

**CHALLENGES OF MOTHERS CARING FOR CEREBRAL PALSY CHILDREN AT
THULAMELA LOCAL MUNICIPALITY, IN THE VHEMBE DISTRICT, SOUTH
AFRICA**

By

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DECLARATION

I, **TAKALANI MILLICENT DANGALE**, hereby declare that the mini-dissertation for the Master of Public Health degree at the University of Venda, hereby submitted by me, has not previously been submitted for a degree at this or any university, and that this is my own work in design and execution and that all reference materials contained therein have been duly acknowledged.

T.M. Dangale

24/06/2019

DANGALE T.M

DATE

DEDICATION

This project is dedicated to the Almighty God, my source of strength and to my sister, Dr. Tshilidzi Nevhutanda for her unwavering support.

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ABSTRACT

Cerebral palsy (CP) is the common cause of physical disability in children. The nature and severity of impairments vary, but the demands placed upon mothers are significant. It is one of the prolonged conditions which have become a serious health problem worldwide. The purpose of this study was to explore and describe the challenges of mothers caring for cerebral palsy children at Thulamela Municipality, in the Vhembe District, South Africa. The objectives of this study were as follows: (1). To explore the challenges by mothers of cerebral palsy children in relation to physical, psychological and social care, (2) To explore their challenges in relation to available resources for proper referral of mothers caring for cerebral palsy children. The study used a qualitative approach using explorative and descriptive design in exploring the challenges of mothers caring for children with cerebral palsy. The study population comprised mothers of children with Cerebral Palsy living in the Vhembe District who attends the rehabilitation therapy services at Tshilidzini Hospital. A non-probability, purposive sampling technique was used to select the mothers. Five focus groups, each consisting of eight mothers were composed. Semi-structured group guide consisting of open-ended questions were used. Data was transcribed, verbatim and coded into themes and subthemes using context thematic analysis method. Themes that emerged include: a theoretical framework for the study, effects of caring on the family's socio-economic life, challenges experienced by mothers caring for cerebral palsy children, challenges in relation to education and training and challenges experienced by mothers caring for cerebral palsy. The findings of the study might benefit the society about the challenges experienced by mothers when caring for their disabled children. The study might help government to develop and implement policies which will empower parents and the community as a whole

Keywords: *Challenges; Mother; Caring; Child; Cerebral palsy*

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LIST OF ABBREVIATIONS AND ACRONYMS

ADL	Activities of Daily Living
AIDS	Acquired Immune-Deficiency Syndrome
AIHW	Australian Institute of Health and Welfare
DPSA	Disabled People South Africa
CNS	Central Nervous System
CT	Computed Tomography
CP	Cerebral Palsy
HIV	Human Immune-Deficiency Virus
MRI	Magnetic resonance imaging
MOH	Minister of Health
NGO	Non-Government Organization
NTD	Neurodevelopment Therapy
SANDTA	South African Neuro-Development Therapy Association

CHAPTER 1: INTRODUCTION

1.1 Background to the study

The Centre for Disease Prevention and Control (CDCP) (2016) reported that cerebral palsy emerges as a major public health problem in children around the world. The CDCP (2016) indicated that cerebral palsy is the main cause of physical disability. Cerebral palsy displays a variety of impairments including hearing, visual, speech, cognition behaviours, bowel control and musculoskeletal problems (CDCP, 2016). Cerebral palsy is a complex disorder that needs treatment and management. According to Dambi et al., (2015), rehabilitation services are recognized internationally as a key component of health care which improves the life of children with cerebral palsy. A rehabilitation team includes medical specialists, such as neurologists, eye specialists and surgeons. A comprehensive management program begins in an early stage, which includes parents, physiotherapists, social workers, occupational therapists and speech therapists. All members of this dedicated team manage different aspects of the disorder (Cerebral Palsy Alliance, 2015). There is no cure for brain damage, but therapists' aid with daily activities and hospital routine visits (CDCP, 2016). According to the Cerebral Palsy International Foundation (2015), 1 in every 500 live births is diagnosed with a disability.

The international incidence of cerebral palsy was estimated to be 0, 2 to 0,3% (about 2-3 out of every 1000 births). The prevalence rate of cerebral palsy in advanced countries was 2-3 cases per 1000 live births, whereas that of developing countries was 5-8 per 1000 live births (Dambi, Jelsma & Mlambo, 2015).

In African countries, the prevalence rate of cerebral palsy is estimated to be 10 per 1000 births (Burton, 2015; Donald, 2016). In South Africa, the Disability Action Research Team (DART), cited by McLaren (2014) reported that cerebral palsy is difficult to diagnose. Dambi et al. (2015) indicated that the high rate of cerebral palsy shows that poverty, poor maternal and child health care, a shortage of clean water, overcrowding and poor sewer systems brought health concerns.

1.2 Problem statement

The motivation for this study arose from the researcher's own professional experience with mothers of cerebral palsy children that were undergoing therapy at Tshilidzini Hospital. The researcher works as a Speech therapist and had a series of encounters with mothers of CP children. The children depended on the rehabilitation services because of the disability resulting from their condition. Challenges of mothers caring for cerebral palsy children impact the whole family. The motivation for this study arose from the researcher's own professional experience with mothers of cerebral palsy children that were undergoing therapy at Tshilidzini Hospital. The rehabilitation team at Tshilidzini Hospital plays an active role in addressing physical conditions of children with cerebral palsy. However, limited attention was given to the mothers who are caring for these children in the home environment. The services that are offered at Tshilidzini Hospital are focused on physical rehabilitation of cerebral palsy children, without looking at challenges experienced by mother during care giving processes. On a regular basis, the researcher observed that mothers of cerebral palsy children attending rehabilitation at Tshilidzini struggled to cope with the care of their children. It is good to understand the communities that mothers live in and the challenges they face during Activities of Daily Living (ADLS). The study sought to explain challenges encountered by mothers when caring for cerebral palsy in their homes.

1.3 Rationale for the study

It is important to conduct such research to provide evidence grounded in their problems. The study may help to fill the gaps of information about the challenges faced by mothers when caring for cerebral palsy children. In the Limpopo Province, Vhembe district, there is no statistics of the prevalence rate of children affected by cerebral palsy and it is difficult to obtain the exact incident of this condition. To date, there is no research conducted on the challenges experienced by mothers caring for children with cerebral palsy.

1.4 Significance of the study

The findings of the study may expose a deeper understanding of challenges faced by mothers when caring for CP children in the home environment. The results may assist health professionals, policy-makers, researchers, cerebral palsy children, mothers and the community. Health workers

may apply the knowledge obtained from this study to address different types of family needs in caring for CP children. Professionals may use the findings when planning services for CP children. Mothers of CP children may be able to voice their challenges and may benefit the rehabilitation team in rendering better services for CP children. The findings obtained from this research may help the policy-makers to coordinate the point of delivery across health, social services and education. The findings may also serve as useful information to make recommendations in the field of rehabilitation for CP children.

1.5 The purpose of the study

The purpose of this study was to explore the challenges of mothers caring for cerebral palsy children at Thulamela Local Municipality, South Africa.

1.6 Objectives of the study

The objectives of this study were to:

- Explore the challenges experienced by mothers of cerebral palsy children in Thulamela Municipality in relation to physical, social and psychological care.
- Explore the challenges experienced by mothers of cerebral palsy children in relation to available resources for proper referral of mothers and children who have cerebral palsy.

1.7 Definition of concepts

1.7.1 Cerebral palsy

Cerebral Palsy (CP) is the childhood disorder caused by lesions in the brain occurring before, during or after birth. In this study, cerebral palsy is a condition affecting the control of movement and posture of a disabled child (Centre's for Disease Prevention and Control (CDCP), 2016).

1.7.2 Mother

A mother is a woman who spends most of her time on daily basis with a child. For this study, mothers refer to primary caregivers who take responsibility for physical care of the child with cerebral palsy

1.7.3 Challenges

In this study, challenges refer to situations, hardships and difficulties that mothers experience when caring for CP children in the home environment).

1.7.4 Child

A child is a person under the age of 18 years who has the right to a voice. (Children's Act no. 35 of 2008). For this study, a child refers to a person who has cerebral palsy and who is under 18 years of age.

1.8 Summary

This chapter provided a summary, including an introduction and background to the study. The problem statement, rationale of the study and significance of the study were also described to understand challenges experienced by mothers caring for the disabled children. The purpose of the study, objectives and definition of concepts were dealt with in this chapter. The next chapter will present a literature review.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Based on the objectives of this study, the literature review focuses on the following areas: a theoretical framework for the study, effects of caring on the family's socio-economic life, challenges experienced by mothers caring for cerebral palsy children, challenges in relation to education and training, and challenges experienced by mothers caring for cerebral palsy.

2.2 Theoretical framework for the study

According to Bowen (1978), the Family Systems Theory is a system in which each family member has a role to play. He further states that Family Systems Theory balances and puts stability in the family. The theory describes the interaction in the family. This study used the Family Systems Theory to examine the challenges of mothers caring for cerebral palsy children. According to Calaprice et al. (2017) in Family Systems Theory, mothers have the greatest responsibilities in care-giving in order to meet needs related to health, illness, and managing disability. This study was based on the Family Systems Theory with special attention to mothers who care for cerebral palsy children. According to the theory, the family is not constant; it is continuously changing. Family units face a constant need for change, whether it comes from within or externally. The theory sees mothers' involvement with a child as a success when the family is working together, rather than the child developing all on his/her own. Having a cerebral palsy child affects all members of the family. Family Systems Theory is useful in exploring the experience of mothers in raising cerebral palsy children. The theory enabled the researcher to understand mothers' challenges in the larger contexts of their family dynamics. Families represent different cultures and heritages.

The mothers' interaction and caring for a cerebral palsy child influences the child's development (McClelland, et al., 2015). Mothers' lives are always dynamic and complex, and consist of tasks, roles, rules, communication, resources and relationships. From the Family Systems Theory perspective, an individual with a disability within the family system will impact on the entire family system (Calaprice et al., 2017), because they have increased needs, responsibilities and demands on the family system (McClelland et al., 2015). Families of children with disabilities share common difficulties and challenges including long-term care giving burdens, as well as financial and emotional strains.

2.3 Cerebral palsy

Cerebral palsy, a childhood disability, affects movement and posture (Cerebral Palsy Alliance, 2015). Dr William John Little was the first surgeon to describe cerebral palsy in 1862. He mentioned that the disorder resulted from brain damage which occurs before, during and after birth. Cerebral Palsy appears in the early years of life (CDCP, 2016). Dr Freud Gigmude disagrees with the theory by suggesting that the disorder occurs during brain development (CDCP, 2016). The condition is non-progressive and cannot be healed. Cerebral palsy is a disorder with different types and degrees of motor disability. Cerebral palsy is regarded as the largest cause of disability in childhood worldwide (Cerebral Palsy Alliance, 2015) Cerebral palsy children experience problems such as those of cognitive empowerment, speech problems, and motor and sensory disorders. It affects the psychological health and physical wellbeing of the mothers. Children with cerebral palsy need early intervention (Dambi et al., 2015).

2.4 Effects of caring on the family's socio-economic life

2.4.1 Socio economic life

Mothers of cerebral palsy children experience pressure in care-giving which often leads to crisis and conflict in the family. Mothers have to go through feelings of grief and confusion (Glinac et al., 2017). Mothers of cerebral palsy children experience challenges with those experienced by their children. Negative attitude towards the families who have cerebral palsy children worsens the social trauma (Olawale et al., 2015). According to Holland (2017), mothers of cerebral palsy children stay away from community gatherings to avoid disturbing comments. Mothers struggle to cope with demands of day to day life, which results in poverty and lack of knowledge on how to improve the situation (Glinac et al., 2017). Socio-economic concerns, daily demands and behaviour problems result in increased stress. Mothers of cerebral palsy children experience depression, feel overwhelmed, and blame themselves for not doing better (Olawale et al., 2015).

2.4.2 The impact of care-giving on gender

Mothers of cerebral palsy children accept the role of being caregivers at home. Their family experience division because there is no sense of bonding and working together as a family. According to Dambi et al., (2015) fathers are to be breadwinners in the house. Fathers are not involved in the process of care giving; instead fathers spend their time working (Dambi et al., 2015). Mothers of children with disabilities experience burdens related to doing things such as laundry, cooking for the whole family and washing dishes. According to Ribeiro et al., (2016), mothers need to co-operate to meet the needs of their disabled children, while fathers play the main role of being the head of the family. In some family's fathers support their partners in care giving of their child with disability. Hence both parents experience stress as they adapt to and learn to care for their child, however, mothers are exposed to more challenges as they are mothers and homemakers (Dambi et al., 2015).

2.4.3 The impact of disability on the family

The role of the family changes completely as family members become shocked, frustrated and embarrassed. Mothers of cerebral palsy children feel powerless and defenceless when they think of caregiving responsibilities (Singongo et al., 2015). Dambi et al. (2015) aver that family members become concerned about the acceptance of their cerebral palsy by both the society and community. They become worried thinking about what the neighbours will think about them. The researcher further highlighted that families become helpless when neighbours and friends refuse to allow their children from coming near their disabled children. As previously posited, Mothers experience a higher level of stress than fathers. Mothers' physical and mental health becomes affected and this results in health challenges such as headaches, backaches, dizziness and sleep deprivation (Patel et al., 2017). Mothers of cerebral palsy children sacrifice their own time to care for their children. The blame of having a disabled child is usually shifted to the mothers (Singongo et al., 2015). According to Glinac et al., (2017) giving care to a cerebral palsy child causes

misunderstanding in the family. Glinac et al., (2017) further maintain that looking after the disabled child is time consuming. Families find themselves isolated and lose their family members. Negative attitudes towards cerebral palsy children and their families worsen due to trauma. Disability in the family causes marriage breakdowns, sometimes leading to divorce as partners blame each other (Dambi et al., 2015). Caring for cerebral palsy children is a burden and demands increased overtime. Families tend to think that the child's disability might have come from the mother. Parents of children with disability miss job opportunities, family integration and social activities due to care-giving demands (Dambi et al., 2015).

2.4.4 The impact of the disability on the child

Cerebral palsy children face various challenges affecting the whole-body system. Cerebral palsy affects and impacts children lives negatively. Children with a disability like cerebral palsy rely on their mothers for assistance in bathing, eating, getting to bed, and toilet training. Children with cerebral palsy experience difficulties with activities such as sitting, walking, dressing, playing or interacting with other normal children (Cerebral Palsy Care, 2016). According to the Cerebral Palsy Alliance (2015), children with cerebral palsy display slurred speech, an imbalance of eye muscles, an inability to maintain balance, and poor gross and fine motor co-ordination. Cerebral palsy disturbs motor control of the whole body, including trunks and ribs. According to the Cerebral Palsy Care (2016), children with cerebral palsy have intellectual disabilities which cause learning disorders. Cerebral Palsy Care (2016) shows that cerebral palsy children experience verbal rejection in shopping malls, streets and parks. Mothers of cerebral palsy children become frustrated when community and family members display negative behaviours towards their children. Community attitudes results in disabled children staying at home with their families rather than in institutions.

2.4.5 The impact of the disability on siblings

According to Sonik, Parish, Ghosh and Jaolalsky (2016), children's health is negatively affected when siblings support their mothers when raising children with disabilities. Research shows that children share care-giving activities or housework with their mothers and struggle with other demands such as caring for their ill-health, parents and rearing disabled children (Sonik et al., 2016). Children are also expected to take caregiving as a responsibility when parents are no longer able. Children become the centre of concern to the whole family. Caring for a disabled child is time consuming and places a burden on the siblings (Burke et al., 2015). Sonik et al. (2016) aver that siblings experience challenges of planning, taking over care-giving roles and balancing family needs. Mothers of cerebral palsy children experience anxiety when siblings become jealous. Siblings feel pushed around and families take decisions without their thoughts and feelings (Burke et al., 2015).

2.5 Challenges experienced by mothers caring for cerebral palsy children

2.5.1 Financial burden

According to Ribeiro, et al., (2016), money plays an important role in bringing up cerebral palsy children. Children with cerebral palsy need specialized devices like wheelchairs, assistive devices, and need special schools and specialized therapy (Patel et al., 2017). Apart from specialized needs, children with cerebral palsy require diapers, clothing and a special diet. Mothers caring for children with disability experience financial pressures like transport, medication and medical consultation (Ribeiro et al., 2016). Mothers of cerebral palsy children suffer economic discrimination and employment opportunities. Glinac et al., (2017) reported that employment among parents caring for cerebral palsy children is compromised. Children with cerebral palsy require special attention as they cannot walk and communicate (Dambi et al., 2015). Singogo, et al., (2015) claim that a lack of finance creates strain on family members and it prevents them from accessing services that are required by cerebral palsy children. The demand for money increases daily because the disability is an ongoing task that requires more resources. The mothers of cerebral palsy usually children reside far from the health care service centres. Mothers of disabled children are forced to leave jobs, and this continues to put more strain on the family financially.

Mothers find it difficult to attend therapy sessions because they are unable to afford all suggested therapies. They end up choosing a few therapy sessions that they could afford.

In South Africa, mothers who are caring for children with a disability depend on a care dependency and disability grant. Disability and poverty drain resources for the welfare of cerebral palsy children. Mothers of children with disability face medical and financial challenges. (Singongo et al, 2015). Transport fees for cerebral palsy children double because children travel to and from therapy. Patel et al., (2017), reported that in the study conducted in Botswana with 62 mothers with cerebral palsy which was aimed at finding out the challenges that mothers experienced regarding their children, the findings revealed that mothers experienced challenges in providing medical needs to cerebral palsy children. In a study conducted in Nigeria on challenges faced by mothers with disability, Lawal, et al., (2015) revealed that caring for disabled children poses economic challenges resulting in high medical bills, high school fees and high transport fares. The economic burdens worsen due to unemployment.

Rassafiani et al. (2016) reported that caring for cerebral palsy children increases the financial burden. Additional resources such as daily diapers and special food cause a burden to the family. The burden of caregiving worsens, making mothers helpless to financial challenges. According to the (CDCP, 2016), medical expenses in USA for cerebral palsy children was 10 times higher, compared to that of able children. Children with cerebral palsy require more medical attention because they are vulnerable to infections. The (CDCP, 2016) reported that mothers of cerebral palsy children found themselves owing for doctors' consultation fees, transport, wheelchairs and food.

2.5.2 Psychological burden

The psychological effects of caring for children with cerebral palsy upon mothers have been globally investigated. According to Alberti (2016), mothers of cerebral palsy children face psychological challenges. They experience emotional reactions such as anger, shame, and guilt, feelings of helplessness and frustration. Feelings of fear, denial, isolation, lack of information and poor sleep are also not uncommon (Endo et al., 2015). Psychological challenges are defined as difficulties encountered by carers of cerebral palsy children that affect their emotions and mental well-being (Ong et al., 2016). Ribeiro et al., (2016) conducted a study on coping strategies used by mothers after hearing the outcome of their children's diagnosis. The study findings indicate that

the mothers were stressed, unhappy, worried, showed low energy and had fears of dying and leaving their disabled children on their own. Dambi et al., (2015) highlighted that disability is associated with anxiety, low self-esteem and perceiving failure. Grover et al., (2015) further postulate that psychological challenges are experienced because of financial constraints, loss of job and demands in child-care.

Cerebral palsy children experience difficulties in coping with their environment. Mothers are faced with a burden of care-giving which leads to feelings of guilt and failure (Glinac et al., 2017).

According to Dambi et al. (2015), in a study conducted in Harare and Zimbabwe about experiences of mothers caring for cerebral palsy children found that half of the mothers experienced psychological burdens of depression, discomfort and body pains. Mothers rely on carrying their cerebral palsy children on their backs which leads to fatigue and chronic pain. Daily activities and demands of other children affect mothers psychologically. Mothers of cerebral palsy children become helpless and hopeless about what tomorrow holds for their children (Dambi et al., 2015).

2.6 Challenges in relation to education and training

In education, the emphasis is on inclusion with the mainstream setting although special schools still exist. In South Africa, inclusive education has not been implemented as schools are still divided based on the child's disability. Up to date, there are schools for the intellectually impaired, schools for the deaf, mute and blind, schools for physically disabled and ordinary schools. The education system in South Africa labels learners and learners with disabilities attend special school. Learners without disabilities attend ordinary schools. The training of education is the same; the system is cause for concern because it promotes segregation among schools.

The Revised Strategy on Screening, Identification, Assessment and Support (SIAS) was introduced to support inclusion and identify barriers in learning (Department of Basic Education (DBE) (2014). Poor intervention for children with disabilities disadvantages them in succeeding (National integrated early childhood policy, 2015). Cerebral palsy children need assistive devices and Augmentative and Alternative Communication (AAC) in their lives. Assisting devices should not be underestimated.

In South Africa, the existing infrastructure is not properly built to aid physically disabled children. Facilities such as toilets and ramps are absent. Cerebral palsy children use special devices like walkers, wheelchair and crutches

2.7 Challenges experienced in providing physical care

Caring for physical disabled children is a challenging experience and it requires energy as children with disability need extra care. Mothers of cerebral palsy children need extra time in care-giving tasks like washing, dressing and feeding. Findings from research have revealed that mothers caring for disabled children experience chronic health conditions such as depression, pains and injuries than mothers caring for children with minor problems. Additional tasks disturb daily activities that families are used to. Mothers of cerebral palsy children spend time in care-giving tasks which are physically demanding like positioning, lifting and administering medication to their children. Mothers of cerebral palsy children find themselves unable to fulfil other aspects of life such as spending time with friends. Family members are not involved in assisting and providing care and the burden of care-giving creates pressure on mothers. Mothers sacrifice time to care for their children. Mothers of cerebral palsy children are affected in all spaces of life. After having disabled children, mothers are obliged to expand their day to day activities (Dambi et al., 2015).

2.7.1 Support

Support from family community members and friends safeguards mothers who are caring for cerebral palsy children (Chiripanhura & Nino-Zarazua, 2015). Mothers of cerebral palsy experience extra care giving duties and receive less support from their spouses, friends and community. Communities still accept that the families that have cerebral palsy children experience humiliation in the family. According to Chiripanhura & Nino-Zarazua (2015), families with cerebral palsy children rely on their family units to cope with the situation than mobilizing support from individuals. Mothers in rural areas experience further challenges than those in urban areas due to inadequate social resources (Blomgren Mannerheim, Hellstrom Muhliard and Siota, 2016). Community Based Rehabilitation (CBR) programs play an important role in ensuring mothers of cerebral palsy children adapt to and cope with the burden of care giving (Dambi et al., 2015). Caring for cerebral palsy children impacts mothers in a negative way, especially if care

giving needs are not met. According to Dambi et al., (2015), there is a myth that the condition was caused by witchcraft and ancestral spirits.

A traditional belief plays a major role in children with cerebral palsy. African culture views cerebral palsy children as punishment for the wrong doings from God.

Families fight, accuse and blame each other of witchcraft and for casting a wicked curse to the disabled children. Mothers of cerebral palsy children fall victim to being blamed for bringing the disability. Disability in the family leads to misunderstandings between the spouses, leading to divorce as partners blame each other (Blomgren et al., 2016).

2.7.2 Religion

Religion plays a role in supporting mothers with disability. Religion and faith were found to have an influence on the acceptance of the child with disability, and the family's adaptation to the situation. Religious parents with cerebral palsy children believe in faith healing and engage in joint activities where people provide support (Dambi et al., 2015). A lack of acceptance for the disability triggers stress related issues. Religion provides guidance and inspiration to overcome hardships. Mothers believe that one of the days their children will be healed. The Bible discriminates against people with disability. Disability is regarded as a spiritual curse (Leviticus 21, verses 16 to 23). Dambi et al., (2015) claim that support allows families to be in touch and to share with other families in the same situation. Friends and families who provide support with transportation to attend treatment play a major role.

2.8 Resources available for children with cerebral palsy

Cerebral palsy children need good resources. Mothers receive support from hospitals and community outreach to their homes. Formal support plays a major role for mothers, according to Hayler, et al., (2015), as demands in care giving increases daily. Mothers of cerebral palsy children require skills and knowledge to provide adequate care. Mothers of cerebral palsy children feel neglected by health professionals. According to Hayles et al., (2015), mothers perform difficult tasks such as giving medical treatment and lifting the children. Community Based Rehabilitation (CBR) programs assist mothers with support and health related issues. Inadequate resources

have a negative impact on mothers caring for children with cerebral palsy. Cerebral palsy children benefit from therapy provided by health professionals which improves their body functioning and promotes participation (Sharmaand & Kitters, 2015).

Rehabilitation teams such as physiotherapists, social workers, occupational therapists, speech therapists and psychologists play a significant role by providing assessment, treatment, prescribing equipment and giving advice. Tshilidzini Hospital has a government funded aid and equipment program. Mothers of cerebral palsy children look for information on their own. Mothers of cerebral palsy children struggle to get information (Hyles et al., 2015).

The following rehabilitation team played different roles in assessing and treating children with cerebral palsy: These professionals work together as a team to deliver effective health care intervention. The team provides therapy goals and assist in implementing interventions.

2.8.1 Physiotherapists

- Assist children to move independently;
- Help with the use of a wheelchair; and
- Teach the child to perform tasks such as writing.

2.8.2 Occupational therapists

- Assist in self-care like dressing;
- Develop fine motor activities such as writing and drawing;
- Address cognitive and perceptual impairment
- Assist with adaptation of equipment such as seating

2.8.3 Speech therapists

- Assist with speech, language and swallowing skills;
- Give intervention focus on speech;
- Assist in expressive and receptive language development;
- Assist in helping the child to use special equipment

2.8.4 Social workers

- Provide personal support during times of distress;
- Address barriers that exist in community;
- Give advocacy to mothers and families living with disabilities.

2.8.5 Psychologists

- Assess and do counselling like grief counselling;
- Provide advice and education;
- Facilitate support/network groups. .

2.9 SUMMARY

This chapter reviewed relevant literatures on challenges of mothers caring for the cerebral palsy children. The theoretical framework of this study was presented. A brief history of cerebral palsy and its definition was discussed. Effects of caring on the family's socio-economic life and problems experienced by mothers in social and psychological care were highlighted. This chapter also includes challenges in relation to education and training; Challenges experienced by mothers in providing physical care outside the family were explained. The next chapter will explain the methodology that was adopted in the study.

CHAPTER 3: METHODOLOGY

3.1 Research design

A qualitative, descriptive research design was used to explore the challenges experienced by mothers caring for their cerebral palsy children (Strydom et al., 2015). Research design is regarded as extremely valuable because it presents a picture of a situation, social setting and relationship (Al'Jubeh, 2015). The advantage of an explorative design is that it allows the researcher to gain a broad picture of the research topic under study (Al'Jubeh, 2015).

3.2 Study setting

The study was conducted at Tshilidzini Hospital where mothers of children with CP attend rehabilitation services. Tshilidzini Hospital is a regional hospital in the Vhembe district of the Limpopo province. The hospital is ideally located in the far North of the Limpopo province in the Vhembe district in the Thulamela municipality about 5km from the town of Thohoyandou. It serves as a catchment area for a population of 1.3 million and as a referral hospital for twenty-four (24) clinics, two (2) community health centres' and six (6) community hospitals (Statistics South Africa, 2016). The hospital is located within rural communities of the Vhembe district. The Cerebral Palsy clinic at Tshilidzini Hospital was established in 2005 with the support of the South African Neurodevelopment Therapy Association (SANDTA), international Services Volunteers and other NGOs. The unit provides Rehabilitation Services for cerebral palsy children. The Cerebral Palsy Clinic at Tshilidzini Hospital is one of the government's central localities of activity for Cerebral Palsy. Tshilidzini Hospital plays an important role in running rehabilitation therapy services. The Cerebral Palsy Clinic is one of Tshilidzini Hospital's special clinics and it runs once weekly on Fridays. The Cerebral Palsy Clinic reviews the cases of the children that are referred by 18 clinics, one Health Centre and a doctor within the hospital in the Paediatric Ward and the services are provided freely.

3.3 Study population

The study population consisted of all the mothers caring for cerebral palsy children residing in the Vhembe District. All mothers were attending the rehabilitation therapy services at Tshilidzini Hospital.

3.4 Sampling method

A non-probability, purposive sample of forty biological mothers of children with cerebral palsy was taken for the study. The advantage of non-probability sampling is that it is more effective for conducting exploratory studies (Barratt, et al., 2015). The researcher used her judgment to select the sample based on the specific goals of the research and the inclusion criteria for sample selection. (Barratt et al.,2015). A purposive sampling method was used to select individuals to participate based on their wealth of experience and knowledge of the subject matter readiness to share the knowledge (Barratt et al., 2015).

The following inclusion criteria were used to make the selection:

- Mothers of CP children,
- Mothers of CP children who attend rehabilitation services at Tshilidzini Hospital, and
- Mothers who were ready to share their challenges of caring for a cerebral palsy child.

Their children should:

- Be between 2 and 15 years old, and
- Have been diagnosed with cerebral palsy in the hospital records by a Paediatrician or Medical Practitioner.

3.5 The instrument: Interview guide

In this study, the researcher used a semi-structured interview guide consisting of open-ended questions (Annexure A). Questions from the interview guide were used to encourage mothers to verbalize their problems during the interviews.

3.6 Pre-test

A pre-test was done before starting data collection. Eight (8) mothers were asked to participate and it helped to refine the data collection tool. Conducting a pre-test ensures that the interview guide is workable, acceptable to the participants and manageable by the researcher.

3.7 Procedures for data collection

The researcher made an appointment with the mothers and agreed on a time, date and place; that is, Tshilidzini Hospital. Five focus groups comprising of eight mothers based on their demographic characteristics such as age, educational level, occupation and age of the child were held. The advantage of a focus group is that they create a line of communication and promote self-disclosure to the participants. Focus group interviews were conducted in a physiotherapy room. A notice was placed on the door informing people not to enter to ensure privacy. The researcher conducted focus group interviews in line with the interview guide (Alemneh, 2015.)

During the interviews, the material for data collection was a voice recorder. A notebook was also used to record reflections and impressions of the researcher after each interview. Field notes were used to record non-verbal cues displayed by participants during interviews as described by Alemneh (2015). All interviews were conducted using the mothers' own language which was Tshivenda. The researcher was assisted by two trained research assistants during data collection. The research assistants were trained to use the research instrument and voice recorder before the pre-test. The trained research assistants operated the voice recorder during the interview. They were given a workshop on the procedure for data collection. Each focus group interview lasted approximately one hour. Data saturation occurred during the fourth group, however, the researcher continued to the fifth focus group in order to ascertain that there was no new information coming from the participants. Data collection was then stopped after five group interviews from 40 participants.

3.7.1 Data analysis

Techs' (1990) Model of open coding with eight steps was used to categorize the data meaningfully.

Step 1

The researcher listened to the audio recording to get familiar with the content. The researcher first gained a general impression of the data by reading through the entire transcript as the data was gathered to gain its understanding. The researcher transcribed interviews word-for word.

Step 2

The next step was to select data documents from focus groups and begin to identify common topics from the material. The researcher captured topics in writing

Step 3

During the third step, the researcher listed all the topics and themes that emerged from the data documents. Themes were clustered together in terms of major themes, unique themes and leftovers for each data document.

Step 4

Once the themes were identified, they were abbreviated into codes, which were then written next to the appropriate sections of the text. This step allowed the researcher to detect new themes and codes that were to be integrated into the text.

Step 5

The researcher assigned descriptive names to the themes and created categories for them. From the list of categories, related themes were grouped together, reducing the overall list of themes.

Step 6

Once the researcher made a final decision regarding the abbreviation for each category, the codes were arranged in alphabetical order.

Step 7

Data material related to specific categories were assembled in one place and a preliminary analysis was performed. The goal of this step was to identify and summarize the content for each category and identify information that was pertinent to the study.

Step 8

After extensive analysis, the researcher decided whether the categories were inclusive or exclusive enough and recoded the data accordingly. The following is a summary of the data analysis:

The researcher listened to the voice recorder carefully and transcribed data verbatim using field notes as well. The researcher transcribed verbatim and compared the transcript with the audio tape. Transcripts from focus groups were analysed by reading through them, organizing the data, generating categories, themes and patterns and writing a report. The transcripts and journal notes provided the text for analysis, presenting a complete picture and allowing deeper understanding of the relationship between context and the experience of mothers caring for the CP child. The researcher worked analytically to categorize and interpret the data. Data was organized into manageable units to allow for manual analysis (Morse, 2015).

The researcher read the transcripts several times trying to get a sense of the interview before breaking it into parts. In this investigation, the researcher read through the data to familiarize herself with the data and made notes of the key concepts or ideas found in the transcripts. The researcher described, classified and interpreted the data. Representing and visualizing is the final phase for data analysis. The researcher presented the data: a packaging of what was found in text, tabular or figure form (Morse, 2015).

3.8 Trustworthiness of the study

In qualitative research, trustworthiness is a criterion used to measure the rigour of the research (Hanson et. al., 2014). For the purpose of this study, trustworthiness was employed according to four criteria of Guba and Lincol (1989). Trustworthiness is measured according to four criteria consisting of credibility, transferability, dependability and conformability (Morse, 2015). Each of the trustworthiness criteria are discussed below:

3.8.1 Credibility

Credibility refers to an extent to which the researcher results are true and accurate (Alabbasi and Stelma, 2018). In this study, credibility was achieved by conducting interviews using focus group discussion where free participation was observed. Mothers were able to communicate freely, and their experiences became credible. The researcher asked mothers to sign a consent form to show that their participation in this study was voluntary. The researcher applied prolonged exposure, spending time with the mothers and children with cerebral palsy, she did member checking to verify the responses (Anney, 2014)

3.8.2 Dependability

Dependability is the extent to which the research findings can be reproduced and replaceable by another study. (Alabbasi and Stelma, 2018). The study findings were measured by the procedure employed during data collection, recoding and analyses of data. The researcher ensured dependability by following and documenting all steps and activities of the research process. Dependability was further ensured when researcher and supervisor reviewed and verified the interpretation of the data (Cypress, 2017). The interview conducted with the mothers followed the same interview guide.

3.8.3 Conformability

According to Marshall and Rossman (2014), conformability allows the researcher to describe the whole research process to prove the transparency of the study. In this study, conformability was ensured by allowing findings and interpretations of data to be confirmed by others. To ensure conformability, the supervisor performed a conformability audit by checking the participants' views quoted by the researcher in the transcript from the tape recorder. The researcher confirmed the findings that emerged from the data.

3.8.4 Transferability

Transferability refers to the extent that the research findings can be used to address same issues in different settings following same procedure (Mabundusa, 2014). To ensure transferability, the researcher provided a rich description of all activities and documentation for future researchers to assess the transferability of the research. The researcher ensures all relevant information is obtained in the study. In this study, transferability was demonstrated by providing detailed journal notes as well as transcriptions to allow another individual to acknowledge the process of the whole research.

3.9 Ethical considerations

The following ethical aspects were considered:

3.9.1 Ethical clearance and permission to conduct research

The research proposal was presented to the School of Health Sciences Higher Degrees Committee for quality assessment. The research proposal was further submitted to the University of Venda Higher Degrees Committee for quality assessment and approval. Ethical clearance was obtained from the University of Venda Ethics committee. Permission to conduct the study was granted by the Limpopo Provincial Department of Health after Ethical clearance was obtained. Permission was also granted by the Tshilidzini Hospital Chief Executive Officer (Annexure C)

3.9.2 Informed Consent

The researcher informed mothers about the aim and objectives of the study before giving mothers a consent form to sign. The researcher explained to the mothers the purpose of the investigation, procedures to be followed in getting information, the duration of the study and how the findings would be used or published.

She also provided the participants with a consent form having a delineated area for the signatures of both parties.

3.9.3 Respect to Human Rights

The participants were informed in writing and in person during the explanation and signing of the informed consent (Annexure E). They were told that participation in the study is voluntary and that they were free to withdraw from the study if they wished. Mothers were also told that they would be protected from any damage arising from disclosing information. The researcher informed mothers that the nature of the study would not lead to emotional harm. In case mischief occurred regarding the sensitivity of the topic, the participants would be referred to the a psychologist for counselling. The researcher arranged debriefing sessions for all mothers to ventilate their feelings and reactions to the interviews.

3.9.4 Privacy/Anonymity/Confidentiality

Mothers were not identified by names or national identity documents but by codes which were only known to the researcher. Information obtained during the study was not disclosed without the consent from mothers. Permission to use a voice recorder was required from the mothers.

3.10 Limitation of the study

The study was conducted at the Tshilidzini Hospital Physiotherapy Unit, using mothers of cerebral palsy children whose names are registered in the Rehabilitation Therapy Services Book. The use of a qualitative design in a study constitutes a major limitation because a non-probability sampling procedure was used. The sample size was limited. Detailed descriptions of the research methodology were provided.

3.11 Summary

This chapter explained a detailed process on how the research was conducted. The study design, settings and population were explained. It was followed by sampling size and method that form part of the research. Trustworthiness, ethical consideration and limitations of the study were discussed. The next chapter will explain the results and the discussion that were revealed from the study.

CHAPTER 4: RESULTS AND DISCUSSION

4.1. Introduction

The purpose of this chapter is to present findings and discussion of the results. The results and discussion of this study are identified in themes and sub-themes that were elicited from the interview guide (Annexure A). Common themes emerged from the focus group discussions even though the mothers' experience was unique. Mothers' descriptions of the challenges experienced were conceptualized from tape-recorded discussions.

4.2. Presentation of findings

A total of 40 mothers participated in the study. A semi-structured interview guide containing open-ended question was used. The study consisted of five (5) focused groups, each comprising eight (8) mothers. The interview was conducted in Tshivenda as it was the first language of all the participants. The interview was conducted in the Physiotherapy Cerebral Palsy room. Each group lasted one hour. Participants' names were excluded to maintain confidentiality and anonymity for their families. All the participants were the biological mothers of cerebral palsy children.

4.2.1. Demographic characteristics of mothers

The ages of mothers' who participated in the study ranged from 20 to 46 years. Sixteen mothers were married and 24 were single, and some were separated from the biological fathers of the cerebral palsy children. Thirty-seven mothers of children have matric, and three hold a postgraduate degree. Of the forty mothers, fifteen were employed, twenty-five were unemployed and just taking care of their cerebral palsy children. All the mothers had attended multidisciplinary team therapy sessions for more than four (4) years.

4.2.2. Demographic characteristic of the children

The ages of the cerebral palsy children whose mothers participated in the study ranged from 2 to 6 years. All the children attended rehabilitation services in the Physiotherapy room at Tshilidzini Hospital, and they were all cared for in their homes by their mothers. Siblings provided help by assisting the cerebral palsy children with tasks like spending time with the child while the mother is carrying out daily activities, like doing laundry and cooking for the whole family. The

demographic characteristics of mothers and children who took part in the study are summarized in Table 4.2.3.

Table 4.2.3: Demographic characteristic of mothers and children

CHARACTERISTICS OF MOTHERS IN THE STUDY	NUMBER
Mothers of cerebral palsy children	40
Mothers Ages	13
20-25	
26-30	4
31-35	12
36-45	11
Children's Age	21
2-3	
4-5	14
6	5
Marital status of the mothers	24
Single	
Married	16
Widowed	None
Divorced	None
Employment status of the mothers	15
Full-time	
Not employed	25
Educational level of the mother	37
Highest School (matric)	
Post-graduate	3

A summary of the main and sub-themes of the experiences of mothers caring for the CP children is given in Table 4.3. These are then discussed in detail.

Table 4.3 Summary of the findings from mothers caring for cerebral palsy children at Thulamela Local municipality

Theme	Sub-theme
Receiving Diagnosis	<ul style="list-style-type: none"> • Reaction of anger, being guilty and blame • Acceptance • Isolation and Loneliness
Challenges experienced daily	<ul style="list-style-type: none"> • Care-giving Responsibility • Financial burden • Psychological burden • Health • Education
Support	<ul style="list-style-type: none"> • Community • Religion • Support from Family/ friend • Health Professionals

4.3.1. Theme: Receiving Diagnosis

The following sub-themes emerged from this theme: reaction of anger, being guilty, blame; acceptance; isolation and loneliness.

4.3.1.1. Sub-theme: Reaction of anger, guilty, blame

Mothers reported that they experienced various emotions in dealing with the realization that they have disabled children. Mothers in this study articulated that they experienced such feelings as:

disbelief, sadness, disappointment, hurt, shock, fear, denial, unhappiness, embarrassment and anger. This is supported by Burke et al., (2015) who describe diagnosis as emotionally challenging to mothers of cerebral palsy children. One of the participants indicated the following:

Receiving diagnosis was a devastating and a painful experience. Having a child with cerebral palsy has an impact on my entire family, I felt alone as if I was in my own world. My life changed completely, my dreams were shattered as my child depends on me for everything.

Mother 1

Mothers of cerebral palsy children indicated that the disorder of their children affected their lives. Mothers expressed that caring for an unable child was a long-term journey. All mothers indicated that it is not easy to have a disabled child. All mothers reported that they experience isolation from other people and lost weight after being told about their children's disability. The following are one of the responses:

I was devastated to hear the diagnosis. I started visiting one doctor to another and they kept on telling me that there was nothing with my child. I felt like doctors were not giving me more information. I am not coping. I can say I am unable to deal with this situation. I felt like something has been taken away from me. Really, I will never forget what I went through. No one will accept the disabled child. I can say I am ok now but inwardly, I am not coping.

Mother 6

The participant stated that they were disappointed, hurt and unhappy. Sonik et al., (2016) reported that a mother who receives and learns more about her child's diagnosis adapts better. The reports include the following:

Discovering and understanding my child's disability was a process. I was devastated about the condition. It was very difficult to adjust to the condition. My child was very sick during the first two (2) years. It was a lot stressful. I couldn't do anything. I had to take my child to the hospital two to three times each month. **Mother 13**

All mothers felt frustrated and disappointed after learning about their children's diagnosis. The participants indicated that they were not expecting a disabled child when they were pregnant, but they were expecting to give birth to a normal and healthy baby. All mothers expressed the same

view of shock because the child was not expected to be disabled. This is supported by Dambi et al., (2015) who maintain that the initial diagnosis of a child with disability is important because it provides good understanding of the situation (Dambi et al., 2015). One of the research participants commented as follows:

When the doctor broke the news about my child's condition, I didn't believe it. I didn't know the condition. I was confused, worried and concerned about the condition. I was very angry and asking me why this happened to my family. Bringing up a child who is different from others is a big challenge. I was stressed because I was thinking of my family.

Mother 11

All mothers emphasized how difficult and painful it was to receive the diagnosis for the first time. They always recalled their experiences during the interview. According to the CDC (2016), mothers receive their child's diagnosis in different ways. Mothers became aware of their child's condition after delivery, usually before the child is transferred to neonatal intensive Care unit. Some mothers learn about their child's diagnosis from healthcare professionals when their children are not sitting, crawling, rolling or walking. Their comments were emphatic as follows:

*The day I received the diagnosis I felt out of control. I was unable to cope with the news. I also refused to accept the baby thinking that they made a mistake of taking somebody's child. I started to be concerned and thought about the impact that this child would cause in my relationship. **Mother 21***

After the birth of my son, I felt like the whole world was turning upon me. I was confused as I was looking forward to having a normal child. I was in shock and felt ashamed of myself. I was frustrated and developed loneliness. I wanted to have my own space because I had that anger as I couldn't understand why God gave me such a baby.

Mother 16

All mothers have experienced unexpected life of caring for cerebral palsy children. All mothers described their frustrations of having a disabled child. All mothers described their children's diagnosis as frightening and one of the participants responded as follows:

*I didn't believe what I was seeing, that my child is disabled. The way in which the doctors explained to me the child's condition made me to become bitter and hurt, thinking that my child will look that like that for the rest of his life. I didn't know the implication of the diagnosis. I was afraid of the unknown. **Mother 26***

*I started searching and reading about the condition and how it occurs. I regretted why I became pregnant. I was always blaming myself. I thought I had done something wrong during pregnancy. I was disappointed. **Mother 31***

All mothers of cerebral palsy children emphasized that all family members contributed in terms of emotional stability. Mothers described that after their children's diagnosis, acceptance was not easy. Challenges experienced by mothers signified a form of loss, not only to their children but loss to the mothers themselves. The responses include:

I was in shock and felt guilty. I started looking for diagnosis. I didn't have direction. I didn't know where to start because I was frustrated and confused. I failed to believe what the doctor was telling me. I was unhappy, sad and disappointed. I started searching around visiting witch doctors for explanation and thinking I would get different answers.

Mother 36

All mothers admitted that they prepared themselves for the future regardless of all the challenges and difficulties experienced in their lives. This is supported by Dambi et al., (2015) who maintain that diagnosis is the most emotional challenge to parents of children with disability. Mothers experienced mixed feelings towards diagnosis and difficulty to accept the disability (McBride & Victorio, 2017). All mothers found it difficult to admit to their children's condition.

4.3.1.2. Sub-theme: Acceptance

All mothers reported that it was very difficult for them to accept that their children were born with a disability. Below are some of their responses:

I was emotionally disturbed. It was difficult to adjust myself. I had to call a family meeting and explain that I have a disabled child. I did it to be accepted and gain support. I was very

*angry. I found myself in my own world. I didn't understand and started blaming God. It took me some time to understand his condition. **Mother 2***

I was traumatized. I am just praying that I must not go through this again. My life changed, I started to have a lot of pressure and stress. I don't have a maid. I found it hard and to accept the disability was very difficult. I lost my expectation because I am now a mother of a child with cerebral palsy. I just prayed and said this child is a blessing from God.

Mother 4

*It was difficult to cope with the diagnosis of my child. I started to accept the child's condition and let my frustration pass, then I started to focus on the present situation. To tell you the truth, adjusting yourself after receiving the news that you have given birth to a disabled child is a big challenge. It is difficult to handle it. My dream of having a normal child was crushed. The excitement of having a baby was shattered. **Mother 10***

*It was hard to accept, and I didn't know what cerebral palsy meant. I didn't know what to do. Discovering that your child is disabled was the most difficult moment. The news came when I least expected it. I always ask myself what wrong I have done. I also started going around searching for information about the diagnosis. I also shop around doctors seeking for more information about the diagnosis. **Mother 20***

4.3.1.3 Sub-theme: Isolation and Loneliness

All mothers stated that they were stigmatized which resulted in embarrassment and emotional distress (Singongo et al., 2015). Mothers described the feelings they had following their children's diagnosis and their comments include the following:

*Ash, it took me more than two years to accept my child's disability. I felt terrible. I felt like I am a little bit crazy. I got lost and started crying. I was not ready to hear that my child is not ok. I used to spend my time alone in denial thinking about my disabled child. I became angry and started blaming myself. **Mother 15***

Having a disabled child is not child's play. I was confused. I didn't know what to do. I used to stay away from family members. I felt embarrassed. It took time to be myself as I am now.

Mother 18

4.3.2 Theme: Challenges experienced daily

All mothers expressed their feelings of having multiple roles in the family, they showed their frustrations. Mothers explained that family time and daily routine to their disabled children changed the wellbeing of their family. All mothers explained the challenges that they encountered. All mothers experienced care-giving as an unbearable and difficult situation. Mothers stated that they had to shoulder some of the responsibilities to their children so that they could assist them with daily living activities.

4.3.2.1 Sub-theme: Caregiving Responsibility

All mothers stated that they have a huge responsible to accomplish daily. They must lift up the child when going to the toilet. This finding was supported by Dalyand et al., (2015) who maintain that similar activities were revealed in the study conducted in Iran on the mothers caring for cerebral palsy children and challenges of caregiving. These were some of their narratives:

*You have to wake up early due to the tight schedule. I spend most of the days with my child; I must attend therapy once a week and do household chores. My child is becoming bigger physically, lifting him becomes a challenge. Every day to me is a busy day. I must do caregiving whether I like it or not. The day to day routine is a challenge and stressful. It is hard, but I have to accept the disability. I see daily living experience as death in the family because I have to accept it. **Mother 15***

*Care-giving experience with a cerebral palsy child impacts on my ability to support other family members. Since the birth of my son, my life has become more difficult. I am always tired and strained before going to sleep. I am worried because my child is a burden on my siblings, my child's sister and brother take responsibilities of being therapists. **Mother 10***

All mothers reported that managing other responsibilities with children diagnosed with cerebral palsy is a challenge; most mothers reported that they are unemployed. All mothers explained that they were unable to carry their children and they are also unable to leave them at home. Feeding their children is another issue which most of the mothers experienced. Their responses include:

*I have to take care of other children. Young mother as I am, going through all this stressful demand. I am telling you it is too much for someone as young as I am (mother started to cry). Just imagine sleeping late every day. My life has changed completely; I have to change diapers, cleaning up after feeding. I think all these things are a burden to me. **Mother 19***

*I am alone in the family with my other children. My husband left me after the birth of my disabled child. My child gained weight and now she is heavy, bathing her is not an easy task. I struggled to clean her, she cannot stand so I experience serious problems during bathing. I have to put her in the basin or on the floor because she is heavy. **Mother 9***

*My child does not want to sleep at night, so I have to wait until she falls asleep. My child is always crying and making noise till late. My child always disturbs other children the whole night, I see care giving experience as time consuming. I am experiencing a lot of challenges as my child is growing and gaining weight. My child's body sometimes becomes stiff, which causes complications. Bathing my child is a difficult task and it is time consuming . **Mother 24***

*I see feeding my child as a major challenge; I have a schedule for eating. My child does not eat; I spend three hours to feed my child. My child cannot swallow quickly, my child eats solid food, whenever I try to feed my child food come out again, so I make sure the texture of food is good. Sometimes I don't know how to handle it because during feeding, my child becomes aggressive. It is difficult for me to ask for someone to help. **Mother 13***

*I have to fetch water, do laundry and cook for my family. No one is helping me with the daily household chores. I am unable to sleep, every day I must wake up as early as possible to prepare food for my disabled child and later during the day I prepare food for the whole family. **Mother 21***

*Ooh my sister, I don't have time to rest. I don't have time to go out of this house, my child is heavy and makes it difficult for me to carry him. My child cannot walk so I am always in the house with him. **Mother 25***

Mothers are concerned about caregiving demands which they are experiencing. They experience feelings of anger, tiredness and frustration. The concerns are expressed in the following comments:

*I am experiencing sleeping problems due to too much duties of caregiving. I don't sleep well. I sleep on one side because the other side is very painful. I must lift my child up and carry her on my back. My child is very heavy because she has a bigger body. She is growing very fast. I suffer from fatigue due to excessive care-giving duties. I don't have time to rest unless the child is asleep. **Mother 5***

*I became angry and end up beating my child due to frustration. I experience shoulder pains because my child is heavy. I experience sleeping problems especially when my child becomes very ill. The whole body is painful because of walking a long distance carrying my disabled child, I feel like killing myself so that the problem can end. **Mother 1***

*My child is growing up and it is very difficult to lift her up. The problem is to lift her up, I cannot lift her up alone and I don't have assistance. I struggle to carry her. Each time I ask for assistance from my older child or family members. I struggle when my older child and family members are not present. I have to accept that my child is different from other children. **Mother 9***

Caring for cerebral palsy children gives additional challenges for mothers and their families. Parents encountered many challenges in relation to daily responsibilities as parents spend their time and energy taking care of the cerebral palsy children. Responsibilities increase and there is a change in their own lifestyle. Parents have less time for their needs as they spend time caring for the cerebral palsy children (Dalyand et al., 2015). Some of the responses include:

I feel lonely and burdened because I must bath him, feed him and change his clothes as he cannot do that for himself. My social life changed after giving birth to my disabled child. I

*feel powerless and worried about my child. I am rejected by everybody. They always gossip saying by saying that I have given birth to a vegetable. **Mother 17***

4.3.2.2 Sub-theme: Finance

According to Dambi et al., (2015), caring for a child with a disability is time consuming and has financial implications. Money plays an important role in bringing up cerebral palsy children. The cost of living is too high, ranging from special diet, transport, medication, therapy and consulting doctors at the hospital. It was noted that mothers were not working, and they do not have sources of income. This is supported by Singogo et al., (2015) who assert that mothers of cerebral palsy children experience financial pressure like medication, visits for treatments and buying special foods. The responses elicited from the participants include the following:

*Costs of caring for cerebral palsy children and meeting their everyday needs is high, for example, I have to buy special food, diapers and getting transport to the hospitals to attend cerebral palsy clinic. I am getting low income from the government grant. The money I am receiving every month is very little. I am experiencing financial stress. **Mother 37***

According to Ribeiro et al., (2016), stated that financial burdens create strain on family members and prevents them from accessing services that are required by cerebral palsy children. Increased financial demands put additional strain on the family because they are unable to adjust their family budgets and the mother's comments include:

*I am experiencing financial stress. It is hard to maintain the quality of daily care. Financial status of my family has been affected severely by having a child with cerebral palsy. Becoming a mother, caring for a cerebral palsy child brought new and unexpected costs. I struggle to meet my child's needs. The money which I receive for my child does not cover costs for special diet and going for doctor's appointment. **Mother 25***

A lack of funds has been reported by all mothers. The burden of caregiving for a disabled child creates more stress which affects the family income (Patel et al., 2017). Mothers reported that

looking after a disabled child affected the whole family. The pressure they received was overwhelming and they felt that could not cope. One of the participants commented as follows:

*My husband drinks alcohol. The money which was supposed to buy things for our disabled child goes down the drain. What my husband is doing puts a strain on the family budget. Sometimes we sleep without food because we have to buy diapers for my child. I don't know why life is like this, the whole family needs money to survive. If we can have money to buy basics and pay bills it will be much better. **Mother 7***

All mothers with disabled children experienced financial strain. According to the research conducted, families reported an increase in overall expenditure (Dambi et al., 2015). The findings in the in the present study support the views that finance assists mothers to adjust the process of caregiving. The comments include:

I am experiencing challenges when it comes to money. The household money is little and not meeting the needs of the entire family. I have to buy special diets for my child. I have applied for disability grant, I am still waiting for the outcome. The process of completing forms was fast and easy but the challenge is the waiting period which is unduly long.

Mother 22

According to SASSA (2017), South Africans are receiving a care dependency grant of R1780 a month. Some mothers expressed lack of knowledge of where to apply dependency grant because they don't have necessary documentation like identity documents and birth certificates (Saloojee et al., 2016). One mother commented the following:

*I take my child to a nearby Day Care Centre. I am looking for a job because the money I am receiving from the government is little. If I can find a job, things will be easier. Regular hospital visits are affecting my finances. The money I am receiving is not meeting my child's needs. **Mother 39***

Dealing with disability is a huge stress for a young mother. Mothers reported that they wanted caregiving support in terms of money. Mothers complained that the grant they received was too

little. Mothers also stated that they needed the best service for their children, but they cannot afford to access such due to financial constraints. One mother replied the following:

*I require finances because no one supports me with transport expenses to ferry the child for treatment. This is too much for me. I am struggling because I have to pay for transport to and from the hospital. I am appealing to the government to increase the grant so that we can meet other children's needs. **Mother 14***

Caregiving is an ongoing task that requires more resources like money (Patel et al., 2004). The demands for these resources increase daily when the biological mothers continue to care for their children with disability. Some mothers replied as follows:

*I receive money from my family and friends. I rely on the child's grant. I struggle to buy basic items for my disabled child. The amount received from the government is too little. I am pleading to the government to increase the funds. If the government increases the grant it will ease the financial burden of caring for my child. **Mother 6***

4.3.2.3 Sub-theme: Transport

All mothers reported that they experience challenges regarding transport as they are supposed to travel long distances to take the child to hospital. Their responses include the following:

*I travel a long distance and spend the whole day on the road. I have to hire a car each time I visit the hospital. I am obliged to travel monthly to obtain therapy treatment for my child. My wish is to have a job so that I can help my child with proper and decent care. I spend all my time looking after him. **Mother 26***

The majority of the mothers who participated in the study were housewives and they pointed out that it was difficult for them to attend treatment at the hospital. The transport system in the area was poor or inadequate especially for cerebral palsy children. Their comments include the following:

Poor public transport affects my disabled child. When I think about the appointment date, I get sick; I must borrow money to take my child to the hospital. The money I am getting from

the social grant does not meet all my needs. I struggle to use public transport to the hospital.

Mother 29

I spend more than fifty rand for a single trip to the hospital; I travel for hours when taking my child to cerebral palsy clinic for rehabilitation. I use taxi to reach the hospital; sometimes the taxi driver does not accommodate the wheelchair” Mother 11

*Transport is a problem, especially for us who use wheelchairs, I am from a poor family where there is no monthly income received. It is difficult to carry a wheelchair in a public transport, sometimes I don't attend treatment because of transport constraints. **Mother 2***

It is difficult to transport a wheelchair in a public transport; you have to pay extra money because the wheelchair will occupy a potential passenger's space. It is a big problem and there is nothing you can do rather than to pay the taxi fare which you hardly have.

Mother 23

*I have to carry my child on my back to reach a point where I can get a taxi, transporting a disabled child is very expensive and time consuming. Taxi owners do not have space for wheelchair users. **Mother 3***

4.3.2.4 Sub-theme: Mothers Health

Mothers reported that they became stressed due to the burden of caring for cerebral palsy children. Mothers reported that the burden of caring for disabled children increased their blood pressure level and led to diseases such as diabetes. Mothers described how they isolate themselves and noted that they experienced health problems due to lifting their children which resulted in back injuries and tiredness. The responses include:

*I have disrupted sleep due to ill health. My life changed after having my disabled child. My child is not well so I have frequent trips to the hospital day and night. I am experiencing back pain which I never had before. I am always awake during the night to care for my child and to change his nappies. My health is also affected. My child is not talking. I must think on his behalf. I have to feed and bath him daily. **Mother 35***

*I am doing multiple jobs daily. I get tired of regularly picking the child up. I am always experiencing fatigue. Ash, I don't have time to relax. The demand of caring for the child is too much and it is affecting my life. Lifting and carrying my disabled child has caused me backpain. It is difficult for me to do daily routines like looking after the siblings, in-laws and the disabled child. **Mother 8***

4.3.2.5 Sub-theme: Education

Mothers perceive special school as good to help their children with cerebral palsy. They stated that special school will loosen the burden of care. This view is supported by the ideas in cooperated with the National Integrated Early Childhood Policy (2015). Mothers explained their concerns about the special school in Vhembe district. and concluded that they do not see the Department of Education providing any services to their cerebral palsy children. The following are some of their responses:

*There is insufficient support from the Department of Education. I feel concerned and worried because in the whole province, there is no school for cerebral palsy children. I think children with cerebral palsy are not taken into consideration. If you can look, my child is unable to be independent due to unavailability of special schools in the area. **Mother 9***

*In Vhembe district, there is no school for children with cerebral palsy. Just imagine, the only school I know is in Gauteng, I cannot take my child there because it is too far. I think Limpopo Department of Education must do something about this. If each district can have its own school, it would be a great achievement. **Mother 23***

*My child is seen as disabled, and she is not fit to attend school. The government is not assisting me with anything. I keep my child at home because there is no special school or a day care centre that accommodates cerebral palsy children. The special school I know of is outside Limpopo province. The very same school that I know of requires you to bring a child at your own expense. I have learned that you have to pay transport at your own expense. Just imagine, during holidays you must take your child home at your own expense, that is, at the end of each school term. **Mother 4***

4.3.3 Theme: Support

Mothers expressed their experience with community they were living in. Mothers stated that the community was not supportive; community did not show any interest on disability. They noted that after the birth of their disabled children, their social relationships with community was negatively affected. All mothers spent their time talking about the attitude of their community.

4.3.3.1 Sub-theme: Community

According to Singongo et al., (2015), community avoids children with physical disabilities and put remarks in a negative way. It is supported by Dambi et al., (2015) who talks about the attitude of family and community members who rejected the families of disabled members. The following were the mothers' comments:

*Community started to ask lot of questions on how I gave birth to such a disabled child. They regarded disability as a disgrace to the entire community. The comments which they normally pass are so stressful. Most of the community members are negative towards my child's disability. **Mother 13***

*You know what? It is so painful when people look at you, come closer to you and say words which are unacceptable. I became powerless and I was unable to express myself. Attitudes, especially those that are publicly expressed towards my cerebral palsy child are unbearable. **Mother 7***

*I decided to keep my disabled child indoors and make sure that no one sees him. I did this because I feel I am under pressure with my own community. I find the way they behave to be very hurtful. They show disrespect to my disabled child and the entire family. **Mother 5***

According to Dambi et al., (2015), children with disability are excluded from the activities in the communities. Mothers indicated that they experienced community's stigma and pointed out that it was becoming worse and unacceptable. Community sees disability as a sense of shame to the

family. Some community sympathizes with families having disabled children. The comments include:

It hurts when the community stigmatizes you. It affects me, and I do not have control over the community's attitude. My community sees cerebral palsy children as different from other children. Community attitude is impacting negatively on my child and my family; I no longer take my child with me to the shopping mall because of people's attitude towards disability.

Mother 17

I receive judgmental comments and being stigmatized. Community did not have interest in supporting my family; all they did was to reject us as a family. I am tired of being stigmatized by the society. I took a decision of not taking my disabled child to public gatherings. In my opinion, this has a negative effect on my wellbeing as a parent.

Mother 21

In South Africa, physically disabled children are viewed differently by different people in the community. Families with disabled children are teased by community (Singongo et al., 2015). All mothers expressed their concerns about community perception on disability and care-giving. Mothers of cerebral palsy children explored community perceptions and attitude towards their children. The following are some of their comments:

*Community use direct comments about my child and that makes me feels angry. I see that society is failing to understand my situation as a mother. I see their conduct as unacceptable, I find it disturbing. The community is against me and my family because I gave birth to a disabled child. I don't understand what to do. I don't have access to my community's street or mall because they always say adverse comments. **Mother 27***

*I cannot say anything about my community; I do not see anything wrong that they are doing, and those who are close to me have good hearts. My community showed me support and respect. I sometimes attend community gatherings as I always go out, I feel welcomed by my community. **Mother 31***

Mothers of cerebral palsy children are worried about the way in which the society and family members behave towards their children. Community members behave negatively towards mothers who were caring for cerebral palsy children. All mothers felt different about the way they were treated by the members of the family. One mother responded as follows:

*My Community did not want or accept my child. I used to go around if there is a community meeting. Community will start looking at me in a bad way. They would send community leaders to come and tell me that children like mine are not allowed to be in the community gathering, I feel like my child is being discriminated. **Mother 36***

4.3.3.2 Sub-theme: Religion

Mothers rely on religion and spiritual beliefs to cope with their situation. Religion plays an important role in supporting mothers of cerebral palsy children. Praying is used as a tool to cope. Mothers believe that having a disabled child is a test from God. According to Blomgren et al., (2016), mothers use spiritual belief as their coping strategy for their caregiving role. Mothers' faith makes them to accept their children's condition. Mothers view cerebral palsy children as a blessing and a gift from God. It is supported by Dambi et al., (2015) who aver that praying to God and attending church services was identified as religious support to mothers of cerebral palsy children. The comments include:

*Through praying, I gained strength and I developed positive attitude about my child's improvement. God gave me this child, so I have faith and believe that God will help me to take care of the child." "God gave me this child with disability. I have to accept and love my child. I think God has a purpose in giving me this child. It is a gift from God". "I have faith that God will change my situation and make my son normal again. My faith enables me to carry on with my normal life. **Mother 16***

Mothers of cerebral palsy children value the support offered by church leaders. All mothers indicated that the church plays a crucial role in adjusting the burden of caring for cerebral palsy children. Mothers mentioned that they engage in prayers to deal with the stress and burden of caregiving. Mothers believed that prayers from their churches helped them to overcome and cope with the situation. Their responses include the following:

*Ooh my God, my church plays an important role in supporting my family. Church members normally come to spend time with me and my child. Most of my church members do a great job of visiting and offering prayers to support me. I am always weeping and praying to God and giving thanks to him for giving me this Good Samaritan. **Mother 11***

According to Blomgren et al. (2017) indicated that, religion was found to have a positive influence on the acceptance of children' disability. Faith and prayer play an important role in enabling mothers to stay strong and prepare themselves spiritually to face the reality that they have disabled children. It was noted that most mothers were Christians. They believe God will help overcome what they were going through.

All mothers showed deepest trust in God. Mothers relied on God to perform miracles and cure their children. Mothers believe in praying day and night asking God to give them inner strength to gain positive attitudes. All mothers showed that prayer was their coping mechanism. Praying all the time was supported by all mothers. They responded as follows:

It is God's plan to have this type of a child; I have two children who are normal. There is nothing to do to change the situation. I pray day and night to God so that he can give me courage and power to overcome the situation. I ask God to help me to be strong. I know God will bring a solution to this situation; my church helps me to cope with the situation.

Mother 5

*I am blessed because the church members always come to my house to see and pray for the whole family. My pastor is my pillar of my strength. I think my child's disability is from God and it can happen to anyone else. It is a blessing from God. **Mother 1***

Raising a child with disability brings spiritual growth. Mothers who spend more time interacting with their children gain closure and become patient with their children. Mothers expressed their feelings by stating that they have hope of divine intervention through their faith in God. Mothers stated that religion is an important resource which they depend on. When mothers faced challenges with disability in their families, they resort to prayer to help them adjust psychologically. Religion has a positive cognitive impact on the lives of all mothers interviewed.

Religion has been found to offer mothers who have children with disability with the opportunity for personal growth and acceptance of the child. It is supported by Dambi et al., (2015) that mothers with cerebral palsy children accept that God gave them a special gift. Dambi et al., (2015) assert that religious mothers receive more support than non-religious mothers. Their responses include:

*Having a child with disability taught me patience and perseverance. I started spending time with my church members praying. I put everything to God. I know God will never fail me or forsake me. My faith became strengthened and I started to be submissive to God and started to accept what he gave me. **Mother 3***

Cultural beliefs by people with disability have an impact on their health and social wellbeing (as cited by Salojee, 2016). Cultures differ, and traditional beliefs cannot be taken for granted. Most mothers spoke openly about their cultural beliefs. Mothers took their children to traditional healers and western doctors. Their comments include the following:

*The traditional healer told me that the disability was caused by witchcraft. He also said family members bewitched my child. The traditional healer gave my child medicine to drink. Since I went to the traditional healer, nothing has changed". "I took my child to a traditional healer with the hope that he will tell me the cause of the problem. The traditional healer promised to heal my child, but it didn't happen. The traditional healer told me that the cause of disability is an evil spirit. He promised to cast that spirit away, but there was no improvement. **Mother 15***

According to Dambi et al., (2015), caring for a disabled child in African culture was associated with evil spirits and regarded as a taboo. Family members blame mothers for having brought disability in the family. Comments include

*My family members have different beliefs and it became difficult for us to work together to achieve similar goals for providing support to my child. My family took me from one traditional doctor to another try to seek for an explanation of what might be the cause of the problem. All traditional healers didn't give me any promise and it didn't bring any change to my child's condition. My family didn't get a concrete answer, so they decided to give up because it was not bringing any change to the child. **Mother 9***

4.3.3.4 Sub-theme: Family Support

According to Chiripanhura & Nini-Zarazua (2013), family members need to support each other in difficult times. It is supported by the study conducted by Dambi et al., (2015). A family works together and pulls together following the birth of disabled children and everyone has the role to play (Dambi et al., 2015). The mothers' responses include:

*I think my extended family members were very supportive. I am telling you, they were involved from the start. If I am busy with my child's laundry, my mother-in-law will watch my child. Truly speaking, my family was my backbone" **Mother 3***

*Having a child with cerebral palsy led to the improvement of my relationship with family members. The experience of taking care of my disabled child brought all families closer to my family and to God. Truly speaking, my family members are more involved in the welfare my disabled child. Family members accepted my child's diagnoses though it was hard to deal with it. **Mother 17***

All mothers indicated that the support system played a major role which helped their families to adjust following the diagnosis. Mothers reported that they enjoyed receiving support from other people. Some mothers use family as their main supporting network. More emphasis was on their own parents, in-laws, friends, health professionals, church, sibling and their partners.

The study findings correlate with the literature on mother's caregiving of cerebral palsy children which shows the importance of the family in offering support to each other (Chiripanhura & Nini-Zarazua, 2013). The mothers' responses include:

*My family life changed as it was disrupted by the birth of my cerebral palsy child. My mother was obliged to move in to stay with us to help me in terms of caring for the child. My friends and church members are always here to support me. I can see that it created a strong bond and connected us as a family. **Mother 24***

Marital relationship serves as buffer to parent stress. Literature shows the positive effect of parent's relationship with their spouse. It is supported by Blomgren et al. (2016) who assert that disability in the family leads to misunderstanding between the spouses leading to divorce as partners blame each other. The responses include the following:

*The birth of my child brought change in my family, especially in my marriage. My marriage became severely affected. I became a career of my disabled child. My marriage suffered due to the responsibility of caregiving to my disabled child. We have limited time as a couple to spend together. **Mother 14***

According to Chiripanhura & Nino-Zarazua (2014), family support brings stability in the family as a whole. Activities which mothers engaged can promote the family's togetherness. Caring and helping each other in the family is very important. The findings are supported by the literature which states that support from family members serves as a rescue from family crises (Chiripanhura & Nino-Zarazua, 2014). The responses include the following:

I am not getting any support from my husband. He left me after he discovered that the child is disabled. He couldn't take the pressure of helping. I am receiving support from my family". "My husband organizes his shift work so that he can be at home during the day to support me in caring for our daughter. I am receiving support from my in-laws. "After the diagnosis of our child, my husband and I developed a strong relationship. He is always there for me. He transports me and my son to the hospital during appointments.

Mother 10

Most of the mothers experienced hurtful attitudes towards their cerebral palsy children. Mothers noted that family members showed no interest to visit or interact with their children. Acceptance by extended family members was seen by mothers caring for their cerebral palsy children as stressful.

Some mothers reported to have taken a decision to distance themselves from extended family members who appeared to reject their children. In support of this, the current study revealed the mother's experiences of frustration and challenges when managing the disabled child (Brazilian et al., 2016). The mothers' responses include:

*I feel like suffocating by the pity which my friends showed. I feel oppressed by the stigma which is attached to my child's disability. When I look at it, it is clear that my friends is lack knowledge on disability. **Mother 39***

Families become closer to each other to help in caregiving responsibilities. Few mothers indicated that disabled children brought change in their day to day lives.

The degree of support and comfort that I am getting is great and amazing. There is a big change in my family. My extended family is supporting me and my husband. My husband is working, when I am sick he takes a day off to help me and to manage the child.

Mother 22

*The birth of my child brought change in my family, especially in my marriage. My marriage became severely affected; I became a care-giver of the disabled child. My marriage suffered due to the responsibility of caring for my child. We have limited time as a couple to spend quality time together. **Mother 25***

Few mothers reported that they are still having ties with friends. Even if they are taking care of their disabled children, they mentioned that they still have strong friendships. Few mothers noted that they sometimes have time to go out with friends. Mothers explained that they don't leave their children behind; they go out with their cerebral palsy children to socialize. Mothers stated that even if they are outdoors, they continue doing care-giving tasks. The following responses were elicited from the participants:

*Friends played an important role in the upbringing of my child. I am telling you, my friends are highly involved in care-giving tasks. Friends alternate to visit me and when they arrive in my home, some will be doing household tasks like preparing meals, babysitting, and sometimes, taking my child to the hospital for appointments. **Mother 8***

All mothers reported that social relationships are difficult to maintain especially when you have a disabled child. Mothers explained that their social lives changed due to care-giving responsibilities

for their cerebral palsy children. They indicated that they have lost their friends due to caregiving responsibilities. The mother's responses include:

*It is a big challenge to have a friend when you know that you have to babysit and that you may not have time to go for shopping. My friends decided to distance themselves from coming to my house. You know this type of experience hurts me and it is very disappointing. I tried to keep my friends' relationships going, but it didn't work. I accepted that they are scared. I have lost contacts with most of my friends; I thought they will accept my child unconditionally. Losing friends causes feelings of reflection and distrust. **Mother 13***

4.3.3.5 Sub-theme: Health professionals

There is gap in terms of information from the health professionals about the cause of cerebral palsy. Public services are available in the hospital, but mothers had to travel long distance to access as they were living in rural areas. All mothers noted that there is a shortage of doctors in the hospital and clinics. According to Cerebral Palsy International Foundation (2015), therapists provide assistance for daily activities and hospital routine visits. The mothers' responses include:

*Each time I find a different health professional or therapist. I must start over again to explain issues concerning my child. It is frustrating, and I lost trust in receiving the best care ever. I suggest that there should be a doctor during our therapy sessions to check our children and explain to us where the problem lies with our children. I visit the hospital once in a month and the therapist assist our children to perform exercises and give us training on how to exercise our babies. **Mother 38***

The area where we are receiving treatment is overcrowded and small. There is lack of privacy during treatment. All mothers wait and stay in the same room; I am not satisfied with the services I am receiving for my child. Therapists see us once in a month and it is difficult to see progress. I think it would have been better if they book and see our children every two weeks, I am not happy about the way in which the hospital is rendering services.

Mother 36

According to Dambi et al., (2015), rehabilitation services are recognized internationally as a key component of health care. All mothers' experiences with therapists develop good relationship to

rehabilitation therapy. All mothers reported to struggle with balancing therapy due to daily demands of everyday life and their reports include:

*Professionals are playing a major role and without their support many of us would find it difficult to manage the physical and emotional strain of caring. The level of support received from health professionals is good to our children's progress because we can manage the situation. **Mother 5***

All mothers revealed that they got more information regarding the disability from the professionals. All mothers reported that health professionals taught them on how to meet the specialized needs for their children. In every rehabilitation session, they train mothers how to take care of their children. Health practitioners provide health support and advice such as information and guidance about the resources. The mothers' responses include:

*Therapists from the hospital are very creative, they advise you to roll a blanket at home and to continue doing activities which will help your child improve in exercises from the hospital team as it helps me a lot. I can see improvements and change in my child's body; she can now sit and crawl. **Mother 7***

All mothers stated that sensitive and positive information from health professionals gave them hope. Good communication from medical personnel was also reported by another researcher. Community Based Rehabilitation (CBR) programs assist mothers of cerebral palsy children to adapt with the burden of care-giving (Feelay et al., 2014). The mothers' responses include:

*A Rehabilitation team attends to my child and sometimes sacrifices lunch time to see everybody. I have problems with appointment dates as they are too far; it is difficult to see progress. They don't tell us why the children are not walking, crawling or sitting, they just tell us to continue with the exercises. **Mother 38***

4.4 Summary

Data collected was analysed from mothers caring for cerebral palsy children. The results were discussed with literature control. The emerged themes and sub-theme were also explained using literature review. Chapter Five will discuss the summary of the conclusion, limitation, recommendations and suggestions for further study.

CHAPTER 5: SUMMARY, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 Introduction

In this chapter, the summary of the conclusions and recommendations are presented based on the study findings.

5.2. Summary of the study

The aim of the study was to explore and describe the experiences of mothers caring for cerebral palsy children at Thulamela Local municipality. The objectives of this study were as follows:

- To assess the challenges experienced by mothers of cerebral palsy children in relation to physical, social and psychological care,
- To explore their challenges in relation to available resources for proper referral of mothers and children who have cerebral palsy.

A qualitative, descriptive research approach was used in this study. The target population was mothers caring for cerebral palsy children at Thulamela Local municipality, in the Vhembe district of South Africa. The researcher used a purposive sampling method and eight (8) mothers were interviewed to refine data collection instrument. Data collection used a semi-structured interview guide. Tech's Model of open coding with eight steps of content analysis was used to analyze data. Emerging themes and sub-theme were used to discuss the participants' utterances.

5.2.1 Receiving diagnoses

The study found that during the disclosure of children's diagnosis, mothers describe a state of shock, confusion and numbness. Mothers struggled to accept and deal with the diagnosis. Mothers expressed unhappiness, disbelief and embarrassed. Mothers of cerebral palsy children went outside to look for solution. Mothers explained their experiences of despair and sorrow. Mothers showed sadness especially when they observed the physical differences of their children as compared to others. After the birth of the disabled child, mothers started managing the unexpected life.

5.2.2 Challenges experience daily

The study revealed that caregiving for a cerebral palsy child increased the caring burden to the mothers and the whole family. Caregiving of a disabled child impacts on daily activities. Mothers of cerebral palsy children identify the day to day activities as hard tasks which need patience. Paying attention to the situation encourages mothers to have hopes for their children's future. Mothers described physical demands as unbearable. Mothers experience difficulties during feeding, bathing and putting diapers. Mothers explained that they encounter hardships when performing other responsibilities such as fetching water, cooking for the whole family and doing laundry. Mothers experience financial difficulties as they live in squalid conditions with poor infrastructure. Lack of money to buy special needs for children with cerebral palsy was cited as a major concern by all the mothers. The research participants revealed that they experience financial difficulties because they have to attend regular therapy, visit traditional healers and buy clothes for their cerebral children.

5.2.3 Support

Mothers of cerebral palsy children felt bad about the way in which they were treated by the community. They feel bad because of their disabled children. Mothers revealed that they were excluded by family members and that their in-laws blamed them for having disabled children. The study further found that both mothers and children experience discrimination and stigmatization. Mothers were unsupported by community. Mothers experience social embarrassment from their own community. Mothers of cerebral palsy children experience rejection from the community. Mothers spend most of their time in the rehabilitation clinic. Mothers gather and receive therapy and guidance on how to raise and care for their children.

Health professionals play a major role in giving therapy on health-related issues. Religion plays an important role as mothers receive support from church member and the church provides a haven which enables them to share and discuss their problems. Mothers gain hope from religious beliefs. They have faith in God. Mothers have faith in God and hold the belief that their children will be healed one day. Spiritual beliefs help mothers to cope and to accept their children with a disability.

5.3. Limitations of the study

The study focused on mothers who live in the Vhembe district of the Limpopo province, who attend a Cerebral Palsy clinic at Tshilidzini hospital. There was no data from other districts. To ensure transferability, the researcher provides rich description of all activities and documentation for future researchers to evaluate the transferability of the research. The researcher ensures all relevant information is obtained in the study. Rehabilitation services rendered at Tshilidzini hospital will guide transferability. In this study, transferability was demonstrated by providing detailed journal notes as well as transcriptions to allow another individual to acknowledge the process of the whole research.

5.4 Conclusion

The following conclusions have been drawn from the findings of the study. Mothers, family, extended family and friends experienced problems in caring for disabled children. The challenges experienced are as follows:

- The financial burden affected the entire family
- Mothers experienced pressure on their relationship
- Mothers experienced insufficient support from family, friends and community
- Mothers experienced more demands on physical health
- Mothers experienced difficulties in maintaining social relationships
- Mothers experienced disrupted sleep, limited time and freedom
- Mothers struggled to use public transport to hospital and were unable to attend rehabilitation clinic frequently.

5.5 Recommendations

The following recommendations are made based on the conclusions of the study:

- The researcher suggests that all therapy sessions should be done by the same clinician. One on one therapy sessions will enable therapists to help the mothers to cope with the treatment
- Health programs need to be implemented to help the mothers of children with cerebral palsy.
- Health education will assist mothers with more information to increase awareness among the mothers about the cerebral palsy treatment and how to cope with disability.

- Health education can be done using pamphlets written in the local language illustrating condition, treatment and coping strategies.
- It can be health talks while mothers are waiting for their treatment in the waiting room.
- Implementing outreach clinics in the community to cut the travelling distance and transportation cost
- Information about policies and legislation is should be made available
- There is no special school for cerebral palsy cerebral children in the Limpopo province. The Department of Education should provide special schools in rural communities for cerebral palsy children.

The outcomes and recommendations of this study can be used by all stakeholders including policy makers and researchers to promote health for mothers in rural and urban communities.

5.6 Suggestions for further studies

- There is a need for further research on the experiences of parents caring for disabled children in the African context between the rural and urban mothers.
- There is a need for a study which focuses on different cultures in South Africa to compare and support those who are affected with disability
- Further research is needed on the challenges experienced by mothers of cerebral palsy children. Health professionals should explain their experiences when breaking the news of diagnoses to mothers of cerebral palsy children.
- This study involved only mothers of cerebral palsy children. Future research is required to include the entire family.

5.7 Summary

The findings reveal that mothers of cerebral palsy children experience health problems, psychological, social and financial challenges as they carry out their caregiving role.

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Annexure A: Interview Guide

INTERVIEW GUIDE FOR MOTHERS CARING FOR CEREBRAL PALSY CHILDREN

Demographic Questionnaire

Please tick the appropriate responses where applicable

Mothers' Age							
Marital status							
Married		Single		Divorced		Separated	
Employment status							
Full time		Part-time					
Educational level							
High school		Post graduate					
Occupation							
No of children		Age of the child					

1 Tell me more about the challenges of caring for a CP child and how it impacts on different aspects of your life for example: your relationship with other people, your health, and your employment status or work life?

2 Do you receive any support? What kind of support? Can you describe the form of support you receive from the family members including relatives, friends, siblings, neighbours and the community as a whole?

3 How has this experience of caring for a child with cerebral palsy affected your role as a mother e.g. social life, friend's leisure including holidays, independence and schooling?

4 How do you feel about the needs of this child as you experience them daily?

5 Caring for a child with disability is a unique experience. What are your experiences in caring for your cerebral palsy child?

6 As a mother, what do you consider to be your needs in terms of financial, psychological, spiritual and religious aspects?

Annexure B: Consent form

MOTHERS CONSENT FORM

TITLE OF THE STUDY: CHALLENGES OF MOTHERS OF CHILDREN WITH CEREBRAL PALSY IN THULAMELA LOCAL MUNICIPALITY OF VHEMBE DISTRICT, LIMPOPO PROVINCE OF SOUTH AFRICA

I Takalani Millicent Dangale have read the information on the aims and objectives of the proposed study and was provided with the opportunity to ask questions. The aim and objectives of the proposed study were sufficiently clear to me. I have not been pressurized to participate in any way.

I understand that my participation in this study is entirely voluntary and that I may withdraw from the study at any time. Further, I consent to the interview being AUDIOTAPED and that the audiotape will be erased upon completion of the study. In order to ensure confidentiality and anonymity, the participants will not be identified by names or national identity documents but by codes which will only be known to the researcher. The researcher will not reveal any information obtained during the course of the study without the consent of the participants. Their identifying information will not be recorded on any other measuring instruments

The results of this study may benefit different stakeholders, such as health professionals, government (policy- makers, programme planners), researchers, cerebral palsy children, the community and mothers in general. Health professionals may apply the knowledge obtained through this study to address different types of family needs in caring for CP children. Health professionals may use the findings obtained from this study when planning services for CP children. Mothers of CP children will be able to explain their challenges and may benefit the rehabilitation team in planning for the services of CP children. The findings obtained from this research will help the policy-makers to coordinate the point of delivery across health, social services and education. They may also serve as useful information to make recommendations in the field of rehabilitation for CP children.

I hereby give consent to participate in this study.

Name of Mother

Place

Signature of Mother

Place

Date

Witness

Statement by the Researcher

I provide verbal and written information regarding this study. I agree to any future questions concerning the study as best as I am able. I will be adhering to the approved protocol.

Name of Researcher

Place

Signature

Date

Annexure C: Letter To Mothers

PO Box 527
VHUFULI
0971

Mothers
Tshilidzini Hospital
P/Bag X 9245
Shayandima
0945

Dear Mothers

REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY

I wish to conduct a research study as part of the requirement for a Master's in Public Health in the Department of Health Sciences at the University of Venda.

The aim of the study is to explore the challenges of mothers of children with cerebral palsy in Thulamela Local Municipality of Vhembe District, Limpopo Province of South Africa. I will appreciate it if you agree to participate in this study. Participation in this study is entirely voluntary and that you may withdraw from the study at any time. The interview will be AUDIOTAPED and that the audiotape will be erased upon completion of the study. All information that you choose to provide will be held in confidence by the researcher, and all individual identifying information will be omitted in the final document.

In order to ensure confidentiality and anonymity, the participants will not be identified by names or national identity documents but by codes which will only be known to the researcher. All personal information will be kept confidential. Anonymity will be assured, and the participant will be allowed to withdraw from the study at any time.

The results of this study may benefit different stakeholders, such as health professionals, government (policy- makers, programme planners), researchers, cerebral palsy children, the community and mothers in general. Health professionals may apply the knowledge obtained through this study to address different types of family needs in caring for CP children. Health

professionals may use the findings obtained from this study when planning services for CP children. Mothers of CP children will be able to explain their challenges and may benefit the rehabilitation team in planning for the services of CP children. The findings obtained from this research will help the policy-makers to coordinate the point of delivery across health, social services and education. They may also serve as useful information to make recommendations in the field of rehabilitation for CP children.

Ethical clearance will be obtained from the Research, Ethics and Publications Committee of the University of Venda.

Your permission will be greatly appreciated.

Yours truly

TM Dangale

Mrs Takalani Millicent Dangale
STUDENT

Prof. H Akinsola
SUPERVISOR

Dr N. S Mashau
CO-SUPERVISOR



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila

Ref:4/2/2

Dangale TM
University of Venda
Private Bag X5050
Thohoyandou
0950

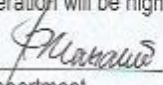
Greetings,

RE: Challenges of mothers caring for cerebral palsy children at Thulamela Local Municipality, Vhembe District of South Africa.

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
 - Research must be loaded on the NHRD site (<http://nhrd.hst.org.za>) by the researcher.
 - Further arrangement should be made with the targeted institutions.
 - In the course of your study there should be no action that disrupts the services.
 - After completion of the study, a copy should be submitted to the Department to serve as a resource.
 - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
 - The above approval is valid for a 3 year period.
 - If the proposal has been amended, a new approval should be sought from the Department of Health.

Your cooperation will be highly appreciated.


Head of Department

30/09/2015
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
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RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Ms TM Dangale

Student No:
11541536

PROJECT TITLE: Challenges of mothers caring for cerebral palsy children at Thulamela Local Municipality, Vhembe District of South Africa.

PROJECT NO: **SHS/15/PH/10/2605**

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Prof H Akinsola	University of Venda	Supervisor
Dr NS Mashau	University of Venda	Co-Supervisor
Ms TM Dangale	University of Venda	Investigator - Student

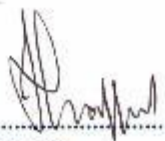
ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: May 2015

Decision by Ethical Clearance Committee Granted

Signature of Chairperson of the Committee:

Name of the Chairperson of the Committee: Prof. G.E. Ekosse



AA



University of Venda

PRIVATE BAG X5050, THOHOYANDOU, 0850, LIMPOPO PROVINCE, SOUTH AFRICA
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OFFICE OF THE DEPUTY VICE-CHANCELLOR: ACADEMIC

TO : MR/MS TM DANGALE
SCHOOL OF HEALTH SCIENCES

FROM: PROF J.E. CRAFFORD
DEPUTY VICE-CHANCELLOR: ACADEMIC

DATE : 16 APRIL 2015

DECISIONS TAKEN BY UHDC OF 05TH MARCH 2015

Application for approval of Master's research proposal in Health Sciences: T.M Dangale 11541536

Topic: "Experiences of mothers caring for cerebral palsy children at Thulamela local Municipality, Vhembe District of South Africa."

Supervisor:	UNIVEN	Prof. H.A. Akinsola
Co-supervisor:	UNIVEN	Mrs. N.S. Mashau

UHDC approved Thesis proposal



Prof J.E. CRAFFORD
DEPUTY VICE-CHANCELLOR: ACADEMIC