PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY: EXPLORING THEIR EXPERIENCES AND SUPPORT STRUCTURES IN DIEPSLOOT, JOHANNESBURG METROPOLITAN AREA, GAUTENG PROVINCE.

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DECLARATION

I, Faith Maronga-Feshete declare that this research report is my own unaided work and that assistance obtained has been in the form of professional supervision from Dr Sonti Pilusa and Ms. Abigail Dreyer. It is being submitted for the Degree of Master of Public Health at the University of the Witwatersrand, Johannesburg. Ethical clearance to conduct the study was obtained from the University of the Witwatersrand Human Research Ethics Committee (Medical), approval number: M2011133. No part of this dissertation has been submitted before for any degree or examination at any other university.

29 August 2022

Signature of candidate Date

DEDICATION

To my parents, Apollinaris Morris Maronga and Farayi Hwami-Maronga,

for your hard work and the upbringing you gave me.

To Lloyd, Jaden and Inca,

For your love and unwavering support throughout this project and always.

ABSTRACT

Background: Most children with Cerebral Palsy (CP) are dependent on their caregivers for their activities of daily living. This places a huge responsibility on caregivers. Studies on the experiences and needs of primary caregivers of children with CP in Africa and specifically in South Africa are limited. The structures and tools needed to take care of the primary caregiver need to be explored and documented. It is important to understand the perceptions of caregivers of children living with CP on the resources and structures available to them to provide relevant, comprehensive interventions.

Methods: An explorative qualitative study design was used. Semi-structured interviews were conducted with primary caregivers of children with CP. All interviews were audio-recorded. Data analysis was guided by Colaizzi's seven-step methodology.

Results: Ten caregivers were interviewed. The study revealed financial, psychological, social and physical challenges faced by the caregivers. Caregivers also reported positive experiences from providing care such as strengthened relationships, building resilience, a sense of fulfilment and an increase in CP knowledge. Inner strength was identified as a strong support structure. There are various unmet needs that become barriers to self-care and to the role of caregiving that need to be addressed to lessen the burden of providing care.

Conclusion: The needs of caregivers should receive more attention as they carry out their caregiving role. Areas of concern such as self-care, poverty, discrimination, access to health care, and lack of health promotion knowledge need to tackling the challenges that caregivers face in their role. Healthcare interventions should cater not only for the children with CP but for their caregivers as well.

Key words: cerebral palsy, primary caregivers, experiences, support structures

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- The participants of this study, for welcoming me into your homes and allowing me a glimpse into your lives, even if it was just but for a moment.

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LIST OF ABBREVIATIONS

ACPF	African Child Policy Forum
CDG	Care Dependency Grant
CSG	Care Support Grant
COVID 19	Corona Virus Disease of 2019
CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification Scale
KZN	KwaZulu Natal
NPO	Non-Profit Organisation
NGO	Non-Governmental Organisation
SADA	South African Disability Alliance
SANDSD	South African National Department of Social Development
SASSA	South African Social Security Agency
WHO	World Health Organization
QOL	Quality of Life

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DEFINITION OF TERMS

Primary caregiver: An individual who is the main carer and is mostly responsible for taking care of the child at home.

Formal caregiver: Health carer formally trained to provide care patients

Informal caregiver: Untrained carer, usually a family member, providing care to a patient

Professional: A person performing an activity which requires a certain level of education, training or skill and have demonstrated that they meet the required standard of competency in that area (1).

Cerebral palsy: A group of permanent disorders of the development of movement and posture due to nonprogressive disturbances in the foetal or infant brain (2).

Support structures: Refers to formal and informal strategies that caregivers use to cope with the strain of being the primary caregiver to a child with CP.

CHAPTER 1

1.1 Introduction

This chapter provides a detailed background of the study. It provides an overview of literature related to the prevalence of cerebral palsy globally and continentally. It outlines the problem statement that guides this study as well as the justification for undertaking this research. The chapter also outlines the research question, aim and objectives of this study.

1.2 Background

The 2011 Profile of Persons with Disabilities in South Africa Report indicated that 10.8% of children between the ages of 5 and 9 had a disability while 4.1% and 2.6% of children aged between 10-14 and 15-19 respectively, had disabilities (2). This data does not include the population group of children under the age of 5 years. It is important to have data in this age group because identifying children with disabilities early is important to make sure that they receive timely treatment and rehabilitation. In many cases, there is late detection of disabilities in the children (5). The lack of surveillance for disabilities in general, especially among children, limits planning for services needed by these children across their lifespan (3).

Cerebral Palsy (CP) is reported to be the most common cause of childhood disability globally (3 ,4). CP describes a “group of permanent disorders of the development of movement and posture” due to nonprogressive disturbances in the foetal or infant brain (7). In recent years, the global prevalence of cerebral palsy has been estimated between 2.0 to 2.5 cases per 1000 live births (5, 10). The prevalence of CP is however higher in low-income countries and poorly resourced settings (4). CP prevalence was estimated at 2–10 cases per 1000 births in African settings (10). This may be an underestimate because in the African context, neurologic conditions are seldom reported (8). The prevalence of CP in South Africa has been reported between 1% and 8% (10) or 10 cases per 1000 live births in other literature recorded in 2002 (3). More recent prevalence data is lacking in South Africa due to the poor surveillance of cerebral palsy in the country.

CP presents in various ways and severity (10, 5). Children with CP may have impaired sensory and intellectual capabilities. They have varied limitations in mobility and other

physical activities. As a result, children with CP require long term care, which greatly exceeds the usual needs of normally developing children. In turn, the demands of care also exceed the expectations of their caregivers in providing care (11). Therefore, it is paramount to ensure that caregivers providing care have the support they need to meet the demands of providing such care.

In South Africa, there are various structures that have been put in place by different entities to uphold the broad rights of all children with and without disabilities and reduce the burden of care on caregivers (3). The government of South Africa through the Departments of Health, Social Development and Education has implemented various legislative and policy reforms to improve the quality of and accessibility to services for specifically children with disabilities (3). For example, the Social Assistance Act, under the Social Development Department has attempted to alleviate the financial burden of care for persons with disabilities on their families through the care dependency grant (3). In addition, organisations such as the South Africa Disability Alliance (SADA), African Child Policy Forum (ACPF), and many other private entities, also represent the efforts and input of civil society towards upholding the rights and improving resources for people with disabilities (3). However, despite the strides made to date, in redressing the plight of the long-neglected population of children with disabilities, more attention is still required from the different sectors of the government in areas such as health, education and social welfare (5) as well as civil society. Interventions should also include the support systems for caregivers of children with disabilities, and this study specifically focuses on the caregivers of children with CP.

The International Classification of Health and Disability states that the health of a child with CP is greatly influenced by the environmental context the child lives in (12). The immediate environmental context that a child develops in includes the family. The family 'environment' is recognized as the most important factor that contributes to a child’s ultimate well-being. Therefore, there should be efforts to support parents or caregivers and enable them to provide a conducive environment for children to thrive. Family or caregiver centered support has been shown to create parent satisfaction in providing care and better mental health for the caregiver (12).

In low and middle-income settings, the complex care and support needs of children with cerebral palsy are often met by their family (3, 4). The population of children with CP, who in and of themselves cannot always access or utilise services, is heavily

reliant on their caregivers. Caregivers are responsible for facilitating the access and utilisation of the resources that have been provided for children with CP and other disabilities. Support for caregivers of these children is an important factor that affects the extent to which rights are upheld and resources are utilised. In Ghana, caregiver quality of life (QOL) was greatly improved through local support groups training which emphasised on caregiver empowerment (4). Though there was little effect on child health, the improvement in QOL of the caregiver is a positive outcome. It is clear that there is need for more interventions that support caregivers (21).

1.3 Statement of the problem

Most children with CP are dependent on their caregivers and are often taken care of at home. While this takes the burden of care off chronic care institutions, it places a huge responsibility on informal caregivers or families of children with CP (11). There is a significant number of caregivers and families of children with CP that grapple with the challenges of caregiving, but little research has looked into the domain of support for these caregivers. Though there are several gaps in matching the needs and the services provided for caregivers of children with disabilities, there is evidence that can inform the necessary interventions. Overall, studies on the needs of caregivers of children with CP are limited, in Africa and specifically in South Africa. Even more lacking are the views and perceptions of caregivers on the support that they need and are receiving. Research has not established the perceptions of caregivers on services that are made available to them. Limited studies have explored parental awareness and perceptions of services for children with disabilities elsewhere (13).

Globally, CP is the most prevalent cause of physical disability in childhood (7) and it is known that caring for a child with CP can be difficult and stressful. It impacts the health and QOL for both the child and the caregiver (11, 12), yet not enough is documented on the knowledge that caregivers have on support services that will reduce these negative impacts of care on them and their children. In the South African context, caregivers' perceptions on formal and informal support structures have not been assessed. It is important to understand the perceptions of caregivers of children living with CP on the resources and structures available to them in order to provide relevant, comprehensive interventions.

1.4 Aim and objectives of the study

The study aims to explore and describe the experiences of primary caregivers of

children with CP and their support systems in the Johannesburg Metro, Gauteng Province.

Objectives:

a) To express the daily experiences of caregivers of children with CP in their role and their support systems as they provide care to children with CP
b) To explore the facilitators and barriers faced by caregivers of children with CP in the Diepsloot area, Johannesburg Metro

1.5 Significance for the study

In view of the high prevalence of CP in South Africa (3, 5), there is need for various support structures for these children and their caregivers to lessen the burden of care. Caregivers providing informal care are likely to go through various stresses due to the emotional impact of care, isolation of carers, housework, sleep disruptions, providing care for other children or family members as well as having means for sustaining these livelihoods (5). It is necessary to establish the relationship between the support structures available and the way that these structures are viewed and consequently utilized by the caregivers of children with CP. The offered support services must be what the caregivers deem essential for them in caring for children with CP and find acceptable and therefore are willing to use.

Where the government or other sectors have made provision of services, this study will help bring awareness to caregivers and explore the factors influencing utilization of the available support structures. If there is no such provision of needed services, this study will inform future strategies in providing for unmet needs. It will inform interventions and services that meet needs of caregivers of children with CP. This is important in ensuring that investments are made in the right places and consultations engaging the caregivers of these children are made an essential part in formulating policies and services that are beneficial to them. This can only be effectively accomplished with an understanding of the lived experiences of caregivers and hence the need for such qualitative research.

In conclusion, in this chapter a brief background was discussed. The study aim and objectives were outlined. In the next chapter, the review of previous studies will be discussed.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction to the literature review

This section will review studies that explore the experiences of primary caregivers of children with cerebral palsy. It will survey their challenges and the support structures available to them in performing their caregiving role. Literature on facilitators and barriers to accessing support for caregivers will also be briefly reviewed.

Scientific databases used in this review are PubMed, Google Scholar, Scopus, and Science Direct. The keywords used to identify relevant literature are cerebral palsy, cerebral palsy in Africa, caregiver QOL in cerebral palsy, support in caring for a child with a disability and challenges in taking care of a child with CP. The literature used in this review was published between 1998 and 2022.

The literature review chapter will be presented in the following format.

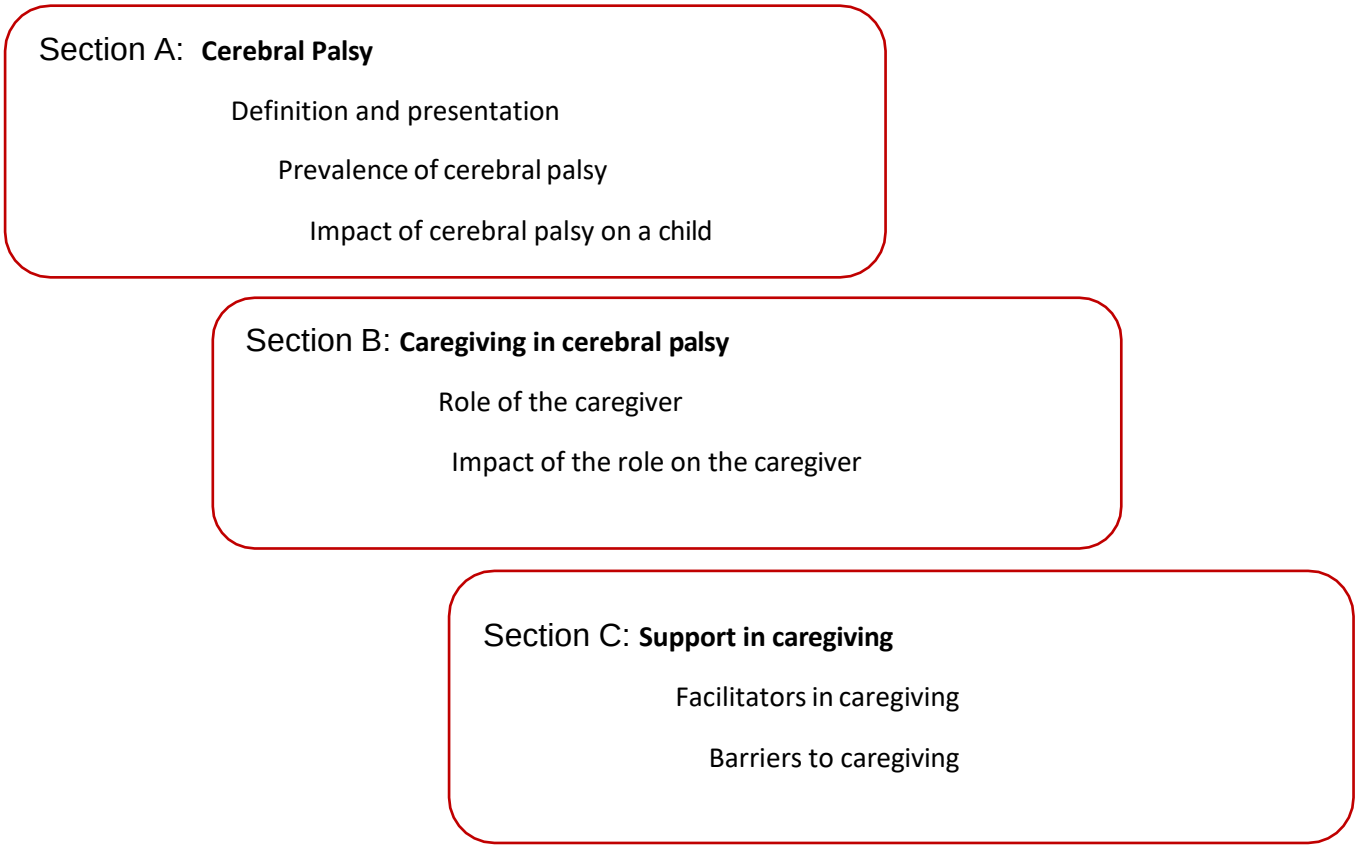


Figure 2.1: Schematic diagram outlining the sections in the literature review

Section A

2.2 Cerebral Palsy

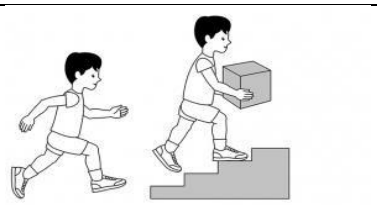
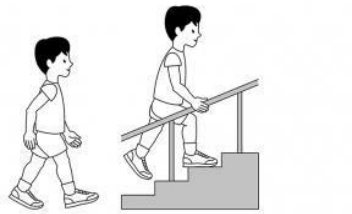
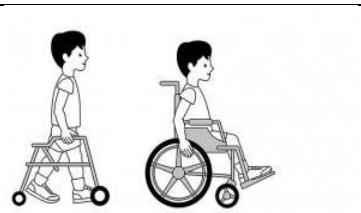
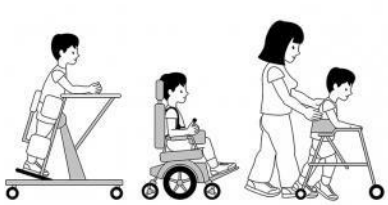
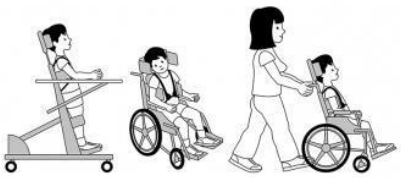
Cerebral palsy (CP) describes a “group of permanent disorders of the development of movement and posture” as a result of nonprogressive disturbances in the foetal or infant brain (1 ,2). The motor disorders in cerebral palsy, which also assist in its diagnosing, are disturbances in sensation, cognition, perception, musculoskeletal development, communication and behaviour (6). Though the injury or disturbance in the brain is nonprogressive, the clinical presentation of the condition may change over time as the brain matures (6). This is important to note as some children may appear to worsen or improve over time as the clinical presentations change.

There are various factors that may result in an injury occurring to the fetal or an infant’s brain. In some cases, the cause of prenatal brain injury is unknown, but some common risk factors include low birth weight of less than 2001g, preterm delivery less than 32 weeks, perinatal asphyxia, infections such as toxoplasmosis, rubella, cytomegalovirus, herpes, neonatal or childhood meningitis (7). The most common causes of CP in the African context were identified as birth asphyxia, kernicterus, and neonatal infections. Prematurity or low birth weight were also listed other causes of cerebral palsy in Africa (10). This is in contrast to what has been recorded in the United States and in Europe where prematurity or low birth weight are the major causes of CP (10).

Cerebral palsy can be divided into four major types based on the predominant motor disability. These types are spastic, dyskinetic, ataxic and mixed cerebral palsy (8). Within these types are variations in presentations and severities. The various types of cerebral palsy disorders are characterised by a wide spectrum of abnormalities ranging from muscle tone, movement, posture, impaired sensory and intellectual capabilities, behavioural as well as socio and psychological limitations (5,6). Children with CP also have varying functional levels and may have limitations in physical and daily life activities such as independent feeding, dressing, bathing, and mobility. While some children may be independently mobile, others may be restricted to a wheelchair or other specialised modes of sitting or transportation (7). The GMFCS is a tool used to categorise the gross motor function of children with CP (46).

It comprises levels 1 to 5, as illustrated in Table 4.2.1b below (15).

Table 2.2.1 GMFCS:

LEVEL	GMFCS ILLUSTRATION	DESCRIPTION
I		Walks without limitations indoors or outdoors and climbs stairs without limitations. Speed, balance, and coordination are reduced
II		Walks with limitations indoors or outdoors, climbs stairs holding on to a rail. Experiences limitations walking on uneven surfaces and inclines, in crowds or confined spaces
III		Walks indoors or outdoors using a handheld mobility device and climbs stairs holding onto a railing. May require a self-propelled wheelchair when travelling longer distances, outdoors or on uneven terrain
IV		Self-mobility with great limitations and may use powered mobility
V		Physical impairments restrict voluntary control of movement and have no means of independent mobility. Transported in a manual wheelchair

2.2.1 Prevalence of CP

In recent years, the global prevalence of CP has been estimated between 1.5 to 4 cases per 1000 live births (11). Reports from high income countries such as Australia and in Europe show that CP prevalence ranges from 1.5 to 2 cases per 1000 live births (6). Higher rates of approximately 3 cases per 1000 births were reported in the US, Taiwan and in Egypt (6).

In African countries, prevalence varies from country to country (10). Research done in African settings such as Zimbabwe and Ghana has shown an estimated CP prevalence of 2 to 10 cases per 1000 births (12, 13). Some literature points out that this may be an underestimate because of poor reporting of neurologic conditions in the African context (13). A study done in Ghana also indicated that cerebral palsy is under researched in the African context (4). Considering the possible underreporting and the under researching into cerebral palsy that is seen in Africa, it may be argued that the prevalence of CP is higher than recorded. In addition, low-income countries such as in Africa generally have a higher prevalence of children with disabilities than in high-income countries. This is deduced from research which shows that 80% of the world estimated 150million children with disabilities live in poorly resourced areas (13). The prevalence of cerebral palsy in South Africa was estimated at 10 cases per 1000 live births in 2002 (3). More recent prevalence data is lacking due to the poor surveillance of cerebral palsy in the country. Misconceptions on the etiology of CP or other disabilities have varying impacts on statistical recording. A South African study showed that in some settings, CP is attributed to spiritual causes and rituals (8). Such misconceptions on the etiology of CP or other disabilities have varying impacts on statistical recording of the prevalence of CP.

2.2.2 Impact of CP on a child

Children with CP experience varying limitations and restrictions in performing functional daily activities and social participation (12). Some of the challenges children with CP face include complex limitations in self-care such as feeding, bathing and mobility (9). Other comorbidities include visual, speech and hearing impairments, orthopedic deformities, general poor health, malnutrition due to feeding problems,

epilepsy (5,8,11). Epilepsy is the most common coexisting condition in Africa (10). There is also evidence showing that children with CP have a greater mortality rate when compared to normally developing children (12). Children with CP combined with epilepsy are at an even higher risk for premature death(10). This increased vulnerability is worsened by the fact that an estimated eighty percent of children living with both cerebral palsy and epilepsy, reside in resource poor regions such as Africa (10).

With possible developmental delays in gross motor skills, fine motor skills, sensory skills, language, vision and hearing abilities, as well as social, emotional and behavioural development (15), children with cerebral palsy face multiple challenges. Due to all these comorbidities, cerebral palsy has a significant impact on the QOL of life of the child affected. The multiplicities of health challenges also implies possibly a lifetime of dependency on others for activities of daily living and livelihood. Consequently, cerebral palsy also impacts families and caregivers of children living with the condition. The following segment looks at the role that caregivers play in the lives of children with cerebral palsy.

Section B

2.3 Caregiving in Cerebral Palsy

Taking on the unexpected role of caregiving to a child with CP is challenging and can be stressful (5,9). Some scholars liken the initial news of a diagnosis of a disability to a life crisis with negative reactions and feelings similar to bereavement (16). Families that receive the news of a family member diagnosed with a disability such as CP may even go through some stages of grieving such as disbelief, denial and bargaining before accepting the diagnosis (16). Literature indicates that while some families may be able to negotiate this path and move into acceptance, it is inevitable that some families will require assistance as they face the medical, psycho-social and financial strains of having a member with cerebral palsy (16).

In view of the fact that CP is a chronic condition, in most instances, it requires care to continue in the home environment. The burden of providing the extensive and intensive care required by a child with CP then falls on family members. In most cases, the exceeding dependency and care demands of the child are thrust on the caregiver, usually on a long term basis (11), and without being adequately prepared to execute

the role (10). When a child is diagnosed with cerebral palsy, the caregiving role becomes more stressful than when taking care of a child with normal developmental milestones (17). The needs of children with CP greatly exceed those of normally developing children (17). Caregivers therefore play a significant role in the livelihoods of children with cerebral palsy.

Children with CP require labour intensive care from a competent, confident and skilled caregiver due to their dependency and comorbid health conditions (4). As a result, additional layers of significant pressures and stresses are added on to the family unit (13,12). Caregivers invest their effort, time and finances sometimes at the expense of their own careers, other family members, their emotional wellbeing and physical health. Depending on the degree of autonomy and independence of the child (18), the demands of a child with CP place great strain on the primary caregiver and the family as a whole.

2.3.1 Impact of having a child with CP on health and well-being of a caregiver

Research shows that the care requirements for a child with cerebral palsy are diverse and, in most cases, intense such that they affect the caregiver's quality of life (QOL) (6;13). Long-term informal or home-based care has negative emotional, physical and functional health consequences on the caregivers, impacting the caregivers' QOL (2). Generally, dyads of children with CP and their caregivers are characterised by poor QOL (19). Having or raising a child with CP increases the risk of stress or depression in caregivers (20). Various studies have shown higher levels of stress, anxiety, depression, emotional and physical exhaustion in caregivers of children with CP when compared to caregivers of normal children (15,16).

In nearly all contexts, caregivers of children with disabilities are commonly faced with a varied range of difficulties in performing their caregiving role (20,11). Low levels of family and community knowledge, high levels of stigma (12), physical and emotional exhaustion (4) resulting in the isolation of the child and social exclusion of the mother or caregiver (23) are some of the challenges faced by caregivers. These factors have a negative effect on the parenting and caregiving capabilities of caregivers and ultimately on the health of the caregiver (2).

In an Africa context, attitudes of stigma and discrimination, which in most cases are shaped by traditional or social beliefs, affect the psychological and physical health of

caregivers (10,9,11). The continuous exposure to and experiences of difficulties in providing care as well as negative family or community perspectives all combine and inadvertently result in the poor health and well-being of the caregiver.

The challenges and difficulties of providing care to a child with cerebral palsy are worsened in low to medium income countries (10). Generally, in low-income countries, the QOL of a caregiver with a child with cerebral palsy is indisputably poorer than that of a caregiver of a child with normal developmental patterns (13). Poverty has been shown to highly correlate with negative attitudes to children with and families of children with CP (13). This may be due to lack of awareness and no access to information in poorly resourced settings (13). Stigma has a negative impact on the caregivers and the children in their care. As a result of stigmatisation, caregivers may not seek support and refrain from engaging in relations that may be helpful to them (19). This adds on to the pressures of caregiving as they are forced to isolate and carry the burden of caregiving on their own. In the African context, mothers, who traditionally have the role of caregiving, tend to be affected by this phenomenon more than the fathers (20).

Between a caregiver and a recipient, the health and wellbeing of one inevitably affects the other in various ways. Challenges faced by the child may affect the caregivers' physical, psychological and social wellbeing (19). Similarly, challenges faced by the caregiver also affect the child's overall wellbeing. Some research has found a correlation between caregiver health and the child's level of independence and behaviour (19). Cultural and societal views on cerebral palsy also shape the caregiver's attitude toward their child with cerebral palsy (24). A hostile attitude fosters aggression from the caregiver towards the child (25). On the contrary, some caregivers become protective to shield the family from society's negativity. Both responses may be straining the caregiver and may cause psychosomatic health challenges (25).

2.3.2 Impact of having a child with CP on family relationships

Having a child with a disability introduced into a family requires the family to restructure and reorganise their lives to accommodate and allow for the comfort and growth of the child (26). In doing so, family relationships and responsibilities may also require restructuring and reconstruction (18). The needs of a child with cerebral palsy may easily exceed the needs of other family members individually. When the caregiver,

who is normally the mother, is unable to cater to the needs of her other children or family members, possible negative psychological and social issues impact other family members (27). Perceived or actual feelings of neglect by other family members result in strained family relations (27). When family relations are strained, they add on to the stress and burden of the caregiving role. Such experiences may be cyclic and the accumulative effect of these negative cycles in relations may affect other children well into their adulthood. This in turn may also affect the health of the caregiver through possible stress, worry or depression. Having a child with cerebral palsy or a disability has been shown to strain otherwise healthy relationships and exacerbate the strain in already strained relationships (12). In some relationships, having a family member living with physical challenges brought family members closer (28). Closeness occurs with establishing a better relationship through empathizing with each other over the child's disability.

2.3.3 Impact of having a child with CP on financial wellbeing

A child's long-term illness or disability may have financial implications on the family involved (22). Financial costs associated with caring for a child with a chronic condition such as cerebral palsy can substantially affect a family's financial stability (22). The financial demands of care for the child with disabilities can exceed the resources at the parents' disposal, exhausting any extra earnings (29). This may contribute to increased stress and somatic illnesses as well as perpetuating the cycle of poverty (29). Literature shows that there is currently little research that analyses parents' experiences regarding available financial support in assisting them in giving care to children with disabilities (22). Generally, caregivers of children with cerebral palsy or other disabilities require financial support. This is shown in studies done in Finland, South Africa, Ghana and Zimbabwe which indicated that families of children with long-term illnesses and disabilities needed financial assistance (20,27,11).

The burden of caring for a child with a long-term illness or disability was also found to cause fatigue which in turn affected employability of the caregiver (22). Due to the high care demands from a child with cerebral palsy, most caregivers struggle to find the time and energy to engage in financially beneficial employment (22). Providing fulltime care for a child with cerebral palsy or other disabilities limits plausible means of earning a meaningful income for most caregivers. They may become stuck in a poverty cycle,

dependent on family donations and governmental social grants. Thus, having a child with a chronic condition directly contributed to unemployment and the family's financial situation holistically (22). In instances where caregivers did receive state financial support, they were of the view that the allowance was insufficient in compensating for the time spent caring for their child's illness as well as the mental strain involved in providing care (22).

The financial strain on the caregivers can affect access to healthcare and affect social integration for the child with CP. A study carried out in a low-income setting in Brazil implied that the need for caregivers to travel for healthcare services for their children with disabilities was a source of financial strain. Financial difficulties posed hindrances to effective social integration of the child and his or her family. With no access to special schools or assistive devices due to financial constraints, children are unable to realise their full potential (31). This impacts on the health equity WHO statement where all people must have an opportunity to attain their full health potential without anyone being disadvantaged from achieving this potential due to social circumstances (32).

In this section, literature on the impact of CP on the child and on the caregiver was reviewed. The following section, literature on the support required in caregiving as well the facilitators and barriers to caregiving will be discussed.

Section C

2.4 Support in caregiving

There is a need for support to families and caregivers of children with CP. In addition to their physical and mental disabilities, children with CP are clinically fragile and socially vulnerable (23). Their caregivers require support from different sources, including social services and professionals, friends, and extended family. As already established, having a child with CP changes family dynamics (33). Family member functions need to be adjusted to meet the extra demand of care placed by a child with cerebral palsy. As research in most African contexts, has repeatedly shown, the burden of care lies mostly on the mothers (15, 9). Without the necessary shift in family responsibilities, all care related tasks may be placed on one person, straining and exposing them to the stress factors associated with provision of care. An example of family support can be illustrated in a study done on the experiences of grandparents with grandchildren with disabilities. The study found that grandmothers offer different

types of assistance such as baby sitting and constitute important sources of support for families (14).

In another study, spousal support was considered the most important support that mothers needed, and it correlated with a lower burden of caregiving (7). Without the initial layer of social support provided by a spouse or family, the caregiver is vulnerable to distress. When caregivers have inadequate support, they may be unwilling to talk about their emotional challenges in order to avoid overloading those people that are already providing some sort of support (25). Furthermore, caregivers would rather opt to ask for physical or practical assistance instead of help with their emotional wellbeing (25).

2.4.1 Facilitators in the caregiving role

A study done in Ghana on the perceived social support and resilience in caregivers of children with special needs shows that caregiving in a child with a disability is challenging and caregivers rely on social support to achieve their caregiving goals (16). Social support is broad, being inclusive of family, neighbours, friends, co-workers or community members, and governmental and non-governmental initiatives that help alleviate the burden of providing care.

It is important to highlight that it is not the quantity of support that has positive outcomes but rather the quality of the support that is given. One study differentiates between received support (that which is given) and perceived support (that which is needed) (27). The study emphasises the fact that perceived support has a higher correlation to positive health outcomes than received support which may not be needed at the time (27). Perceived social support from a spouse and the immediate extended family is critical in reducing the negative psychological outcomes for mothers and primary caregivers of children with CP (16).

In the African context, and in other poorly resourced settings, raising children is a communal effort in which larger kinship groups and communities help with childcare and other tasks (28). This interdependency is essential, more so in children with special needs. Neighbours, friends or extended family may watch over the child while the mother runs errands without an expectation of monetary compensation. Husbands not only play a protective and supportive role, but also provide for the family. These support mechanisms make it easier for caregivers to carry out their role by reducing

the caregiving burden. This results in positive health outcomes for both the child and the caregiver. The entire family ultimately benefits from adequate perceived support.

Community and caregiver educational programs have been shown to reduce the burden of caregiving through empowering caregivers. In Ghana for instance, a participatory training delivered through a local support group for the purposes of empowering caregivers resulted in improved caregiver quality of life (QOL) (29). On the contrary, an educational study done in South Africa to determine the effect of a group-based educational intervention on caregivers' stress levels and QOL showed a poor correlation between an educational program and the improvement in the stress levels and QOL of the caregivers (13). Though this programme did not achieve a reduction in stress levels and an improvement in the QOL of caregivers of children with CP, it was beneficial in showing the value of received versus perceived support. Educational programs are beneficial in most settings, but it is possible that in the particular South African setting, other factors played a far more important role in the stress levels and poor QOL of caregivers. Such compounding factors have to be identified and addressed for the educational programme to achieve desired goals.

Non-profit organisations for people with disabilities can play a supportive role in alleviating the burden of caregiving. Working towards de-stigmatisation and advocating for caregivers and the children under their care, non-profit groups or organisations are beneficial in lightening the burden of caring for children with disabilities including CP (16).

In addition to social support, being optimistic and spiritual are other coping mechanisms that alleviate the burden of caregiving. Optimism and spirituality add a layer of protectiveness over the caregivers from the negative emotional and psychological effects of having a child or taking care of child with CP. Some research as shown that women found belief in God and other religions to be a source of strength and comfort when psychologically strained by the demands of care giving (26). While spirituality and dependence on faith beliefs increases in some women, the opposite is true for others. The relief that spirituality brings to the stresses of having a child with CP is not necessarily a universal perception. Some mothers report having lost their faith and spirituality as a result of having a child with a disability.

Resilience is a personal assert that caregivers lean on substantially in their role. In South Africa, caregivers of children with CP endure the hardships of poverty, isolation or abandonment as well as discrimination (34). Despite these challenges, and contrary to most studies, a study done at George Mukhari Academic Hospital indicated that caregivers are generally happy, healthy and satisfied with their lives (34). Though research has proven that caregivers demonstrate high levels of psychological and physical distress as well as personal, financial, family, and social problems, other research has shown that assuming the role of caregiving does not necessarily cause negative health or psychological outcomes (19). Caregivers had adopted coping mechanisms that enabled them to not only carry out their caregiving role but also raise their families within the means available to them. The resilience and strength exhibited by caregivers of children with CP becomes an assert that helps them cope with their care giving role. While some caregivers isolate, others develop higher levels of tenacity and resilience as a way of coping with the situations that they find themselves in (35). The building up of this inner strength occurs over time and is necessary for carrying on with the long-term role of a caregiver to a child with cerebral palsy as well as maintaining the functionality of the family. The reasons why some caregivers cope better than others are varied and may differences in the behaviours of children, caregiving demands or autonomy of the child and the functionality of the family (36).

Financial constraints have been proven to increase the burden of care for children with disabilities. South African policies recognise the need for child security in low-income households. In addition, they also acknowledge the added strain of taking care of a child with a permanent or chronic disability. According to the South African Gauge the South African Social Security Agency (SASSA) disburses social grants on behalf of the Department of Social Development to nearly 12.5 million children between the ages of 0-17years of age. In October 2019, the child support grant (CSG) was recorded as R430.00 per child per month (30). In addition to the CSG, SASSA also disburses the care dependency grant (CDG) which is given monthly to caregivers of children with disabilities. The grant is meant to cover any additional costs that the caregiver might incur as a result of having a child with a disability. This grant is only given following a medical assessment that determines the eligibility of the child. The gauge recorded the disability grant to be R1 780.00 per month as from April 2019 (30). These social grants are used in many households not only for the needs of the child

but also for taking care of entire households (37). This cushions caregivers from bearing the full load of providing care.

2.4.2 Barriers in the care giving role

In most communities, the role of caregiving is assigned to mothers or women in the family (38). One of the female identities in the African cultures which has traditionally been assigned to women for generations, is that of nurturing and caregiving of the family (39). It is therefore expected that in African settings and other third world settings, when a family member has a disability, the mother is the primary caregiver. This discriminatory expectation disempowers women or mothers who are caregivers to pursue their career pathways. Research has shown this to be the case in communities found in South Africa, Uganda, Mexico, Zimbabwe (37, 12). The challenges of caregiving therefore become challenges that mothers, or women are expected to face in taking care of their children with disabilities and the rest of their family.

Research suggests that there is a link between having a child with a disability and an increased risk of poverty (18). Financial instability is in some cases a result of inability of caregivers to combine and manage caregiving and economic activities. Caregiving is a fulltime, physically and emotionally tiring occupation which leaves caregivers fatigued and unable to find, concentrate on or keep a job (31). As a result, even where opportunities may be available, time constraints as well as depleted physical and mental stamina may prohibit caregivers of children with CP from pursuing those opportunities. Results from one study indicated that mothers of children with CP tend to spend most of their time caring for their children at the expense of devoting time to themselves, their health or vocations (22). Extra costs emanating from transportation, therapies, assistive devices, special diets, nappies add to the financial burden of families of children with CP or other disabilities (18). Without the financial capacity to meet these basic needs, the role of caregiving is distressful, in many cases forcing caregivers to forego their own needs. Studies done in Finland indicated that though parents of children with disabilities and chronic medical conditions needed financial assistance, they did not access it and perceived the state provided financial support system as necessary but too complex (18).

To satisfy the role of caregiving to a child with CP or any other disability, the self-sacrificial trait is in most cases heightened (35). This results in most mothers of

children with cerebral palsy sacrificing their own health, personal development and ambitions for the sake of the child and the family at large. Over an extended period of time, these self-sacrificial acts may affect one's emotional and mental health (35). Caregivers become prone to emotional stress, depression and sometimes repressed hostility. Due to these factors, psychosomatic disorders are a common feature in mothers of children with disabilities including cerebral palsy (38, 39, 33). Despite these adverse health outcomes, caregivers view the benefits of this self-sacrificial attribute as superseding the detriment that activities of caregiving cause to their own health (27). Over years, the strain of these necessary and vital duties compounded with other factors discussed here, results in the poor health of the caregiver.

In addition to emotional and psychological challenges, another effect of having a child with CP is the physical strain on the caregiver (39). Physical strain occurs as a result of the physical challenges that are inherent in the duties of caregiving such as assistance in activities of daily living (bathing, positioning, toileting) . In their early years of life, children with CP may have health challenges that affect their eating patterns, sleeping routines and general feeling of well-being. The need for constant care from the caregiver, coupled with other daily commitments causes significant physical strain (42). As the child grows older, the strain of lifting, bathing, dressing and negotiating travelling challenges become a reality that the caregiver has to navigate. For instance, mothers in resource deprived settings have to carry their children on their backs when attending medical appointments (11,10). The limitations that children with CP have in performing age-appropriate activities of daily living translate to an increase in the physical strain and assistance that the caregiver gives (12).

In addition to the physical challenges of providing care, there are also the social challenges that caregivers face. Discrimination and stigmatisation of cerebral palsy or other disabilities lead to the social withdrawal of caregivers and their children. This is common in traditional African settings such as reported in Zimbabwe and Ghana (12). Disability is perceived differently in every culture and belief system. Attitudes of individuals and communities are informed and influenced by their cultures and beliefs. The extent to which a child living with a disability or cerebral palsy receives care and interventions from their family and community is also informed by these perceptions (6).

A study done in Zimbabwe highlighted that CP was viewed as punishment from

ancestors for the parents' wrongdoing or the mothers' promiscuity. As a result of such stigmatisation, there was isolation of mothers of children with CP and their children (9). In Ghana, mothers of children with cerebral palsy reported feelings of stigma and shame, with their children being treated as if they were not human. Some mothers were left by their husbands and families were unwilling to care or even touch the child (8). The quality of the lives of the caregiver and the child were negatively affected, making it difficult for caregivers to perform their role adequately.

In Tanzania, the birth of a child with a disability is a 'bad omen' or an indication that the family sacrificed their child's wellbeing in rituals to acquire riches (6). In South Africa, most people attributed cerebral palsy to spiritual (32) causes while in Kenya it is thought of as a result of bewitchment or God's anger (6). Such views increase difficulty in caregiving as they reduce the chances of a caregiver seeking support from extended family or social services. In isolating themselves and their children, caregivers also withdraw from the communities and social mechanisms that are in some cases meant to provide some support or comfort. Such isolation and withdrawal has been linked to negative impacts on the psychological and physical health outcomes. In an extension of negative attitudes and perceptions from extended families and communities, parents or caregivers' perceptions towards their own child may be distorted (20). Therefore, the cultural context in which a child with CP is being raised will either make it easier or difficult for a caregiver to carry out their caregiving role.

Intricately linked to cultural context and beliefs is the aspect of lack of knowledge regarding cerebral palsy (34). Lack of public awareness of the causes of cerebral palsy increase the difficulties faced by caregivers (32). For effective caregiving, the caregiver has to be competent and confident in their skills and knowledge of cerebral palsy (6). Lack of knowledge and skills regarding the complications of cerebral palsy makes the caregiving role even more daunting. Caregivers that know what to expect are better equipped and more confident to deal with the future of their children that those that are not. Empowering caregivers with the knowledge that they need and will need in the future gives them good self-esteem and the confidence that they need in their role (29). Regarding communities, ignorance and fear feeds into the social stigmas and misconceptions surrounding cerebral palsy and other disabilities.

Due to the demands of care giving, many primary caregivers, such as mothers, have

significant time constraints that prevent them from investing in themselves, socially, educationally or in gainful employment. As a result, they themselves are financially deprived and become financially dependent on social services or on their spouses or extended family. This cascade of events may place strain and unfulfillment on the caregiver. Though many mothers of children with cerebral palsy would like to be gainfully employed, they also want to be the primary caregivers to their children. This scenario impacts one's satisfaction with their lives and may influence self-esteem as well as increase frustrations.

When the factors of stigmatisation and low self-esteem, isolation, financial difficulties, physical and emotional strain are pooled together, the challenges that caregivers face become substantial. Without adequate support, it is inevitable that caregivers' QOL deteriorates as a result of having a child with CP.

Conclusion

In this chapter the impact of CP on the child and on the primary caregiver were discussed. The facilitators and barriers to the role of caregiving were also outlined. In the next chapter, the methodology followed to address the study aim will be presented.

CHAPTER 3

METHODOLOGY

3.1 Introduction to methodologies

This section relates the methods employed to address the aim of the study. This research study aimed at exploring what the experiences, emotions, opinions and feelings of primary caregivers of children with cerebral palsy with regards to support in their role.

3.2 Study design

The study design used in answering the research question was an explorative qualitative design. The study design allowed for capturing varied personal expressions by participants. The design was purposely selected as it allows flexibility and provides a holistic presentation of the participant during the interview. The use of techniques such as probing, observations of one in their home environment, note-taking during the interview all combined to give depth and detail to the interview. The explorative qualitative study design provides information that aids in the development of ideas and hypotheses for further qualitative or quantitative studies. In order to understand these complex life experiences and extract information out of the individual and unique experiences of the caregivers, a qualitative design had to be employed.

3.3 Study setting

The study was carried out in a predominantly informal settlement called Diepsloot. Diepsloot is located in Region A of Johannesburg Metropolitan Municipality, 40km north of the city of Johannesburg. Historically, Diepsloot emerged from people that were being evicted from neighbouring farms and privately owned land in the 1990's. There were no amenities or infrastructure in place at the time. Over time, this reception area has continued to grow, and population densities continue to rise. Currently, Diepsloot's population is estimated at half a million (29). Diepsloot comprises of informal and formal settlements divided into several residential areas called extensions. Extensions 4,5,6,9 and 10 are government subsidized houses and extensions 2 and 7 are houses built by landowners. Extension 3 comprises of partially subsidized houses. Extensions 1, 12 and 13 form the largest sections of informal settlements (30).

In addition to the immigration of South Africans to Diepsloot, the area has also received many unregistered immigrants who come as job seekers from other African countries such as Zimbabwe, Mozambique, Somalia, to name a few. As a result, densities have increased over the past years. In South Africa, density is generally accepted to be low at less than 40 units/ha, medium at between 40 and 100 units/ha and high at more than 100 units/ha. Diepsloot has an estimated density of 300 dwelling units/ha (43).

High unemployment rates, intolerable crime levels, poor water and sanitation systems, issues of adequate and appropriate housing, service delivery and effective local governance plague Diepsloot. The existing amenities are overburdened by the increasing population (43). Most facilities are dysfunctional due to poor resourcing. While South Africa has an average unemployment rate of 27%, Diepsloot's unemployment rate is estimated to be 75% (44). With such high levels of unemployment, QOL is poor and most of the residents live below the poverty line.

Due to the high unemployment rates, most families are dependent on government social grants. However, the governmental and other organisations' subsistence measures are barely sufficient for many. The most commonly accessed grants include the child support grant, old persons' grant and the disability grant where appropriate. The Social Relief of Distress grant was recently established in response to the COVID 19 pandemic. Though these financial assistance platforms are available, beneficiaries are limited to South African nationals, permanent residents and registered refugees. Most foreign nationalities in Diepsloot are undocumented immigrants and therefore do not meet the legal requirements for such governmental support.

It is at the backdrop of this township that the Bona Lesedi center was founded in 1999. At the time of the study, Bona Lesedi was a non-profit organization, running on donations from different organizations. Bona Lesedi provided day care to children with physical and mental challenges. At the time of the study, Bona Lesedi attended to over 100 children with different diagnoses (31). Some of the medical conditions seen at Bona Lesedi are cerebral palsy, Down Syndrome, and a spectrum of intellectual disabilities. This study only focused on the caregivers of children with CP. This group represented the children with the severest physical disabilities. Hence, they were also the group with the most physical dependency in activities of daily living.

Bona Lesedi runs on a minimal budget. The premises has some dilapidated and abandoned buildings that need to be renovated if they are to be used. The tennis court is overgrown with grass and out of use. According to Bona Lesedi manager, the fees paid by the patients' caregivers are highly reduced and not adequately sufficient for the operation of the center.

The staff from Bona Lesedi (some on which are voluntary workers) run a day-care program for children, conduct home visits and provide mobility devices where possible. The centre has various partners that help deliver care and support services to the children and their caregivers. Support services include support groups for parents and caregivers as well as counselling by the resident social worker at the centre.

3.4 Study population and study sample

The study population comprised of primary caregivers of children with CP whose children attended day care at Bona Lesedi. A primary caregiver was defined as the individual who was mostly responsible for taking care of the child at home. To meet the inclusion criteria, the primary caregiver and the child had to reside in Diepsloot or immediate surroundings, the child under their care must have been medically diagnosed with CP and under the age of 18.

The NPO provided a list of names of parents or guardians with children identified as meeting the inclusion criteria. Ten children that met the requirements of age, diagnosis and area of residence were identified. Their primary caregivers were listed to participate in the study. These caregivers were contacted telephonically and upon giving their consent, they were recruited into the study. The study was explained to the participants in order for them to give informed consent. All ten primary caregivers identified gave consent to participate and they were all included in the study. All primary caregivers agreed to meet the interviewers in the privacy of their homes.

3.5 Data collection tool

The interview guide was developed by the researcher and consisted of two sections (Appendix 1). Section A captured the demographic information of the child (age, gender, diagnosis, gross motor functional level) and demographic information on the primary caregiver (age, gender, level of education, employment status, language

preference). Section B consisted of open ended questions that targeted the caregivers' views of support systems (available, used and needed) and the facilitators and barriers to accessing the support systems. The aim and objectives of the study informed the interview questions. The probes were inserted to guide the interviewer to obtain information from the participants that was specific to the study objectives.

3.6 Data collection procedure

The pilot interviews were carried out to ascertain the adequacy of the research tool and to be acquainted with the process of data collection. A pilot study was conducted in which two caregivers were interviewed. The study was explained to the participants. After the informed consent was granted, semi-structured interviews were carried out at the participants' residences. The interviews were conducted in languages participants preferred. Quizzing was used to encourage participants to share more on their experiences. Field notes were taken from the researcher's observations of body language, family interactions and living conditions. All the interviews were recorded using an audio-recorder.

Following the piloting, minor amendments to the questionnaire were made in making questions more open ended to allow the participants to tell their story The logistical process of identifying the homesteads of the caregivers living in an informal setup were challenging. It was difficult to locate house numbers and addresses in the various extensions. Consequently, in the main study, a research assistant was nominated from the NPO who was familiar with the informal settlement. With this assistance, the research proceeded with better success rates in locating the caregivers.

Covid 19 precautions were followed during all the interviews. Researchers and participants sanitised hands and wore masks. Interviews were conducted outside with 1meter social distancing being maintained.

3.6.1 Main study

The same procedure followed in the pilot study was followed. Semi-structured interviews using an interview guide were conducted. Some interviews were conducted in Zulu, the most common language in Diepsloot (26). Others were in English and Shona (the languages spoken by the main researcher). All interviews were audio-recorded. Interviews averaged 45minutes to an hour. They were all conducted at the households of the participants. Field notes were taken at each interview.

3.7 Data analysis

The audio recorded interviews were pseudo-named for confidentiality and stored on the researchers password protected electronic device. The audio interviews were transcribed in the language that the interviews were conducted. These transcripts were then translated into English for analysis.

The MAXQDA 11, version 18.2.0 software was used in the general sorting, organisation of data and analysis. The data was analysed using the thematic analysis. The Colaizzi's procedural steps were used (33) as follows: (a) all transcripts were read repeatedly to understand the different experiences and the general themes. (b)Statements that revealed the caregiver's perceptions on support systems around them were extracted from the transcript. (c)The researcher formulated meanings from the caregiver's statements and phrases. (d) These were then arranged into clustered themes. (e) An exhaustive description of the clustered themes were formulated. (f) These descriptions were authenticated by obtaining feedback from participants. Finally (g) the participant's feedback was incorporated into the descriptions of participant's experiences.

3.8 To ensure trustworthiness the following strategies were employed:

3.8.1 Credibility

Credibility is an important criteria of qualitative study that looks at the extent to which the researcher has truthfully presented the views of the participants (45). In this study credibility was established firstly by capturing the participant's expressions via audio recordings and verbatim transcribing of the interviews. The translations were done by persons experienced in the languages used during interviews. Having interviews in the home of the participants afforded the researcher first-hand observation of the caregivers context. Member checking was done telephonically on some of the interviews to ensure that recorded findings were consistent with the messages participants had communicated. During analysis of data, regular debriefing session were held with the peers and supervisors and inputs captured and incorporated. A codebook was generated for use in analysing the whole data set. Once the themes had been named, they were analysed using available literature in order to produce a report with a valid argument (27,28).

3.8.2 Dependability

Dependability refers to the consistency of the researcher in data collection over a period of time (45). The researcher established dependability of the study through detailing the study process in logical and easily traceable documentation. The detail with which the researcher recorded the data collection process shows the consistent steps taken at each interview. This will allow for easy examination of the research process and replication of the methodology by future researchers.

3.8.3 Transferability

Transferability refers to the extent to which the findings of a study are applicable to other settings (45). Through providing a detailed description of the study settings, the researcher ensured that transferability to a similar context may be applicable. Generally, transferability is limited in qualitative studies. However the provision of detailed sampling procedures and study context will allow some degree of generasability to similar settings.

3.8.4 Confirmability

Confirmability speaks to the accurate and non-biased representation of the participants' responses by the researcher (45). To ensure accurate and non-biased reporting, the researcher used a number of direct quotations from the participants which added to the objectivity of the data. An external translator was used to check for accuracy of translations and increase objectivity of the transcriptions. There was collaboration with peers and supervisors' and their inputs were incorporated during the analysis process which included establishing of codes and assessing their accuracy. The researcher and supervisors conducted meetings to discuss the codes and reached consensus on the codes presented through dialogue.

3.8.5 Positionality

The researcher grew up in Zimbabwe and was raised in a loving and caring medium income family. Family values of care, consideration and hard work were engraved from an early age. She attended the University of Zimbabwe and after a few years of practicing physiotherapy in Zimbabwe, she immigrated to South Africa. This research was inspired through working with neurological conditions in a special needs school

and in Zimbabwe's and South Africa's public hospitals. The experiences seen while working in these settings as well as the interactions with parents of children with neurological conditions led to the enquiry of this research. The researcher is passionate about the underprivileged or the disadvantaged.

3.9 Ethical considerations

The data collection process attempted to take all ethical concerns into consideration. Permission from the NPO was granted (Annexure 5) Informed consent was voluntarily obtained from all participants (Annexures 3 and 4). No participants were coerced to participate in the study. Participants' privacy and confidentiality were observed throughout the data collection and data analysis processes.

Ethical clearance was obtained from the University of Witwatersrand, Human Research Committee (Medical), clearance certificate number M2011133 (Annexure 6). Clearance was obtained on the 4th of December 2020 and data collection commenced in the same month. Delays in data collection were delayed by the different stages of restrictions during the COVID 19 pandemic.

CHAPTER 4

PRESENTATION OF RESULTS

4.1 Introduction

The focus of this section is to present the findings of this research study. Section A presents the demographic profile of the caregivers, the children under their care and the context in which caregivers provide care. Section B presents the experiences reported by the caregivers in their caregiving roles. Section C presents the facilitators and barriers faced by caregivers in performing their role are presented.

All caregivers recruited to participate in the study were interviewed in their homes. Prior notifications and confirmations made and attendance of community meetings by the researchers, all worked to build trust and familiarity with the researchers.. All of the caregivers were informing the researchers of their lifestyles and challenges as they saw an opportunity to be heard and maybe receive assistance. The central point of the study is to show that providing care for a child with cerebral palsy is an often stressful and demanding task. As a result, caregivers of children with cerebral palsy require immense support from various sectors in order for them to accomplish their role effectively.

4.2 Section A: Demographics

4.2.1 Demographic profile of the caregivers

The demographic information variables that were included in the study are gender, age, educational level, nationality, marital status, employment status and period in the caregiving role. A total of ten primary caregivers whose children were attending day-care at Bona Lesedi NPO in Diepsloot participated in the study. All the caregivers were parents of the child with cerebral palsy and had taken care of their children from birth. Caregivers were aged between 28 years and 60 years of age. The median age for caregivers in the study was 42.2 years, with most caregivers within the 25 to 40 age group. Eight of the caregivers were mothers while only two were fathers to children with CP. Though most caregivers are in the working population bracket, only three caregivers were formally employed, while the other seven were unemployed. The caregivers had varied sources of income. Sources of income included salaries of caregivers or their spouses, governmental child and disability support grants, pension

funds, earnings from small informal businesses such as selling vegetables, tenants' rentals, family and church donations. All caregivers lived in brick structures of varying sizes. The Figures below summarise caregivers' demographic information.

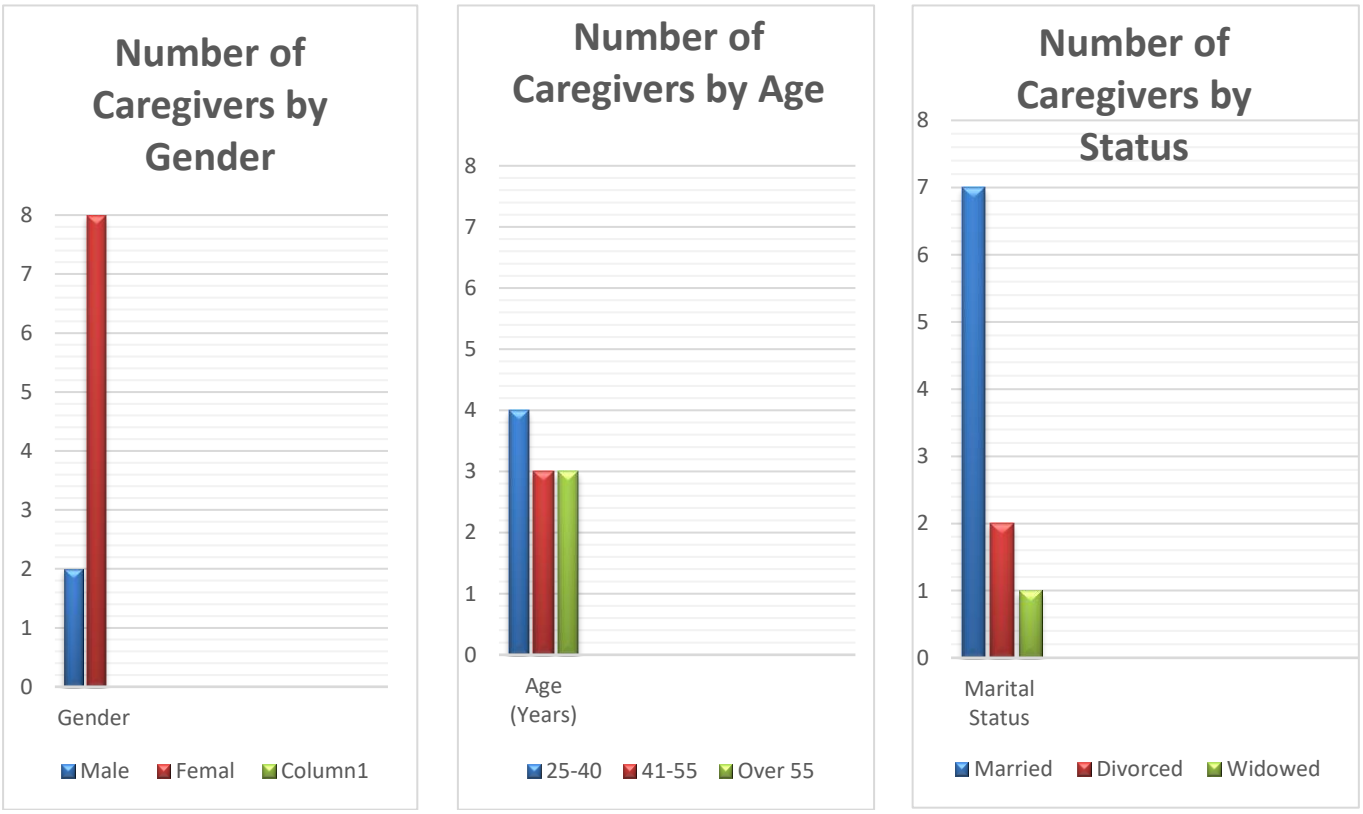


Figure 4.2.1 Number of caregivers by gender, marital status and age

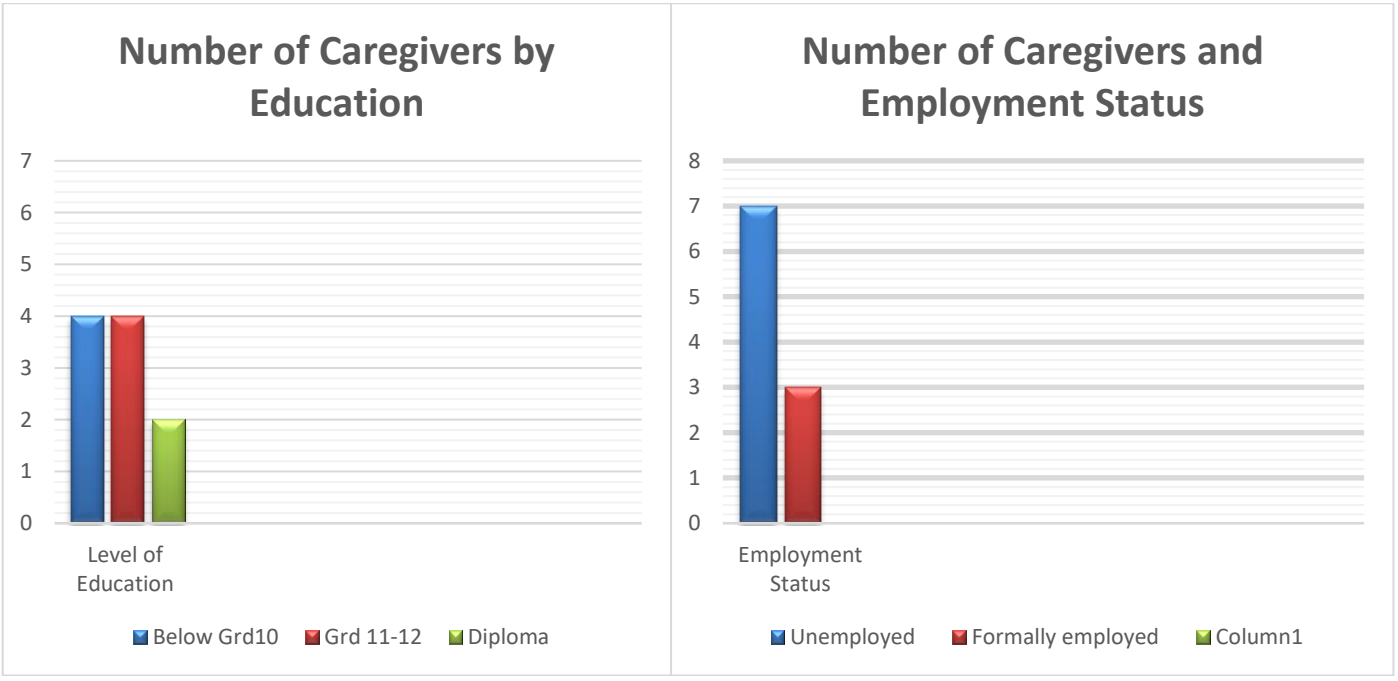


Figure 4.2.2 Level of education and employment status of caregivers

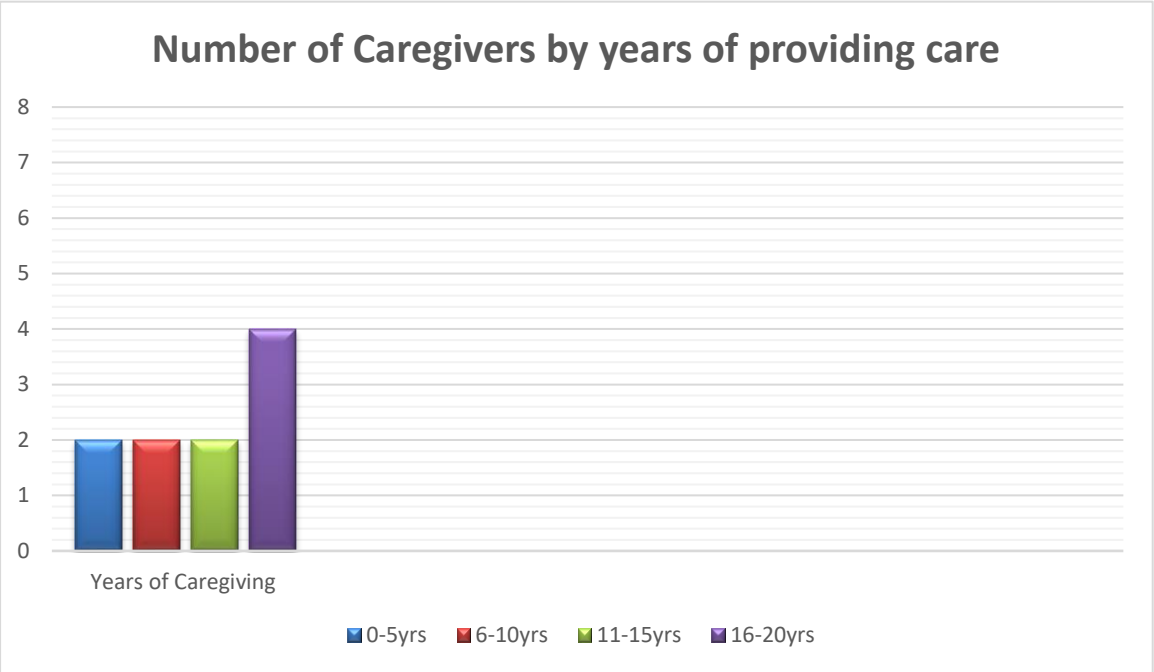


Figure 4.2.3 Years of providing care

4.2.1 Demographic profile of the children in the study

Table 4.1 below summarises the children's demographic information involved in the study. The ages of the children whose caregivers were interviewed ranged from 4 years to 17 years of age. Four were girls while six were boys. Only two children were functionally ambulant. One child used a walking frame and the other self-propelled on the floor. At the time of the interviews, none of the children attended day-care or special needs schools due to the Covid 19 school restrictions.

Table 4.2.1a Demographic profile of the children in the study

Caregiver	Sex	Age of child	GMFCS Level	Assistive devices
1	M	4 years	5	Shona buggy
2	M	6 years	5	Shona buggy
3	F	4 years	4	Baby stroller
4	F	8 years	5	Baby stroller
5	F	16 years	4	Walking frame, wheelchair
6	M	17 years	5	Shona buggy

7	M	16 years	5	Shona buggy
8	M	15 years	5	Wheelchair
9	M	15 years	5	Car seat, wheelchair
10	F	16 years	5	Car seat, Wheelchair

Most of the children were a level Five on the Gross Motor Function Classification System (GMFCS).

4.2.2 Living conditions in the context of providing care

All the included caregivers lived in Diepsloot, Gauteng Province. Diepsloot is an informal settlement area with high unemployment rates, poor sanitation, inadequate housing and generally poor service delivery in social systems. Population densities in Diepsloot are high, with more than 300 dwelling units/ha. In South Africa, density is generally considered high at more than 100 units/ha (24). Coupled with high levels of unemployment, the QOL is poor, and most of the residents live below the poverty line (44). Though most families are dependent on government social grants, the subsidies are barely sufficient (47). Undocumented immigrants also form a considerable percentage of the population. However, undocumented immigrants do not meet the legal requirements for such governmental support (48). In this context, cohabitation of extended families is a common phenomenon. The poor socio-economic environment within which caregivers of children with CP perform their role significantly increases the burden of caregiving.

Most caregivers resided with extended family members who are underage or unemployed. The living spaces are confined and in all households, the child with cerebral palsy shared the bedroom with either the parents or caregiver. Some houses were on the first floor with no balustraded stairs. Another house was reported to have flooded from the rains the night before. Street paths were littered and rugged. All households had access to electricity and running water either inside the house or from a tap in the yard.

4.3 Section B: Description of themes: Experiences of caregivers

The role of caregiving to a child with cerebral palsy is extremely challenging in several different ways but also rewarding in others. There are negative and positive

experiences lived by caregivers as they perform their role. Various challenges and positive experiences were recorded in the interviews and are presented below. These negative and positive experiences represent the daily lives lived by caregivers and the circumstances under which they perform their role. The themes and subthemes that emerged related to the experiences of caregiving were:

Theme 1: Challenges in providing care to a child with CP

Subthemes: Financial challenges

Psycho-social challenges

Physical challenges

Challenges with services

Theme 2: Positive experiences of providing care

Subthemes: Strengthened relationships

Building resilience

Increase in knowledge of CP

Sense of fulfilment

4.3.1 Presentation of themes

Theme 1: Challenges in providing care to a child with CP

Caring for a child with CP was challenging financially, emotionally, physically and socially for all the caregivers.

4.3.1.1 Subtheme: Financial challenges

Most of the caregivers highlighted that their household expenses increased significantly due to the needs of a child with CP. Various aspects of providing care such as buying diapers, dietary supplements and special food, transport costs, hiring temporary care, and paying fees in special schools require substantial finances. One of the caregivers expressed that:

> *"It is very expensive actually to have a disabled kid because you need a lot of things. First of all, pampers, then the kind of food you give him, you must make sure you choose the right food. He does not just eat anything"* (Caregiver A).

The financial challenge of caring for a child with CP was universal across almost all households. Most caregivers of children with CP also had siblings of the affected child and or extended family members under their care who also required their financial assistance. Being the sole financial provider and having other dependents in the household increases the financial strain. These two factors exacerbate financial difficulties faced by caregivers of children with CP. Caregiver C emphasised this point when she said

> *"It is challenging in finances. Isn't it now these other kids are also dependent on me, I am the breadwinner. That's why I feel heavy loaded because these other boys are also dependent on me, they want big things and then this one (child with CP) also* (Caregiver C).

Nearly all of the caregivers (nine out of ten) received a disability grant for their child from the government. The disability subsidy is paid monthly and was the same amount for all caregivers interviewed. The caregivers who received the subsidy reported that though grateful for the financial assistance, it was insufficient to meet the financial needs posed by cerebral palsy. One participant indicated that:

> *"... the social grant is for King (child with CP). That is all the money we get. I cannot count for my brother's kids' grants because my mom even has to add some more money for their school transport because we took them in, they are staying here with us. The money is not enough for the whole month so whoever has money has to add on top. If I have, I cannot keep more to myself."* (Caregiver B).

The financial expense of taking care of a child with CP was a lot due to the cost of nappies, food, transport cost, cost of accessing health care and paying someone to take care of the child in the caregivers' absence. Caregivers E , D and I expressed their financial challenges as follows:

> *"You know when you buy her pampers, for example, a pack is R310.00 and inside they are 28 and they don't last her the whole month. You buy at least twice and when you look at this R1800.00, taking out R620.00. What is she going to eat? You start to have stress. Isn't it what I like for her is to eat, be dressed, but you find that it's not enough. You also have to have transport money to go to the hospital to fetch her medication. When you leave her with*

someone from outside you have to pay" (Caregiver E).

"Sometimes, I have to take him to a hospital twice in a month and I hire transport. From here to Kalafong it is R500.00" (Caregiver B).

But his (Child with CP) things are expensive at the shop, so there is nothing that I can do when I don't have money" (Caregiver I).

In efforts to provide comfort for their child, caregivers place themselves under significant financial pressures. Some caregivers strained themselves financially to accommodate and meet the needs of their children even when they were not financially sound to do so. One caregiver expressed that:

"The situation forced us to have a car even when we saw that it was not the right time for us to buy a car but it was difficult to take him to the hospital using a taxi" (Caregiver F).

Employment is an additional source of finances to social grants. However finding and keeping employment was challenging for many caregivers. Lack of work adjustments made it difficult for caregivers to look for employment and to remain employed, thus worsening their financial situations. The time consuming nature of caregiving also made looking and maintaining employment difficult for caregivers. These factors inadvertently worsened the financial situations of caregiver. One caregiver reported that it is not because she does not want to work that she is unemployed but rather that caregiving is demanding and takes a significant amount of her time. Due to the time-demanding nature of her caregiving role as the primary caregiver, she does not have the time to look for employment. Caregiver J explained that:

"... *it (CP) changed my life because I didn't have time to look for a job. I was looking after her all the time until I found this job where I can come with her to work because it is a creche"* (Caregiver J).

Another caregiver reported:

"...I have to take care of him, I can't go to a job. Who will look after him when I am not here?" (Caregiver I).

Balancing employment and the caregiving role was physically and mentally strenuous

"I would prefer to work the night shift so that when I go to work at night, my

mom will take care of him and then daytime when I come back, I know I'm going to bath him, feed him and then later when I go to work again they will be available" (Caregiver B).

" If I'm at work, as I said I am a caregiver and I was working with private patients. I have to focus on my patient and then on the other side your mind is at home thinking of my child and so you have to balance those two. For me, from my side I think life is not easy at all because as I said if I'm at work and something happens at home, they call then I have to see what to do. Remember I am working with patients but I also have a patient at home. So if something happens at home, what may I going to do if they can't find me a reliever at that time? So it becomes a big challenge. And let's say he had fits or they have to nebulise him, or let's say my mom doesn't feel well?" (Caregiver B)

Keeping a job when caring for a child with CP was sometime difficult. When the child was admitted to the hospital the caregiver was expected to stay with the child at the hospital This requirement was burdensome to caregivers who were or employment commitments. One caregiver who was unemployed at the time of the interviews reported that she had been employed before but had to stop working due to this requirement by hospitals and which her employers were unable to accommodate. She explained that:

"...my problem was that when they admit him at Kalafong Hospital they also admit a parent. So that was my problem. At work they couldn't understand that monthly you have to take two days, to take him for check-ups and come admission, you have to be admitted with him...there came a point he was going for his second operation (due to hip displacement) then that's where the problem started. Then I said ok, it's better if I leave the job and focus on him that's when I left my job" (Caregiver B).

Another caregiver explained that he could no longer continue with his informal form of employment due to the COVID-19pandemic restrictions. He reported that:

"...but now because of corona it was difficult to operate, difficult to do anything due to the restrictions of the corona virus. You remember that they said the old people should stay at home, more than 50years, so if I'm selling something here and you look at me and you see that this is an old man, can you buy it?"

(Caregiver A).

One participant who did not receive the disability grant was an illegal immigrant who reported that she did not have the documentation necessary to qualify for the social grant. As a result, she faced even more significant financial challenges without financial support from the government. When commenting on financial assistance, the participant expressed that receiving financial assistance will be helpful:

> *" ...would help me very much because yes you know finances are really a problem to us foreigners because we can't get a grant, we can't survive, so that will help me very much"* (Caregiver J).

4.3.1.2 Subtheme: Psycho-social challenges

The social experiences of caring for a child with CP included lack of self-care, strained relationships and negative social constructs and perceptions. All caregivers had challenges in more than one area relating to this subtheme.

- Challenges with self-care

Caregiving was identified as time-consuming, significantly impacting the wellness of the caregivers. Even though most caregivers had established routines and some received support from friends and family, they ultimately were responsible for the child. Most caregivers largely neglected self-care as their lives revolved around caring for the child with CP.

Caregiver B remembered vividly and illustrated her feeling when her child was younger and diagnosed with CP. In her description, she expressed the desperation that led her to neglect herself as she attempted to comprehend cerebral palsy and attend to her child's needs. She reported that:

> "*...at first I felt like I was running like I'm losing my mind, not knowing what to do because I was focusing more on him (child with CP) than on myself and I was always stressed..."I focus on him a lot and so my own time is very little"* (Caregiver B).

- Emotional and Psychological challenges

The caregivers described emotional challenges experienced in the journey of caregiving. The emotional trauma of having a child with CP was evident in all caregivers. The disappointment of not having a healthy child was common in nearly all the caregivers. While some caregivers verbally expressed their disappointment, others showed disappointment and despair in their facial expressions and body language. One caregiver expressed that:

> *" At first I was disappointed; I was not accepting this condition. I was stressed and I was slimming, losing weight because of stress. At least for now, I have accepted but ... it's a problem so actually in your mind it's not an easy thing to cope with it but you have to tell yourself this is what God gave me. Maybe with that we are trying to tell ourselves so that we cope but it's frustrating"* (Caregiver A).

This echoed the experiences of another caregiver who also reported that:

> *"Truly speaking, I was disappointed because he was my first born and from my family, I've never experienced such a thing that Hope has. It started with him..."* (Caregiver D).

Another caregiver expressed her disappointment after having had healthy children before. She expressed that she:

> *"... was disturbed because, you know when you have had kids before who were never like this you start to have stress and asking yourself what has happened now, what is happening"* (Caregiver E).

The inability of the caregivers to communicate with their children was a source of emotional distress. They had no means to communicate with their children and understand their needs except for their self-taught instinct. One emotionally aggravated caregiver expressed his predicament. He explained that:

> "...*and sometimes we don't know anything. I could be trying to feed him and he doesn't want and I don't know if he doesn't want to be fed by me, or the food is not nice or the food isn't right, what is wrong with the food, is it not enough sugar, is it not enough salt, what do you want?. So it's a big challenge to feed. Feeding only, and there are other things that need to be done… If they can help*

us to make sure these kids can communicate. That is the main thing, communication. If he can try to communicate and say I want to do this, I want to do this.., I know he cannot speak but sign language or whatever he can say yes or no" (Caregiver A).

Another caregiver shared the same experience. She indicated that:

"...the challenging thing is that he can't talk, and everything you must think for him, like what do you want? Even if he is in pain you can just see that something is wrong but where, you don't know. You just have to take him to the doctor because you can't give him medication when you don't know what is wrong" (Caregiver H).

- Abandoned by partners

Caregivers of children with CP experienced blame and abandonment by close relations, which added to their emotional stress. Nearly all caregivers had a negative experience in some of their relationships due to having a child with CP. Some caregivers reported being abandoned by spouses or partners. An elderly caregiver taking care of a teenage child with CP reported that her husband had left her and stayed in another neighbourhood. She expressed her disappointment, highlighting that:

" I don't even want to speak to him, that will cause me to stress and not be able to raise my child. I don't need him, he should have stood with me from the beginning but he didn't (Caregiver E).

Another younger caregiver reported that her relationship with her partner ended after the birth of her son. She expressed that:

" *As I said, at first, I told you how my son was, big hair, big eyes and he didn't have a forehead and he was thin...I could see his father struggling, I never attended a support group at hospital, he is the one that was attending because he couldn't accept the condition. That is when we broke up because I saw that he was blaming me a lot. ' Why did you have to bleed during your pregnancy'? But I tried to explain that they said it was the placenta..."* (Caregiver B).

- Traditional misconceptions

Most of the caregivers' conduct was based on traditional misconceptions surrounding the aetiology of CP and disabilities in general. Families accused each other of possible

witchcraft, thereby adding to caregivers' stresses regarding having a child with CP. Caregiver E expressed that:

> "*At the beginning our families, you know our African families, my family wanted to blame her family for Gift's condition and her family wanted to blame my family. Luckily, us as parents didn't want to blame anyone, we just accepted that he is our child and he is our responsibility and we cannot pass that to anyone"* (Caregiver F).

Another caregiver pointed towards suspicions of witchcraft, reporting that people around them misled them into thinking that there were other people to blame for their child's condition. As a result of this misconception and misinformation, caregivers delayed seeking medical help, attempting other non-medical sources they knew to assist with issues of witchcraft. The caregiver indicated that:

> "*We only accepted late that the child is disabled, because people will tell you this child is like this because of other people. We went out everywhere, to other places, looking for help with her. We then realised this is nothing. At last we decided to go to Coronation Hospital when we saw that the child is not getting better. That's where we find out that the child was born with CP"* (Caregiver G).

- Community discriminatory behaviour

Discriminatory behaviour by the community significantly increased the challenges of providing holistic care. One caregiver expressed that:

> "*When he was still young the one other thing I hated was when someone came to me and said 'shame' to me. I hate that word, 'shame'. Sometimes it's even an older person, you can't talk back and they will say shame and then my tears will start rolling. At that time you can see that when you come with him, people will start distancing themselves and then look at you like it is for the first time that they see something like that... So I will get more angry. 'Why can't you ask me, why do you look at him like that.' I get frustrated"* (Caregiver B).

In nearly the same way, another caregiver expressed hurt when relating the community's responses when they see her child. The preferential treatment given to an average child compared to a child with CP was a cause of strain. She gave an example that:

"*If you have a baby and I see your baby and I don't say 'hello, hello baby,' to play with the baby, then what do you think? Can you say this person is happy for my child? Or sometimes they say, 'hey boy you don't talk.' They don't say 'hello boy,' they say, 'oh you don't talk,' then what am I supposed to think? It's useless to talk to them, just keep quiet. The main thing with these kids is it's not easy for other people to accept especially somebody who doesn't have a kid like that in his or her family, it's not easy"* (Caregiver A).

Such misconceptions by community members and discrimination made the role of caregiving more challenging than necessary. Some caregivers had resorted to isolating themselves to protect themselves and their children. Though this is detrimental to raising a child with cerebral palsy, many caregivers reported self-isolation and isolating the child as a better alternative.

"I avoid those ones. I don't care what they say. I look after my child only, I know that they talk, but I don't care....and as I was saying I am not used to a lot of people, I don't even go to other people's houses and there is no one who comes here" (Caregiver C).

The role of caregiving mainly was assigned to women. This social construct resulted in the marginalisation of women in seeking employment, attending social events and taking time out for themselves to recuperate. In one instance, a caregiver expressed that:

"I don't normally attend meetings, my husband does. The problem is I stay behind with the child" (Caregiver G).

4.3.1.3 Subtheme: Physical challenges

Another aspect that posed a great challenge is the physical toll of the caregiving role on caregivers. The children in the study were highly dependent on their caregivers for daily activities of living. Most caregivers reported that it was easier to provide care when the children were younger. However, as they grew older and heavier, the physical toll became more significant.

"Now Tshepo is growing, many things I fail to do with him because even lifting him up hurts my back because he is heavy" (Caregiver D).

"So the biggest challenge I have is that he's growing. We can't put him on our

backs anymore. When you carry him, he's tall, and then when I carry him he looks thin but he is really heavy, I don't want to lie" (Caregiver B).

"He is too heavy but we have to lift him to the bath and we sit him on that kids' plastic chair and then bath him there" (Caregiver F).

The older caregivers not only have to come to terms with the physical strain of caring for their children but also the fear that there may be no one to take care of their children should they themselves fall ill or pass on. Caregiver C expressed that:

"There is no one who is helping me. It's me who is fighting everything here at home. It's me alone, there's no one even from my family. So if I am no longer here what will happen?" (Caregiver C).

The lack of appropriate assistive devices and adapted community services to assist in care exacerbated the caregivers' physical strain .. One caregiver expressed that:

"...I no longer go to the Clinics because they keep us in a long queue with a heavy child on your back" (Caregiver D).

4.3.1.4 Subtheme: Challenges with services

Caregivers used various services within their community to provide adequate and holistic care.

- Healthcare system

Due to the chronic nature of CP, the caregivers used healthcare services for medication, medical and rehabilitation care. Caregivers raised numerous issues regarding the health care system and their children's care. All caregivers found the accessing healthcare system burdensome in terms of the frequency of consultations, the availability of the health care facility and the inaccessible transport system.

Attending numerous health appointments in one month was challenging for the caregivers, as expressed by caregivers I and F:

"I go there (the hospital) for ENT, audiology and convulsion clinic. Sometimes maybe three times a month. Even yesterday I went there, I was there to collect medication for him" (Caregiver I).

"When he was small, it was like every month we had to go for an appointment and it was so difficult to go with him using a taxi" (Caregiver F).

Regarding clinic facilities, some caregivers reported that though there are clinics within the community, the clinics were not well equipped to attend to the needs of children with CP. As a result, one caregiver had to go to the hospital further away.

> "M*ostly she doesn't go to a clinic, when she is sick, we take her straight to the hospital, at the clinic she goes only to get some injections and some medication. In our local clinics, they do say that they don't take a child with CP"* (Caregiver G).

Another caregiver expressed that:

> *"what makes it difficult is the issue of clinics, Sanele only goes to the hospital for all her appointments, so that gives me problems because I have to carry her from here to go and catch a taxi and she is heavy. Because here at the clinic she doesn't get help. I don't know how this issue could change, because you just go to the hospital for one thing, epilepsy medication, that gives me a problem"* (Caregiver E).

The need for appropriate services and appropriate assistive devices was highlighted again by another caregiver who highlighted the challenge of caregiving with few resources. She expressed that:

> *Another challenge, maybe the most important we have been complaining about, is the lack of comfortable wheelchair "* (Caregiver G).

In addition to travelling long distances for medical services, some caregivers reported lack of or poor communication between them and the medical professionals assisting their children. The caregivers highlighted that they did not receive adequate health information on cerebral palsy. Without enough information and understanding of that information, the task of taking care of a child with CP became a daunting journey into the unknown. One caregiver expressed that:

> "*they didn't explain to us to what was going on and if the child is going to be disabled. We took the child and we thought everything was alright. Then after a longer period we found that the child cannot sit down and cannot act like a normal child. Then we went back to the hospital and they checked the kid. Then one of the doctors told us the child is going to be disabled, will never grow up and will never be a normal person. Then we came back. We didn't know from the first time that we left the hospital"* (Caregiver A).

Another caregiver expressed that though the doctors had explained, they did not understand the implications of the condition at the time. The amount of information may be overwhelming and foreign to the caregivers, leaving them confused. The caregiver expressed that:

> "*...that same day in the afternoon she (the wife) called me and tried to explain that Gift will be different from other kids, I didn't understand...I went to see them and Gift was still at the hospital. We saw Gift together and doctors explained to us but I was confused. Some of the things I didn't understand"* (Caregiver F).

Misinformation by medical professionals also created unpleasant healthcare system experiences and increased the stress of being a caregiver to a child with CP. One caregiver pointed out the fear they lived with because of a comment from a health care professional regarding their child. They expressed that:

> *"When he was about 2 years old, we went to another doctor when we were staying in Alexander, the one who told us Gift won't reach 16 years. And every time I was aware of that and I'm checking and I'm living with that thought that 'Gift won't reach 16, Gift won't reach 16'. So I keep watching because it's what the doctor told me that according to his condition, he will not reach 16. And yet next month he is going to be 16"* (Caregiver F).

- Public transport

Another service frequently used by caregivers and is a source of strain and negative experiences is the public transport service. The transport system is not disability friendly making travelling with a child with CP stressful.

One caregiver of a teenage child expressed that:

> *"...the challenge is he is tall so in a taxi his legs are too long and you have to put him on your lap and then you will have to squeeze to fit in. So I like sitting next to the door but then the driver doesn't want a child to sit next to the door so you have to explain the reason why you don't want to sit in the middle, that it's because of the legs"* (Caregiver B).

> *"the drivers they don't have a problem, they will be the ones coming to help you but you know there are their passengers, 'hey we have jobs', 'we are going to work', 'we are late', 'you are taking too long' and then you get angry and then*

when you start to talk back it's like you are being rude, so aah yah, at the taxi rank I fight every day, I fight every day at the taxi rank. For my son I fight" (Caregiver B).

The caregivers incurred extra costs when using the public transport system (taxis), as reported by this participant:

Unless if you pay for the whole seat so that you can be comfortable and the legs can be comfortable because you cannot travel a distance like from here to Pretoria, always balancing the child and holding the legs, you will get tired" (Caregiver B).

Even the paid transport that was organized to transport the children to the daycare centre was unreliable.

"with the school transport, you know even yourself, it does not have an exact time. Sometimes it gets here late, around 9am, sometimes it's not the same driver" (Caregiver G).

- Housing and electricity services

The housing and electricity services in Diepsloot also affected the caregiving role. Diepsloot is mostly an informal settlement and access to basic services such as housing and electricity is a challenge for the caregivers. The caregivers highlighted that the high rental costs were an expense they struggled with. Lack of electricity was also a challenge in providing care. They expressed that:

"Look, here we are renting, rent every month is R2000, every month you want nappies, food. So even if they can help us with a house, it can help because we cut on the rent" (Caregiver H).

"Diepsloot has a problem with electricity...Remember he has asthma and sometimes I have to nebulise him. He hasn't had an asthmatic attack but if he has flu, sometimes he gets chesty so you have to nebulise him and so without electricity its difficult" (Caregiver B).

- COVID 19-pandemic restrictions

In addition to the daily challenges of providing care, the COVID-19 pandemic also posed different challenges for caregivers. Though the pandemic had negative effects on the general public, it impacted caregivers of children with disabilities in unexpected

ways. Due to the COVID-19 pandemic regulations, schools were closed down, forcing caregivers to take their children out of day-care centres. Caregivers were continuously providing care, around the clock, without the relief offered by daycare centres. They also had to change daily care routines and source external caregivers where possible. Many caregivers lost their sources of income while others were confined to their homes due to the fearful risk of contracting the virus and passing it on to their compromised children. One caregiver who is a trained caregiver and employed through an agent related that:

> *"Actually the agency, it does have a job but my problem is that I'm a chronic patient, I have high blood pressure, and my son also is a chronic patient with CP and my mom also is a chronic patient so I'm scared to go outside and work and then come back with the disease. Sometimes when they called me to offer me a job but then they tell me that it is a COVID patient so I'm scared to do that"* (Caregiver B).

Theme 2: Positive experiences of providing care

Although caring for a child with CP was challenging, most caregivers expressed positive experiences of providing care.

Caregivers found various positive experiences that they attributed to their role. Caring for a child with CP strengthened relationships, built resilience, brought a sense of fulfilment and increased health knowledge related to providing care to children with CP or related health conditions.

4.3.1.5 Subtheme: Strengthened Relationships

Some caregivers experienced stronger marriages due to having a child with CP. Sharing responsibilities over the child seemed to build stronger and reliable relationships. One caregiver reported that their marriage became more stable as a result of their child with cerebral palsy. She expressed that:

> *"our marriage became more stable. Now we are also praying and we are more open with each other and that helps us"* (Caregiver G).

Another caregiver explained that the shared responsibility and love over their child has helped sustain their relationship. He expressed that:

> *"I believe, luckily, we had so much special love for Gift (child with CP) so that*

made us think that Gift is not her (the mother) responsibility alone or my responsibility alone and that made our marriage survive...We just accepted that he is our child and he is our responsibility and we cannot pass that to anyone. It is true no marriage is smooth but when we have our differences we make sure that doesn't affect Gift" (Caregiver F).

While some caregivers isolated themselves and their children, other caregivers established relationships and experienced a sense of community and normalcy through relating with other mothers and caregivers of children with CP. Caregivers communicated regularly, talking about their children and attending each other's child's birthday parties. One caregiver explained that:

"w*e normally talk, like yesterday I spoke to another caregiver, she called my sister and asked to speak to me, and we spoke. She said, how is King and I said, how is Joy? The last time I saw them, it was December. They came to King's birthday in October, November we went for Ronnie's birthday, (Caregiver I's son), who also has CP. And then December it was Joy's birthday but then I could not go because King wasn't feeling well but then my two younger sisters went. The friendships are there"* (Caregiver B).

4.3.1.6 Subtheme: Building Resilience

As a result of taking on the new and demanding role of being a caregiver of a child with CP, nearly all of the caregivers reported gaining a sense of resilience in the form of acceptance, self-confidence and self-reliance over the years of performing their role and self-confidence. One caregiver expressed that:

"*This thing (CP) I am used to it, it no longer bothers me. At the beginning I used to stress, I saw this as a lot of work, but now I have accepted., I don't feel anything now"* (Caregiver C).

"...I think I'm fine. I have done this (caregiving) for the past 17years and yoh, that is a long time. I think I'm fine now" (Caregiver B).

"*I have accepted a lot, both my child's situation and mine. It's not easy. Because I have accepted, it looks like it's easy and yet it's still not easy"* (Caregiver E).

4.3.1.7 Subtheme: Increase in the knowledge of CP

Another positive experience that the caregivers indicated was attaining knowledge on CP and related morbidities over the period of caregiving. Through acquiring skills, they have gained confidence and become competent caregivers. One caregiver expressed her confidence in her role, sharing that:

> *"If maybe they can say go to number 10 or they are opening a center, go and teach them about CP, I would be the first one to go...The information they gave us on epilepsy, helps us a lot because there is a child next door who has epilepsy and he got an epileptic attack on the street. We had to go rush and help him. So the information helps us a lot. It also helps us to help others"* (Caregiver B).

Most of the caregivers have progressed from being fearful of their child's condition to managing it successfully and appropriately after being shown and taught different techniques. Most of the interviewed caregivers had attended either caregiving courses or training offered by the therapists. As a result, they had acquired knowledge that was helpful to their children and their families and communities. One caregiver expressed that,

> "*Being a mother of a child with CP comes with a lot of challenges, but then you also learn a lot, a lot. You get* m*ore knowledge about health, especially CPs"* (Caregiver B).

> *"it helps me a lot because they teach me, last year for example, I can say last year, she wasn't crawling. So, they taught me how to do the exercises to help her learn to crawl. I started going to BL when she wasn't sitting down. Now, she can sit, she can crawl, I'm looking forward to her to stand or to walk"* (Caregiver J).

Another positive experience was that caregivers became open towards searching for information on social media. The use of media as a source of information is a positive experience for caregivers as it gives them solutions that they may otherwise be unaware of. This is a positive outcome facilitated by having a child with CP and being creatively self-reliant and improved problems solving skills. One caregiver expressed that:

> "*when I get home from hospital, I will remember that word, I will Google and find more information about what's going on. At first I didn't know that he had*

quadriplegia because they didn't tell me that he is a quadriplegic. I only heard the doctor saying it, after the students went out then I ask him what he meant when he said my child is a quadriplegic. I googled and got even more information" (Caregiver B).

Caregiver F also highlighted the same use of media. She reported that:

"...then I also use social media. I just go there and then I google and get some information on his condition" (Caregiver F).

4.3.1.8 Subtheme: Sense of Pride

Nearly all the caregivers expressed a sense of pride and joy in their children despite their challenges. One caregiver of a teenage boy with CP said:

"*I'm proud of my son, I'm really proud of my son. Even if maybe he is just gone for 5minutes, I want him back. I'm proud and I'm happy with him"* (Caregiver A).

Another caregiver of a teenage boy expressed that:

"I want to tell them the way Tshepi is. He is friendly, he likes people and he likes gospel music. He makes me happy" (Caregiver D).

Yet another caregiver expressed her pride over her daughters' progress reporting that:

"Sanele is very sweet. Sanele can play if you are playing with her. Sanele is a neat person. She can tell when it's time to change her pampers" (Caregiver E).

4.4 Section C: Facilitators and Barriers in caregiving

Under this theme, the findings for the second objective of the study are presented. The support structures available (facilitators) as well as their unmet needs (barriers) are outlined. Caregivers were able to identify the barriers and facilitators to care as they related their experiences in response to the first objective.

Theme 1: Available support structures (Facilitators in caregiving)

Subthemes: Self-support

External support

Theme 2: Unmet needs (Barriers in caregiving)

Subthemes: Healthcare system
Adequate financial assistance
Work accommodations
Community support groups

The themes will be presented below with their relevant sub-themes and direct quotations from caregivers to illustrate these themes.

4.4.1 Presentation of subthemes

The caregivers were able to identify available support that lessens the burden of providing care. Self-support and other external support structures such as family, community and governmental and non-governmental structures were identified.

4.4.1.1 Subtheme: Self-support

Nearly all caregivers identified "self" as a valuable resource in caregiving and the child with CP. They looked within themselves for strength to take care of their children. On being asked how she coped, one caregiver explained that:

> *"I sat down, I told myself that if I keep thinking about this one thing it will not help me with anything. So I gave myself strength"* (Caregiver C).

Another caregiver highlighted that she needed to strengthen herself. She reported that:

> *"I didn't go for counselling. I just counselled myself. I didn't want to go. So I counselled myself. What else could I do, I don't have a mother, I don't have a*

father, I am just Ella's mum. I don't have a sister, I don't have nothing, only my kids" (Caregiver A).

Caregiver E also expressed that: *"I help myself by standing on my own and I did it, didn't I?"* (Caregiver E).

- Ability to accept

Other aspects of self that were mentioned also included the ability of the caregiver to accept and love the child. They highlighted the importance of acceptance of the child by the caregiver, family and the community in lessening the burden of providing care to the child. One caregiver of a teenage son simply expressed that:

"Firstly you must accept and you must love him (child with CP). That will make it a bit easy" (Caregiver F).

"Me accepting it (CP condition) and my kids, that makes it easy to look after Sanele (Child with CP)" (Caregiver E).

Caregiver B also reported the same sentiments as the other caregivers. She advised that:

"*...and then for him to heal accept him then you will see, he will be growing. Most of the people when I go with him, they are surprised that he is 17, he looks so small. So if you can accept, every day he'll be growing. I just accepted him"* (Caregiver B).

Caregivers also relied on their instinct when caring for their children with CP. They have acquired a sense of understanding their children without much verbal communication. This has become a self-acquired tool that lessens the burden of care. Caregiver G expressed that:

"I can see when she's not alright, when she is not feeling okay I can pick that up, that no, today she's not alright. There are signs I know" (Caregiver G).

The use of body language, clues, experience and instinct are facilitators to providing care that caregivers have learnt and are unique to individual children. One caregiver expressed that:

"*Yes, he can give me a clue that now it's time for me to make number two. And also even if it's wet, he will be restless, he will complain and complain until you*

come and give him the attention" (Caregiver B).

- Ability to adapt

Adapting to the child's needs and the changes those needs demand is a self-acquired tool that assists caregivers in their role. Caregiver E indicated that all her other kids were normal (did not have a disability) and as a result, she had to learn and adopt new techniques, which she had not done with her other children. Another caregiver expressed that:

> "*To me my social life has changed. But now it looks like normal to me. It's a norm to me to understand that I have a child with a disability. I have got to adopt a new life of saying that this kid is like this"* (Caregiver A).

The use of schedules and routines also assists caregivers to provide care. All of the caregivers interviewed were able to relate a uniquely tailored routine that was functional for them and their family. One caregiver related that:

> "*In the morning when she wakes up, I start with bathing her, prepare breakfast for her. Before I bath her I put her here, I stretch her hands, her legs..."* (Caregiver C).

- Spirituality

Self-support was also identified in the form of the caregiver's spirituality. One caregiver pointed out that she gets help from God who gives her the strength to be a caregiver.

> *"I can say, I get help from God. He gives me strength to do this(caregiving)"* (Caregiver C).

4.4.1.2 Subtheme: External support

External support from family, community, governmental and non-governmental structures was also highlighted as facilitators to providing care.
Family members, spouses and friends provided support for most caregivers. For one caregiver, it was her children who supported her the most.

> *"it's my children, they are the ones supporting me, being always behind me all the time, for looking after me"* (Caregiver E).

For another caregiver it was a friend. They reported that:

"...there is also Mamthembu there, she is a mother and sometimes when I am going somewhere, going to town to buy groceries and pampers, I sometimes call her to stay with my child" (Caregiver G).

Another caregiver reported getting this form of support from her spouse.

" ...if am not around, I leave the child with him (husband), and he manages very well" (Caregiver J).

Caregiver A identified a neighbour as providing support to them. He reported that:

"when I was working, we would say that the school transport drops him off at our neighbour's house and when the mother comes back she goes and fetches him there" (Caregiver A).

Support from the government

The governmental support through the disability grant and the child support grant were important for the caregivers. Caregivers who received the disability grant viewed it as essential in addressing some of the child's financial needs including that of the family at large. The amount of money received was consensually inadequate to cater for all the needs of a child with CP amongst all the caregivers who received it. One caregiver stated that:

"Government assistance helps a lot, even now we survive through the government" (Caregiver E).

"My mom lost her job due to COVID, we survive with the grants. The grants we get are for King and my sister's two kid" (Caregiver B).

Other forms of government support included free access to health care and medication. Caregiver C expressed that:

"I get his medication easily. I get it from the clinic, and it's for free, I don't have to pay and that is very helpful" (Caregiver C).

Some of the caregivers also identified the local clinic as a source of support that makes caregiving less challenging. The clinic had, in some instances, made accommodations for caregivers. Caregiver C reported that:

"...at the clinic they say if there are no symptoms that shows that she is not

alright, then there is no need to take her, I should just follow her dates and send kids to collect her medication" (Caregiver C).

Support from community organizations

Non-Governmental Organisations (NGOs), churches and political parties in Diepsloot were a source of support by the caregivers. Political parties and NGOs provided food parcels, especially during the COVID pandemic. Churches also gave emotional and spiritual support to the caregivers.

"Sometimes the people at the church see that you are emotional and they come and they talk to you and they pray with you and after that you feel strong again" (Caregiver F).

"Since COVID we haven't gone to church, but otherwise yes, my mom's church, they do a support group, sometimes they do come here to pray for us" (Caregiver B).

Support groups with other caregivers of children with CP

Relationships with other caregivers were crucial to the wellbeing of the caregiver and in lessening the challenges of providing care. One caregiver reported that she would rather speak to other mothers of children with CP than her neighbours and other people. She expressed that:

*"...Neighbours here, no, not them. Many people do not understand the child, a support group is better for sharing more than neighbours" (Caregiver D). S*he added that she met with "*mothers of same children as mine. We meet there and discuss and yes it helped. Talking about things that I was not doing and they advised me"* (Caregiver D).

Another caregiver expressed that:

"well it (the diagnosis of CP) did affect me but now I'm fine because I can join other moms then we can talk about our kids and its fine" (Caregiver H).

Theme 2: Unmet support needs

While the caregivers enjoyed some support from various sources, they also had numerous unmet needs such as continuity of professional care, more financial and community support, and work accommodations.

4.4.2.1Subtheme: Support from the healthcare system

The caregivers needed continuity of professional care and long-term rehabilitation for their children. Medical professionals such as therapists were not always available for follow-up care in the community. The resultant discontinuity of care impacted the provision of assistive devices. Assistive devices were a major unmet need for most caregivers. Some children outgrew their assistive devices, while others needed individualised modifications to their devices.

> *"With him if we are using a taxi it's very difficult to go with a buggy, it takes time to pack it and it takes time to take everything out and then the problem of fitting it into the taxi. Something that you can easily fold like a prem would be better"* (Caregiver B).

The unavailability of communication devices and communication techniques has largely not been addressed. One caregiver whose child could potentially use a communication device expressed that:

> *"...communication will make my job easier but I don't know how to learn the sign language. If I did, I would have taught him how to do the sign language then I know I have solved the problem"* (Caregiver A).

4.4.2.2 Subtheme: Adequate Financial Support

The numerous financial demands of a child with CP are a continuous unmet need for all caregivers, including those employed. One caregiver reported

> *"I have said that the cost of the child is very high, we need to make sure that the kids are staying at par with the other kids, by financing them, making sure they have got the right things"* (Caregiver A)

Caregivers were also concerned about the financial viability and continuity of the NPO their children attend for day-care. Caregiver I indicated that it would be helpful if donors were available to assist in meeting the financial and devices needs of the NPO in order to keep the centre running. She expressed that:

> *"...they (donors or government) must keep funding the centre that our children go to because it helps us"* (Caregiver I).

Another caregiver shared the same thoughts indicating that:

"...the other things we need are for our centre. We need to ensure that the centre is funded and everything runs well. I don't know where they can get those things or facilities, if they could get those devices I think it could help. It can really help the kids to be on their feet. Some of them have much understanding of what they are doing" (Caregiver A).

4.4.2.3 Subtheme: Work Accommodations

Caregivers are also faced with the unaddressed issue of employers being unable to accommodate caregivers of children with CP in the workplace. One previously employed caregiver reported the difficulties of not having appropriate accommodations in the work environment. Due to lack of work accommodations, she had left employment. She explained that:

". "At work they couldn't understand that monthly I have to take two days to take him for check-ups" (Caregiver B).

Caregiver J also expressed how her life and employment prospects had changed due to having a child with CP. She stated that:

"Yes, it changed my life because I did not have time to look for a job. I was looking after her. No job could take me and her (child with CP). Until I found this job where I can come with her to work because it is a creche" (Caregiver J).

Yet another caregiver who is employed in the community expressed that:

"At work my bosses change, some understand, some don't. Last year my boss could say go check on the child if I was working late, but this year it's different" (Caregiver F).

4.4.2.4 Subtheme: Community Support Groups

Caregivers also reported the need for mobilising caregivers of children with disabilities into functional and accessible support groups that can lobby for support for their children. Caregiver D expressed that:

"If parents come together and speak with one voice, its better. When parents don't come together it's difficult to get help" (Caregiver D).

Conclusion of results

In conclusion of this chapter, the qualitative study design using face to face in-depth

interviews enabled the collection of rich data resulting in the themes presented. The findings of the study answered the study objectives, giving insight into the daily experiences of caregivers of children with CP in Diepsloot and the support needed and currently available to them. The following chapter analyses and discusses these findings.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1 Introduction

This chapter discusses and interprets the research findings outlined in the previous chapter. The study explored the experiences of primary caregivers of children with CP in their role as caregivers in a resource strained environment. The results will be discussed in their themes and subthemes, guided by the research objectives.

5.2 Findings and interpretations

5.2.1 Demographics

Most caregivers (aged 25 to 40) are in the working population bracket and this may be reflective of the South African population demographics which has the highest adult population in the 25 to 40 age group (49). Other countries such as Zambia have the same demographics (50) and the young to middle age population constitutes the greatest percentage of caregivers of children with CP. This may be a trend in developing countries as the same finding demographic structure of caregivers was also reported in Zimbabwe (12).

Most of the caregivers were unemployed even though this is a relatively young, economically active population group. This is likely due to the high levels of unemployment in Diepsloot and generally in South Africa. South Africa has some of the highest unemployment rates in the world (51). Literature indicates that in 2010, the rate of unemployment in S.A in the 15 to 30 years age group was 42% and of adults over 30 years was 17%. (52). With such high unemployment rates, it is to be expected that some caregivers would be unemployed, not necessarily due to the demands of caregiving but also due to the national trends in unemployment. Having said that, caregiving does impact on the ability of caregivers to be gainfully employed over a long period of time as will be discussed in this section.

5.2.2 Experiences of caregivers of children with CP

The findings reveal a wide range of challenges faced by caregivers of children with CP on a daily basis. Nearly all caregivers highlighted the same challenges indicating that caregivers in the same settings are likely to face similar challenges. In this study,

caregivers sacrificed their time, financial, physical, psychological and social wellbeing for the comfort and well-being of their children. These self-sacrificial traits of caregivers increased stress levels associated with the caregiving role, resulting in caregivers' poor QOL (38). This finding is in line with other studies that showed that caregivers' QOL is negatively impacted by various factors such as increased socioeconomic challenges (53), psychological, discriminatory treatment, poor accommodations in social services (38). Even daily activities such as feeding and bathing posed significant difficulties (54). Considering that the experience of caregiving to a child with cerebral palsy is laden with challenges, caregivers require immense support in order to safeguard their welfare and that of the child.

- **Financial challenges**

Of most significance were the financial challenges faced by all caregivers regardless of marital status, level of education or employment status. Having a child with CP significantly increased household expenses due to the high material demands of a child with CP. This was also observed in a pilot study by the South African National Department of Social Development (55). The pilot study assessed the elements of the financial and economic costs of disability to households in South Africa. The pilot indicated that there is likelihood of poverty in families with children with disabilities due to increased expenditures (55). The situation is worsened by the fact that having a child with CP also decreased the chances of being gainfully employed (56).

In addition to the high unemployment rates in S.A and the general unavailability of opportunities (52), caregivers of children with CP uniquely faced limitations due to time constraints, fatigue and lack of work accommodations. An Indonesian study indicated that the disability of a family member predisposes the entire family to the increased the risk of poverty (57). The study also showed that the absence of adequate social protection schemes, increase in health-related expenditures and reduced household income combine to predispose such families to a cycle of poverty (57). Another study also reiterated that families of a person with a disability require more additional sources of income when compared to families without a member living with disabilities (58). Again, this was noted to be as a result of increased household expenditures. According to Shahtahmasebi, families supporting a child with disabilities are more likely to be exposed to persistent and or recurrent poverty, descend into greater lack and less likely

to escape from poverty (33). Children with CP have higher rates of hospitalisations than the general population and their hospital admission and appointment rates increase over time (59). Subsequently, transport and hospital-stay costs alone place a major financial strain on caregivers and their families. The lack of work accommodations for those caregivers that are employed is a major source of burden (38) and a factor that intensifies poverty and lack in families with members living with disabilities.

Policy must not only attend to the needs of the child living with disabilities but must also consider primary caregivers of such individuals living with disabilities. Without adequate financial assistance, caregivers in deprived settings are unable to meet the financial demands of caring for a child with CP. Financial support is paramount to the health and wellbeing of caregivers and children with CP. Its absence or inadequacy is a consistent source of stress and strain to the caregivers.

- **Emotional and Psychological challenges**

This study revealed that having a child with CP is a traumatic and emotional event characterised by disappointment (for not having the expected child) and despair (at the diagnosis of CP). This finding is supported by a Spanish study conducted in 2015 that looked at the feelings of loss in parents of children with CP (60). The study found out that having a child with CP triggered feelings of loss, shock and a traumatic experience in the parents (60). Another study described learning of a child's diagnosis of CP as a crisis, with refusal to accept the diagnosis, anger, fear and uncertainty as common reactions (61). When looking at the parental stress and social support of caregivers of children with CP, Lima et al reported that, generally, caregivers exhibit signs of physical and mental strain (31). Having acknowledged the initial distress of having a child with CP and the continued daily distresses of caregiving, Lima's study noted that there is little correlation between the child's level of dependency and the stress levels in caregivers (31). This observation was also noted in this study. All caregivers, regardless of the child's level of function reported similar challenges and similar causes of strain. This points to other factors that impact the psychological wellbeing of caregivers besides the child's level of function. After the initial shock and feelings of loss, caregivers' mental wellbeing is shaped by other external variables (discussed later), not necessarily related to the caregiver and the child.

This is supported by a study done by Robinson et al (53) showing that caregiving per se does not lead to symptoms of depression, poor health, or social isolation. These outcomes are a result of other factors that impact the caregiving role (62). Such factors may include social engagement, employment, income and family finances, utilisation of health and social care services as well as the mental and physical health of family members (63). It is important to note that not all caregivers experience negative consequences (62). However, efforts must be invested in finding the causes of distress amongst caregivers and address them.

The finding that caregivers of children with CP prioritised their children's health needs over their own is also common in other settings. Some studies done in Ghana (13), Zimbabwe (12) and Sri Lanka (19) support the experience that caregivers prioritise their children's needs over theirs. Though the child's health needs impact the caregivers' own health and wellbeing, this is a secondary concern for the caregivers (63). Caregivers not only compromise on self-care but also on the care given to other family members without cerebral palsy (38). Primarily, their responsibility was to care for their child with cerebral palsy. Various social challenges also made it even more difficult for caregivers to focus on their children let alone on themselves.

These findings also allude to the difficulties in readying parents or caregivers to the realities of CP and assisting them to process information at their disposal. In most Low to Medium Income Countries, caregivers do not receive sufficient information from their health professionals or are not in a position to assimilate the information at their disposal (64). The psychological effects of having a child with CP should be anticipated and caregivers equipped with coping strategies, training, and daily resources necessary to preserve the wellness of both the child and the caregiver. A study on the psychological interventions in reducing stress, depression and anxiety among parents of children with developmental disabilities showed that once-off psychological interventions have short-term effects in reducing psychological strain (65). Varied approaches in providing psychological support should therefore be implemented.

Accessible support structures in training, education, physical and mental health care are long term requirements for caregivers. Programs should be specific in addressing the concerns of the caregivers at the particular stage they are at. Staggering psychological interventions with a long term approach to providing support, throughout

the lifespan of the child, is an important aspect of addressing compassion fatigue and burnout (66).

- **Social challenges**

Relationship complexities and cultural practices were shown to have a large impact on the burden of caregiving in the study. Issues of abandonment of mothers by spouses as well as self-imposed protective self-isolation were common. Community instigated isolation was also prevalent in the study. The findings indicate that children with disabilities, including CP, and their caregivers isolate from society due to lack of appropriate mobility or assistive devices, fear of discrimination and general lack of public support. A Zambian study looking at the challenges faced by mothers caring for children with CP also reiterates that mothers of children with CP are socially isolated and face marital problems stemming from having a child with CP (39). The same experiences were also reported in Zimbabwean and Indian settings, (11;44), where mothers were abused by their spouses for having a child with cerebral palsy.

Another challenge faced by mothers in this setting, as shown in the demographics, is that women mostly assume the role of caregiving due to cultural socialisations. Various African studies indicate the same finding that more women than men assume the role of caregiving (40, 31). As a result, male partners may have the liberty to abandon their caregiving role and in some cases abandon their families altogether. Cultural dispositions towards disability in the African context such as discrimination, blame, spiritual connotations of punishment or witchcraft, worsen the burden of caregiving. Singogo et al (58) also noted the same findings of negative attitudes, accusations of witchcraft and promiscuity as cultural factors increasing the distress of caregivers of children with CP (39). Cultural beliefs and misconceptions need to be addressed in order for caregivers to take on their role more efficiently and for them to garner the support they need from communities. Education of caregivers on CP is important in order to dismiss the myths of non-medical causes of CP, starting with the caregivers and their families and extending to the communities. Without the family's and the community's financial, emotional and physical support, caregivers face overwhelming difficulties.

- **Physical challenges**

As noted above, the demands of caring for a child with CP directly affect not only the psychological but also the physical wellbeing of the caregiver (67). As the child with CP grows, the physical strain on their caregivers increases considerably. This is similar to a study on the “Quality of Life and Burden of Caregiving Among the Primary Caregivers of Children with Disability in Rural Karnataka” which revealed that caregivers of older children experienced back-pain, headaches and were easily fatigued (41). Caregivers were considered to be “invisible patients” due to the toll that their role took on their wellbeing (41). As the children get older and heavier, the need for assistance and better mobility devices or transport systems became more apparent. Challenges faced by caregivers in obtaining appropriately modified assistive devices should be addressed. However access to assistive devices is generally low in South African deprived communities (68) and this results in increased physical, financial and emotional strain to those living with disabilities and their families. To meet these additional demands is an exertion that undoubtedly requires assistance. In addition to the physical strain caregivers face in their caregiving role, they also have different forms of activities that they engage in outside caregiving such as household chores or activities to financially provide for their families.

- **Challenges with services**

For services to enhance the wellbeing of a child with CP, they have to be available and accessible to meet the demands of the evolving complexities of CP. The health care system and service planners can use the known prognosis of CP to anticipate the needs of children in their databases and plan accordingly. This is helpful in provision of services such as assistive devices. Research has shown that children with CP have higher rates of hospital admissions in comparison to the general population (59). This study revealed that the health care system was inaccessible in terms of distances travelled, affordability of transportation and accommodations for caregivers. Mandatory admission of a child with a parent burdens caregivers who may have other children or employment commitments. This study revealed that the healthcare system is inclined to focus on and prioritise the child with CP. The health care system may need to cater for the unique needs of individual patients and caregivers. Transportation departments in collaboration with health departments may assign designated

wheelchair friendly vehicles to service different community sections. These will be used for the transportation of children attending their medical appointments, increasing access and utilization of facilities.

Velho looked at transport accessibility for wheelchair users and cited that inaccessible transportation not only negatively affects health seeking behaviours but also excludes people with disabilities from meaningful community participation (69). The public transport services require modifications to accommodate people with disabilities including children with CP and their caregivers. Measures to ensure that public transport operators adhere to such policies need to be in place. Without such interventions, the lack of transportation options (38) will remain a burden for caregivers and the children under their care. Inadequate social grants is a phenomenon recorded widely by recipients of such services from governments (20, 44). Other measures such as provision of transport for consultations will greatly subsidize the social grants received by caregivers.

The health care system has already taken steps in improving service delivery by arranging for parents to collect repeat medications without bringing the child. This reduces time and transport costs as well as the physical burden of carrying the child to the facility. Further improvements may still be implemented. Some services such as rehabilitation and support therapies need to be made available at facilities closer to patients' communities, such as clinics. Community based health workers can gather information and advice on the state of the child, the caregiver and possible need for interventions by various therapists. They may also provide home support for caregivers through delivering medications or following up on the welfare and needs of patients to reduce the physical toll and transport costs of going to facilities.

Although the experience of caregiving was challenging the next section shows that there were positive experiences in providing care.

Positive experiences of providing care

The positive experiences on providing care to children with CP included: resilience fulfilment, self-growth and attainment of knowledge on CP and strengthened relationships.

- **Resilience and fulfilment**

Some studies report that not all caregivers experience negative outcomes but rather some have rewarding and fulfilling outcomes in performing their caregiving roles (70) (62). Being a caregiver of a child with disabilities in a resource strained environment resulted in building resilience and fortitude over time (70). Even though all caregivers in the current study had unmet needs of varied forms of support, they resiliently carried on with their roles, finding fulfilment in their children and in caring for them. Windle defined resilience as a process in which one negotiates and manages stressful situations and adapts to the different "sources of stress or trauma" (71). The individual's inbuilt qualities and their life experiences create tenacity and an internal environment which assists in the adaptation process in the face of adversity (71).

In this context, resilience speaks to a caregiver's ability to continuously shift and adapt to the physical, psychological and socio-economic demands of the caregiving role. Resilience is dynamic and not necessarily an inherent state that is immovable (70). As such, resilience can be built and can fluctuate through different phases of challenges. The quality of being resilient cushions caregivers from negative outcomes such as burn-out and frustration (70). Resilience was positively linked to relationship satisfaction, positive affect and better quality of life (70). Through built resilience and despite the burden of care, caregivers were able to experience joy and pride from their children. Therefore, support services and strategies that allow caregivers to 'bounce back' need to be identified and promoted to support resilience in caregivers thereby preserving a better QOL. Resilience is so important that in one study, it was noted to have a greater effect than social support on distress (72). Affection from care recipients brings fulfilment to the caregiver (28). Caregivers receiving affection and gratitude from their children with cerebral palsy in gestures such as smiling, recognition of voices and showing excitement or contentment brings fulfilment to the caregiver. Caregivers should be aware of these cues as a form of communication and an expression of gratitude and joy from their children. Some research has shown this to be a source of strength for caregivers (28).

- **Increase in the knowledge of CP.**

In order to cope with having a child with CP, caregivers require information and skills that equip them to effectively manage their caregiving role. Pushed by the uncertainty of their competence to perform their role or even fear of doing something wrong in the caregiving role, caregivers actively engaged in acquiring information from different sources (61). Proactive caregiving is a positive trait that enables caregivers to made decisions by themselves, evaluate and reflect on their decisions (73). Caregivers that receive training fair better in their role when compared to uninformed caregivers and are better empowered to create and initiate coping strategies that improve their QOL (68, 54). To ensure that caregivers actively engage in self-growth and acquire information on CP, information needs to be readily available, accessible and accurate throughout the different stages of CP.

The skills and information on CP acquired from therapists is a necessary form of support that alleviates the stress and burden of caregiving. Self-growth through continued education and skilling of caregivers is an invaluable tool in positioning caregivers to be successful in caregiving through capabilities (73). Contrary to these findings, an educational intervention on stress levels and QOL of caregivers of children with CP was not effective in reducing the caregivers' stress or improving their QOL (17). This could have been a result of the limitations of the study such as a short time interval between pre and post testing of the intervention. However, in support of the findings of this study, a support programme carried out in Ghana showed a significant improvement in the wellbeing of caregivers (3). Even simple caregiver interventions have the potential to change caregiver attitudes, gain social support for them and ultimately improve their wellbeing if they are tailored to address the pertinent issues from the caregivers at a particular time. Intervention programs require prior research to ensure they deliver the kind of support that caregivers require and meet a specific need highlighted by the caregivers.

- **Strengthened relationships**

The common thread of findings indicate that having a child with a disability negatively impacts relationships (69,58,11). On the contrary, this current study revealed that some marriages were strengthened over the common goal of protecting and providing for the child with CP. In support with the study's findings, strengthened family

relationships as an outcome of providing care has been noted in long term neurological conditions in other settings (70).

The experience of caregiving has both challenging and positive experiences. Participants in this study highlighted some support structures that make caregiving manageable.

5.2.3 Support structures for caregivers

- **Self-support**

The study findings pointed out that self-support is the most common form of support available and employed by caregivers. Internal resources, such as inner strength, spiritual strength, instinct, acceptance, ability to adapt, and love, form an all-important structure in caregivers' ability to cope with stress (66). Being able to self-regulate and self-center brings caregivers the ability to handle and resolve pressures. Caregivers who have positive control of their minds and bodies and are able to cultivate positive feelings are better equipped to confront and successfully navigate difficult circumstances (73) Equipping caregivers with tools to tap into their inner self strength would enhance the caregivers' ability to support themselves. Empowering caregivers to maintain a positive outlook on themselves and their capabilities allows them to see the positive aspects of care. Such interventions need to be developed and implemented to promote 'self' as a sustainable, long term, support structure. Empowerment has effects on acquisition of coping strategies, self-determination, reduction of burden, caregiver self-efficacy (73) and should be promoted as a concept to aid caregivers. The World Health Organization (WHO) Ottawa Charter for Health Promotion proposed empowerment as a strategy for health promotion. Empowerment, aspects of which include drawing out and manifesting a person's inner strength, is a part of the expansion of self-help or self-support and is an important concept of giving care (73).

- **Government services**

All caregivers highlighted the importance of financial support in the form of social security grants received from the government. This financial support was not only vital for the upkeep of the child with CP but the entire family. Some studies have shown that social security grants such as the Child Support and the Care Dependency Grants

from SASSA alleviate poverty in significant ways in families of people living with a disability in South Africa (37) In many cases these are the only sources of income for families (37). In contrast, another South African study reported that the disability and child support grants reduce inequality in communities but not necessarily cushion against poverty (75). What is common is that social grants attempt to protect against the risks brought about by disability, unemployment and old age. The researcher is of the opinion that families of children with CP are not cushioned from poverty by social grants but rather are propped to be comparable to their communities. Research done globally has indicated that the grant is insufficient to meet all the out-of-pocket expenses of caring for a child with CP such as transport costs, food, clothing, special schools and in some instances assistive devices (43, 70).

Health costs in a child with CP are so high that a study done in the US on medical expenditures attributed to CP, indicated that on average a child CP incurs health costs approximately 13 times more than a healthy child (76). With such high expenditures, policies that alleviate the financial burden need to be implemented for children with CP and their families. The free access to medical care and modification of assistive devices reduces the full brunt of the economic burden and the general burden of having a child with CP (77). Though there is free access to medical care, services such as social workers, occupational and physiotherapists, community health workers services are needed on a long-term basis. Continuity of long-term care through availing these professionals to perform home visits is an unmet need for most caregivers even though the presence of these professionals ease the burden of care and feelings of isolation or abandonment.

Service professionals continuing with home care through rehabilitation home visits has been shown to be more valuable than providing the same service from a centre (78). Through such visits, tailored interventions and emotional support are provided to the caregiver. There is generally a high demand, by caregivers, for rehabilitation therapists and other professionals to provide therapy for children with CP and continue with long term care (79). Community based rehabilitation must be strengthened and training community health workers with rehabilitation techniques could assist in giving support to caregivers.

There is little to no literature that documents the experiences of unregistered foreign nationalities raising children with cerebral palsy in low income settings in South Africa.

Considering the financial and psycho-social challenges faced by residents, one can only wonder the extent of difficulties faced by this cohort. This study revealed that this group of caregivers faces the same challenges which are compounded by lack of governmental financial support and self-imposed isolation in fear of being identified. A Norwegian study looking at the QOL amongst immigrant parents with a child with complex health needs reported that they lacked support and migrant parents with language difficulties struggle to cope even more (42). Insufficient resources to meet the child's needs worsened the distress of caregiving (42). Relevant structures are needed to look into the plight of these caregivers to support their wellbeing.

The health care system in the Diepsloot area has made accommodations for caregivers to collect some medications without bringing the child to the facility. Such facilitators are welcome is alleviating the financial, physical and emotional challenges in caregiving. However, some aspects of the public services such as housing, transport and education have not been sufficiently addressed to reduce the burden of care on caregivers. This study showed that lack of public transport for wheelchair users is a barrier to children with CP travelling for appointments or with their families. Housing needs are a concern amongst most caregivers in low income settings in South Africa (80). The 2012 Situation Analysis of Children with Disabilities in South Africa [33] emphasised that inadequate living conditions are particularly negative for children with disabilities. Priority may be given to such households when addressing housing challenges in low-income settings.

- **Family and community support**

It is established from numerous studies (78, 54) that support from the family and community reduces burden of care in CP. These are important facilitators in successful caregiving. Spousal support was the most important form of family support wanted by caregivers. Acceptance of the child’s condition by spouses, especially husbands, was a significant factor in maintaining the marriage relationship.

Support groups also offer emotional peer support and provides a safe space for caregivers to divulge, seek help and share ideas. The study by Whiting et al revealed that caregivers valued the emotional support that they experienced from family members and when interacting with other families of children living with disabilities through support groups or social media (63). They are an essential support system for the well-being of caregivers and that of the child. This has been well documented in

various studies (77, 69, 67). Having shared experiences with others creates acceptance, a sense of belonging and understanding that caregivers are in constant need of in otherwise unsupportive or hostile settings. What was important was for caregivers to feel that the person they were talking to could potentially understand their circumstances. The study by Wijesinghe et al (78) concluded that spousal support and social support correlated with lower caregiver burden leading to better caregiver wellbeing (81). However, the negative social constructs and misconceptions around disability remain a challenge or a barrier that amplifies the burden of caregiving. There is therefore a need for caregivers to have support groups and surround themselves with like people (39).

Support also extends to work accommodations given to primary caregivers of children with CP. Employment prospects for the primary caregiver significantly decrease as most caregivers devote their time and lives caregiving. This is a barrier to economic empowerment of caregivers. Due to a lack of work accommodations, some caregivers were unable to maintain employment requirements and were forced to choose between caring for their children or being employed. In as much as there are policies to protect people with disabilities, primary caregivers of children with CP also would also benefit from protective legislation that allows them to also earn a living.

CHAPTER 6

CONCLUSION

Primary caregivers of children with CP face a myriad of challenges in their role and require support. Their challenges are complex and require multi-dimensional interventions. The disbursements of the disability and the care dependency social security grants are vital for the livelihood of children with CP and their families. However, family and community support is equally important for the physical, psychological and social wellbeing of caregivers. Issues of poverty, discrimination, compromised access to health are, and lack of health promotion knowledge compromise the health and well-being of caregivers and inadvertently, that of the children in their care.

'Self' is a form of support that should be recognised, developed and be invested in, so that caregivers are better equipped to perform their role. It is important that social services are targeted at lessening the burden of care experienced by caregivers of children with CP.

6.1 Recommendations

Policy

Social grants should be continued at all costs and regularly revised for the sustenance of families with members living with disabilities.

Measures such as providing free or subsidized transport for medical consultations, providing long term nutritive support and meeting basic hygiene needs such as diapers will assist in supplementing the social grants.

Policy makers in work or employment accommodations must ensure adequate work accommodations are made available not only to people living with disabilities but to their caregivers as well. This will allow caregivers to attend to their children's health needs when necessary and retain their jobs.

Inaccessibility of services due to various reasons is a challenge to the caregivers and negatively impacts on the wellbeing of both the child and the caregiver. Accessible and accommodating clinics, hospitals and other social services are a necessity when caring for a child with such multiple needs as found with CP.

Community conscientization on cerebral palsy must be implemented in communities

to help address the issue of stigmatisation. Rehabilitation or nonprofit organisations' teams already present in communities may be engaged and trained to disseminate knowledge around cerebral palsy and reduce stigma and discrimination.

Practice

Healthcare for children with CP should be tailored to meet the needs of this group and their caregivers. Strategies that reduce or provide for travelling long distances for consultations, assist in provision and modification of assistive devices as well as offering long term support should be implemented. Collaborations in providing services are important for this population.

Home visits by professionals must be maintained throughout the lifespan of the child with CP. Feelings of isolation and desertion can be curbed if health professional teams work together to assist caregivers in their environments.

Governmental, non-governmental organisations as well as training institutions' assistance is required to ensure continuity of care for children with CP and their caregivers.

Support groups are an essential support system for the well-being of caregivers and that of the child. As a result, support groups need to be run efficiently and be kept relevant in order for caregivers to continue benefitting from them.

6.2 Contributions of this study

This study will provide beneficial information to different stakeholders vested in the care of children with CP or other similar disabilities. An additional layer of performing the role of caregiving in a pandemic can be drawn from the study and assist by bringing attention to the different needs that arise in such a time.

This study provides detailed qualitative data which adds to the body of knowledge on the experiences of caregivers of children with CP.

The study demonstrates the hardships of caregiving and sheds light on the need for interventions that improve the QOL and self-care of caregivers.

This study provides a reference for future studies in the same or similar contexts. It also provides gaps in interventions for long term care of children with CP their caregivers thus facilitating future research.

6.3 Study limitations

The study was conducted during the COVID 19 pandemic. Globally, the pandemic posed unique challenges. Caregivers became responsible over their children around the clock, without the usual relief provided by schools and care centres. As a result the emotional, physical and financial challenges were heightened. This may have inclined caregivers to reporting more intensely on the negative aspects of caregiving.

Though quizzing was used in interviews, language barriers and loss of expressional information in translation may have occurred during data handling. Participants were caregivers whose children attended day-care at BonaLesedi NPO. The views and experiences of these caregivers may be different from other caregivers whose children do not attend day-care at all or at the same centre.

Focusing on the caregivers of children that attend one facility, in one district and under one municipality will limit the study's generalisability. The study specifically looked at Diepsloot and participants were sourced from a single NPO. The behaviours and perceptions of caregivers that send their children to the center may be arguably different from those of caregivers that do not. The outcome of the study may therefore not be an accurate presentation of all caregivers of children with CP in Diepsloot.

Some caregivers had pre-conceived ideas of imminent assistance when being interviewed. Though the researchers attempted to disperse this belief, it is possible that it may have affected the responses given by participants during the interviews. This is a possible limitation to the study when there is underreporting or exaggeration on responses in an effort to create an impression that will get them some assistance in monetary terms or otherwise.

Potential strengths

All interviews were conducted in the homes of the participants. This allowed the researcher to observe family interactions and living conditions, obtaining non-conversed information. Being in the participants' homes provided depth and perception into the interviews. The field notes taken from these observations gave the researcher a clearer memory of each household, enhancing the richness of the data and its analysis. Having the interviews done in a language that the participant was comfortable with allowed for better communication and expression of the participant's feelings and thoughts. These are strengths that have added to the vigor of the study.

6.4 Lessons learnt

The lives of caregivers of children with CP are hugely impacted by the role of caregiving and they require long term support from different sectors in order for them to carry out this role in an effective and efficient manner for them and the children under their care. Empowered caregivers have the courage to challenge the status quo in social settings, helping them and their children to live their lives fully. There is need to concertise communities on CP so that communities may be a much needed source of support rather than a barrier to effective caregiving.

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ANNEXURES

ANNEXURE 1

Plagiarism Declaration Report

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I FAITH MARONGA-FESHETE (Student number: 1928239) am a student registered for the degree of MASTERS IN PUBLIC HEALTH in the academic year 2017.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: _____ Date: 22 March 2022

1

ANNEXURE 2

Final interview guide

Study title: PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY: EXPLORING THEIR SUPPORT STRUCTURES IN DIEPSLOOT, JOHANNESBURG METROPOLITAN AREA, GAUTENG PROVINCE.

Interview introduction.

Good morning / afternoon and thank you for giving me the opportunity to interview you. My name is Faith Feshete and I am studying towards my Maters in Public Health with the University of Witwatersrand. You have signed the consent forms for me to interview you and record this interview. The interview will take approximately 45 minutes to an hour.

The purpose of the study is to explore the views of primary caregivers of children with cerebral palsy in the Johannesburg Metropolitan area on support for them. I would like to understand from you the way you experience and perceive support in your role as a caregiver.

I have some questions that I will ask you but feel free to provide additional relevant information. Please try to respond loudly and clearly for the recording. When I capture this information, I will be removing your name so all that you say will remain anonymous.

Interview.

Date:

<u>Demographic data of the caregiver.</u>

Gender: M F

Age:

Level of education	1. Primary school	
	2. High school	
	3. Tertiary	
Marital status	1. Single	
	2. Married	
	3. Divorced	
	4. Widow	
Employment status	Yes	
	No	
IF YES, specify employment		
	Full time	
	Part time	
	Seasonal	
Nationality		
Housing structure	**Brick structure**	
	Shack	
	Flat unit	
	Other (specify)	
Household income	**R0-R49 000/annum**	
	R50 000-R100 000/annum	
	R101 000-R150 000/annum	
	R151 000-R200 000/annum	
	+R200 0000	

Demographic data of the child.

Gender: M F

Age:

Medical diagnosis as documented by a medical practitioner:

Relation to child	Son / Daughter	
	Niece / nephew	
	Grandchild	
	Other	
Co-morbidities	Speech and language impairment	
	Epilepsy	
	Visual impairment	
	Vomiting and reflux	
	Constipation	
	Other	
Level of function	1. Ambulant independently	
	2. Ambulant with walking stick or crutches	
	3. Using a simple wheelchair	
	4. Using a specialized or modified wheelchair	
	5. Other	
Attending school or care-center	Care center	
	Special school	
	Other	
Number of siblings		

Question 1: Can you tell me about the child under your care

Probes: What happened to the child? What can he or she do and not do? How long have you been taking care of the child?

Question 2: Can you share your experience as a caregiver to the child?

Probes: Tell me about how you care for the child. Your daily routine and activities of daily living (eating, bathing, sleeping patterns, travelling, schooling). How has being a caregiver affected your life? (Probes: Psychologically, Emotionally, Financially, Socially)

Question 3: Can you share with me who / what helps you take care of yourself?

Probes: Family, neighbors, friends, community, clinic, nurses or other. Explain the role they play in supporting you? What is it that makes it easier for you in your role as caregiver? What makes your role as a caregiver challenging?

Question 4 Can you tell me of any other support that you get that helps you carry out your caregiving role better?

Probes: What support do you receive as a caregiver to a child with cerebral palsy?

Question 5: What support do you actually need as a caregiver to a child with cerebral palsy?

Probes: Financial, emotional, physical, psychological such as support groups, counselling.

Question 6: Can you tell me what makes it easier or harder for you to access support in the area?

Probes: what kind of support have you tried to access for yourself or your child in the area? What kind of support was it? What made it easy to access the support? What made it difficult or challenging to access the support?

Question 7: What kind of help or support do you wish you had in order to help you take better care of yourself?

Probes: Counselling, support groups, financial assistance, transport, alternative carer

Question 8: Do you have any suggestions on how support for caregivers of children with CP can be improved?

Probes: What are some of the ways that might assist caregivers of children with CP get support more easily?

Question 9: Is there any other information you would like to add to the interview?

Probes: anything that we might have discussed in the interview or anything you feel may be related to the interview.

Thank you very much for allowing me to interview you and contributing to this research study.

ANNEXURE 3

PARTICIPANT'S INFORMATION & INFORMED CONSENT DOCUMENT

Study title : Primary caregivers of children with cerebral palsy: Exploring their support structures in Diepsloot, Johannesburg Metropolitan Area, Gauteng Province.

Sponsor: Self
Principal Investigator: Faith Maronga-Feshete
Research Assistant: Agrippa Thabethe
Institution: University of the Witwatersrand
Researchers telephone number(s): 087 1355 450
Daytime numbers: 087 1355 450 / 084 336 8217
Date of first informed consent discussion:
Time of first informed consent discussion:

Dear Participant

INTRODUCTION

My name is Faith Maronga Feshete and I am a Masters' in Public Health student at the School of Public Health, University of the Witwatersrand. As part of my study program, I have to undertake a research project. You are invited to volunteer in this research study. The information here is to assist you understand the project and make an informed decision if you would like to take part in the study or not. If after going through this information you still have any questions, please feel free to ask the investigator.

THE NATURE AND PURPOSE OF THIS STUDY

The research is looking at caregivers of children with cerebral palsy. The aim is to explore the views of these caregivers on the support in their care giving role in their area. Support refers to any help or assistance that the caregivers use in order to take care of themselves and also the child under their care. By carrying out this research, we would like to learn the different mechanisms that caregivers use to carry out their role as caregivers. In addition, we will also get an understanding of what caregivers advise to be the support that really need and the factors that hinder them when trying

to get support in taking care of themselves and their child. This information will inform the general public, policy makers and other interested institutions on the best ways to help caregivers of children with cerebral palsy.

EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves participating in an in-depth interview. The interview will take approximately 45minutes to an hour. It will also be audio recorded. From the interview, I would like to get information on who or what supports you in taking care of the child. I also would like to understand what support is there, if any, for you as the caregiver and is not for your child. Lastly, I would like to know what support structures you know of, you use and the factors that make accessing and utilising these support structures easier or harder for you. I request that your responses to the questions be as detailed and as accurate as possible. Please pose any questions that you might have to the researcher. If you choose, for any reason to withdraw from the study, you are free to do so without any penalties against you.

RISK AND DISCOMFORT INVOLVED.

We understand that talking about the child under your care may be emotional and stressful. For that reason, we have the services of a social worker that can be referred to you if the need arises. There are no other risks that you are exposed to by participating in this study.

POSSIBLE BENEFITS OF THIS STUDY.

Caregivers will be able to equip each other on what support they use to cope with their care giving roles. Interventions from interested institutions may be more accurately directed to the areas that are pointed out by the caregivers and consequently be more helpful in alleviating the burden of caregiving.

I understand that if I do not want to participate in this study, I will not be discriminated against in any manner.

I may at any time withdraw from this study.

If you choose to participate in this research study you will be asked to sign an informed consent form and give permission to be interviewed and audio recorded.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of the Witwatersrand. Written approval will be granted by these committees.

CONTACT INFORMATION

Should you have any questions regarding the study please contact:

Principal researcher:

Faith Feshete: 084 336 8217 faithfeshete@gmail.com

Research supervisors:

Dr. Sonti Pilusa
Sonti.Pilusa@wits.ac.za
011 717 3715

Abigail Dreyer
Abigail.Dreyer@wits.ac.za
011 717 2438

Contact details of Health Sciences Research Committee, University of Witwatersrand.

Shaun.Schoeman@wits.ac.za - 0117171408 or
Charmaine.khumalo@wits.ac.za - 011717 1788

CONFIDENTIALITY

All records from this study are confidential. Research report will be written in such a way that all confidentiality is preserved. Data will be kept for two years if published or six years if not published, after this period it will be destroyed. In the event of data sharing with other researchers for academic purposes written permission will be sought from Human Research Ethics Committee (Medical).

ANNEXURE 4

CONSENT TO PARTICIPATE IN THIS STUDY

I have read or the researcher has read to me, in a language that I understand, all the information above. I understand the information and was given an opportunity to ask questions. I am satisfied with the answers to the questions I asked. I am aware that I can pull out of the study if I so wish. I hereby voluntary agree to participate in this study and have received a signed copy of this informed consent agreement.

Participant's name…… Date.....

Participant's signature……..…….…….. Date……..…….

Investigator's name……..…… Date……

Investigator's signature……..…….…… Date……..….

Witness name and signature…….……. Date…….

ANNEXURE 5

PERMISSION FOR AUDIO RECORDING

I am asking for permission to audio record the interview.

I agree that the researcher may record the interview. The researcher will take out any names of people or places that might be mentioned in the interview when the interview is typed.

……	……..	……
(Signature of participant)	(Date)	(Printed name)

ANNEXURE 6

PERMISSION LETTER FROM STUDY SITE

Date: 18 April 2020

Permission to conduct research study.

Dear Sir/Madam

Bona Lesedi Disability Centre is a non-profit organisation that suppor
intellectual and/or physical disabilities. The Centre was established
as a community based rehabilitation centre. Our primary work
visits for those living with disabilities. Beyond that, our purp
education and communication, thereby reducing social e
people with disabilities into society. We intend to em
with disability and create a society in which pe

This note serve to confirm that Bona Les
Student number 1928239 permission

Sincerely,

Aggripa Thabed
Centre Man

ANNEXURE 7

Ethical Clearance Certificate: University of the Witwatersrand

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R49 Ms F Maronga-Feshete

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M2011133

NAME: (Principal Investigator)	Ms F Maronga-Feshete
DEPARTMENT:	School of Public Health Medical School University
PROJECT TITLE:	Primary caregivers of children with cerebral palsy: exploring their support structures in Diepsloot, Johannesburg Metropolitan Area, Gauteng Province
DATE CONSIDERED:	Ad hoc
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms S Pilusa
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	4 December 2020

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **November** and therefore reports and re-certification will be due in the month of **November** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

07 January 2021
Date

ANNEXURE 8

Similarity Report.

Supervisor Abigail Dreyer:

Supervisor: Sonti Pilusa

FAITH MARONGA-FESHETE MPH RESEARCH REPORT MARCH 2022 .pdf

ORIGINALITY REPORT

13%	10%	9%	%
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