parent, which makes them grow without knowing the father figure. This situation needs change, so as to ensure that CP children grow knowing their fathers.

5.3 Conclusion on the objectives of the study

The study aimed at investigating the psychological and social challenges experienced by children with cerebral palsy and their families. This investigation was made possible by adhering to the following objectives which gave direction and guidance that led to the achievement of the aim of this study.

The following are the objectives of the study and the description of whether they were successfully accomplished:

Objective 1

- To get more insights about the nature, and challenges of CP through:
- To identify the psychological and social problems faced by children with cerebral palsy and their families.

This objective was achieved, with detailed information given by the participants, telling their everyday experiences from their communities. They explained all the challenges and problems the child is faced with as well as the family. They also outlined how the challenges the child faces affect them psychologically and socially. A detailed outline was laid in chapter four to address this objective.

- To find figure out the social and emotional effects of cerebral palsy in children and their families.

This objective was addressed comprehensively. The participants explained how the challenges they come across affect them socially and emotionally. They have identified poverty as caused by unemployment as one of the social effects that comes with having challenges of having a child with CP. It is not appropriate to leave the child alone without care for a day long, or send the child to special school, because CP children require special attention; they need to be looked after each and every minute. This leaves parents unemployed because of looking after the child. The child's disability grant is not used to benefit the family instead of the child, and this leaves the child even more vulnerable as his or her medical and everyday needs are not met.

Objective 2

- To find out if there are any programs in place to address the problems and needs of children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.

The study found success also in addressing this objective. The participants have confirmed that there are programs addressing the medical, psychological and social problems of children with cerebral palsy. They have alluded that these programs are

offered only to CP children who form part of cerebral palsy clinic within the hospital, who have been admitted as patients, together with the family if there is a need.

The hospital often put in their year plan, the outreach programs to go to the rural areas to offer their services to children with cerebral palsy and to children of other disabilities.

Objective 3

To investigate social work services provided to children with cerebral palsy and their families in Moses Kotane Hospital, Bojanala District.

The social workers in Moses Kotane Hospital have confirmed that there are number of families who come to look for help for their children. Most parents ask for advice from social workers on what to do and or which special schools are available for them to take their children. They have explained that most parents who look for special schools on behalf of their children are the parents of children who are not severely attacked by cerebral palsy. These are children who are able to do certain things on their own. They said to also assist families who find it difficult to accept and cope with the diagnosis of cerebral palsy on the child. They help them to accept the child who he or she is and to treat the child as person of worth and dignity. They also help people through linking them with relevant resources such as connecting with department of social development (SASSA) for them to apply for disability for the child. Detailed outline on how this objective was met is provided in chapter four.

5.4 Conclusions on literature

Through in depth reading on cerebral palsy as a phenomenon, the researcher reached the following conclusions:

- There is inadequate effort done in academia in terms of understanding cerebral palsy as a psychosocial phenomenon, and understanding it from the psychosocial perspective. There is limited literature focusing on the social and psychological challenges that children with disabilities, particularly cerebral palsy and their families go through.

- Much research has been done on the medical aspects of cerebral palsy and there is less research conducted on the social and psychological aspects on cerebral palsy. Therefore there is poor knowledge about CP as a social and psychological phenomenon.

➢ **Recommendations on literature**

- More focus should be shifted towards CP as a social and psychological phenomenon, and there is a need for research in this particular field.

- There is a need to adopt a bio psychosocial approach to cerebral palsy. An individual should be seen as a bio psychosocial being and therefore when looking as CP as a condition affecting human beings, it should not be seen only as a medical condition but as a social and psychological condition as well.
- More research should be conducted on cerebral palsy as a psychosocial phenomenon in rural areas. This will lead to literature been created about CP in rural communities and how it affects people's everyday lives.

5.5 Recommendations

Based on the findings reached by the study, the researcher would like to make the following recommendations:

- There is a need for education to be given to the communities on different types of disabilities, particularly cerebral palsy. This will enable the community to stop treating children with CP badly, and to start recognising them as people of worth in the community. Making people aware of CP will reduce the stigma that is out there at our communities towards CP and other disabilities. The department of health should come up with awareness campaigns and to appoint relevant professionals from the department to carry out this role.

- More schools for children with special needs like CP need to be built. The department of education should make it a priority that special schools are built

so that children with CP can learn. This will also allow parents of children with disabilities to look for employment, which will ultimately reduce the rate of unemployment and poverty in their families. Most families survive with the disability grants of these children which automatically means children with CP do not have their needs met, because the money is not used to cater for their special needs.

- Parents should be taught to take responsibility for their children. Department of social development should make special programmes that teach parents particularly the fathers of the importance of a child growing in the presence of both parents. They should be made aware that despite the child being born disabled, it does not mean that they should abandon them. Most children with CP grow up without a father figure in their lives. This definitely needs to change, because their fathers are alive. They intentionally get out of their children's live. There is a need for every father to a child with disability to be educated on the importance of a father figure in every child's live, because it has become a routine for fathers to abandon their children because they are disabled.

- Resources should be made available at rural health centres so as to afford children with CP an opportunity to access them easily without having to travel long distance for services. More professional staff such as physiotherapists, occupational therapists and social workers in hospital setting should visit local clinics just like doctors, to provide their services instead of just staying at the hospitals and wait for patients. Not everyone can afford to travel long distance looking for their services at the hospital. There is a need for these health professionals to be hired specially to work at rural health centres, so to avoid going to hospital only ones a month for services, by children with CP.

- There is a need for recognising that people with disabilities should have easy access to the services that other people have. All public buildings and government institutions should be made friendly and easy to access also to people with disabilities. Wheel chair ramps needs to be build where they are

not available, more particularly in places such as churches, community halls and all government departments and other places.

- Parents of children with CP should be given more education on the importance of taking children for physiotherapy at an early age. Most parents wait until the child is old before they start taking the child for physiotherapy and this makes it hard for the child with CP to learn to perform certain basic tasks.

- More budged needs to be allocated to people with disabilities, particularly children. This could be done through increasing the disability grant, so that people with disabilities can be able to meet their daily needs.

➢ **Recommendations for future research**

There is a need for repetition of the same research in Townships, to determine whether the challenges experienced by children with cerebral palsy and their families exist as it does in rural communities.

There is a need for a study to be conducted to determine suitable programmes needed to address the identified challenges on cerebral palsy in rural areas.

More research needs to be conducted to advance literature on cerebral palsy with special focus to the psychosocial nature of it.

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APPENDIXES

APPENDIX A

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

Title of the research project: An investigation of psychosocial challenges faced by children with cerebral palsy in Bojanala District North West Province

Researcher: John Obakeng Keforilwe

Contact details: 061 378 5321

I Keforilwe John Obakeng invite you to take part in my research project. Please take some time to read the information presented here, which will explain the details of this project. You are free to ask questions about any part of the study that you do not fully understand. It is very important to ensure that you are fully satisfied that you clearly understand what this research entails and how you could be involved. You are fully assured of the following:

- Your participation is voluntary and you are free to refuse to participate.
- If you say no, this will not affect you negatively in any way whatsoever.
- You are also free to withdraw from the study at any point, even if you do agree to take part without giving any reason.
- This study has been approved by the Higher Degrees Committee of the Faculty of Human and Social Sciences of the North West University Mafikeng.

What is this research study all about?

The aim of the study was to investigate and identify the psychological and social problems experienced by children with cerebral palsy and their families in the North West Province in Bojanala District. For the purpose of this study, a primary carer of a child with disability has been defined as an individual who is responsible for the care and daily decision making of that child. Therefore understand the daily challenges experienced by the child and the family of the child on daily basis.

Most of the studies that have been conducted on cerebral palsy focus mainly on the medical aspects of cerebral palsy and less on the psychosocial aspects of it. This study is significant because it is possible that children with CP and their families experience psychological and social challenges and enough has not been identified and noted in the literature.

A study of this nature can help both medical and social service professionals realise that children with CP and their families goes through many challenges than the presented ones. It will therefore enable them to come up with better intervention strategies that will bring about sustainable change and development in their lives. The study could also be useful to enable policy formulators to develop already existing policies with the intent to protect the rights and needs of people living with disabilities.

The study will be conducted at a time and place that suits you. Approximately 25 individuals will participate in this study. Data collection will commence with the completion of a biographical questionnaire. This will be followed by a semi-structured interview questions consisting of questions that relate to your challenging social and psychological experiences as a parent/caregiver of a child with CP and the challenges that the child experience as well.

The interviews will be conducted face to face with a group of 6 participants and the last group will have 7 participants, which all makes four group sessions, and I (a Social Work Masters student) will be conducting the interviews. Each interview will be approximately 60 minutes long. With your permission, the interview will be tape-recorded so that it can be transcribed as verbatim for the data analysis.

Why have you been invited to participate?

You have been invited to participate in this study as you have been identified as a primary caregiver of the child, and therefore know the challenges the child goes through together with the family on daily basis.

What will your responsibilities be?

Your only responsibility in this study is to take part in a once-off semi-structured interview that will last approximately 60minutes. You will be asked questions on the challenges that the child and you as the family go through on daily basis.

What benefit do you have for taking part in this CP study?

There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in South Africa, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the challenges that children with CP and their families experience, and could help policy makers formulate new policies or amend the already existing policies to address the challenges that people with CP go through on daily basis.

What risks are there in taking part in this CP study?

The only foreseeable risk for participants in the proposed study is that individuals might experience emotional discomfort or distress during the interviews, as they will be sharing personal details of their lives. However, there are social workers in Moses Kotane Hospital and they are available for counselling and debriefing session for the participants affected emotionally in the interview process.

Who will have access to your medical records?

Any information that is obtained in this study will be treated as confidential and any information that can be connected to a participant will not be disclosed without their concern.

Lastly you will receive a copy of this information and consent form for your own records.

Appendix B: Biographical Questionnaire

Biographical information

Instructions: Please fill in your biographical information. Indicate your choices by a tick of **X** inside the box, and write **N/A** if not applicable to you.

Name and Surname:

……

Age: ……

Gender: Male **OR** Female

☐ ☐

Ethnicity: White Coloured African Other*

☐ ☐ ☐

If other, please specify:

……...

Marital Status: Married **OR** Not Married

☐ ☐

Home language: …….....

Email-address:

……

Contact-number:

…….....

How long have you been a caregiver:

……

Number of hours spent with the child everyday:

……

Occupation: Part-time **OR** Full-time **OR** Unemployed

☐	☐	☐

Age of the child being cared for: ……

What type of Cerebral Palsy does your child have:

..……

APPENDIX C

DECLARATION FORM BY PARTICIPANTS

I hereby consent to participate in the research project. The purpose and procedures of the study have been explained to me. I fully understand that my participation in this study is voluntary and that I may refuse to answer any particular question or withdraw from the study at any time without any negative consequences. I understand that my responses will be kept confidential.

Name of Participant: ——————————————————

Date: ——————————————

Signature: ——————————————

APPENDIX D

CONSENT FORM FOR AUDIO-TAPING OF THE INTERVIEW

I hereby consent to tape-recording of the interview. I understand that my confidentiality will be maintained at all times and the tapes will be destroyed after any publication arising from the study or four years after completion of the study if there are no publications.

Name: ——————————————————

Date: ——————————

Signature: ——————————————

APPENDIX E

SEMI-STRUCTURED INTERVIEWS QUESTIONNAIRE

- Can you tell me about your life and your experiences before you gave birth to a child with CP?
- At what stage did you figure out that you are carrying a child with CP?

- How did you feel after been told?
- What did you expect to happen?

- Did the medical personnel explain to you what is CP after he told you that the child has it?

- To whom did you break the news?

- How are you related to the person?
- How did he/she take the news?

- How did the immediate family members take the news?

- Are they supportive?

- How does the community feel about the child, and the family?

- Do you ever get negative treatment from the community?
- How does the treatment make you and the family feel?

- Tell me about your day with the child?

- How do you know what the child needs?
- What else do you do during the day with whom?

- What challenges are you facing since you gave birth to a child with CP?

- Where is the father to the child?

- Has he been supportive ever since the child's birth?

- How is the relationship between the father and the child?

- Did you ever feel life is unfair? if so why?

- Do you still feel the same way? if so why?

- Where you stressed after finding out the child's condition?

- Do you ever feel the same again? if so why?

- How has having a child with CP changed your sleeping pattern?

- How has the child's condition changed your personality? (behaviour, attitude)

- Do you receive assistance from any persons or institution? if so, who?