The experience of caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa.

by

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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Summary

It has been suggested that the complex needs of children with neurodevelopmental disorders are best addressed with a family-centred approach. As this approach has been increasingly incorporated into healthcare systems over recent years, most children with disabilities are now able to remain at home as opposed to living in institutions or group homes. Many parents have thus been forced to adopt the role of a primary caregiver for their child that has been diagnosed with a disability or chronic condition.

This study aimed to investigate the experiences of caregivers for children with cerebral palsy in rural communities of the Western Cape, with a specific focus on the barriers and facilitators that they encounter. An exploratory qualitative design was employed and 15 individuals (aged 27-62), who were identified as caregivers for a child with cerebral palsy through purposive sampling were interviewed. Thematic analysis was used to analyse and generate themes from the semi-structured interviews that were conducted with participants.

A number of barriers to caring emerged including the personal consequences of caregiving, difficulty adjusting to caregiving duties, environmental conditions, lack of access to healthcare services, lack of respite services, and negative perceptions towards disability. Various facilitators to caring were also identified, namely personal coping methods, personal transformation, social support, relationship with one’s child, community resources, child’s crèche, and financial assistance.

The five levels of the Social Ecological Model were used to conceptualise the discussion of these findings and links were made to the existing literature on the caregiver experience in the developing context. In this process it was found that participants often encountered similar barriers and facilitators to caregivers for individuals with other types of conditions, such as HIV/AIDS, autism, mental illness, cancer, and neurological disorders. This could suggest that caregivers residing in developing countries share similar experiences, regardless of the condition of the care receiver.

Although participants received support from a number of sources that aided them with their caregiving duties, it is evident that they still encountered gaps in the provision of a number of important services, including lack of information from healthcare professionals, lack of community programs to reduce stress and promote empowerment, and lack of disability-friendly facilities. It is vital that caregivers have access to these services to ensure their child's well-being as well as their own. There is thus a need to explore how these services can be made more accessible to caregivers in rural communities.

Keywords: cerebral palsy, caregivers, barriers, facilitators, childhood disability, rural communities

Opsomming

Daar word voorgestel dat die komplekse behoeftes van kinders met neuro-ontwikkelingsversteurings die beste aangespreek word deur ‘n familie-gefokusde benadering. Aangesien hierdie benadering meer geredelik geïnkorporeer is in die gesondheidsorg sisteem oor die afgelope paar jaar is meeste kinders met gestremdhede nou in staat om by die huis te kan bly in plaas daarvan om in inrigtings of groepshuise te woon. Baie ouers is dus geforseer om die rol as primêre versorger aan te neem vir hulle kind wat gediagnoseer is met ‘n gestremdheid of kroniese toestand.

Hierdie studie se doel was om die ervarings van versorgers van kinders met serebrale gestremdheid in landelike gemeenskappe van die Wes-Kaap, te ondersoek, met ‘n spesifieke fokus op die hindernisse en fasiliteerders wat hulle ondervind. ‘n Ondersoekende kwalitatiewe ontwerp is gebruik en onderhoude is gevoer met 15 individue (ouderdomme 27-62) wat deur doelgerigte steekproefneming geïdentifiseer is as versorgers van ‘n kind met serebrale gestremdheid. Tematiese analise is gebruik om die semi-gestruktureerde onderhoude wat met die deelnemers gevoer is te analiseer en temas te genereer.

‘n Aantal van die hindernisse tot versorging het na vore gekom en sluit die persoonlike gevolge van versorging, probleme om aan te pas by die versorgingspligte, omgewingstoestande, tekort aan toegang tot gesondheidsorg dienste, tekort aan verligting dienste en negatiewe persepsies teenoor gestremdhede in. Verskeie fasiliteerders tot versorging is ook geïdentifiseer, naamlik persoonlike hanteringsmetodes, persoonlike transformasie, sosiale ondersteuning, verhouding met hulle kind, gemeenskapsfasiliteerders, kind se speelskool en finansiële hulp.

Die vyf vlakke van die Sosiale Ekologiese Model is gebruik om die bespreking van hierdie bevindinge te konseptualiseer en verbintenisse is gemaak met bestaande literatuur wat handel oor die versorger se ervaring in die ontwikkellende konteks. In hierdie proses is gevind dat deelnemers dikwels dieselfde hindernisse en fasiliteerders ondervind as versorgers van individue met ander tipe toestande, soos MIV/VIGS, outisme, geestesiektes, kanker en neurologiese versteurings. Dit kan moontlik beteken dat versorgers wat in ontwikkellende lande woord dieselfde ervarings deel, ten spyte van die toestand van die persoon wat die versorging ontvang.

Alhoewel deelnemers ondersteuning van ʼn aantal bronne ontvang het wat hulle help met hulle versorgingspligte, is dit duidelik dat hulle steeds gapings ervaar in die voorsiening van ŉ aantal belangrike dienste, insluitende ŉ tekort aan inligting van gesondheidsorg werkers, ŉ tekort aan gemeenskapsprogramme om stres verligting en bemagtiging te bevorder en ŉ tekort aan gestremdheid-vriendelike fasiliteite. Dit is baie belangrik dat versorgers toegang het tot hierdie dienste om die welstand van hulle kind en hulself te verseker. Daar is dus ŉ behoefte om te ondersoek hoe hierdie dienste meer toegangklik gemaak kan word vir versorgers in landelike gemeenskappe.

Sleutelwoorde: serebrale gestremdheid, versorgers, hindernisse, fasiliteerders, kinderjare gestremdheid, landelike gemeenskappe

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Table of Contents

List of Tables

Chapter 1: Introduction

1.1 Introduction and Need for the Present Study

Cerebral palsy (CP) is a neurodevelopmental disorder of movement and posture that commences during the prenatal period or during early childhood, and persists throughout one's lifespan (Bax, Goldstein, Rosenbaum, Leviton, & Paneth, 2005). CP is considered to be one of the most common causes of childhood disability and its global prevalence has been estimated to be 2-2.5 per 1000 live births (Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013). In Africa CP rates have been found to be even higher, with an estimated prevalence of 2-10 cases per 1000 births (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014).

Due to the integration of the family-centred approach into healthcare systems, most children with disabilities are now able to live at home as opposed to staying in special institutions or group homes (Davis et al., 2009). This approach posits that each family is unique and that families are the experts when it concerns their children's daily care needs (King, Teplicky, King, & Rosenbaum, 2004). Due to the varying degrees of the condition, children with CP often require greater involvement from their caregivers, as they have certain care needs that extend beyond those of others of the same age who do not have the condition (Guillamón et al., 2013). Moreover, caring for a child with disability often requires substantial resources, such as time and money (Brehaut et al., 2004).

It is still not known why some caregivers are able to cope and yet others do not (Chakravarti, 2008; Guillamón et al., 2013). However, several barriers and facilitators have been identified as having an influence on caregiver quality of life (Guillamón et al., 2013). Caregivers often experience challenges, such as financial strain, stigmatisation from others, lack of access to services, and lack of information (Davis et al., 2009; Donald et al., 2014; Thrush & Hyder, 2014); while adequate support systems, religion, financial aid, and a positive attitude have been identified as facilitators to caring (Davis et al., 2009; McManus et al., 2006; Thrush & Hyder, 2014).

The majority of studies that have explored the caregiving experience have focussed on the challenges involved in caring for disabled children (Chakravarti, 2008; Davis et al., 2009; Hamzat & Mordi, 2007; Huang, Kellet, & St John, 2011; Isa et al., 2013; Murphy, Christian, Caplin, & Young, 2006; Ones, Yilmaz, Centinkaya, & Caglar, 2005; Raina et al., 2005; Resch et al., 2010; Whittingham, Wee, Sanders, & Boyd, 2011); while less emphasis has been placed on the resources (Bayat, 2007; Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005). Furthermore, most of the studies on the caregiving experience have been conducted in middle- and high-income countries (Byrne, Hurley, Daly, & Cunningham, 2010; Davis et al., 2009; Fernández-Alcántara et al., 2014; Whittingham et al., 2011), while limited evidence has been gathered in developing countries such as South Africa (Barratt & Penn, 2009; Geere et al., 2012; Gona, Mung'ala-Odera, Newton, & Hartley, 2010; Hartley et al., 2005; Huang et al., 2011). It is vital to explore the caregiving experience in developing countries, as it possible that caregivers encounter unique barriers and facilitators in a context such as South Africa, where there are often financial, geographical, and transport limitations. Therefore, the purpose of this study was to explore the experience of caring for a child with CP in rural communities of the Western Cape, South Africa, in order to ascertain the barriers and facilitators that caregivers encounter through their daily caring roles.

1.2 Definition of Key Terms

1.2.1 Cerebral palsy

Cerebral palsy is defined as a developmental condition that encompasses various disorders of posture, tone, and movement; which develop early in life and are not considered to be caused by any recognised progressive disease (Bax et al., 2005; Mutch, Alberman, Hagberg, Kodama, & Perat, 1992; Nelson & Gretcher, 1999; Smith & Kurian, 2012).

1.2.2 Caregiver

A caregiver's primary responsibility is to assist another to perform certain activities that are essential for survival, social membership or human functioning; such as bathing, cooking, feeding, cleaning, and dressing (June Spector & Tampi, 2005). In this study, a caregiver referred to either a primary carer, parent, or foster parent who was caring for a child with CP.

1.2.3 Primary caregiver

A primary caregiver for a child with a disability has been defined as the individual who spends the most amount of time caring for that child. Furthermore, a primary caregiver is responsible for the care and daily decision making for that child (Brehaut et al., 2004). For the purpose of this study, a primary caregiver is regarded as the person who spends the majority of their time caring for a child with CP. The term caregiver and primary caregiver will be used interchangeably in this study.

1.2.4 Rural community

In the past, the definition of rural and urban in South Africa was influenced by the principles of apartheid (Laldaparsad, 2006). The collapse of apartheid resulted in a modification of local government in South Africa, which led to the re-definition of municipal boundaries across the country (National Treasury, 2011). As a result, the definitions of rural and urban in South Africa are different compared to those used in other countries (Laldaparsad, 2006). Following South Africa’s transition to democracy in all spheres, the Rural Development Task Team and the Department of Land Affairs (1997) defined rural communities as having two major characteristics: They are areas in which individuals depend on natural resources, and they encompass large settlements of individuals who depend on migratory labour or social grants from the state in order to survive.

1.2.5 Barrier

A barrier has been defined as any situation or obstacle that needs to be overcome in order to make progress (Stevenson, 2010). For the purpose of the present study, barriers will refer to any aspects that make caring for a child with CP more difficult for individuals.

1.2.6 Facilitator

A facilitator refers to any factor that makes a process or situation easier to deal with (Stevenson, 2010). For the present study, a facilitator will encompass any support, services, or processes that are helpful to caregivers for children with CP.

1.3 Outline of the Research Project

Chapter 2 will provide a review of the literature in relation to the experiences of caregivers for children with CP. This will include an overview of CP, its etiology, epidemiology, clinical picture, diagnosis, as well as the factors related to caring for a child with CP. This will be followed by a discussion of the barriers and facilitators involved in caregiving, as well as their applicability to the South African context.

Chapter 3 will introduce and describe the Social Ecological Model (McLeroy, Bibeau, Steckler, & Glanz, 1988), the theoretical framework that was used to guide investigation and to explain the experiences of caregivers for children with CP. This chapter will provide a discussion of the main tenets of the Social Ecological Model (McLeroy et al., 1988) and how they are applicable to the caregiver experience.

Chapter 4 will outline the research methodology that was utilised in the present study. This will include a discussion of the rationale, research question, as well as the aims and objectives that were used to guide the present study. Thereafter, the research design, participants, as well as the sampling and data collection procedures will be discussed. Finally, the processes that were used to conduct data analysis and ensure trustworthiness will be described, followed by a discussion of the ethical considerations.

Chapter 5 will present the results and key findings that were emerged during the present study. The main themes and subthemes that were obtained through thematic analysis of each semi-structured interview that was conducted will be conveyed in this chapter.

Chapter 6 will provide a discussion of the key findings in relation to previous studies that are in line with this topic. This chapter will also incorporate a theoretical framework of the Social Ecological Model (McLeroy et al., 1988) to interpret and explain the results of this study. The present study will conclude with an examination its limitations, as well as recommendations for future research on this topic.

Chapter 2: Literature Review

The following chapter will review the current literature in relation to the experiences of caregivers for children with cerebral palsy or other chronic conditions. This will be achieved by providing an overview of cerebral palsy by examining its etiology, epidemiology, clinical picture, its diagnosis in children, factors influencing social participation, as well as the factors related to caring for a child with cerebral palsy. Thereafter, the barriers and facilitators to caring for a child with cerebral palsy will be discussed in detail; this will be achieved by referring to the most relevant studies on this topic.

2.1 Background to Cerebral Palsy

A significant portion of the world's present population is comprised of individuals who are physically, emotionally, or intellectually disabled (Isa et al., 2013). The United Nations has estimated that roughly 600 million individuals experience some form of disability and that children account for 150 to 250 million of these cases (Isa et al., 2013; United Nations Children's Fund, 2003). It has been estimated that approximately 10% of children experience developmental disorders that require long-term caregiving and access to healthcare services (Raina et al., 2004). One such chronic disorder is CP, which often has adverse effects on functional development, social participation, and quality of life of children (Chakravarti, 2008; Eunson, 2012).

CP is defined as a developmental condition that encompasses various disorders of posture, tone, and movement; which develop early in life and are not considered to be caused by any recognised progressive disease (Bax et al., 2005; Mutch et al., 1992; Nelson & Gretcher, 1999; Smith & Kurian, 2012). CP often results in disability or activity limitation which can be attributed to events that occurred in the developing infant brain, and may also be accompanied by disturbances of behaviour, cognition, communication, and/or sensation (Bax et al., 2005). Although the initial anomaly, injury, or lesion that leads to CP is often a fixed event, the clinical pattern of presentation may alter with time as the CNS develops and matures (Sankar & Mundkur, 2005).

2.2 Etiology

It has been noted that CP develops as a result of injury to the brain that often occurs before the completion of cerebral development (Krigger, 2006). Since the brain continues to develop during the first two years of life, it is thus possible that CP results from brain damage that occurs either before, during, or after birth (Bass, 1999; Bax et al., 2005; Smith & Kurian, 2012). Three main causes of CP have been identified; namely brain malformation, brain damage, and disorders of brain function with no evidence of structural abnormality (Eunson, 2012). All other factors associated with CP are referred to as risk factors (Eunson, 2012).

Since there are a variety of individual events or disorders that make up this pathologically and etiologically heterogeneous disorder, it is difficult to determine the actual cause among multiple cases of CP (Bax et al., 2005; Jones, Morgan, Shelton, & Thorogood, 2007). Although a severe event such as uterine rupture is often sufficient enough to cause CP, more often it is not a single factor that causes the disorder but rather multiple concurrent risk factors that predispose individuals to CP (Nelson, 2008). The conditions and risk factors associated with CP have thus been grouped according to the time period in which they occur; namely the prenatal, perinatal, or postnatal period (Eunson, 2012; Jones et al., 2007).

2.2.1 Prenatal period. Approximately 70 to 80% of CP cases develop before or during birth and arise from mostly unknown causes (Griffin, Fitch, & Griffin, 2002; Krigger, 2006). The prenatal precursors of CP include congenital malformation, exposure to radiation, maternal bleeding, maternal seizures, genetic abnormalities, exposure to environmental toxins, multiple births, intrauterine growth restriction, abnormalities of the brain structure, irregularities of blood flow to the brain, nutritional deficits, and pre-eclampsia (high blood pressure before 20 weeks gestation) (Dzienkowski, Smith, Dillow, & Yucha, 1996; Myers & Shapiro, 1999; Noetzel & Miller, 1998; Radeka, Taylor, Taylor, Wheeler, & Griffin, 1996; Sankar & Mundkur, 2005).

2.2.2 Perinatal period. One of the most common risk factors for CP is premature birth, where the risk for CP rises with a decrease in gestation age and where the greatest risk for CP occurs among infants who are born before 37 weeks gestation (Eunson, 2012; Jones et al., 2007). Prematurity is frequently accompanied by the underdevelopment of the respiratory system which can result in lack of oxygen to the foetus (Griffin et al., 2002). Low birth weight (less than 2.5kg) has also been linked to CP, where infants who are small for gestation age (SGA) are at a greater risk for experiencing hypoxic-ischaemic encephalopathy, an injury caused by asphyxia where the brain does not receive enough oxygen during the process of labour (Eunson, 2012; Griffin et al., 2002; Krigger, 2006). In many cases gestational age is not known, which has resulted in the inclusion of prematurity and intra-uterine growth restriction under the heading low birth weight (Gladstone, 2010). Other perinatal risk factors include breech births, lengthy or short labour, placental complications, maternal fever during labour, delayed onset of breathing as well as perinatal infection (Eunson, 2012; Griffin et al., 2002; Sankar & Mundkur, 2005).

2.2.3 Postnatal period. In approximately 10 to 20% of patients, CP is acquired during the postnatal period (Krigger, 2006; Sankar & Mundkur, 2005). Postnatal risk factors for CP usually arise due to brain damage that could be the result of motor vehicle accidents, falls, seizures, viral/bacterial infections of the central nervous system, or traumatic events such as drowning (Griffin et al., 2002; Krigger, 2006; Sankar & Mundkur, 2005). The length and severity of the event, injury, or infection usually influences the resulting damage to the CNS, which ranges from mild to severe manifestations of intellectual and motor impairments as well as other accompanying conditions (Griffin et al., 2002).

The most frequently reported etiologies among African studies were kernicterus (a condition of severe jaundice which is associated with high levels of bile pigment in the brain and nerve tissue), neonatal infections, and birth asphyxia (Donald et al., 2014; El Tallawy et al., 2013; Karumuna & Mgone, 1990; Ogunlesi & Ogundeyi, 2008). These findings are in contrast with the majority of studies that have been conducted in Europe and the United States, where almost all studies have identified low birth weight or prematurity as one of the major risk factors for CP (Gladstone, 2010). It is possible that infants who are born prematurely in low-income areas do not survive to an age where CP can be determined due to lack of antenatal care, which could account for the discrepancy in these etiologies (Bangash, Hanafi, Idrees, & Zehra, 2014; Gladstone, 2010).

2.3 Epidemiology

Prevalence refers to the proportion of the population who have a particular condition or disorder at a certain point in time (Blair & Watson, 2006). The present global prevalence of CP has been estimated to fall between 1.5 and 2.7 per 1000 (Eunson, 2012). However, there are often variations in the rate of CP due to differences in the provision of prenatal and postnatal care across contexts, as well as the differing measures used to ascertain prevalence rates across studies (Bangash et al., 2014; Eunson, 2012; Gladstone, 2010). A systematic review and meta-analysis conducted by Oskoui et al. (2013) found the prevalence rate of CP to be between 2 and 2.5 for every 1000 live births. This figure is consistent with previous findings such as a study conducted by Odding, Roerbroeck, and Stam (2006) who found the prevalence rate of CP to be above 2.0 per 1000 births and a review conducted by Hirtz et al. (2007) who calculated the prevalence of CP to be 2.4 per 1000. The rate of CP has yet to decrease over the last four decades despite significant advances in neonatal care, enhanced management of difficult deliveries and premature births, as well as attempts to improve maternal health (Eunson, 2012). This is mainly due to the increased survival of infants who are born prematurely or with low birth weight as a result of improved obstetric care, which inadvertently increases the risk for CP among these infants (Bangash et al., 2014).

The prevalence rates of CP in regions across Africa are not as clear, as there have not been many population-based studies conducted in developing countries despite the higher levels of disability in such contexts (Couper, 2002; Donald et al., 2014; World Health Organisation, 2011). It has been noted that higher prevalence rates of CP have been observed in rural communities and less developed areas (Couper, 2002; Donald et al., 2014). A systematic review conducted by Donald et al. (2014) found that the prevalence of CP across Africa varied from 2-10 per 1000 births (Couper, 2002; El Tallawy et al., 2013). Conversely, previous studies conducted in regions of South Africa, such as KwaZulu Natal, Mpumalanga, and the North West province reported much higher prevalence rates consisting of 33 per 1000, 64 per 1000, and 52 per 1000 respectively (Corneljie, 1991; Kromberg et al., 1997).

There are thus inconsistencies in findings regarding the prevalence of CP in South Africa despite its relatively large impact in Africa and abroad. It has been suggested that inadequate antenatal care often increases the risk for prenatal, perinatal, and postnatal birth complications during pregnancy, which could increase the risk for CP in the unborn child (Bangash et al., 2014). In many cases, healthcare facilities are primarily located in urban areas, which means that healthcare professionals and services are too far away to access, especially when individuals live in rural regions (Borg, Lindström, & Larsson, 2011). This forces individuals to give birth at home, which increases the risk of birth complications due to the absence of healthcare professionals (Nelson, 2008). It is thus possible that an increased rate of birth complications could have resulted in the aforementioned inconsistencies in CP prevalence rates across South Africa. Furthermore, the methods that were used to determine the prevalence of CP across these studies ranged from hospital records to door-to-door surveys, which could account for discrepancies in prevalence rates (Donald et al., 2014).

2.4 Clinical Picture

Individuals with CP usually have increased muscle tone or tension of the muscles leading to rigidity, however, there are also cases where normal or reduced muscle tone is observed (Smith & Kurian, 2012). Four groups of CP have been identified; namely the spastic, athetoid, ataxic, and mixed types (Katz & Johnson, 2013). The spastic type accounts for approximately 70% of CP cases and is characterised by loss of motor control as well as hyper-tonicity (Katz & Johnson, 2013). The spastic type usually results in hemiplegia (where one side of the body is affected), diplegia (where the legs are affected more than the arms), paraplegia (where both legs are affected) or quadriplegia (where all four limbs are affected) (Katz & Johnson, 2013). The athetoid type accounts for 20% of CP cases and is characterised by involuntary writhing and jerking movement (Katz & Johnson, 2013). The ataxic type accounts for 10% of CP cases and is characterised by tremors, weakness, or lack of coordination (Katz & Johnson, 2013). Although diminished motor ability, which often results in restricted activity, is the defining feature of CP, many children with CP can often also experience deficits in cognition, communication, perception, speech, and sensation (Bax et al., 2005; Brehaut et al., 2004).

Numerous individuals with CP often experience other impairments which hinder their capacity to function in day-to-day life and may cause greater activity restriction than the motor impairments which are usually associated with CP (Bax et al., 2005). CP is associated with various comorbidities which could be classified as neurological disorders, such as hydrocephalus (accumulation of fluid in the brain), epilepsy, as well as visual and hearing difficulties; gastrointestinal problems, including swallowing difficulties and constipation; behavioural or learning problems, comprising of autistic features, depression, and sleep difficulties; and skin problems, such as pressure sores and drooling (Aisen et al., 2011; Bax et al., 2005; Smith & Kurian, 2012). Individuals with CP are also susceptible to dental decay and poor oral hygiene, hip dislocation and scoliosis, as well as respiratory infections (Smith & Kurian, 2012).

The term CP can thus be used to describe a variety of motor difficulties that could range from an individual who experiences impairment of a single limb, to a wheelchair bound individual who is unable to perform voluntary movements as well as self-care functions, such as bathing, dressing, and feeding (Brehaut et al., 2004; Eunson, 2012). Since the restrictions that accompany CP occur from early childhood and persist throughout one’s lifespan, it is thus evident that individuals with CP require greater involvement from their parents and/or family members, as they have various care needs that extend beyond those of others of the same age who do not have the disorder (Guillamón et al., 2013).

2.5 Social Participation

Traditionally impairment was understood as a physical construct that was either brought about by infection, germs, injury, or illness (Abberley, 1987). Furthermore, any impairment that was not the result of these factors was thought to be the result of "'normal' wear and tear on the human body" (Abberley, 1987, p. 10). However, it has recently been recognised that impairment is influenced by the interaction between an individual and their environment as opposed to being determined by physical characteristics alone (Majnemer et al., 2008). An individual's level of impairment could thus be shaped by a combination of attitudinal, physical, and social factors (Majnemer et al., 2008). As opposed to minimising individual barriers, rehabilitation programs have shifted their emphasis onto the importance of functional participation and success among individuals with disabilities (Majnemer et al., 2008). It has been noted that there are a variety of benefits to social participation, such as the development of skills, friendships, personal interests, as well as a sense of identity (Majnemer et al., 2008).

As noted, children with CP experience an array of motor impairments in addition to impairments in other domains, which often influences their ability to communicate, move, socialise, or perform certain cognitive tasks (Majnemer et al., 2008). As a result of these impairments, children with CP are at a greater risk for decreased participation in leisure activities (Majnemer et al., 2008). One of the greatest hindrances to social participation is the perception of being different to others (Sandström, 2007). It has been noted that this perception stems either from exclusion or special treatment from others (Sandström, 2007). Individuals with CP often develop a false sense of security when they are overprotected by their parents or healthcare professionals, which can exacerbate feelings of difference when these individuals are exposed to the 'normal' world for the first time (Sandström, 2007, p. 435). Furthermore, by educating individuals in a setting where there are only other disabled individuals, children with CP could experience a greater shock when they encounter new school or work situations for the first time (Sandström, 2007).

Feelings of difference can also be influenced by the way others perceive and treat individuals with disabilities in social settings, where others often do not understand that disabled individuals could be competent or where they are surprised when disabled individuals display competence (Sandström, 2007). The challenges that children with CP experience can thus be attributed to perceptions within society, which mirrors the sentiments of the Social Model of Disability (Union of the Physically Disabled Against Segregation, 1975) that impairment is often socially constructed. It would thus be important to identify and challenge the factors that hinder social participation in order to initiate health promotion strategies and policies that would allow children with CP to participate in society (Majnemer et al., 2008).

2.6 Diagnosis

Adjusting to the birth of a child with disability can often test the resources of parents and families of the affected child, as they encounter a unique set of tasks related to the requirements of a long-term disability in addition to their standard childcare practices (Guillamón et al., 2013; Raina et al., 2004). In most cases, parents receive their child's diagnosis in two main ways: some are informed after they visit healthcare professionals for medical assistance when they realise that their child is not reaching certain developmental milestones, such as sitting, crawling, rolling over, and walking; while others are informed of their child's diagnosis prior to release from a neonatal intensive care unit following a difficult delivery (Huang, Kellet, & St John, 2010).

The period directly after the diagnosis has been described as the most emotionally challenging time for parents (Whittingham, Wee, Sanders, & Boyd, 2013). It is not uncommon for parents to experience mixed feelings towards a diagnosis of CP (Huang et al., 2010; Whittingham et al., 2013). On one hand parents experience relief after learning their child's diagnosis, as it lifts their feelings of uncertainty regarding their child's condition (Huang et al., 2010; Whittingham et al., 2013). However, it is often difficult to accept a diagnosis of CP, as it destroys the hope of being a parent to a healthy child (Huang et al., 2010; Whittingham et al., 2013). Furthermore, parents have reported feelings of sadness and grief for both the parenting moments that they would not experience as well as their child's lost potential (Whittingham et al., 2013). Several parents have also experienced feelings of injustice that anyone should give birth to a child with a disability (Whittingham et al., 2013).

The diagnosis of a developmental disorder such as CP thus requires parents to alter their expectations as well as their caregiving practices (Bourke-Taylor, Howie, & Law, 2010). It has been speculated that it is necessary to understand the role of caregivers of children with disabilities in order to reduce and remove the barriers that they experience (Bourke-Taylor et al., 2010). As a result, there has been an increased focus on the impact of caring for children with disabilities on the health and well-being of their caregivers (Guillamón et al., 2013). In line with such interests, the present study specifically focussed on the experience of caregivers of children with CP.

2.7 Caring for a Child with Cerebral Palsy

Caring for any chid is regarded as an ongoing task that requires significant resources, such as money and time (Brehaut et al., 2004). However, the demand for these resources can increase considerably when one is caring for a child who has a disability or a chronic disorder (Brehaut et al., 2004). The presence of a disability or a chronic disorder often has a significant impact on the independence of the affected child, but can also affect their families, especially those individuals who are long-term caregivers (Isa et al., 2013). At present there are no interventions that can provide a cure for CP, however, there are treatments that can be used to improve the functional status of individuals with CP (Larivière-Bastien & Racine, 2011). The current management for CP is centred on a multidisciplinary team that is made up of paediatricians, nutritionists, eye specialists, neurologists, orthopaedic specialists, occupational therapists, physiotherapists, physical therapists, social workers, psychologists, private educators, and parents (American Association of Orthopaedic Surgeons, 2013; Ones et al., 2005).

Despite the multitude of experts who play a role in the lives of children with CP, it has been argued that the parents of a child with CP are always the central part of that child’s life and as a result, the enduring, intensive care required by children with this disorder is mostly provided by a close relative or a parent (Hamzat & Mordi, 2007; Ones et al., 2005). Moreover, privately funded assistance is unaffordable at times and remuneration from the state is often unattainable by individuals with disabilities, which results in the provision of assistance and care by non-familial or community members (Thrush & Hyder, 2014). Caregiving thus falls onto unpaid friends or family members of the individual with disability, especially in developing countries such as South Africa (Hamzat & Mordi, 2007).

It has been suggested that the complex needs of children with neurodevelopmental disorders are best addressed with a family-centred approach (King et al., 2004). This approach posits that all families are unique, that parents are the experts when it comes to understanding their children’s needs, and that a supportive family and community environment can foster optimal child development (King et al., 2004). As this approach has been increasingly incorporated into healthcare systems over recent years, most children with disabilities are now able to remain at home as opposed to living in institutions or group homes (Davis et al., 2009; King et al., 2004). This shift in healthcare has required family members to become more involved in the care of their child and to take responsibility for a multitude of caregiving tasks (Raina et al., 2004). Consequently, an increasing number of parents are required to adopt the unexpected role of a caregiver, which requires copious amounts of physical, emotional, social, and financial resources (Murphy et al., 2006; Raina et al., 2005).

Several definitions of caregiving have been proposed, however, for the purpose of the present study a primary carer for a child with disability has been defined as an individual who is responsible for the care and daily decision making regarding that child (Brehaut et al., 2004). Furthermore, caregiving involves assisting another to perform certain activities that are essential for survival, social membership or human functioning; while also performing activities that individuals are unable to perform themselves, such as bathing, feeding, and dressing (June Spector & Tampi, 2005). The role of family caregiving can thus take on a completely different meaning when a child is faced with functional restrictions and the possibility of long-term dependence, where parents are often obligated to maintain the requirements of daily living while simultaneously managing the health problems of their children (Raina et al., 2005).

It has been argued that home environment has a significant effect on the development and health of any child (Bourke-Taylor et al., 2010). However, children with chronic disorders or disabilities are even more reliant on their families for their health and successful integration into the community (Bourke-Taylor et al., 2010). Even though a nurturing environment at home could minimise the impact of the child’s impairment and maximise their capabilities, it is also possible that the constant provision of high quality care to children with enduring physical limitations, such as those associated with CP, could result in negative implications for the child, family, and even the community (Brehaut et al., 2004; Davis et al., 2009; Raina et al., 2005). This is due to factors such as a decrease in productivity at work as well as increased health costs among caregivers, which could decrease family income (Brehaut et al., 2004; Davis et al., 2009).

It is vital to note that not all parents are equally affected by the task of caring for a child with a chronic disorders such as CP, as there are some families who are able to cope relatively well in the face of adversity (Guillamón et al., 2013). At present it is still unclear why some caregivers are able to cope well and yet others do not (Chakravarti, 2008; Guillamón et al., 2013; Raina et al., 2005). However, there has been an increasing interest into the factors that could influence the emotional well-being of parents who care for children with CP, as such insights could be incorporated into interventions that assist individuals to improve their adaption to chronic disorders and care (Guillamón et al., 2013). One approach to understand the caregiver experience is to examine the facilitators and barriers that have been reported to influence caregiver quality of life (Raina et al., 2005). The following section will discuss the barriers and facilitators to caring for children with CP that have been identified in the literature. Each of these challenges and facilitators are discussed from a broader perspective and then applied to caregivers in South Africa where possible, in order to demonstrate their relevance in this context. Since there are often a greater number of barriers that impede caregiving duties, the barriers will be discussed prior to the facilitators.

2.8 Barriers to Caring for a Child with CP

This section outlines the following barriers to caregiving: Financial burden, lack of access to services, stigmatisation, marginalisation and exclusion, concern for the future, inadequate public facilities, as well as a lack of personal life and social relationships.

2.8.1 Financial burden. It has been found that caring for a child with disability is often associated with financial burden, where caregivers have reported that just providing the basic necessities for children with CP is substantially costly (Davis et al., 2009; Donald et al., 2014; Thrush & Hyder, 2014). Expenses usually include medical visits and treatments, travel expenses, cost of medication, special foods, additional housing space, and even funerals (Thrush & Hyder, 2014). A study conducted by Thrush and Hyder (2014) found that caregivers frequently experience reduced productivity or loss of income, as they reduce the number of hours they work or stop working altogether. In developing countries, parents who have caregiver roles often lose their jobs due to the significant amount of time that they need to spend with their children, which often places financial pressure on the family as a whole (Murphy et al., 2006; Thrush & Hyder, 2014). Caregivers are thus confronted with a double setback, as they require increased finances to support their children, but they experience reduced opportunities to work due to the extensive needs that accompany a child with disability (Bourke-Taylor et al., 2010; Murphy et al., 2006).

Although it appears that the cost of caring for a child with disability is taxing regardless of financial status, it seems that this economic burden can have a greater impact among caregivers from developing countries (Thrush & Hyder, 2014). In many developing countries, the combination of lack of income and financial pressure can force families to give precedence to the individual with the chronic disorder or disability, which results in the scarcity of food and medication for other family members (Donald et al., 2014). Money for the education of the other children is often not available and parents are forced to take loans due to their financial insecurity (Thrush & Hyder, 2014). In an attempt to lessen the financial burden of caregiving, families resort to selling their assets, such as jewellery, vehicles or property, and even take on extra jobs when possible (Thrush & Hyder, 2014).

Not only do financial barriers create strain in families, but they also sometimes impede access to quality services (Resch et al., 2010). Caregivers have argued that financial status frequently prevents them from attaining the necessary services that are required by their child (Resch et al., 2010). Many vital needs thus go unmet due to the financial status of the family, and parents are forced to seek financial assistance from other sources. Access to funding is also a frequent barrier to caregiving, as individuals struggle to access financial aid in order to cover the expenses that accompany their child's disability (Davis et al., 2009). Several caregivers have argued that they do not qualify for financial aid because their financial status does not fall in the range of poverty, meaning that they are not 'poor' enough to receive assistance (Resch et al., 2010). Globally, bureaucracy has been identified as one of the principal barriers to attaining financial entitlements for individuals with disabilities, where the process of applying for financial aid is often time consuming and exhausting for caregivers (Davis et al., 2009: McManus et al., 2006). Many caregivers have noted that they are frequently confronted with waiting lists in all avenues when they attempt to obtain any form of financial aid, which can often lead to frustration and anxiety (Bourke-Taylor et al., 2010).

To compensate for the challenges that often accompany disability among children and adults, the South African government introduced a system that is unique to the African continent, namely the distribution of disability grants (Loeb, Eide, Jelsma, Toni, & Maart, 2008). In South Africa, disabled children who are under the age of 18 and who require permanent care are eligible for a care dependency grant of R1350 ($129) a month (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2006; South African Government Services, 2014). A study conducted by Saloojee et al. (2006), who explored the health and welfare needs of disabled children in a peri-urban township in South Africa, found that only 45% of the 78% of children who were eligible for the state funded care dependency grant were receiving it. Caregivers identified bureaucratic obstacles as one of the greatest barriers to receiving the grant, as they were often confronted with long waiting periods and were repeatedly provided with the incorrect forms (Saloojee et al., 2006). Furthermore, some caregivers also expressed a lack of awareness that their child was eligible for a grant, a lack of knowledge of where to apply for the grant, and a lack of the necessary documentation (such as identity documents or birth certificates) to apply for the grant (Saloojee et al., 2006).

2.8.2 Lack of information. Lack of access to important information is one of the most common concerns for caregivers of children with disabilities (Resch et al., 2010). Desire to obtain information is an aspect of the caregiving role that is present from the time when a diagnosis is made (Resch et al., 2010). However, the initial attempt to obtain information about their child's disability has been described as one of the most difficult and time consuming process by caregivers (McManus et al., 2006; Resch et al., 2010). Caregivers have argued that they were never informed about their rights as caregivers, the rights of their child, or which institutions they should turn to for assistance (McManus et al., 2006).

Caregivers note that although their children have a multitude of specialists, each with their own field of expertise, they are still left to find information on their own, which can be tiring (McManus et al., 2006). Caregivers are thus left to find their own information regarding special education, financial aid, or even programmes for their children to attend (McManus et al., 2006). Moreover, the pursuit for information can be further complicated when caregivers struggle to acquire information from, and to share information with, the multitude of professionals who are involved in their child's care (Golden & Nageswaran, 2012; Resch et al., 2010). A possible reason for this frustration is that different healthcare professionals do not coordinate and/or communicate well with one another as well as with caregivers (Golden & Nageswaran, 2012; Resch et al., 2010).

Furthermore, caregivers are not always provided with adequate information about what their child might need and at times they feel that their child's healthcare providers are not informed enough to assist them with their own needs (McManus et al., 2006). Caregivers thus resort to gathering information through ‘word of mouth’ from others, which often results in them receiving contradictory advice (McManus et al., 2006). In developing countries such as South Africa, caregivers often receive limited guidelines and recommendations for the management of disabilities, as few healthcare workers are trained with the skills that are necessary to care for a child with CP, which can often result in mistrust of healthcare professionals (Donald et al., 2014; Huang et al., 2011). Huang et al. (2010) found that parents often feel as though healthcare workers lack the adequate knowledge about CP or they are too careless to provide the optimal medical assessments and treatments to children with disabilities. Furthermore, Saloojee et al. (2006) speculated that there is limited coordination between education, health, and social development departments in South Africa, which can result in caregivers being ill-informed of the resources available to them. Owing to this lack of information and mistrust of healthcare providers, many caregivers are left feeling isolated (McManus et al., 2006).

2.8.3 Lack of access to services. Accessing services for their children is one of the major concerns that caregivers have; where they consider adequacy and availability, cohesion of services, as well as their role as advocates and/or organisers to be of prime importance (Bourke-Taylor et al., 2010). Caregivers have noted that they experience difficulties when attempting to access and retain services, and that the quality of these services tends to be variable (Bourke-Taylor et al., 2010). Initially caregivers may struggle to navigate the services that their children might need, as they describe the process to be disjointed and complicated (Bourke-Taylor, 2010). Part of navigating the healthcare system involves dealing with variability in the services that are offered by healthcare professionals, where caregivers deal with several organisations that provide equipment or supplies because one organisation is seldom able fulfil all of their requirements (Golden & Nageswaran, 2012). Caregivers are often faced with the mistakes or inefficiencies of the organisations with which they work; where it is not unusual for organisations to send incorrect supplies, the wrong quantity of supplies, or no supplies at all (Golden & Nageswaran, 2012). Caregivers are thus required to advocate with healthcare professionals and organisations to get the services that their child requires (Golden & Nageswaran, 2012).

It is evident that many caregivers devote large amounts of emotional resources and time in order to plan, find, and retain services for their children (Bourke-Taylor et al., 2010). This process can result in individuals having to complete a substantial amount of paperwork in order to acquire the most basic services, which can be confusing and frustrating (Bourke-

Taylor et al., 2010). Caregivers have also indicated that they do not feel well supported by the assistance offered by healthcare services and that when they need help, it is mostly not available (Davis et al., 2009). Consequently, caregivers often feel that they need to work very hard and be extremely proactive to locate the support that they need (Davis et al., 2009).

One of the greatest barriers that restricts access to comprehensive services is geographic location (Larivière-Bastien & Racine, 2011). In many regions of South Africa, healthcare services are typically located in centralised areas, which means that the treatments as well as the equipment that aids caregiving and mobility are often too challenging to access, especially for individuals who reside in rural areas (Borg et al., 2011). Families who stay in urban areas would thus have greater access to services such as out-of-home respite care, in terms of the distance between their homes and the location of respite facilities (Yantzi, Rosenberg, & McKeever, 2006). Such respite facilities allow children with disabilities and chronic needs to stay for a short period of time, which can allow their caregivers to take time for themselves (Yantzi et al., 2006). These facilities are sometimes available to individuals in rural areas, however, they often have to travel for hours just to get there (Yantzi et al., 2006).

In many rural communities of South Africa, the nearest hospital can sometimes be as far as 30 kilometres away and transport costs can often consume up to 5% of a family’s monthly income (Saloojee et al., 2006). Various caregivers in rural parts of South Africa rely on a system of informal public transport that does not always accommodate individuals with disabilities (Saloojee et al., 2006). In many cases, caregivers are thus forced to carry their children to their appointments or to make use of expensive private transport (Saloojee et al., 2006). In cases where unemployment rates are high and family income is low, the ability of families to prioritise their child’s healthcare needs can be adversely affected, especially when there is a lack of visible progress in their child’s treatment (Saloojee et al., 2006).

It has been argued that restricted access to healthcare providers and facilities, as well as a lack of assistive technology (including wheelchairs and other ambulation aids) has led to a gap in treatment for children with CP in various countries across Africa (Njambi, Kariuki, & Masinde, 2009). Furthermore, the availability of transport also influences whether or not children with non-ambulatory CP as well as their caregivers are able to access healthcare services, and as previously mentioned, in many cases public transport is not suitably equipped to accommodate individuals in wheelchairs (Donald et al., 2014; McManus et al., 2006). In countries such as South Africa, where a variety of factors limit access to services and equipment, caring for a disabled child can require more physical effort than it would in high income countries, which increases the risk for injury among caregivers (Geere et al., 2012). Negative physical consequences for caregivers could include back and shoulder pain from having to constantly lift and carry their child, which often leads to an inability to perform regular day-to-day tasks (Murphy et al., 2006).

2.8.4 Stigmatisation, marginalisation, and exclusion. Resch et al. (2010) reported that a major concern among parents of children with disabilities is that their children are integrated into their communities and schools. Schools have been identified as an important means to improve social participation of children with CP, however, caregivers tend to prefer mainstream schools as opposed to special schools, even though these schools frequently lack specialised personnel (McManus et al., 2006). A possible reason for this preference is that special schools tend to be located too far away from the homes of families with disabled children, which prevents the opportunity for social interaction with other children in the neighbourhood (Green, 2003; McManus et al., 2006). However, attendance at a special school allows children with disabilities to interact with others who share similar circumstances (Green, 2003).

Since mainstream schools have been including children with disabilities for many years, this concern goes beyond mere physical or academic inclusion, but rather refers to inclusion in the social facets of schooling (Resch et al., 2010). In many cases, children with CP are unable to move about at school due to lack of mobility, which can reduce their interactions with their peers and subsequently leaves them feeling as though they cannot relate to their classmates (Huang et al., 2011). School can thus be very isolating for children with disabilities, as their peers might struggle to relate to them and begin to view them as ‘different’ (Huang et al., 2011). It is also possible that children are excluded by their teachers, who might reject them or refuse to help them improve their academic performance (Huang et al., 2011).

Another barrier that caregivers experience is the adverse reaction of the community towards their child, which is often described as one the greatest challenges to manage and overcome (Bourke-Taylor et al., 2010; Resch et al., 2010). Caregivers have argued that they endure a specific kind of public scrutiny because they are parents of a child with an observable disability (Bourke-Taylor et al., 2010; Whittingham et al., 2011). Parents have noted that it becomes increasingly challenging to parent their child in a positive manner when they are in public due to the embarrassment or shame that they feel as a result of the response of others (Whittingham et al., 2011). Since others often do not know how to deal with a child with a disability, children as well as their caregivers are often excluded from social events, such as birthday parties or weddings, and such negative public attitudes can leave them feeling isolated (Bourke-Taylor et al., 2010). It has been noted that chronic emotional distress among caregivers is not caused by the severity of their child's disability, but rather by the perception of stigmatisation by others in the community (Green, 2007).

Stigmatisation of children with disabilities can be manifested by children and even adults who stare or even verbally reject these children when they are in public places, such as shopping centres, parks, or even on the street (Donald et al., 2014; McManus et al., 2006). Furthermore, caregivers have noted that it can be frustrating and unpleasant when others display such behaviours towards their child when they are out in public (McManus et al., 2006). It is also not uncommon for caregivers, especially mothers, to face stigmatisation from members of their family because they birthed a child with a disability (Chakravarti, 2008). In many African countries, children with disabilities as well as their families are frequently cast out from society due to stigmatisation, which forces them to encounter many economic, political, and social challenges as they can be denied the basics of education, healthcare, recognition, and socialisation (Donald et al., 2014).

In many South African cultures there is a negative connotation attached to the concept of disability, where individuals with disability are not viewed as equals by others in their community (Wazakili, Mpofu, & Devlieger, 2006). Many parents of children with disabilities are ridiculed by others who tease them and claim that they did not give birth correctly (Wazakili et al., 2006). Furthermore, a common cultural belief is that the presence of a disability is associated with witchcraft (Hartley et al., 2005). However, not all children with disabilities are confronted with negative attitudes. In some cases children with disabilities are accepted and included by their peers as well as their parents, where they are involved in recreational and domestic activities (Hartley et al., 2005; Wazakili et al., 2006). At present, perceptions toward disability in South Africa are shifting towards a more positive connotation, where family and community members are slowly starting to see disabled children as a gift as opposed to a curse (Hartley et al., 2005; Wazakili et al., 2006).

2.8.5 Concern for the future. Green (2003) suggests that one of the most common outcomes of the perceived experience of stigmatisation is concern among caregivers for their child’s treatment in the future. Anxiety about the future is frequently expressed among parents who are the primary caregivers for children with disabilities, where mothers mostly worry about a time when they might not be there to protect their child from a world where stigmatisation occurs (Chakravarti, 2008; Green, 2003; Murphy et al., 2006). Since CP is a variable and permanent disorder that lasts throughout ones lifespan, caregivers often worry what would become of their child when they are no longer present to care for them (Murphy et al., 2006). Furthermore, many parents are under the impression that no one could care for their child as well as they are able to, which increases their anxiety for the future (Chakravarti, 2008).

Whittingham et al. (2011) found similar sentiments amongst a focus group of caregivers for children with CP. These caregivers were concerned for their children’s future and desired assistance from professionals to ensure that they were doing everything within their means to stimulate their child’s development in realms such as communication, socialisation, and independence (Whittingham et al., 2011). The anxiety and emotional stress that accompanies caregiving tends to increase over time due to this concern for the future, especially when there are a lack of community programmes that could assist their child when they are too old for public education programmes (Murphy et al., 2006). In many cases, parents are hopeful that their other children or family members will take care of their disabled child when they are no longer around (Chakravarti, 2008).

2.8.6 Inadequate public facilities. Caregivers have also encountered physical challenges that can prevent access to certain public and/or private places (Bourke-Taylor et al., 2010). In many cases, wheelchair accessibility is inadequate, which makes it difficult for individuals to enter or move around places such as shops, cinemas, or schools (Donald et al., 2014; McManus et al., 2006). When public domains do not have a disability-friendly environment that takes the needs of the child into consideration, they create a barrier to the child’s involvement in activities outside of the home (Huang et al., 2011). The combined effect of the inadequate design of public facilities and the negative attitudes of others can result in the withdrawal of children with CP and their caregivers from social engagements (Huang et al., 2011).

Transport enables individuals to travel, to visit others, and to explore, as well as to participate in work, social, and school activities (McManus et al., 2006). Certain families with a child who has a disability have a vehicle that is equipped to transport non-ambulant individuals (McManus et al., 2006). However, parents have noted that transporting their child is still difficult even with a disability-friendly vehicle, as they are required to accompany their child on every trip because there are no alternative forms of public transport (McManus et al., 2006). A significant barrier in developing and developed countries is the lack of suitably equipped means of transport, where taxis or even buses are not adapted to accommodate wheelchair users (Donald et al., 2014; McManus et al., 2006).

Healthcare services and schools can also be ill-equipped to accommodate individuals with disability or chronic disorders. A study conducted by Donald et al. (2014) found that there is often a shortage of personnel who are trained to utilise the tools that are necessary to care for and manage children with CP, particularly in rural African areas. Furthermore, it has been found that when infrastructure does exist, it is inhibited by limited equipment and facilities for rehabilitative services (Donald et al., 2014). Huang et al. (2011) found that mothers of a child with CP tend to feel powerless when schools fail to provide an environment that is conducive to the needs of their child, as this can impede school attendance and assimilation into school life.

2.8.7 Lack of personal and social relationships. Thrush and Hyder (2014) reported that one of the major social implications for caregivers is social withdrawal from various activities and a restricted social life. The lack of information regarding services and the challenge to navigate the complex healthcare system has forced caregivers to coordinate the care of their children (Golden & Nageswaran, 2012). Some parents have indicated that the majority of their time is taken up by their caregiving duties, which include a range of specific tasks involving the administration of medication, conducting physical therapy exercises, assisting with mobility, advocating for their child, as well as organising appointments and equipment (Bourke-Taylor et al., 2010; Davis et al., 2009; Golden & Nageswaran, 2012; Whittingham et al., 2011). Parents have also reported that having a child with CP caused the majority of their parenting tasks to grow in intensity and duration, such as the provision of supervision, tailoring activities to fit their child’s needs, and assisting their child with those activities (Whittingham et al., 2011).

Due to their child’s complex care needs and dependence during the night, parents have also reported that their sleep can also be frequently disrupted (Davis et al., 2009). The fatigue that tends to accompany these care activities and long-term periods of sleep deprivation can prevent caregivers from even considering to leave their home (Davis et al., 2009; Yantzi et al., 2006). This can make it difficult for caregivers to maintain social relationships that were formed before the birth of their child, as parents often feel that their lives have become so different compared to their friends' and that their friends are not always sure how to interact with their child (Davis et al., 2009). Caregivers have thus indicated that caring for a child with CP can be both socially and mentally isolating, as they are unable to share their thoughts and feelings with others who might not relate to their experiences (Davis et al., 2009).

It is also possible for caregivers to experience changes in their familial relationships (Davis et al., 2009), as indicated by a study conducted by Sen and Yurtsever (2007) who found that 42.9% of the families of children with CP experienced drastic internal changes, including marital discord and even divorce. The birth of a child with a disability can cause additional stress in family life and could even result in spouses arguing or blaming one another, which can put pressure on marital relationships (Bourke-Taylor et al., 2010; Sen & Yurtsever, 2007). There is a common misconception that friends, family, and neighbours are available to provide respite (Yantzi et al, 2006). However, parents are rarely assisted by members of their extended family, as they do not have the knowledge and experience to provide the level of care required by children with chronic disorders or disabilities, which forces parents to cope on their own (Bourke-Taylor et al., 2008; Chakravarti, 2008; Golden & Nageswaran, 2012).

In some cases both spouses are involved in their child's care, where they either alternate or share the caregiving tasks (Bourke-Taylor et al., 2010). Parents have noted that their primary focus is on their child's care when both parents are active caregivers, which can diminish the opportunity for couples to spend time alone (Bourke-Taylor et al., 2010; Davis et al., 2009). Furthermore, in other cases respite services are often difficult to attain and mothers tend to adopt the role of primary caregiver at home, while many fathers assume the responsibility of being the breadwinner for the family (Bourke-Taylor et al., 2010; Murphy et al., 2006; Yantzi et al., 2006). Many mothers have noted that one of the greatest challenges to their partnership is a spouse who is absent or unhelpful (Bourke-Taylor et al., 2010). It has been speculated that fathers work extended hours due to the financial pressures that are associated with caring for a child with disability, or some fathers react to their child's diagnosis by devoting all of their time to their work in order to avoid going home so that they do not have to face the reality of their child's disability (Bourke-Taylor et al., 2010).

2.9 Facilitators to Caring for a Child with CP

Although there are many challenges that can make the task of caring for a child with CP burdensome, there are also a variety of facilitators that make caregiving easier. This section will discuss the following facilitators to caring for a child with CP: Stronger family relations, religion and spirituality, changed perceptions, as well as optimism.

2.9.1 Stronger familial relations. It has been reported that a family support system is one of the most vital resources for children with CP as well as their caregivers, as it assists them to cope with their daily tasks and prevents them from feeling isolated (Davis et al., 2009; McManus et al., 2006; Thrush & Hyder, 2014). Although relationships with relatives can sometimes be strained, it has been noted that the presence of a child with special needs or a disability can often bring a family closer together (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009). Many family bonds become closer and more cohesive, as family members are required to unite and cooperate to meet the complex needs of the child (Green, 2007; Myers et al., 2009). Although it can sometimes be difficult to work together so closely with family members, several parents have noted that the processes involved in caregiving have strengthened their familial bonds (Bayat, 2007; Myers et al., 2009).

The family as a whole are frequently required to compromise important personal, familial or social events in order to juggle the many duties that accompany a disabled child (Myers et al., 2009). However, parents have noted that working together has led to more deeper and meaningful relationships with their partners as well as their children, even if important events are missed (Myers et al., 2009). The combined effect of this motivation to assist the afflicted child to progress and reach developmental milestones is often the means for family members to adjust and function proficiently in spite of the challenges that they face (Bayat, 2007).

Furthermore, in many cases children with developmental disorders have been found to have a positive impact on their siblings (Bayat, 2007; Myers et al., 2007). In a study that explored resilience among families of children with autism, Bayat (2007) found that the presence of autism in one of the children brought all of the siblings closer together. Siblings have also been found to develop greater compassion, sensitivity, and have even been noted to become quite protective of their siblings (Bayat, 2007; Myers et al., 2009). Immediate family members such as siblings can also be an important source of respite for caregivers who are not able to access other formal or informal care providers (Yantzi et al., 2006). However, since few family members possess the necessary expertise and skills to meet all of the child's needs, time away is often limited for caregivers even when this form of support is provided (Yantzi et al., 2006).

This form of informal support is especially significant for caregivers in a context such as South Africa, as individuals who reside in rural communities often lack access to important services or healthcare professionals, and are thus forced to cope with all aspects of caregiving on their own (Donald et al., 2014; Hartley et al., 2005; Thrush & Hyder, 2014). In their South African based study that examined the needs of disabled children in a peri-urban township, Saloojee et al. (2006) found that emotional support is mainly provided to caregivers by their immediate family members as opposed to people's associations or support groups. This is possibly because individuals often have a lack of trust in healthcare professionals, they are afraid to disclose their child's condition to anyone outside of their family due to stigma, they are not aware of support services available to them, or there are simply no support services provided in their communities (Donald et al., 2014; Huang et al., 2010; Saloojee et al., 2006). Such findings suggest that family members are an important resource for caregivers in this context. Similarly, a study conducted by Jonker and Greeff (2009) on families living with individuals with mental illness in an underprivileged area in the Western Cape found that a family's ability to work together and the improved strength of the familial unit as a result thereof was positively correlated with their ability to adapt. Furthermore, certain characteristics of individual family members; including emotional support, mutual respect, and love for one another were found to positively affect resilience of the family unit as a whole in 61.8% of participants (Jonker & Greeff, 2009).

2.9.2 Religion and spirituality. Several caregivers have stated that the resilience and courage of their child often serves as a source of strength as well as inspiration, which makes the task of caring a spiritually fulfilling one (Davis et al., 2009; Marshall et al., 2003). It has also been noted that raising a child with disability can lead to a journey of spiritual growth and transformation for many parents (Zhang & Rusch, 2005). The time that parents spend interacting with their children on a daily basis results in their transformation into better people, as they become more compassionate and patient through their caregiving duties (Zhang & Rusch, 2005). The task of living with or caring for a child with special needs can thus have a positive spiritual impact, where some family members discover a new spiritual belief, while others experience a re-awakening of their convictions (Bayat, 2007).

Bayat (2007) argued that having a spiritual belief system is one of the means for parents to develop adequate coping strategies for their caregiving roles. Although the initial period after diagnosis may be accompanied by denial, depression, and sadness, it has been noted that a belief in a higher power as well as faith have given many caregivers the courage and strength to make sense of their situation (Poston & Turnbull, 2004; Zhang & Rusch, 2005). Moreover, the strength that caregivers gain from their faith often serves as a resource that enables them to accept their child with special needs and to manage the accompanying challenges (Poston & Turnbull, 2004). Certain parents tend to add religious and spiritual meaning to their situation, which results in a belief that their child has special value (Bayat, 2007; Marshall et al., 2003). This causes parents to view their child as a blessing or a test of faith that was gifted to them so that they can develop into better human beings (Bayat, 2007; Marshall et al., 2003; Zhang & Rusch, 2005). Furthermore, the strength and personal well-being that family members gain from their belief systems or faith often enables them to ameliorate challenges that arise in other areas of their everyday life (Poston & Turnbull, 2004).

In South Africa, religion plays a major role in the lives of many individuals from diverse cultural and traditional backgrounds (Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006; Zhang & Rusch, 2005). Jonker and Greeff (2009) found that 67.6% of their participants relied on religion and spirituality as a coping mechanism. Processes including prayer, faith, a relationship with God, and the conviction that there is a bigger purpose in life have been identified as factors that give individuals strength during difficult periods (Jonker & Greeff, 2009). Furthermore, religious activities outside of the home, such as church attendance, prayer groups, or Bible study, have been identified as a means to gain emotional and spiritual support from others in the religious community, which assists caregivers to cope with their everyday challenges (Jonker & Greeff, 2009; Makoae et al., 2008). This form of support can be an important resource for caregivers in a country such as South Africa, where access to adequate support services as well as healthcare professionals is often limited due to financial, geographic, and transport difficulties (Marshall et al., 2003; Thrush & Hyder, 2014).

2.9.3 Changed perceptions. Caregivers have also expressed that by caring for a disabled child, they have been transformed into more competent and stronger individuals who are equipped with a greater appreciation for the more important aspects of life (Green, 2007; Myers et al., 2009). This new outlook allows individuals to examine life from a different perspective and can result in changed priorities for the family as a whole, where parents and children often learn not to waste their energy on trivial matters (Myers et al., 2009). Many caregivers have thus noted that they have learnt a great deal by slowing down and by taking their tasks one day at a time, which allows them to take the time to enjoy life as much as possible and to appreciate each milestone that their child reaches (Myers et al., 2009). In a study that examined coping strategies among HIV positive individuals in five African countries including Lesotho, Malawi, South Africa, Swaziland, and Tanzania; Makoae et al. (2008) found that one of the greatest coping strategies among these individuals was to focus on the immediate task and not worry about insignificant matters. By focusing their energy on the present, it has been argued that individuals are less prone to feel overwhelmed by their caregiving duties (Quinn, Murray, & Malone, 2013). Focussing on caring duties one day at a time could be a vital coping mechanism for caregivers from rural communities who do not receive much professional support, do not have the time to manage their problems, and have no choice but to focus on their work (Akintola, 2008).

Through their daily interactions with disabled children, many caregivers have also been found to develop a greater awareness of issues and individuals that they had never encountered before they became caregivers (Myers et al., 2009). Consequently, these caregivers have admitted that they have become more conscious and sensitive towards persons with special needs (Myers et al., 2009). In a study that focussed on the benefits and burdens of parenting a child with disability, Green (2007) found that caregivers of children with disabilities have a greater ability to look beyond an individual’s appearance or disability and perceive the person underneath than they could before. It is expected that many caregivers first approach their caring roles having had little exposure to individuals with disabilities (Green, 2007). However, through their endeavours to gain access to services for their children, many caregivers are exposed to the world of disability, which increases their comfort levels around individuals with disabilities or special needs (Bayat, 2007; Green, 2007).

In keeping with this improved awareness, Green (2007) found that many individuals experienced a personal growth for the better as a result of the processes involved in caregiving. It has been noted that caregivers of children with development disorders are sometimes prone to develop greater compassion, patience, and appreciation for those who are different (Bayat, 2007). Moreover, these individuals tend to become less judgemental and more accepting of individuals with disabilities as well as their families (Bayat, 2007). In line with such findings, by exploring the perceived rewards of informal caregivers for individuals living with AIDs in South Africa, Akintola (2010) found that caregiving enabled individuals to achieve self-growth through emotional and psychological development. Since caregiving can be a demanding and strenuous task, individuals have been found to develop a great deal of compassion, love, and patience for the individual they are caring for (Akintola, 2010). Furthermore, these caregivers also expressed that it is vital to have unconditional love for the individuals they are caring for and to not discriminate against them (Akintola, 2010).

Through advocating and caring for a child with disability, many caregivers have stated that they have gained invaluable skills as well as an improved sense of confidence that can often overflow into various areas of life and can even become a vital source of self-esteem (Green, 2007). It is through these skills and confidence that caregivers become more equipped to face any situation that they might encounter (Green, 2007; Phelps, Hodgson, McCammon, & Lamson, 2009). Bishop (2014) found evidence for this resource among a sample of individuals from the Western Cape who care for family members with schizophrenia, in that these caregivers revealed that they gained valuable knowledge from their experiences as family caregivers. Furthermore, this knowledge led to greater feelings of control and an improved ability to develop suitable solutions to the challenges that emerged in their daily lives (Bishop, 2014; Hartley et al., 2005).

2.9.4 Positive outlook. In the presence of a child with special needs, many caregivers are forced to generate and make use of new coping strategies on a daily basis (Bishop, 2014). One such coping mechanism is to make use of positive reframing (Bishop, 2014). When caregivers possess the ability to reframe their situation in a more positive manner, it allows them to develop hardiness and resilience (Bishop, 2014). In essence, positive reframing allows an individual to find positive meaning in a difficult situation through the activation of deeply held values (Gupta & Singhal, 2004). This form of coping encourages individuals to focus on the importance of the duties they are performing and it serves as an important means to assist these individuals to sustain their duties over an extended period of time (Gupta & Singhal, 2004). Positive reframing can thus be an important resource for caregivers of children with enduring disabilities such as CP, as they would need to perform their duties with compassion and patience over a long period of time.

It is also vital to examine caregiver resources and traits, as these can play a role in ameliorating personal distress (Given, Given, & Sherwood, 2012). One of the personality traits that has been linked to positive outcomes, in spite of the presence of adversity, is an individual's inclination towards optimism (Given et al., 2012). Individuals who possess a sense of optimism are often better equipped to endure the many hardships that accompany caregiving. This is because optimism among caregivers has been associated with lower rates of depression, less worry and delay to seek medical care, as well as increased hope for a positive outcome following medical care; which makes this trait one of the most effective protective mechanisms against the caregiving burden (Given et al., 2012).

The physical condition of the individuals they care for can also be a source of stress for caregivers, especially when they are physically disabled (Akintola, 2008). At first it might be difficult to care for individuals who are in a pitiable condition, however, over time caregivers are able to appraise the situation and make adjustments that allow them to cope (Akintola, 2008). It is thus important for caregivers to accept the reality of caring for individuals who are bedridden or immobile (Akintola, 2008). Bishop (2014) found that it was vital for family carers to accept a condition or illness as part of their lives and to approach it one day at a time. By accepting their situation, caregivers were equipped with the ability to make meaning out of it (Bishop, 2014; Walsh, 2003). When caregivers can make meaning out of their situation, their stress levels will decrease and they will be able to find different ways to cope with it (Bishop, 2014; Walsh, 2003). Therefore, by accepting their situation caregivers would be able to focus their energy towards the resources that would make coping possible.

From the available literature, it was noteworthy that there are a greater number of barriers that have been identified in caregiver studies in comparison to the facilitators or coping factors. Most studies on the caregiver experience have focussed on the barriers that are associated with caring for a child with CP (Chakravarti, 2008; Davis et al., 2009; Hamzat & Mordi, 2007; Huang et al., 2011; Isa et al., 2013; Murphy et al., 2006; Ones et al., 2005; Raina et al., 2006; Resch et al., 2010; Whittingham et al., 2011) while less emphasis has been placed on the facilitators that make caregiving easier (Bayat, 2007; Hartley et al., 2005). Although it is important to acknowledge the barriers that often influence various aspects of a caregiver's life, it is equally important to focus on the facilitators that might serve as vital coping mechanisms that could make the caregiver burden easier to manage.

The quality of life of children with CP has received much focus in the literature, while less emphasis has been placed on the quality of life and health of caregivers for children with CP (Byrne et al., 2010; Davis et al., 2009). Since the health of a child is influenced largely by the well-being of their caregiver, it is vital to explore how individuals can be better equipped to manage their caring duties (Murphy et al., 2006). Furthermore, the majority of information regarding the impact of caregiving has been accumulated from studies conducted in developed countries (Davis et al., 2009; Green 2007; Katz & Johnson, 2013; McManus et al., 2006; Murphy et al., 2006; Raina et al., 2005; Resch et al., 2010; Whittingham et al., 2011); while less emphasis has been placed on the caregiver experiences in developing countries (Donald et al., 2014; Thrush & Hyder, 2014). There is thus a need to explore this topic in further detail, especially in the context of a developing country such as South Africa. It is for this purpose that the present study aimed to explore the barriers and facilitators that may influence the process of caregiving in rural communities of the Western Cape, South Africa.

2.10 Summary

This chapter provided an overview of the literature in relation to the experiences of caregivers for children with CP. A background of CP was provided by discussing its etiology, epidemiology, clinical picture, diagnosis, as well as the factors related to caring for a child with CP. To highlight the experiences of caregivers for children with CP, the barriers to caregiving and the facilitators that make caregiving easier were discussed. This discussion also included an application of these various barriers and facilitators to the South African context. The following chapter will provide an overview of the Social Ecological Model (McLeroy et al., 1988), the theoretical framework that was used to interpret the results of this study.

Chapter 3: Theoretical Framework

This chapter will describe the theoretical framework that was chosen to guide investigation and to explain the experiences of caregivers for children with CP. This will be achieved by discussing the importance of theory in research. Thereafter, the different levels of the Social Ecological Model will be defined and described; namely the individual level, the interpersonal level, the community level, the institutional level, and the societal level (McLeroy et al., 1988). Finally, relevant examples related to the caregiver experience will be provided for each level of the Social Ecological Model in order to demonstrate the applicability of this model to the present study.

3.1 The Importance of Theory

Anfara and Mertz (2006) have argued that theory has an important role in research, regardless of whether one is using a qualitative or quantitative approach to explore a specific topic. Furthermore, theory plays a vital role in the framing and implementation of all aspects of a research study (Anfara & Mertz, 2006). In qualitative studies, the role of theory often extends beyond the margins of one particular study (Anfara & Mertz, 2006). It is thus through the guidance of a theoretical framework that investigators are able to carry out a particular research study (Anfara & Mertz, 2006). However, the utilisation of theory should not be restricted to only creating a framework that structures a research study; rather it should also provide the foundation for the planning of interventions (Sales, Smith, Curran, & Kochevar, 2006). This means that the theory must be strongly linked to the procedures that are implemented as well as the tools that are selected as part of intervention planning (Sales et al., 2006).

In order to determine the theoretical framework for the present study, I consulted several theories that could have been utilised to explore the caregiver experience. These included the model of Functional Support (Sherbourne & Stewart, 1991), which explores five different measures of social support (informational support, emotional support, tangible support, instrumental support, and social companionship); the Family Resilience Framework (Walsh, 1996), which acknowledges the potential for personal and interpersonal growth in the presence of adversity through the use of the key processes for resilience (family belief systems, problem-solving processes, and family organisational patterns); and the Social Model of Disability, which views society as being responsible for disabling the physically impaired by excluding and isolating them (Union of the Physically Disabled Against

Segregation, 1975). However, after consideration of these theories, the Social Ecological Model (McLeroy et al., 1988) was chosen as the theoretical framework that would be used to guide investigation and to explain the experiences of caregivers for children with CP. This particular type of model was chosen because it places emphasis on the interconnected relationship between individuals and their social contexts, which allows one to examine the challenges and resources of caregivers at not only the individual level, but also at the broader social level (Bronfenbrenner, 1977; Liburd & Sniezek, 2007). Furthermore, this model also allows one to illustrate how the overall well-being of caregivers can be influenced by numerous factors, including child behaviours, parenting tasks or even the individual-environment interaction (Resch et al., 2010).

3.2 The Social Ecological Model

The Social Ecological Model is considered to be a variation of Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1977) and it explains healthy and unhealthy behaviours as being shaped by five levels of influence; namely individual factors, interpersonal processes, institutional factors, community factors, as well as social policy, structures or systems (McLeroy et al., 1988). These five levels are interrelated, where a change in one level will not only influence the individual but will also cause a ripple effect in the other levels. It is for this purpose that the Social Ecological Model was used in the present study, as it would allow one to identify how caregivers are influenced by the various interrelated systems that form part of their daily life.

The most specific sphere of influence is the individual level (McLeroy et al., 1988). This particular level focuses on biological and personal characteristics that influence human behaviour, such as age, levels of education, and employment status (Gregson et al., 2001). Factors pertaining to the individual level can also include behavioural choices as well as cognitive and psychological factors, such as attitudes, perceptions, knowledge, skills, and personality traits (Gregson et al., 2001; McLeroy et al., 1988). An example that is applicable to this study would be the caregiver's experience of their child's diagnosis with CP, the financial burden that is experienced by caregivers when they are unable to obtain employment, or concern for their child's future when they are no longer present.

The interpersonal sphere of influence encompasses all primary groups that serve as a source of interaction, social identity, and support for a given individual, such as acquaintances, family members, friends, neighbours, peers, and work colleagues (McLeroy et al., 1988). Individuals exist as part of a dynamic social context, where the actions and attitudes of others influence their behaviours (Gregson et al., 2001). Furthermore, social relationships can also be central to the development of social identity, as they provide vital social resources, including access to new social contacts, emotional support, information, tangible assistance, as well as assistance to fulfil certain responsibilities and obligations (Israel, 1982). An example of this level of influence would be the positive or negative interactions that take place between a caregiver, the child or children in their care, members of their family, neighbours, as well as friends. This can include tangible assistance with the child with CP or emotional support from friends or family members during challenging periods.

The third level of influence concerns the characteristics of the institutions or organisations with which an individual interacts (McLeroy et al., 1988). This includes factors that shape behaviour in the private, public, and non-profit spheres (Gregson et al., 2001; McLeroy et al., 1988). Resources at the institutional level aim to facilitate the integration of efforts to promote health in various programmes and aim to improve access to services within various communities (Fleury & Lee, 2006). These institutions can include public agencies, businesses, churches, or service organisations that reach large portions of the population through their practices and procedures (Gregson et al, 2001). Examples of the institutional factors that impact the caregiving experience can include practices within the healthcare system, such as weak referral systems in clinics or hospitals as well as a lack of access to vital services.

The community sphere of influence refers to the contexts in which social relationships occur and it seeks to identify the environmental characteristics that influence human behaviour (Gregson et al., 2001; McLeroy et al., 1988). Community resources often have an important impact on the formation of a supportive personal and physical context (McLeroy et al., 1988). Stokols (1996) argued that the environment can serve as a source of danger when there is poor sanitation or perceptions of an area as unsafe; while it can also serve as a source of health resources when there is exposure to cultural practices that promote health behaviours or access to primary healthcare services. Examples of the community level within the present study could include the adverse environmental conditions within a particular community that impact the living conditions of caregivers as well as their children, or it could include the availability of support from community members and organisations.

The broadest level of influence that forms part of the Social Ecological Model includes social policies, structures, and systems (McLeroy et al., 1988). This level includes societal factors that influence attitudes towards individuals with disability as well as factors that can create or prevent inequalities between different groups within society (Gregson et al., 2001; McLeroy et al., 1988). These can take the form of laws that maintain or support healthy behaviour, social and cultural norms regarding disability, as well as health and economic policies (Gregson et al., 2001; McLeroy et al., 1988). These policies can encompass broad societal factors including economic, educational, health, and social policies that create a climate where health is maintained and where there are few economic or social inequalities between groups (Gregson et al., 2001). An example could include the state's provision of the disability grant to individuals who are physically disabled in order to compensate for the challenges that often accompany disability.

3.3 Summary

This chapter outlined the theoretical framework that was used to describe and interpret the experiences of individuals who care for a child with CP in terms of the barriers and facilitators to caring, which influence their abilities to cope with their caregiving roles. This was achieved by discussing the importance of theory in research, the tenets of the Social Ecological Model, and the different levels of this model; namely the individual level, the interpersonal level, the community level, the institutional level, and the societal level (McLeroy et al., 1988). In order to demonstrate the applicability of this framework to this study, relevant examples of possible factors that could form part of the caregiver experience at the different levels of the Social Ecological Model were provided. This framework was used to guide data collection and to interpret the findings of this study. The chapter to follow will outline the methodology that was utilised for the present study.

Chapter 4: Method

4.1 Introduction

This chapter will provide an overview of the methodology that was incorporated into the present study. Firstly, the rationale and motivation for this study will be provided. Thereafter, the research aims and objectives will be presented. This will be followed by a discussion of the research study design, participant characteristics, as well as the procedures involved in data collection. Moreover, the processes that were utilised to conduct data analysis and to maintain trustworthiness will be described. Finally, the ethical considerations that were incorporated into the present study will be outlined.

4.2 Rationale for the Present Study

To date, many of the studies that have investigated the caregiving experience have been conducted in developed countries comprising of middle- and high-income areas, while low- and middle-income regions have received less attention (Thrush & Hyder, 2014). The lack of studies on the caregiving experience in developing countries is concerning, as disability rates are often higher across these regions (World Health Organisation, 2011). For instance, the prevalence rate of CP in Africa has been estimated to be between 2 and 10 per 1000 live births, which is dramatically higher than the global prevalence rate of 2-2.5 per 1000 births (Donald et al., 2014; Oskoui et al., 2013).

In developing countries such as South Africa, it has been speculated that the complex relationship between disability, poverty, and health is often influenced by the environmental and social contexts in which individuals with disabilities as well as their families live (Parnes et al., 2009). Therefore, it is possible that individuals encounter unique challenges and resources in developing countries that have not been identified in the literature from developed countries (Davis et al., 2009; Donald et al., 2014; Thrush & Hyder, 2014). This could include factors such as lack of access to financial aid, cultural beliefs regarding disability, and lack of disability-friendly transport (Awokuse & Xie, 2014; Davis et al., 2009; Donald et al., 2014; Thrush & Hyder, 2014). For this reason, it is vital to explore the caregiving experience in a developing context such as South Africa.

Since healthcare services are often located in more centralised areas, access to the treatment and equipment that aids caregiving and mobility is often too challenging for individuals who reside in rural areas (Borg et al., 2011). This could mean that caregiving is often accompanied by a greater number of challenges in rural communities, which is why it is necessary to focus on such regions. After conducting a literature review, it was found that caregivers often encounter a significantly greater amount of challenges than resources. However, by exploring the experiences of caregivers of children with CP in rural communities of the Western Cape, it is possible that suggestions can be made on how caregivers could attain more resources and how they could cope with the challenges that they encounter on a daily basis. By examining this underexplored facet of caregiving, the present study could improve our understanding of the caregiving experience in rural South African communities.

4.3 Research Question

The present study aimed to explore the following question:

- What are the experiences of caregivers for children with cerebral palsy residing in rural communities of the Western Cape, South Africa?

4.4 Aims and Objectives

The present study sought to investigate the experiences of caregivers of children with cerebral palsy, with primary focus on:

1. The types of barriers these caregivers face that are associated with caring for a child with cerebral palsy; and
2. The facilitators that these individuals receive that assist them to adjust to the illness as well as their caregiving duties.

4.5 Research Design

Since caregivers provide such vital services to their families as well as society, it is important to explore and understand their experiences (Resch et al., 2010). Despite its capacity to attain a rich understanding of individual experiences, there has been an underutilisation of qualitative approaches due to perceptions that they are too subjective (Resch et al., 2010). However, Merriam (1995) argued that qualitative research is useful when one seeks to understand a particular phenomenon or situation, and to understand how a particular group of participants experience their daily roles. This study, which sought to investigate the experiences of caregivers for children with CP, implemented an exploratory qualitative research design. This particular design was utilised for the present study, as qualitative methods allow researchers to perform comprehensive studies on specific topics and they produce vast amounts of detailed information, which will enhance our understanding of the cases and conditions being studied (Patton, 1990).

4.6 Description of Participants

Purposeful sampling methods were used to identify potential participants for the present study. This sampling strategy allows one to identify a selection of participants that would provide the most in-depth responses in relation to a specific topic of interest (Patton, 1990). Inclusion criteria for each participant thus necessitated that they were the primary caregiver (parent or individual responsible for daily care and decision making) of a child with CP, they were older than 18 years of age, they could conduct the interview in English or Afrikaans, and that they resided in a rural community in the Western Cape. For the purpose of the present study, a rural community is defined as a large area consisting of individuals who depend on natural resources, migratory labour, and/or social grants from the state in order to survive (Rural Development Task Team & the Department of Land Affairs, 1997). This mostly included individuals who resided in or near informal settlements in various rural locations across the Western Cape.

According to Morrow (2005), it is ideal to aim toward larger sample sizes of approximately 12-15 participants in order to reach a point where no new information arises from the interviews. I thus conducted 15 semi-structured interviews with the identified participants that lasted between 30 and 90 minutes. However, the number of interviews ultimately depended on theoretical saturation or the point where no new themes were emerging from participants (Lincoln & Guba, 1985). By the twelfth interview I had found that various themes had been repeatedly mentioned during the preceding interviews and that no new information was emerging, as saturation had been reached. At this stage, I had already scheduled the last three interviews and I wanted to ensure that I had obtained the most detailed description of the caregiver experience. Furthermore, the only male participant was one of the final three interviews and I thought that it would be valuable to obtain a male caregiver’s perspective. For these purposes I conducted the last three interviews.

A total of 15 participants were included in the present study. One participant was male while the remaining 14 were female, and participants ranged from 27 to 62 (mean = 44) years of age. The participants consisted of six coloured and nine African caregivers. Seven of the participants were single (46.67%), two were widows (13.33%), and six were married

(40%). Ten of the participants were the mothers of the child they care for (66.67%), three were foster mothers (20%), one was the father (6.67%), and one was the grandmother (6.67%). Eleven of the participants were unemployed (66.67%), one was an unpaid caregiver, and all but one of the caregivers were receiving a grant from the state. For those participants receiving it, the grant often served as the only source of income for the household, as many of the participants could not find employment due to the demands of caregiving. Finally, the years of caregiving experience ranged from 3 to 23 (median = 13) years among participants (see Table 4.1).

Table 4.1

Demographic description of participants

Participant Code	Age	Race	Gender	Marital status	Relationship to child(ren) with CP	Years of caregiving experience
F1	62	African	Female	Widow	Grandmother	12
F2	49	African	Female	Single	Mother	10
F3	29	Coloured	Female	Single	Mother	13
F4	62	Coloured	Female	Married	Foster mother	10
F5	33	African	Female	Married	Mother	14
F6	33	African	Female	Single	Mother	5
F7	41	Coloured	Female	Married	Mother	7
F8	55	Coloured	Female	Married	Mother	15
F9	48	Coloured	Female	Single	Mother	14
F10	27	Coloured	Female	Single	Mother	8
F11	31	African	Female	Married	Foster mother	3
F12	47	African	Female	Widow	Foster mother	18
M13	54	African	Male	Single	Father	18
F14	40	African	Female	Married	Mother	18
F15	41	African	Female	Single	Mother	23

Note. Participant code: F = Female, M = Male; 1 = Number of interview; Relationship to child(ren) with CP = the degree to which the caregiver is related to the child(ren) with CP. Mother would thus denote that the caregiver is the mother of the individual(s) with CP.

There were subtle differences between participants in terms of their age, employment status, marital status, the age of the child or children being care for, as well as the years of caregiving experience. This resulted in a heterogeneous sample of participants. Due to the variable nature of the condition, it is possible that the carers of children with CP would have varying experiences, which might make the sample more representative of the broader population of caregivers. The overall focus of this study was to explore the experiences of a specific group of individuals (caregivers for children with CP); while factors such as the age of the child, the years of experience, and the relationship to the child were not the main focus and could thus vary.

4.7 Data Collection Procedures

In order to select a sample of caregivers for children who have been diagnosed with CP, I contacted the Eastern Cape Cerebral Palsy Association with an explanation of the nature of the present study and received a list of several contacts for organisations in the Western Cape. After forwarding my request to the aforementioned organisations, I received feedback from two; namely Shonaquip (a supplier of wheelchairs to individuals with physical disabilities in South Africa) as well as the Western Cape Association for Persons with Disabilities, who referred me to several of their rural branches. Participants were thus identified by social workers for Shonaquip, the Drakenstein Association for Persons with Disabilities, as well as the Breede Valley Association for Persons with Disabilities, who obtained a list of individuals who met the inclusion criteria of the study and inquired whether they were interested in partaking in it. Thereafter, the names and contact details of potential participants who had expressed interest were forwarded to me so that I could contact them and schedule a meeting with them.

Data collection took place over the period of May and June 2014 in several rural communities in the Western Cape, including the Breede Valley, Du Noon, Khayelitsha, Philippi, and Wellington. Individuals who met the inclusion criteria were contacted via telephone, they were informed of the particulars of the study, and they were invited to participate. Thereafter, a once-off meeting was arranged at a time and place that suited each participant. In order to reduce their transportation costs, participants were either met at their home, at their child’s school, or at a community centre in their area. A quiet room was provided by the staff when the interviews were conducted at a school or the resource centre. I was accompanied by a social worker to each interview, as they had already established rapport with the identified participants and introduced me to them, which made it easier to connect with the participants.

Prior to the start of any data collection, the purpose and relevance of this study was explained to each participant and they were asked to sign an informed consent form that outlined the nature of this study (see Appendices D & E). Due to the incorporation of a qualitative research design, the method of data collection was a semi-structured interview. In order to assist the transcription process, each interview was recorded once permission had been obtained from the participants. Each interview commenced with a biographical questionnaire that explored the participants age, gender, the age of the child they care for, and how long they have been caregiving (see Appendices B & C). Thereafter, participants were asked broad open-ended questions in order to elicit their personal experience of caring for children with CP (see Appendices F & G).

These interviews were guided by the following questions:

1. How did you feel when your child was diagnosed with CP? How do you feel about it now?
2. What are the main challenges that you have experienced as a caregiver? Who or what makes caregiving difficult for you?
3. Tell me about your support systems? Who or what makes caregiving easier for you?
4. Tell me about a typical day for you. How does your day begin? What all do you do during the day and with whom?

I also made use of probing techniques during these interviews to ensure that I was obtaining as much data as possible from each participant. Each interview ended with me thanking the participants for their involvement in the study, after which they were given a R75 meal voucher as a token of my appreciation for their participation.

4.8 Data Analysis

Data analysis is one of the most complex phases of a qualitative research project (Thorne, 2000). It is vital for a qualitative researcher to continually engage with analytic processes throughout research procedures in order to develop results that translate raw data into meaningful knowledge (Thorne, 2000). There are a variety of analytical methodologies available for use in qualitative research, depending on how the investigator intends to organise, conceptualise, refine, and interpret the research data (Thorne, 2000). Common analytic approaches include discourse analysis, ethnography, grounded theory, phenomenology, and thematic analysis (Braun & Clarke, 2006; Thorne, 2000). Although these approaches share the goal of developing codes and categories from a particular data set, they differ in terms of their overall focus and research procedures (Thorne, 2000). For example, grounded theory perceives the primary focus of qualitative research to be the generation of theories regarding a particular phenomenon, which is typically achieved by conducting primary studies where data collection and analysis occur simultaneously (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Thorne, 2000). Discourse analysis perceives speech to be shaped by ideological or social influences, and seeks to analyse the way individuals communicate in order to discover the underlying meanings (Thorne, 2000). In ethnography, a researcher seeks to understand cultural rules and behaviours by observing or participating in a particular situation (Thorne, 2000). Phenomenology is not focussed on discovering patterns or themes in order to understand human experience; rather it seeks to uncover the essence of human experience through an intensive examination of individual cases (Thorne, 2000). Finally, thematic analysis is concerned with the identification of recurrent or prominent themes within a particular data set (Dixon-Woods et al., 2005).

4.8.1 Thematic analysis. Thematic analysis was utilised to analyse the data of the present study in order to identify the barriers and facilitators to caring for a child with CP. Thematic analysis is a technique that is used to identify, analyse, and report themes or patterns within a data set (Braun & Clarke, 2006). This type of analysis is appropriate for any research project that seeks to gain knowledge through the use of interpretation (Braun & Clarke, 2006). Thematic analysis differs from other methods of analysis that strive to identify patterns across a data set, as it is not linked to a specific theoretical framework and can thus be used in conjunction with a variety of theoretical frameworks (Braun & Clarke, 2006). Thematic analysis also does not require the technical and theoretical knowledge that are required by other analytical methodologies, such as grounded theory or discourse analysis (Braun & Clarke, 2006). One of the greatest benefits of using thematic analysis is that it is a flexible approach, which means that themes can be identified in multiple ways and still produce a rich description of the data (Braun & Clarke, 2006). It would thus be appropriate for a novice researcher to utilise thematic analysis to analyse a qualitative set, since it is a relatively simple method to incorporate (Braun & Clarke, 2006).

This approach is not free from criticism, as it has been argued that a theoretical grounding could provide a sense of depth and purpose to a data set that thematic analysis might not produce (Pringle, Drummond, McLafferty, & Hendry, 2011). It has also been noted that due to the flexibility of this approach, which allows for a variety of analytic options, it can be unclear what the actual aims and procedures of thematic analysis entail (Dixon-Woods et al., 2005). Furthermore, it has been contended that thematic analysis is often limited to a mere description, with little interpretative power, if it is not used in conjunction with an existing theoretical framework that can support the analytical assertions that are being made (Braun & Clarke, 2006; Dixon-Woods et al., 2005). However, it has been proposed that if thematic analysis is undertaken in a meticulous manner, then it is possible for an investigator to produce an insightful analysis that answers the research question (Braun & Clarke, 2006). Furthermore, Braun and Clarke (2006) have proposed a concise and clear six step approach that can be applied to a data set in order to thoroughly conduct thematic analysis. It was for this purpose that thematic analysis was chosen as the analytic methodology for the present study, as the ultimate aim was to identify and describe patterns as well as themes within the data that represented the greatest barriers and facilitators among caregivers for children with CP.

4.8.2 Steps of thematic analysis. The qualitative data for the present study was analysed by integrating the six steps of thematic analysis that are proposed by Braun & Clarke (2006). These steps were used in conjunction with the Social Ecological Model (McLeroy et al., 1988) in order to analyse the data of the present study. In line with this method, the first step involves immersing oneself in the data, which can be achieved by transcribing the data, followed by reading it and re-reading it until one is familiar enough with the data to generate preliminary ideas from it (Braun & Clarke, 2006). I conducted all of the interviews with the participants myself, which allowed me to form ideas about the data at an early stage. After the interviews were transcribed, I read and re-read the transcripts in order to familiarise myself with the data. Although I did not transcribe the interviews myself due to time constraints, I read the interview transcripts while listening to the audio recordings of each interview in order to ensure that all of the transcripts were an accurate representation of the recorded interviews, which also allowed me to gain more familiarity with the data. During this phase I began to note interesting aspects of the data, which could be used in the later phases of analysis.

The second step entailed the generation of initial codes from the data set, which involved identifying interesting aspects of the data and then collating the data to each code (Braun & Clarke, 2006). By the time I began coding, I had already familiarised myself with the data and had thus formed initial ideas about it. During this phase, I coded interesting aspects of the data that appeared to be relevant to the research question (Braun & Clarke, 2006). I first coded each transcript by hand, where I noted interesting aspects of the data in the margin of each transcript. Thereafter, this process was undertaken electronically by creating a table with three columns in MS Word for each interview, where the interview transcript was pasted in the leftmost column, the code was entered into the middle column, and the potential theme was entered into the rightmost column. Once I had systematically worked through each interview, paying full attention to all items, I was then able to search for repetition of codes across the data set (Braun & Clarke, 2006).

Once initial codes had been identified and the data had been collated, the third step required me to sort through the codes in order to identify themes and merge coded extracts to form the main themes (Braun & Clarke, 2006). During this stage, the focus shifted from the codes to the themes, where the codes were organised into themes (Braun & Clarke, 2006). By integrating thematic analysis, I was able to use my own judgement to identify themes within the data. Themes are typically classified as information that appears frequently across a data set (Braun & Clarke, 2006). Furthermore, a theme can also be chosen based on its capacity to provide information within the data that can be used to answer the research question (Braun & Clarke, 2006). It is vital to note that the importance of a theme cannot be determined by quantifiable methods; rather it is determined by its relevance to the research question (Braun & Clarke, 2006). For the present study, these themes represent the barriers and facilitators that were identified by caregivers of children with CP. After I had coded the data, I began searching for themes across the data. This was achieved by creating a table for each level of the Social Ecological Model (McLeroy et al., 1988); namely the individual, interpersonal, community, institutional, and societal levels. The coded extracts that were relevant to each level were pasted into these tables so that I could collate the codes and search for patterns of repetition within the data set (Braun & Clarke, 2006). I also made use of mind maps for each of the different levels of influence and used this in order to group these codes into themes and sub-themes (Braun & Clarke, 2006).

During the fourth stage, I refined the themes that I had already identified during the third step, which required me to establish whether the themes correlated with the coded extracts as well as the entire data set (Braun & Clarke, 2006). It became evident that certain preliminary themes were not really themes, that other themes needed to be broken down into separate themes, and that some themes were overlapping (Braun & Clark, 2006). Two approaches were employed to review and refine themes during this stage (Braun & Clarke, 2006). The first required me to review at the level of the coded extracts, where I re-read the collated extracts in order to ensure that they formed a coherent pattern (Braun & Clarke, 2006). Once I had established that the themes formed a coherent pattern, I was able to move onto the second stage of reviewing the themes. The second approach required me to review at the level of the entire data set, in order to ascertain whether the themes represented the entire set and to code any items that might have been left out in the previous stages of analysis (Braun & Clarke, 2006). By the end of this stage I had knowledge of the various themes, I understood how they were connected, and I was aware of the overall story that they revealed about the data (Braun & Clarke, 2006).

During the fifth step, I defined and further refined the themes that were identified in the previous stages (Braun & Clarke, 2006). Thereafter, it was vital to identify where each theme fit into the broader description that was being provided about the data (Braun & Clarke, 2006). This involved identifying the “essence” of each theme and determining what aspects of the data were being captured by each theme (Braun & Clarke, 2006, p. 92). During this stage, I returned to the collated extracts for all of the themes and arranged them in order to provide a coherent account of the data with accompanying quotations. By the end of this process I was able to define and describe each theme with clarity. I was also able to distinguish between themes and sub-themes, as well as to understand why certain themes fit together while others did not (Braun & Clarke, 2006).

The sixth step entailed writing a report with vivid examples which validated the overarching argument; this was accomplished by making use of direct quotations from the interviews to describe the themes that were identified (Braun & Clarke, 2006). During this stage I completed the final analysis and the report of the results (Braun & Clarke, 2006). The nature of the data was discussed and described in such a manner that the complex story of the data would be relayed to the reader (Braun & Clarke, 2006). It is vital that the final report provides a clear, comprehensive, rational, stimulating, and non-repetitive description of the story being told by the data (Braun & Clarke, 2006). This report attempted to provide more than a mere description of the data by embedding vivid examples within an analytic narrative that told a story about the data and provided an argument that relates to the research question

(Braun & Clarke, 2006). The results of the present study are reported in Chapter 4 according to the main and sub-themes that were identified as barriers and facilitators to the caregivers.

4.9 Maintaining Trustworthiness

According to Long and Johnson (2000), it is vital for any research study to be open to evaluation and critique, as the evaluation of a study is often considered to be a pre-requisite to the application of its findings. Ordinarily, such evaluation is determined by validity and reliability measures, however, the use of such methods has been questioned in qualitative research (Long & Johnson, 2000). Lincoln and Guba (1985) have proposed four criteria that can be used to ensure trustworthiness in qualitative research; namely credibility, confirmability, dependability, and transferability. The criteria and processes that were utilised to improve trustworthiness will be discussed in this section.

4.9.1 Credibility. Credibility is the equivalent to internal validity in quantitative studies, and it is concerned whether ones research findings are truly representative of reality (Decrop, 1999; Merriam, 1995). In order to ensure that the phenomenon under study was accurately recorded, peer debriefing, peer examination, and member checks were employed.

Peer Debriefing. Peer debriefing refers to the process where a researcher will discuss emerging findings with a colleague who is experienced in the field of qualitative research, in order to stimulate the examination and consideration of additional explanations or perspectives throughout the collection and analysis of data (Long & Johnson, 2000). This measure was achieved throughout the research process by discussing and comparing ideas regarding the methods and findings with my supervisor on a regular basis.

Peer Examination. Peer examination refers to the practice whereby an unbiased colleague or peer with knowledge of qualitative methods will examine the research procedures in order to comment on the plausibility of a research study (Krefting, 1991). Before data collection could commence, the research plan for the present study was reviewed by two colleagues from the Department of Psychology at Stellenbosch University who serve on the Departmental Ethics Screening Committee (DESC) and who possess expertise in the field of qualitative research. Thereafter, the research plan was reviewed and approved by the Health Research Ethics Committee (HREC) at the Faculty of Health Sciences at Tygerberg Hospital. I also received continuous feedback from my supervisor and met with her to discuss the research proceedings and emergent findings throughout this study.

Member Checks. Member checking is a strategy whereby the researcher will verify the findings of the collected data with participants in order to ascertain whether it is an accurate representation of their viewpoints (Krefting 1991; Long & Johnson, 2000). One would usually discuss emergent themes with participants in order to establish whether these themes are a true reflection of what was said during the interviews, however, time constraints and geographical barriers prevented me from doing so. This measure was thus utilised during the interviews by clarifying points made by participants through the use of summarising, in order to ensure that I had understood and correctly interpreted what the participants were saying. The social workers were also useful in this regard, as they had previous knowledge of the participants' experiences and could clarify certain points for me before, during, and after the interviews.

4.9.2 Confirmability. Confirmability is the equivalent to objectivity in quantitative research, and is centred on the awareness that qualitative research can never be free of subjectivity (Morrow, 2005). Confirmability assures that the research findings accurately represent the conditions or informants under study, as opposed to representing the beliefs and biases of the researcher (Decrop, 1999). In order manage the impact of subjectivity in the present study, I made use of reflexivity and triangulation.

Self-reflection. Reflection is an important aspect of qualitative research (Long & Johnson, 2000). Furthermore, reflexivity requires the researcher to reflect on their beliefs in a similar manner to how they would examine the beliefs of their participants (Long & Johnson, 2000; Porter, 1993). Possible factors that could have influenced the data collection procedures are the fact that I am a 23 year old female student, who is still gaining experience and credibility in the field of qualitative research. Prior to the commencement of this research study, I had known little about CP, but I consulted various research articles in order to learn more about CP and the caregiver experience so that I was prepared for the interviews with participants. This research project required me to travel to places that I have never visited before, which was nerve-wracking at times, especially when I travelled to informal settlements on my own. Furthermore, as a white female student, I had to bear in mind that I would be interacting with individuals who ranged between 27 and 62 years of age, who had varying levels of education, and who were of a different race and/or culture than myself. Going into the interview process, I was thus nervous how these individuals would respond to my presence and I worried that they might not want to be interviewed by a much younger female from such a different background. However, I found that my age, race, and level of experience did not have a negative impact on the interview process, as the participants were interested in assisting me with this study and seemed genuinely grateful that someone was investigating their experiences. Moreover, I found that I have definitely grown through this experience and that I gained an improved sense of independence through my travels to meet with each participant. I also reflected on my experiences of the interviews with my supervisor during our scheduled meetings and I compiled a descriptive profile for each participant in order to reflect on my experiences of the interview process (see Appendix H). Through this self-awareness, I feel that I was able to minimise the impact of researcher bias.

Triangulation. Triangulation refers to the use of several sources of data, methods of data collection, theories, or researchers (Long & Johnson, 2000). In relation to confirmability, triangulation incorporates a variety of perspectives in order to provide multiple slices of data, which reduces the potential impact of investigator bias (Krefting, 1991; Merriam, 1995). Triangulation of data involves the use of diverse sources of data in a research study in order to obtain a greater understanding of a specific topic (Decrop, 1999; Krefting, 1991). This would usually involve the inclusion of participants, community members, program members, and even other researchers in order to gain insight into a specific phenomenon (Guion, 2002). However, the purpose of the present study sought to focus primarily on the caregiver experience. Therefore, to ensure that triangulation of data took place, a sample of 15 individuals who differed on variables such as age, gender, location, and duration of caring was utilised in the present study. Triangulation of theory is achieved by incorporating ideas from a variety of perspectives in order to explore a particular condition or situation (Krefting, 1991). This is usually achieved by involving individuals from different fields of study in the interpretation of the research data, where validity would be established if each evaluator interprets the same meaning from the data (Guion, 2002). However, it is also possible to include individuals within the field of study, provided that they are of a different ranking to the primary researcher (Guion, 2002). This form of triangulation was thus achieved by discussing emergent themes with my supervisor as well as a doctoral student from the department, in order to compare different ideas and thus incorporate multiple perspectives on the same topic. Triangulation of researchers is achieved by making use of several researchers to analyse the same set of data (Decrop, 1999). This is typically achieved by making use of an evaluation team that consists of colleagues within a particular field of study, where each evaluator would make use of the same qualitative method to analyse the research data (Guion, 2002). Comparisons can be made of each evaluator’s findings and if each evaluator arrives at the same conclusion, then one's confidence in the results can be heightened (Guion, 2002). In order to implement this form of triangulation, the process of data analysis was undertaken by a study team, consisting of myself and my supervisor, who independently analysed the same set of data (Krefting, 1991). Before the final report could be written up, myself and my supervisor discussed emergent themes until we reached a consensus where there were any discrepancies.

4.9.3 Dependability. Dependability can be matched to reliability in quantitative studies, and concerns whether the research findings are consistent (Krefting, 1991). In order to ensure that dependability is achieved in a given study, it is vital to provide an in-depth description of the methods that were used to collect, analyse, and interpret data (Krefting, 1991). Such thick descriptions allow future researchers to replicate the study or to obtain similar results (Shenton, 2004). Furthermore, these in-depth descriptions also enable the reader to gain a thorough understanding of the research procedures, while also allowing them to evaluate whether the appropriate research methods were followed (Shenton, 2004). In order to maintain the dependability of the present study, detailed descriptions of the research plan and the implementation thereof were provided. Moreover, a detailed report of the data collection procedures was also provided, which improved the possibility of replicating this study in the future.

4.9.4 Transferability. Transferability refers to the extent to which the findings of a research study can be generalised to a different context or group, and is thought to mirror external validity (Decrop, 1999). The present study provided thick descriptions of the research topic, the participants, and the study context so that other researchers will be able to ascertain whether their circumstances are matched to those that were explored; which would determine whether the research findings can be transferred. Furthermore, a diverse group of informants who differed on factors including age, gender, and years of caregiving experience were included in the study sample, and a variety of research sites were visited during data collection. Despite the different data collection sites and the diversity of participants, the participants of this study are not truly representative of the broader population, and the results cannot be generalised. This has been recognised as a limitation of the present study (see Chapter 5).

4.10 Ethical Considerations

Before the present study could commence, it was reviewed by two members of the Department of Psychology at Stellenbosch University, after which a request for ethical approval was submitted to the Health Research Ethics Committee (HREC) at the Faculty of Health Sciences at Tygerberg Hospital. Ethical approval was obtained from the HREC with the reference number S14/03/061. Participants who were invited to partake in the present study were briefed on the particulars of the study as well as its relevance. Individuals were also informed that their participation would be voluntary and free of charge. Furthermore, participants received a meal voucher valued at R75 as a token of my appreciation for their participation, and they were reimbursed for any travel expenses that they incurred.

Prior to the commencement of any data collection, informed consent was obtained from each participant. Individuals were also assured that they could withdraw from the study at any time and that there would not be any negative consequences if they chose to do so. Participants were informed that their identity would be protected by assigning each individual a participant code as opposed to using their names, and any identifiable information would be excluded from the results of this study. All of the data, whether tape recorded or transcribed, was locked away in a secure cabinet for the duration of the study, where only members of the study team could access to it. The data will be kept in a secure location for a period of five years, after which it would be appropriately discarded.

The only foreseeable risk for participants in the present study was that individuals might experience emotional discomfort or distress during the interviews, as they would be sharing personal details of their lives. Since this study was exploring the experiences of caregivers, I did not anticipate that any participants would experience emotional discomfort to the point where they would require a referral for counselling. However, I informed the participants that a system was in place whereby my supervisor Dr. Chrisma Pretorius, a counselling psychologist, would refer any individuals to the appropriate healthcare professional should they have require any counselling following the interviews. I found that although some participants became emotional during the interviews it was not due to emotional discomfort or distress, but rather because it was often the first time that someone had approached these caregivers to share their stories. The social workers who accompanied me to the interviews further clarified this for me and made sure that the participants were not experiencing any form distress when the interview was finished. It was thus evident that none of the participants experienced emotional distress to the point where they needed to be referred to a healthcare professional.

4.11 Summary

This chapter provided a description of the research methodology that was utilised in the present study. This description began with a rationale for this study, which outlined the need for an increased focus on the caregiver experience, especially in the context of a developing country such as South Africa. The relevance of this topic in the context of rural South Africa was also discussed by arguing that caregivers in this context might encounter unique barriers and facilitators that have not yet been identified in studies that have been conducted in developed countries. Thereafter, the research question as well as the aims and objectives were reported with a specific focus on the barriers and facilitators to caring for children with CP. The research design that was incorporated in the present study – an exploratory qualitative design – was also described. This was followed by a discussion of participant characteristics, as well as the procedures that formed part of sampling and data collection. Furthermore, the procedures that were used to conduct thematic analysis were also outlined. To conclude the chapter, the means to maintain trustworthiness and the ethical considerations of the present study were discussed. The next chapter will present the results and key findings that were obtained during this study.

Chapter 5: Results

The results of the present study will be presented in this chapter. Although there were differences in factors including the age of the child or children being cared for as well as the years of caregiving experience, several common themes were identified during analysis of the 15 semi-structured interviews. The list of themes and sub-themes that were identified during thematic analysis can be found below in Table 5.1. During thematic analysis, themes and sub-themes were first grouped as either barriers or facilitators to caring; thereafter, they were categorised according to the five levels of the Social Ecological Model (individual factors, interpersonal processes, community factors, institutional factors, and societal factors) (McLeroy et al., 1988). These themes are reported from the most specific to the broadest level of the Social Ecological Model, and are not reported in any order of importance.

Table 5. 1

Challenges and resources: The main themes related to the caregiving experience that were identified at the different levels of the Social Ecological Model during thematic analysis

	Level	Main theme
Facilitators	Individual	Personal coping mechanisms Personal transformation
	Interpersonal	Relationship with child Social support
	Community	Community resources
	Institutional	Child’s crèche
	Societal	Financial assistance
Barriers	Individual	Consequences of caregiving
	Interpersonal	Difficulty adjusting to caregiving duties
	Community	Environmental conditions
	Institutional	Lack of access to adequate services Lack of respite services
	Societal	Perceptions toward disability

5.1 Barriers

During the data analysis, six main themes emerged as the most salient barriers that were faced by the sample of caregivers. These barriers included the consequences of caregiving, difficulty adjusting to caregiving duties, environmental conditions, lack of access to healthcare services, lack of respite services, and perceptions towards disability. The main themes and sub-themes that were identified as barriers to caregivers are presented in Table 5.2 below and each of these themes will be discussed in the section to follow.

Table 5.2

The main themes and sub-themes that were identified as barriers to caring according to the different levels of the Social Ecological Model

Level of SEM	**Main theme**	**Sub-theme**
Individual	Consequences of caregiving	Emotional challenges Physical challenges Financial burden
Interpersonal	Difficulty adjusting to caregiving duties	Child's symptoms Feeding difficulties Lack of social life
Community	Environmental conditions	Unhealthy living conditions Seasonal challenges
Institutional	Lack of access to adequate services	Lack of information from healthcare professionals Transport barriers
	Lack of respite	Discontinuation of day-care services Lack of assistance from others Lack of trust in others to care for child Lack of disability-friendly facilities
Societal	Negative reactions from others	Cultural perceptions Social norms

5.1.1 Individual factors. The first main theme that emerged was that participants experienced several personal challenges that were associated with their caregiving duties. These challenges included emotional concerns, physical concerns, and financial burden.

5.1.1.1 Emotional challenges. Several participants reported that caring for a child with CP can be emotionally challenging. At the time of their child's diagnosis, many of the caregivers noted that they had no choice but to accept their child's condition and their role as a caregiver since their child needed them:

> Ek het nie geweet 'n mens moet...dat sy deur sulke baie dinge moet gaan nie…ek het net gevoel sy is my dogtertjie so ek moet daar wees vir haar, ek is haar ma...sy het my hulp nodig en soos ek kan sê net die feit is dat sy niks vir haar kan doen (F3[1]).

> I couldn't say anything. I had to be satisfied. I had to go on (F8).

This challenge appeared to have a greater impact on the four caregivers who reported a child that had been born healthy, but had sustained some form of trauma during their first year of life - such as a seizure, fall, or surgical complication - which had resulted in their diagnosis with CP. These caregivers were suddenly forced to accept that their previously healthy child would not be the same again:

> Ek het net gedink die feit dat hy was 'n gesonde kind. Maar dit is my kind, wat kan ek met hom maak, ek kan hom nie verstoot nie (F9).

> Ek het in die begin sleg gevoel maar later my maar laat saamleef daarmee. Wat kan jy nou maak, dit is nou klaar so. Hulle verduidelik vir my aanmekaar as ek daar kom, daar is niks wat hulle kan doen nie, hy sal vir die res van sy lewe so bly (F10).

Another emotional challenge that emerged during the interviews was that caregivers often worried about their child's future. This concern appeared more prominent among the older caregivers who expressed concern for the time when they would no longer be present to care for their child. One 62 year old caregiver was the foster mother to a child with CP whose mother had relinquished her parental rights. This particular caregiver had hoped to re-unite

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[1] *Note.* Participant code: F = Female, M = Male; 1 = Number of interview

the child with her mother so that her mother could take over caregiving duties when she was no longer able to:

> Ek raak ouer, ek raak nie jonger nie, so ek wil hê dat Angela[2] se Mamma moet tog probeer om haar kind te behandel en dat sy na haar toe moet gaan as ek nie meer kan nie (F4).

The only male caregiver in this study also expressed concern that he was aging and that his wife would struggle to lift and carry their child without his assistance, as she already struggled when he was not present in the home:

> I'm so worried. I don't know whether I'm growing old or what. I don't know how, how's the mother doing. Because sometimes I go to the Transkei, say for two weeks. I don't know how she is coping. Because she can't even take her from here to there (M13).

5.1.1.2 Physical challenges. The daily demands that were required by caregivers also caused them to experience a variety of physical concerns. Almost all of the caregivers who participated in this study were females who had to perform duties such as lifting and carrying their child. These duties were acceptable when the child was younger, however, as the child aged and grew bigger, it became more difficult for the caregivers to perform their duties and numerous caregivers expressed that they had begun to experience physical pain:

> Ja my rug, ja sy's baie swaar my rug kry nogal seer dis hoekom ek haar moet terug sit. Dit pyn, daar's tye as ek op my bed kom dan lyk dit vir my ek kan nie opstaan nie. Soos gisteraand toe kon ek nie opstaan nie want my rug, toe pyn dit, dit pyn te veel (F3).

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[2] *Note.* Names have been changed to pseudonyms throughout to protect participants' identities.

One participant noted that the difficulty of carrying her child was exacerbated by the fact that her child's body was not flexible enough to use a wheelchair, which meant that she had to carry her child to their appointments at the clinic:

> …now she's so heavy and it's not easy for me because her joints are so stiff now, her joints are so stiff. That is why it is so difficult for me to go to the clinic because I have to carry her to the clinic (F14).

The participants who acted as full time caregivers for a number of children with CP noted that many of the children in their care were in their teenage years and were thus too difficult to lift. These caregivers had thus begun to work together to make the task of lifting and carrying easier, however, they noted that it became problematic when there was no one available to assist them:

> There's one who's 18 and she's heavy, and there's one who's 16, she's also heavy. That's why we help one another. Because we can't like carry a heavy child on our own (F11).

> A big problem, it's a big problem to lift her. Sometimes I feel tired; I feel a pain at the back. Also my sister has pain because we are lifting, and sometimes when I'm not around she picks them up alone (F15).

Since many of the caregivers did not have assistance from their family or spouse at night, a number of participants reported that they experienced sleep difficulties due to the demanding nature of their caregiving duties, which often required them to roll their children during the night and to ensure that they were not being suffocated by their blankets:

> When you're with them you are not sleeping well. I'm telling you. You make your rounds during the night, because sometimes even the blanket can suffocate them and so you're supposed to check whether the blanket doesn't suffocate them and are they not getting cold at night…You are not sleeping. It's not an easy job really this one (F12).

> You see she can't, when she's sleeping she sleeps on one side. So she can't roll over and we have to sleep with her. During the night I must wake up then she will cry then I will roll her over (M13).

As a result of these sleep disturbances, several caregiver's experienced constant fatigue and some also expressed a desire take a break from their caregiving duties:

> As ek vir haar klaar opgetel het of so met haar gewerk het dan is ek nogal uitputtend en veral soos saans dan is ek uitputtend, dan is ek moeg (F3).

> Die aflos...ek soek net 'n bietjie uitkom. Ek voel ek is uitgeput. Ek voel ek makeer 'n rus (F4).

Moreover, several participants also reported that they did not have any time to themselves, as they were always occupied with their child's care. One caregiver reported that the only time she was able to rest was when she was asleep, as her son and her chores would keep her busy during the day:

> Nooit nie, ek kan dit nooit doen nie. Brendan vat al my aandag weg. Daar is nie rus kans nie, want ek krap sommer die plek om en maak ek reg en skoon, onder die kooie, ek sit nie sommer stil nie. Saans as ek gaan lê, dan is ek nou bietjie rustig (F9).

5.1.1.3 Financial burden. In addition to emotional and physical challenges, the caregivers in the present study also experienced financial hardships. Since caregiving was a full time obligation for the majority of the participants in this study, a common challenge that these individuals encountered was the inability to secure a stable occupation. One of the participants explained her situation as follows:

> If I could find a job I would be fine…My life has changed because it's difficult for me to do a lot of things; for example I used to sell duvets but since looking after him I've not been able to do that again (F5).

This challenge appeared to also impact the caregivers who had a child enrolled in a crèche or day-care facility. Although these services provided the participants with a short break from their caregiving duties, the time away was not enough for them to find work, as they would need to be available when their child returned in the afternoons. In the following extracts, two of the participants explained their unemployment situations:

> What makes it difficult is when I have found a job. Like the child does not have a specific time he returns from school. He can come back anytime even at two o'clock and that makes it impossible for me to go to work (F6).

> Actually we do take her to school. But you see there are times, it's so, I think we take her by nine, and by two o'clock she's back here. So, I must go, by ten o'clock I must go to work for my own work. By one o'clock I must be here again (M13).

Although fourteen of the participants in the present study were receiving a grant from the state in order to assist them with their caregiving duties, several caregivers reported that they still experienced financial difficulties despite this financial assistance due to the expenses that their child and family incurred:

> Ek sal nie sê dit is genoeg nie, want daar is net daai wat ek kry. Daar is niks moelikheid nie, maar ek sukkel 'n biejie baie met sy kimbies, hulle is duur nou (F9).

> Not enough because I have a family who are depending on the grant and also other kids, I have three kids she is the eldest one and then middle one, the boy, and the younger one (F15).

Another participant explained how it was not always possible to attend her child's appointments at the end of the month since the grant money was used to support the child as well as the rest of the family:

> I really struggle when it's his appointment because I usually only have money from the first of the month until now, but in the middle of the month I really struggle. Sometimes we don't even make it because with his grant money I must feed him, clothe him and pay for his school feels as well as buy things for the older one (F6).

Another financial hardship that the caregivers experienced was the long waiting period to receive their funding from the state. Multiple caregivers reported that the process of applying for the grant was simple; however, the waiting period to receive the funds was found to range anywhere between a few months to a year:

> Dit was nou na 'n jaar toe kry hy eers die geld, eers 'n jaar gewees het. Ek het gedink hy gaan van die begin stadium kry, maar toe sê hulle ek moet wag vir 'n jaar (F9).

This challenge appeared to be particularly problematic for the participants who were employed as full-time carers, as they relied on financial aid to operate their care facilities. One caregiver explained how foster children would be brought to the home for a trial period of three months, during which the carers would rely on the limited resources that accompanied each child, and it was only after these children had been awarded to the home that the application process for financial aid could begin:

> When the social workers bring the child to us they bring the child with clothes, but not many items. Maybe two items like 16 nappies and a R150 voucher. Those things are for the period of three months. And then after they are happy with the way you treat these kids they will leave those kids to us, but if they are not happy they will remove the kids from this centre to another centre…So we are still waiting for the social grant for the new kids that have been here for three months already (F11).

5.1.2. Interpersonal processes. The second main barrier to caregiving concerned how certain aspects of caregiving made it difficult for the participants to adjust to their daily duties. Difficulty adjusting to caregiving duties was often increased by the severity of the child's symptoms, feeding difficulties, as well as a lack of social life.

5.1.2.1 Child's symptoms. Several caregivers reported that the symptoms associated with CP were often challenging to experience. One participant explained the frustration that she felt when her foster child was first placed in her care, as the child had arrived in a sickly state that she struggled to remedy:

> Toe Angela by my gekom het van jare gelede was sy baie siek, sy was 'n siek kind. Ek moes baie insit om vir haar te help beter word, sy het opgegooi en sy was 'n koffiemoer baba...sy het baie, die swart goed opgegooi, haar maag was nie lekker nie. Dit het baie gekos om vir my met Angela reg te handel want Angela was verwaarloos, sy was baie agteruit. 'n Mens kan sien sy was verwaarloos voordat sy by my gekom het (F4).

Two participants who were caring for multiple children with CP recalled instances where they had been exposed to children having seizures for the first time. Since many of the children present at the home were often sickly, another challenge that these participants experienced was the death of children in their care. Although these caregivers were not responsible for the illness and death of those in their care, they reported feelings of guilt that they could have done more to keep these children alive and healthy:

> I didn't know anything about them, anything at all. So there were challenges. Like seeing someone in a fit. I never saw someone having fits in front of my eyes. So when

> a child gets sick at that time of the night and when a child dies in front of your eyes then that's...Those for me were challenges (F11).

> There was a challenge with them, the child got a cot death…When the child's dying in their sleep. The first day when you, maybe you wake up and the child is no more. And it feels like if I did this the child would be here. Yes you've got that instinct that, if I did this and the child will be here and there's nothing happened with the child, and forgetting that it's not your fault. And it's not your place to halt death. And you know but you're blaming yourself (F12).

5.1.2.2 Feeding difficulties. Another aspect of caregiving that participants found challenging was how they would often struggle when it came to feeding their child. This barrier emerged when a child had impaired mobility or when they were a fussy eater. One caregiver explained how her child had become accustomed to his feeding routine and would thus only eat at certain times during the day; while he would also only eat specific types of food:

> He does eat but now he's got tricks that show that he is big. He doesn't eat about 08:00 to 09:00; he only eats about 10:00 to 11:00. I must give him his medication first. He doesn't eat anything like porridge, instant, Weetbix; he only eats oats and sour milk. He doesn't like the yogurts as well (F2).

Another caregiver reported that feeding her child was often frustrating for her and her child, as her child wanted to feed herself but could not due to a lack of mobility:

> Dis net tye wanneer ek vir haar kos moet gee en ek voer vir haar sy is een wat vir my sê sy gaan nie dit vat, of sy gaan nie daai vat nie, maar soos wanneer sy eet is 'n bietjie moeilik want dan...hoe kan ek sê dan stres sy. Sy stres meer want sy wil baie graag self eet en dit maak vir haar moeilik en soos ek sê dis moeilik vir my (F3).

Finally, one caregiver expressed how it took time to learn how to feed the children with CP in her care, as many of them had been hospitalised prior to their arrival at her group home and had thus mainly been fed through a feeding tube. Feeding these children proved to be challenging for this participant, as it required much of her time and patience to teach them to swallow their food without choking:

> I think there in the hospital they were doing it with a pipe. Now we have to teach her to eat. And learn to taste the food. It was so difficult I'm telling you. That child was spitting the food. It was a battle you know. Sometimes you have a child that is, when you feed them it takes me long. Like the tongue, it's big and it's difficult to swallow and so. And it's frustrating and that is one challenge that we have, when you've got the child who's difficult to feed. The choking, you know the mistake (F12).

5.1.2.3 Lack of social life. In addition to coping with feeding difficulties and their child's symptoms, numerous participants reported that they had also experienced a lack of social life since they had become caregivers. Several participants reported that the social relationships that they had formed before they became caregivers had changed over time. One participant explained how her friendships had dissipated, as she found that she had little in common with her friends since she had become a carer:

> Hulle kom daar en hulle sal saam met hom praat, maar ek het nie eintlik nou vriende nie. Ek het mos daai tyd 'n bier gedrink toe het ek 'n klomp verloor (F9).

It was also reported that many participants could not find the time and energy to socialise due to the demands of caregiving, which often left them feeling as though they were trapped at home despite a desire to be surrounded by others:

> Ek het nie die krag om uit te beweeg nie, selfs al kom haal hulle vir my, ek kry dit nie reg om uit te gaan nie, ek sit maar net daar, sal kerk toe gaan, terug kom en in die huis. So as hulle vir my kom haal en vir my vra of ek nie saam met hulle bietjie uit wil gaan nie, ek kan nie, ek sit maar by haar laat ek by haar is want ek weet nie, ek kan dit net nie reg kry om meer uitbeweeg soos altyd nie... soms voel dit dan die vertrekke druk jou vas (F3).

> Ek kan nêrens gaan nie. Sometimes dan voel ek, ek voel asof ek vas is...ek kan nie beweeg nie. Ek kan ook nie gaan na my mense toe soos ek wil nie, ek kan nie. Ek moet eers dink aan Angela, ek kan nie vir haar by enige iemand los nie want sy is my verantwoordelikheid. *If something happened to her*, en dan..dis op my.. Dit is eintlik iets wat ek baie graag wil melding maak...dat ek net 'n bietjie kan asem kry (F4).

Another participant expressed that she did not go out, as it was too difficult for her to take her child with her. However, she admitted that she desired to have a break from her caring duties:

> I don't go out with Nondi because it's difficult and also other parents they have also a problem like me. I don't go out…I said to my friend one day I need a break, if I have someone whom I want to go out man, I get massage or what. I want to take a break one or two days stay away and even if I stay in a hotel then I can get rest (F15)

5.1.3 Community factors. Another main barrier that emerged was the harsh environmental conditions that participants were exposed to in their respective communities. These conditions included geographical barriers, seasonal challenges, and unhealthy living conditions.

5.1.3.1 Geographical barriers. A number of participants reported that they were often unable to access certain facilities due to the location of their homes. One participant noted that she could not access the nearest day-care facilities because it was too far away for her and her child to travel to on a daily basis:

> The only place [school] that we have which I don't think it's going to be easy for me to go, it's too far (F1).

Another caregiver stated that she had located a day-care nearby that had transport available to fetch her child, however, the poor quality of the roads in her area prevented the transport service from gaining access to her home:

> Because sometimes the transport, they told me that the place was not right for their car. They had a Kombi, microbus. Then the road was not good for their cars (F14).

5.1.3.2 Seasonal challenges. Another common environmental challenge that the caregivers reported was the harsh weather conditions that accompanied certain seasons. A specific challenge for the caregivers who resided in informal settlements was the spreading of fires, as well as flooding due to excessive rainfall during the winter months. Two participants explained how it became problematic to escape from a burning or flooded home with a disabled child:

> I must look after him day and night because maybe there will be a fire and now it's winter, the shacks are flooding each and every year. This time you know the rain in Cape Town, so each and every time it's raining there's a big problem and at the same time in the squatter camps when one shack burns automatically so many others do,

> and imagine when it rains and you have a disabled child like that, the risk is very high unlike when there's a child who could run (F2).

> We found out that their shack is being burned and these children are inside them. Maybe the parents are working…they are locked in the shacks and they couldn't help themselves and they would burn to death (F12).

5.1.3.3 Unhealthy living conditions. The final environmental challenge that affected the caregivers was the perception of an unhealthy living environment. Several participants expressed that they worried about their child's health due to the often unsanitary living conditions that they were living in, and many mentioned how they desired to find a healthier environment for their child to live. The following two extract illustrate this concern:

> Even in summer there are lots of rats so maybe the environment where I am staying with the child, it's not good for the child to stay there at all (F2).

> I just wish that my child could have a better place to live because many times I'm in and out of hospital. Often told the child has an infection of some sort because of the filth of the environment we live in. I wish my child could live in a better place (F6).

5.1.4 Institutional factors. A lack of access to healthcare and respite services was also expressed as a barrier to caregiving by the participants in the present study. Lack of information from healthcare professionals as well as transport barriers were found to prevent access to vital healthcare services. Participants also found it challenging to access respite services due to the discontinuation of day-care services, lack of assistance from others, lack of trust in others to care for one's child, and lack of disability-friendly facilities.

5.1.4.1 Lack of information. Several participants reported that they had received little information from healthcare professionals when their child had first been diagnosed with CP. A number of participants explained how they were not aware of the extent of their child's disability, as the doctors had only informed them that something had gone wrong. One caregiver stated that she was only informed that her child was disabled when the social worker assigned to her daughter had told her; while another noted how she was only made aware of CP when her child had been referred to a day-care centre:

> Hulle het vir my gesê sy het mos van die vrugwater ingekry en ek het nie geweet sy is so nie totdat ek nou uitgevind het van die maatskaplike werker wat hier werk en hulle

> wat saam met haar werk het dit eintlik meer oopgemaak en vir my gesê. Dis hoe ek geweet het, anders het ek nie geweet nie (F3).

> Maar ek het nog nie van daai word gehoor van CP, ek het net gehoor hy was gestremd. Hulle het net gesê dat hulle het hom seer gemaak. Ek dink ek het dit hier by die skool eers gehoor. Want hy was nog nie ‘n jaar nie toe verwys hulle vir my hiernatoe (F9).

This lack of information was a source of both confusion and frustration for numerous caregivers. One caregiver who had given birth at a young age stated that the time of her child’s diagnosis was a stressful period for her, as her child’s condition was not explained to her and she was not informed where she could seek assistance:

> I’m going up and down to looking the help for Nondi because her dad was gone that time. I don’t know how to tell you, at that time, I was confused because at that time I’m still young, I was 19 years that time and I didn’t know what was happening (F14).

5.1.4.2 Transport barriers. Another challenge that prevented caregivers from accessing necessary services was transport barriers. One factor that contributed to this barrier was the high cost of transport. Almost all of the participants were reliant on public transport to attend appointments or take their child on outings, as only two participants owned their own car. Several participants reported that public transport was often arranged by the clinic, however, they would need to pay for this service:

> We are supposed to go on the 19th; she is going to change the wheelchair because she has outgrown it. They called to say she should come in and they will fetch us at the taxi rank; I must pay R35 (F5).

> There’s a vehicle that fetches us, which I have to pay for. It takes us to the hospital and then we wait for her father to fetch us and then we all come home with the taxi (F8).

In other cases, caregivers would have to hire public transport in order to attend their child’s appointments. Numerous participants explained how the cost of public transport was often high, as visits to the clinic could take up to an entire day and participants would have to pay the taxi drivers what they would have earned on a regular day:

> We hire a taxi and it costs a lot from here to Red Cross. They charge us R300. It depends on how many kids you're taking. Even if you take one child, they're still going to charge you that money because they're covering that distance. Imagine if you're taking two kids at the same time. And it's going to charge us more and it's a taxi and you have taken that taxi from the rank where it was supposed to be working. If they're going to make R600 on the road, they're going to charge us that R600 (F12).

Another frequently occurring transport barrier was the lack of disability-friendly transport, as many forms of public transport were not equipped to carry individuals using assistive devices. Many of the caregivers found it easier to transport their children using a special type of wheelchair called a 'buggy,' however, most forms of public transport are not equipped to carry this type of wheelchair:

> My husband asked his doctor in Paarl he sends the wheelchair. But he always asks where the buggy is then I say no we can't come with the buggy. When we have the wheelchair we can fold it and put it in the taxi and then when we get to the hospital we just push her in the thing (F8).

> Transport that's a big challenge…Because our busses and taxis don't accept these kind of wheelchairs. They don't have the space…For someone who's getting sick at night with no one around you. Like we don't have any transport. That's the main challenge that we have here… It's difficult, it's really difficult because you see our transport, they don't have access for the wheelchairs. (F11).

This proved to be challenging for certain caregivers, as not all children could be transported in a regular wheelchair due to their rigid posture or stiff joints. As a result, several caregivers had to walk to their appointments at the clinic and push their child in the buggy:

> Ek moet haar maar in die stoel sit en haar stoot, of my man sal haar moet stoot. Or we will get somebody to take us. Dit is 'n bietjie ver, jy kan nie eintlik stap soontoe nie, maar ons het al sommige tye gestap. Maar vandat Angela gesond is, is dit bietjie meer af van my af. Ek sit haar sometimes in die stoel dan neem ek haar vir 'n *walk*. Dan vat ek haar in die stoel, my man sit vir haar in die stoel en dan loop ek saam met haar (F4).

Moreover, another caregiver noted that she would often have to carry her child to the hospital from the taxi rank, since she could not fold the buggy up in the taxi:

> Om vir hom te dra miskien hospitaal toe en so. Daar is taxi. Ek vat taxi, maar om uit die dorp uit te loop hospitaal toe en weer terug is ‘n bietjie moeilik (F10).

One caregiver had hired a private transport service to attend appointments at the Red Cross, however, the service did not operate at the hours when the appointment took place.

> I use the [transport service] but we have a problem with the [transport service] because if you are booking, you’re doing a booking seven days ahead. And if you have an appointment at hospital at 08:00 she didn’t fetch you at 08:00 or 07:00, she starts at 10:00 and up, she didn’t do the right time (F15).

5.1.4.3 Lack of respite services. Another barrier prominent challenge that emerged was a lack of respite services among caregivers. One factor that prevented access to respite services was the discontinuation of day-care services. This barrier was found to be problematic for the caregivers of children who were approaching or had reached 18 years of age, as day-care and schooling facilities would not accept individuals over this age. Two participants explained how the individuals who had been released from caring facilities often had no family or home to return to. As a result, certain caring facilities had begun to keep individuals over the age of 18:

> The other thing like now, you know they are 18, the other institutions discharge them. We don’t have places for 18 and older ones. But for that child we can’t chase that child away because that child doesn’t have anyone. Yes there are siblings, aunties and so, but they don’t want anything to do with her. So, we can’t throw her in the bin and close the bin. We must just continue with her until the end (F12).

> This year the school told me, in fact last year, that they will bring her back because of the age. I was so frustrated. She’s 18 years. They told me they have 18 year olds who don’t have parents. So we are worried when they think about sending her back home because she doesn’t have anyone to look after her. Maybe it’s going to be their start. Because the one is 18 years old. So they said Amanda is going to be the second person now that they help (F14).

Another barrier that contributed to lack of respite among caregivers was the lack of assistance from others. Participants reported how other individuals were not prepared to assist with the care of their child unless they were paid to do so. This was problematic since almost all of the participants were unemployed and relied on their child's grant to survive.

> I wish I can have somebody also who can help me. I must do more now because she's at home but there's nobody who can help me to do that. If they come help then at the end they are expecting something in return (F1).

Participants also reported that it was challenging for them to find an individual to care for their child whom they could trust. Two participants recalled instances where they had no option but to leave their child in the care of their neighbours, which caused them to experience feelings of anxiety and concern that their child was being properly cared for:

> I left him next door. I left him with a girl and she's the same age as Sipho so I don't trust the girls that age. I used to leave him with her mother but now her mother is working (F2).

> I was hospitalised, it was in March I was in hospital; I was worried because a neighbour was taking care of the child. She was with the neighbour; there is my sisters' child who I live with, but she can't feed her, that really made me worried (F6).

The final barrier that impacted access to respite services was a lack of disability-friendly facilities. For numerous participants, there were limited crèches or schools that were equipped to care for disabled children available in their community. In many instances the schools were too far away to access or caregivers felt that their facilities were inadequate:

> Well unfortunately there's no nearest school as such…the doctor said she must go to a real school. I've been there when she was three or four years old, they said no, they can't accept her (F1).

> There's this Community school, where it's not really a school for disabled children, but there's really nothing that they are benefiting from the school (F2).

> What I wanted is for her to get a school, I don't want her to go to that [community] crèche… the problem is I don't think those people are well trained for disabled children, they didn't give them that love, they didn't give them that courage (F5).

One participant explained how she was hesitant to send her child to the day-care in her community, as her child might be singled out by the other children due to her disability:

> Ek sal nie vir haar soontoe stuur want die kinders sal vir haar instaan, van haar guy maak en dit sal haar selfbeeld afbreek, want sy sit in ‘n buggy in en ander kinders loop. En as die kinders uitkom hulle is rof daar en hulle kan haar net omslaan of iets (F3).

Since there were often a limited number of crèches or day-care centres that offered care to disabled children, one participant explained how parents would often resort to sending their child to a school or day-care centre that was not equipped to care for them in order to take a break from their caregiving duties:

> I got the place for her at Crossroads. The conditions at [the day-care] were not good, they didn’t get support from the government, so the kids were sitting on the cushions there and it was very cold. But I didn’t have a choice. So they had transport at that time. Then I had to send her there…The doctor complained about the bedsores even the social worker at Tygerberg complained about the bedsores and ask me: ’Do you love the place?’, but I told her that I don’t have any other choice (F14).

5.1.5 Societal factors. The final barrier that was reported during the interviews concerned the negative perceptions that others held towards individuals with disabilities. These perceptions were found to be influenced by either social or cultural norms.

5.1.5.1 Cultural norms. The participants reported several instances where cultural norms had shaped negative views towards disability. Two prominent cultural norms were the rejection of disabled children and the belief that witchcraft was the cause of an individual’s disability. One participant reported that it was customary for disabled children to be rejected in her culture and that her child was rejected by her family members:

> I went to my mother’s home in East London…Then she told me that I’m not going to be a grandmother to your child…most families don’t accept the kids like this. So I had to look for the shelter, for the shack for me and her (F14).

Due to the rejection of disabled children, one participant explained how there was a lack of awareness of disabled children in her community, as parents would often hide these children in their homes so that the only time others would hear about these individuals was when they would pass away:

> It was bad. They were locking the children away. Then, when maybe there's somebody who's knocking, visiting the house…they will push the child in the room. Hiding the child away. They don't want those children to be seen. It's just heard when one child has died, here's the disabled child. This child was disabled. You didn't even see the child, you know (F12).

Another common cultural belief that these caregivers considered to be challenging was the perception that they had been bewitched. Several participants reported that it was a commonly held belief that disability was the product of witchcraft practices. As a result, many caregivers believed that their child was a punishment from the ancestors:

> They believe it's witchcraft. Yes that's what they believe in. Like this one, her mother believes its witchcraft because she was not born like this. She thinks that she saw something and started becoming like this. They've got different beliefs. Some as I say think it's a punishment, some others say it's witchcraft (F11).

> You know when you've got the disabled child it is as if you are bewitched. It was bad. Maybe they think you were bewitched when you were pregnant. You know. A curse yes. It was bad. Even this thing of locking the children in the shack and so it was coming from that (F12).

5.1.5.2 Social norms. Several participants also reported cases where they had encountered negative reactions from others due to the prevailing social norms regarding disability. Participants recollected instances where they had been exposed to negative attitudes and lack of awareness from others when they would take their child on public outings. One of the greatest social barriers that the caregivers reported was the negative attitude displayed by others in public, where both children and adults would stare, tease, or laugh at their child. Three participants recalled their experiences of these attitudes and expressed frustration as well as sadness that this was happening to their children:

> Ek stoot vir haar 'n bietjie, meestal loop ek met haar, hou ek haar vas laat haar bene kan oefeninge kry en mense sal altyd na staar, vir haar kyk en baie het al vir haar gelag en gespot oor sy so is, maar dan kan ek sien sy kry baie seer. Dis hoekom ek sê ek sal altyd by haar wees veral sulke tye. En mense, kinders spot vir haar en so (F3).

> Vir my is dit bietjie baie hartseer omdat die kinders is altyd so verbaas dan sê ek altyd vir hulle, my antwoord vir hulle is wees net vriendelik. Want hulle is altyd verbaas as hulle vir Wade sien in die park. Toe sê ek "nee Wade is net so normaal soos julle. Wade gaan ook stap" (F7).

> They are discriminated against. It makes you angry. Because it's a human being. Why you staring? It makes you angry. Seriously, it's like they are doing it to you. And they even ask why is he crying? Come and help if you see there's something wrong. I don't know (F11).

Another barrier reported by participants was a lack of awareness or understanding of children with disabilities. Several caregivers noted that they would often encounter others who were unaware of CP as well as its causes, and could thus not understand what these caregivers were experiencing. It is possible that this lack of awareness could stem from the fact that most families would hide their children away so that others would not know that they had a disabled child. One participant explained how others would often stare at her child when she would take her out in public, and she attributed these reactions to the fact that others did not understand her child's disability:

> Hulle kyk baie vir haar en die kinders sal altyd so omkom by haar, om haar staan en vat aan haar. Ek voel seer. Sy kan mos nie help dat sy so is nie, en sy kan mos nie help dat sy nie kan praat nie. Hulle wil hê sy moet met hulle praat, maar sy kan nie met hulle praat nie, maar hulle is klein en hulle verstaan nie (F3).

These negative reactions were often found to affect the child as well as their caregiver. As a result, a number of participants opted to not expose their children to members of the public in order to avoid their lack of awareness and negative attitudes. It is also possible that the adverse reactions from others could have contributed to the social isolation experienced by many of the participants in the present study, as caregivers did not want to expose their children to negative attitudes from others and thus spent most of their time at home with their child, which caused them to feel trapped by their caregiving duties.

5.2 Facilitators

Although the participants experienced several barriers to caregiving, they also reported several facilitators that made caregiving easier for them. These facilitators included personal coping mechanisms, personal transformation, social support, relationship with the child, community resources, the child's crèche, and financial assistance. These main themes and their respective sub-themes are displayed in Table 5.3 below and will be reported in detail the section to follow.

Table 5.3

The main themes and sub-themes that were identified as facilitators to caring according to the different levels of the Social Ecological Model

Level of SEM	**Main theme**	**Sub-theme**
Individual	Coping mechanisms	Acceptance Faith Pursuit of information
	Personal transformation	Improved patience Compassion & desire to become more involved
Interpersonal	Relationship with child	Adjustment over time Devotion to caregiving
	Social support	Immediate family Community members Healthcare professionals
Community	Community resources	Assistance from religious institutions Aid from local organisations Acceptance from community members
Institutional	Child's crèche	Source of respite Progress of child due to work with teachers & healthcare professionals
Societal	Financial assistance	Grant from the government

5.2.1 Individual factors. Two main themes that emerged as facilitators on the individual level were the personal coping mechanisms that the caregivers utilised in order to manage their daily duties and the personal transformation that participants had undergone as a result of their work as caregivers.

5.2.1.1 Personal coping mechanisms. The first main theme to emerge was that a number participants employed several strategies in order to cope with their caregiving duties. One of the mechanisms that allowed participants to adjust to their caregiving responsibilities was the acceptance of their child's disability. Although many participants felt that they had been forced to accept their child's diagnosis with CP, certain caregivers noted that their role as caregivers became easier when they had accepted their child. The following extracts reflect how two caregivers grew to enjoy caring for their children once they had accepted them:

> I have accepted him and I have no problems living with my child (F6).

> You see I felt so bitter you know. But I have to support and accept her…I know that's my card, so I don't mind taking care of her (M13).

One participant explained how it was important for her to accept her child in order for others to do so, and she expressed how she had gained a support system by informing others about her child:

> It's because I accepted my child. I just told myself that I've got this disabled child so I have to accept her as she is… It just an acceptance. And other people love her because of me, I've explained to everybody that I've got this kind of child so that is how I've got the support because I accepted her as she is, I love her (F14).

Participants also found that it was easier to adjust to their caregiving duties when they had gained more information about CP. Caregivers reported that they were able to gain more knowledge on how to care for a child with CP through trial-and-error as well as by enrolling in workshops and short courses. The majority of participants had not been informed about CP prior to their child's diagnosis and were thus required to learn how to care for child with CP on their own, one participant explained:

> At first we couldn't even open their hands. We didn't know that there was a special way of opening their hands…but now we are used to it because we know how to open their hands and now it's easy (F11).

Several participants noted that they had learnt how to perform their caregiving duties through trial-and-error, where they had tried and repeated certain techniques until they were able to find methods that worked for their child. In the following extract, one participant explained how she had taught herself to care for her foster child when she had first arrived:

> Toe Angela by my gekom het van jaare gelede was sy baie siek. Ek moes baie insit om vir haar te help beter word, sy het die swart goed opgegooi, haar maag was nie lekker nie…Ek het maar, die opleiding wat ek het, vir myself het, is dat skoonheid, en

> wat sy eet...ek het nie altyd gehad wat sy moes gekry het nie, maar dan het ek moeite gemaak om vir haar ‘n glas melk *in between* te gee. Gee vir haar baie water, gee vir haar baie *liquids*. Dit het vir my gehelp en dit het haar magie gehelp, ek het dit aangehou tot die siekte weg is. Sy kry dit nie meer nie (F4).

Another caregiver explained how she had learnt to master certain duties, such as bathing and feeding, through repetition after she had initially been instructed how to do them:

> Maybe you started with a person now who taught you. The next day you’re alone. Now I must do the same thing that I was doing yesterday. And you try and it works, and then you try it again and it works. And then you say no okay, now even if there’s nobody around I can do it now. To teach her to sit in her chair. To learn to bathe her, to change her, to feed her and so on (F12).

Participants were also able to increase their knowledge regarding CP by enrolling in the various workshops and courses that were available to them in their respective communities. As a result, many caregivers expressed a desire to become more educated about matters relating to CP. The following three extracts express how participants were able to learn more about CP by attending workshops or courses, while they also acquired knowledge on how to care for individuals with disabilities:

> Something that has helped me are the trainings, I learned from the workshop that we had…I knew how to hold the children because they taught me...I even asked for the Red Cross to come and arrange another workshop because I wanted to know more (F11).

> I was still going to UNISA to do courses with the children as well for a year. I wanted to know more about a person. And more about children with disabilities and all those things. So I went for those short courses at UNISA (F12).

> I’ve been with the workshops where the people told us about this CP and also now I’m doing a course early childhood development at College of Cape Town, I’m doing level five now (F15).

The participants also reported that their personal faith assisted them to cope with their caregiving duties. For several participants, it was vital to possess a belief system in order to be a caregiver and to face the challenges that emerged on a daily basis, as expressed in the following extracts:

> God is good, anything that you get, what you have is only through Him. Although it's so today, tomorrow is going to be fine, you must just believe. There's nothing that is too bad in my mind…without Him I couldn't do this (F1).

> You must be somebody who is a believer. And that thing is helping you and you know that you are doing the right thing. You never go wrong with God, you know… When they are happy you know the children are happy, everything is complete for me now. I can go to church and pray and say thank you Lord (F12).

Furthermore, several participants also believed that they had been blessed with the task of being caregivers and that they had been given this task for a reason:

> This job was given to me for a reason. Because I never really thought that I would be working here. I never even dreamt of being a carer (F11).

> To work with disabled kids you know, it's a blessing for me. It's a blessing for me… we are blessed to be given a heart like that…And I feel that to me, I'm a chosen one. I'm chosen to be with these kids (F12).

> I'm also told that God give me Nondi for a reason and that I'm here because of Nondi. I said God gave Nondi to me for a reason (F15).

Several participants also used their faith to understand why their child had been diagnosed with CP. In many cases, caregivers explained how they believed that their child's disability was not a mistake and that it was part of a greater plan:

> I've told myself that God does not make mistakes. He does not do anything by mistake and my child being like this is not a mistake (F6).

> If God wasn't there, maybe these children wouldn't be here. Because then they are sickly. You see them as sickly children but we're going on and striving and have hope and faith… I know that God is with them. All the time. Next to them, God is there to make it better (F12).

> I do have that belief that if something is happening you know it's God's power you know, there's nothing I can do (M13).

5.2.1.2 Personal transformation. Another main theme that emerged as a facilitator was the personal transformation that several caregivers had undergone as a result of their time spent as caregivers. The sub-themes identified in relation to this facilitator included improved patience as well as compassion and the desire to be more involved. One participant noted how her life had changed for the better since she became a caregiver, as she felt that she had found her purpose:

> My lewe het baie verander, ek moet dit sê. Ek is meer spontaan en ek is op en wakker. Ek is meer besig en die dinge wat vir my besig hou met die kind, dit hou my gesond ook (F4).

Several participants also noted the importance of patience when working with disabled children and how they had become more patient as a result of their caregiving duties, as they would often spend a great deal of time working with a child on one activity before moving to another:

> You must spend a lot of time with one kid. You must make sure that he understands you before you go to the next one… I have become more patient. I have because I can just spend my time working with these kids, I don't mind (F11).

> You know your patience will develop when you're working with these children. It doesn't work when a person is in a hurry and is too excited and so you know you must be patient (F12).

Moreover, one participant reported how her work as a caregiver had caused her to develop a passion for working with disabled children and a desire to become more involved, which inspired her to pursue a career in the education of disabled children:

> I developed passion and love for this job. So that's how everything changed. It actually gave me something to look forward to. Because I worked with them, I have even changed my career. Like I'm thinking of becoming a teacher for severely disabled children (F11).

5.2.2 Interpersonal processes. The next main theme concerned the interpersonal relationships that facilitated coping among the caregivers in the present study. Sub-themes included the social support that caregivers received as well as the relationship that caregivers had with their child.

5.2.2.1 Social support. Numerous participants reported that they received social support from a variety of sources including community members, healthcare professionals, and immediate family. One caregiver stated that one of her friend's was a source of respite when she needed to leave the house:

> When I need to go somewhere then a friend looks after Wade. She would clean him, make sure that he eats, takes his pills and so on (F7).

Several caregivers also reported instances where friends and neighbours from their community had provided them with assistance during challenging periods. One caregiver explained how one of her friends had given her an informal home to stay in when she had first arrived in Cape Town with her child, and how her neighbours had watched over her child while she was attending school:

> So I went to one of my friends. I asked a friend to give me the shack, just to stay there, and it was the time when I studied, sometimes I left early because I had early class. I stayed at the place like this one where there were two shacks, so I made friends with people because I wanted them to look after her (F14).

Another caregiver noted that she had befriended another mother of a child with CP, who had supplied her with meals when she could not afford food and who had assisted her to obtain an occupational therapist, which had helped her to understand her child's disability:

> When I came here I was not working, I didn't have money, Lerato would give me food so that I could sleep having eaten some food and she explained to me about CP as a mother of a child with CP and organised the occupational therapy so that they can explain to me what CP is, what can I do for my child (F15).

Moreover, one participant also explained that one of her friend's had supplied her with information regarding the care dependency grant, which prompted her to apply for the grant for her foster child:

> Iemand, ek dink 'n vriendin van my. Ek het nie geweet van die toelaag nie, maar toe sê sy, ek moet tog, ek moet gaan. Ek was eers 'n bietjie skaam maar toe het ek gegaan en aansoek gedoen (F4).

Another form of social support among caregivers was assistance from healthcare professionals. Since the management of CP is centred on a multidisciplinary team approach, caregivers were often exposed to a variety of healthcare professionals who provided them with vital information concerning their child's feeding, cleaning, and exercises:

> She has to eat at about 5am. I make her porridge because at the clinic I was told she needs to eat soft foods because she has a throat problem. That is why I wake up and make her porridge at 5am (F5).
>
> Totdat ek saam met hom by die kliniek inloop toe sê hulle vir my. Maar hy het mos teruggekom toe het hulle die pypie in sy neus gehad en toe het sister Juanita vir my gewys, tot hy moes nou die kolostomie sak gehad, hoe om hom skoon te hou al oor die dag (F9).
>
> There is a rehab worker working in my area at that time and came to visit me and explained the exercises for Nondi (F15).

One of the most vital sources of social support for caregivers was assistance from their immediate family members. A number of participants reported that they were living with members of their immediate family, including their parents or siblings, who would assist them with their caregiving duties when they were busy or shorthanded:

> By die huis is dit my ma, sy help vir my, sy help vir my lekker en my suster sy het vir my met Kayla gehelp, veral as ek nou met Kayla besig is of so en ek nou hulp nodig en dan sal ek my ma vra of sy nie vir my kan hulp met Kayla nie want daar's tye wat ek vir haar oefeninge gee en dan is hulle altyd daar vir my of vir my te help (F3).
>
> Family they are very fond of Wade. It's not that they are surprised or so, no they give him all the love. My mother is also at home…Sometimes when I'm busy then she would give Wade his food or his fruit. She's very handy in the house… Also my sister…she's always here (F7).

Several caregivers also noted that they received assistance at home from the siblings of the child in their care. One participant explained how she would often have to leave her child in the care of his older sibling, as she struggled to find someone whom she could trust to care for her child when she needed to leave the home:

> My eldest son helps me a lot with Sipho. Most of the time I left him with Vuyo because there's no one who can look after him besides Vuyo. He is the only one who can get him quiet (F2).

Moreover, another participant reported how her two other children would assist her to care for her child with CP by offering to fetch the child water when she would cry during the night:

> I got support in my family so I didn't have a big problem. My son who's 16 years now when he was young and Nondi was crying he would ask me "mummy, what do you want now, do you want water?" He give me water so that she can drink and also that one, the little one also looks after his sister (F15).

Finally, having a supportive partner was also identified as an important facilitator to coping among caregivers, as several participants noted how their partner assisted them with their caregiving duties. One participant, who had received no support from her child's biological father, explained how her current husband had accepted her daughter as his own child:

> I got married…I met the guy who is not her father, but I've told him that I've got this kind of a child and he said it's fine. Yes she is our daughter now. Both of us (F14).

Another participant reported how her husband was her main source of support at home, as he would always be available when she needed him and he would assist with various caregiving duties including feeding and lifting their child:

> My husband, if I call him, he will come. If I ask him to do something he will do it. He helps me a lot. Hy maak partykeer vir haar pap of hy maak vir haar 'n broodjie dan sny hy dit in blokkies, sit dit in die bakkie en sit dit voor haar neer. Hy sal net vir haar in die stoel sit vir my. Ek kon dit eers doen, ek kon haar lekker optel, maar sy is nou groter (F4).

5.2.2.2 Relationship with child. Another aspect that aided several caregivers to cope was the relationship that they had with their child. Participants noted that their relationship with their child fostered adjustment over time and allowed them to develop a devotion to their caregiving duties. Several caregivers reported that it became easier for them to manage their caring duties when they had learnt to communicate with their child in a non-verbal manner. Since her child was unable to speak, one participant explained how she had learnt to understand her child by interpreting her behaviour and expressions:

> As sy net so vir my kyk en sy lê net so, dan weet ek *something is wrong*. Dan vra ek vir haar, Angela voel jy nie lekker nie? Dan sal sy vir my kyk, net so, dan weet ek iets is nie reg met haar nie. Nou wanneer sy lag dan weet ek Angela is happy, sy wil skool toe gaan. Maar, as Angela vir my kyk en Angela maak niks, dan weet ek Angela wil nie skool toe gaan nie, of sy voel nie lekker nie, of *something is wrong* met Angela, dan hou ek haar by die huis (F4).

Another caregiver explained how she was learning to interpret the facial expressions of the children in her care, which had made it easier for her to communicate with them:

> We can communicate. People don't know that we can. I'm now learning to communicate with them and when I come in they get so excited. And when I'm leaving you can see that they are upset…I can see when the child is just crying for fun or…you can see. And you can see if something's not right. You can see their expressions…it makes it a lot easier (F11).

Several participants also noted that it became easier for them to care for their child once they had learnt to treat them as though they were an able-bodied child. One participant stated that he had adapted to his daughter's disability by treating her as though she were like any other child:

> I don't have information. I just care for her like a baby, like any other person, any other child and we feed her just like that (M13).

Another participant recognised that her child was a teenager who needed to be treated in the same manner as abled-bodied children of the same age, and she argued that her child needed to spend time outside of the house with others:

> Sy is 'n mens en sy is 'n jong meisie, sy is 'n teenager, sy moet ook kry wat 'n *teenager* kry...*She's not a prisoner that must just stay inside the house or just sit in the chair,* ek stap 'n bietjie met haar. Ek moet daai vir haar gee, dit gaan nie mooi wees as sy net in die huis is nie. As dit warm is, 'n mooi dag dan sit ons haar buite, sit haar buite. Sy's 'n mens en ons speel met haar en ons praat met haar (F4).

Participants also reported that the vast amount of time spent caring for their child had facilitated their devotion to caregiving and several participants noted that they had learnt to enjoy their caregiving duties:

> I'm used to caring for Wade and I enjoy it now. He is my child (F7).

> I enjoy the job so much. To work with these kids you know, it's like you've been born, you are the parent of a child who's disabled…Like if you're doing the right thing you feel it in yourself. You don't have to be supervised or somebody must watch you or whatever. If you see the child is happy and you know that you did the right thing. To me it was, it became my life to work with these kids, they are my life and I love the job very much (F12).

As participants developed a devotion to their caregiving duties, they also began to develop a closer bond to the child they were caring for. Two participants explained how they had begun to feel as though the foster children in their care were their own biological children:

> Ons is vir haar nou baie lief want sy is al 'n paar jaar by my. Ons is nou vir haar lief as ons eie kind (F4).

> To work with them you feel that, you gave birth to these children. You take the place of that parent (F12).

One of these caregivers went on to explain how rewarding it was to witness the growth of the children in her care, as she was inspired by their resilience:

> Sometimes I feel that, when I look at that child and I say God is so great, because you see that child is thriving and she's got energy. She doesn't get sick at all but she's growing and you've seen this pretty lady. And you know it feels so good. You want these children to live longer and happy lives. You want that child to feel comfortable. In that small life that he has, he must feel happy (F12).

5.2.3 Community factors. Another main theme concerned the community resources that were available to the caregivers in the present study. Participants reported that acceptance from community members, assistance from religious institutions, and aid from local organisations had assisted them to cope with their caregiving duties.

5.2.3.1 Acceptance from community members. Although many participants reported that they encountered negative attitudes from others, it was also found that certain caregivers experienced acceptance from members of their community. The acceptance and inclusion of disabled children by members of the community resulted in reduced feelings of isolation among caregivers:

> Hulle is baie lieflik. Hulle kom loer af en toe in en speel saam met die kinders. Sê nou hulle kom daar na ons huis toe (F10).

> Our neighbours are involving us. Involving themselves. It's what we want and then we don't feel alone with these children. You feel that there's people with these children (F12).

> The children and the next door neighbours, they all know her…they accept her yes (M13).

Several participants also reported instances where community members had provided them with donations for their child, as reflected in the following extracts:

> There was our neighbour, her child was going to have a birthday and then they wanted to come and do the birthday here. But when I explained to them no, they ask me what kind of toys can we buy the children. And I said to them, you know what, what I want for these children, I want them to get warm slippers. That woman brought the money and we went to shop for everyone for the slippers and they are so warm now (F12).

> Even if they do, actually if they do have a, in the street here, they have a Christmas party or a birthday party for a child, they'll bring some cakes for her. Such things yes (M13).

5.2.3.2 Assistance from religious institutions. One participant explained how her church had become a source of emotional support, where she could discuss and pray about her problems with other members of the church:

> We've got a special church, we have few members there. There you must pick your inner, they say your inner soul. What happened today, what is in your heart today. About your work and so and then they just lay down that there was a child who was like this and this. I feel like this and this with my work and then we pray about it. And then when we pray about it...The next week you going to come and give them the feedback about what and then we'll say maybe it was better or it's becoming worse or whatever. Something like that. We've got something like that in our church (F12).

5.2.3.3 Aid from local organisations. Another community resource was the aid that participants received from various local organisations. One caregiver explained the various donations that she had received for the children in her care, such as assistive devices, toiletries, clothes, and blankets:

> Bedding and equipment from Assistaquip[3]. They've also given us the wheelchairs. And the learning equipment. Toiletries they've given us and every time when they've got things, like clothes they do come and donate them. Next and so many things they've given us. And then Polywear, last year they came and gave us some food. Blankets, clothes and even this tree and they renovated the place (F11).

Another participant had received a special type of milk from the local clinic for the children who had feeding difficulties or problems with nutrition:

> We do get milk from our local clinic. Because we've got those, who don't eat and children who are underweight, maybe we had this child who is underweight already because of the alcohol syndrome. They would help us with the milk. So the local clinic do involve themselves (F12).

Finally, one caregiver also received aid in the form of food donations from a large grocery chain for the children in her care:

> And also last year I got a food donation from a company called Belmat. I got the support for the food last year there (F15).

5.2.4 Institutional factors. Another factor that assisted participants to cope with their caregiving duties was their child's crèche. Participants reported that their child's crèche was a source of respite and a source of progress due to the presence of teachers and healthcare professionals.

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[3] Names of enterprises have been changed.

5.2.4.1 Source of respite. One participant explained how her child's crèche had become a vital source of respite, as she struggled to find someone to care for her child when her care facility was closed during school holidays:

> I've got a place in Khayelitsha. We went there with my husband and talk to the people there. They said because they hear the situation…they said they will take her now. Just to relieve me…That's where the problem lies because I have to have someone to look after her that is why it is so easy for her to be at the centre during the holidays like December holidays (F14).

5.2.4.2 Progress of child. A number of participants also noted that their child had progressed due to the exercises and activities they were receiving at their crèche. One of the participants who operated her own care facility noted how various specialists from the community clinic would visit the home in order to provide their services:

> Because also the therapists from the nearest clinic they do come here. Like the dietician, the physios, you know they do come here (F12).

One participant noted that her child was receiving physiotherapy at her crèche, which was a service that she would not usually be able to access when her child was at home:

> The difference now that he is there compared to when he was at home is that there he is getting physio, which he was not doing at home (F6).

Another caregiver noted how her child's school had become a vital source of assistance, as her child had developed since she had begun to receive exercises at her school that had improved her speech ability:

> By die skool werk help hulle ook, soos daar is veranderings wat ek nou kan sien. Toe ek sien die oefeninge wat sy kry by die skool en goed toe begin raak...ek is nou weer rustig want ek weet daar is nou weer 'n hupstootjie vir my met haar. So daar is baie dinge, soos haar spraak, sy kon nie gepraat het nie maar nou kan sy praat. En daar is dinge wat sy vir my sê wat ek het eers gedink het sy gaan nooit sê nie (F3).

5.2.5 Societal factors. The final theme concerned the financial assistance that the participants were receiving from the state, in order to compensate for the financial burden that is experienced by many families of children with disabilities.

5.2.5.1 Grant from the state. Fourteen of the participants in the present study were receiving a financial grant from the South African Social Security Agency (SASSA). Several caregivers reported that the grant was often the only source of income for the household and that they often relied on it in order to survive:

> She gets the care dependency grant, I remember that time was it was R1 200 but they lifted it up, I don't know how much it is now, but there's only that money (F1).
>
> The grant makes the difference…It's the only thing that takes care of everything (F5).
>
> Dit is nou net sy toelaag. Die hele 1000 en soveel… R1 350.00. Dit help vir my. Daar is nooit 'n tekort van kos vir hom of so nie (F9).

One participant discussed the various forms of financial aid that her care facility had been receiving from the state. She explained that the home was receiving a subsidy for transport, a sponsorship for nappies, as well as a stipend for two of the carers at the home that were necessary for the home to function:

> From the state, they've even now increased the money and also sponsored the nappies as well now, like R500 per month for nappies. Also Social Development has started now to move with us little by little because they gave us a subsidy for transport. Then when the children have got appointments we know that even if we hire the car we've got money to pay that… and also the subsidy for two carers. I mean we've got help little by little…It's not enough but at least we've got something to work on. (F12).

5.3 Conclusion

This chapter reported the results of the present study according to the five levels of the Social Ecological Model (individual factors, interpersonal processes, community factors, institutional factors, and societal factors). Various themes and sub-themes were identified during analysis of the semi-structured interviews that were conducted with the caregivers involved in the present study. These themes consisted of the barriers and facilitators that influenced the caregiver experience. The six main barriers to caring that were experienced by the caregivers in the present study included the consequences of caregiving, difficulty adjusting to caregiving duties, environmental conditions, lack of access to healthcare services, lack of respite services, and negative perceptions from others. The seven main facilitators that aided the caregiving process included personal coping mechanisms, personal transformation, social support, relationship with the child, community resources, the child’s crèche, and financial assistance. In the final chapter to follow, the results of the present study will be discussed in relation to the existing literature on this topic.

Chapter 6: Discussion and Conclusion

6.1 Introduction

This chapter aims to provide a discussion of the most significant findings that were collected in the present study. This will be achieved by linking the themes and sub-themes that were interpreted through the lens of the theoretical framework with those that have been identified in the existing literature. Thereafter, the limitations of this study, recommendations for future research on this topic, and concluding remarks will be presented.

6.2 Discussion of the Findings, Theoretical Framework, and Literature

It has been argued that the health and well-being of primary caregivers often has an influence on the well-being of the individuals with disabilities in their care (Brehaut et al., 2004; Raina et al., 2005). The majority of studies that have explored the experiences of caregivers for individuals with CP have been conducted in developed countries, including Australia, Ireland, Spain (Byrne et al., 2010; Davis et al., 2009; Fernández-Alcántara et al., 2014; Whittingham et al., 2011); while fewer studies have explored the caregiver experience in developing countries, including Kenya, South Africa, Thailand, and Uganda (Barratt & Penn, 2009; Geere et al., 2012; Gona et al., 2010; Hartley et al., 2005; Huang et al., 2011). It is for this purpose that the present study aimed to investigate the experiences of caregivers for children with CP in rural communities of the Western Cape, with specific focus on the barriers and facilitators that influence the caregiver experience, as it is possible that caregivers encounter unique barriers and facilitators in a context such as South Africa, where there are often financial, geographical, and transport boundaries (Parnes et al., 2009). Previous studies have found that although caregivers often experience an array of challenges when caring for children with disabilities, they also acquire various resources that aid the caregiving process (Bourke-Taylor et al., 2010; Davis et al., 2009; Golden & Nageswaran, 2012; Green, 2007; McManus et al., 2006; Murphy et al., 2006; Myers et al., 2009; Resch et al., 2010; Whittingham et al., 2011; Yantzi et al., 2006). Similar findings emerged in the present study, as it was found that caregivers encountered a number of barriers that made caregiving more difficult for them to manage; while they also reported several facilitators that assisted them to cope with their caregiving duties.

The findings of this study are comparable to several other studies that have examined the experiences of caregivers for individuals who have been diagnosed with Schizophrenia, HIV/AIDs, intellectual disability, and Autism (Akintola, 2010; Bayat, 2007; Isa et al., 2013; Tadema & Vlaskamp, 2009). Though CP is a unique condition that can be distinguished from other disabilities, it is possible that there might be similarities between the experiences of caregivers for individuals with CP and those of individuals with other conditions. Since there have been limited studies on the experiences of caregivers for children with disabilities in developing countries (Donald et al., 2014; Geere et al., 2012; Hartley et al., 2005; Thrush & Hyder, 2014), this would allow for comparisons to be made between the findings of this study and those of studies that have examined other conditions.

Using the Social Ecological Model as a means to interpret the findings, the main and sub-themes that were identified during analysis were grouped according to the five levels of influence; namely individual factors, interpersonal processes, community factors, institutional factors, as well as societal factors (McLeroy et al., 1988). The different levels of influence that form part of the Social Ecological Model (McLeroy et al., 1988) will be used to contextualise this discussion, where the themes and sub-themes that emerged on these levels of influence will be presented and linked to previous findings.

As noted in Chapter 2, the individual level concerns the biological and personal characteristics that influence human behaviour, including levels of education, employment status, and age (Gregson et al., 2001). Examples relevant to this study could include financial hardships that were experienced by caregivers due to the inability to obtain employment or concern for the time when they would not be around to care for their child. The interpersonal level comprises of all primary social groups, including peers, family, friends, and neighbours (McLeroy et al., 1988). Examples could include having family members who assist with caregiving duties or assistance from friends and neighbours during challenging periods. The community level concerns the environmental characteristics that influence human behaviour (McLeroy et al., 1988). Examples of community influences could include unhealthy living conditions or support from the community organisations. The institutional level concerns the characteristics of the organisations or institutions with which an individual interacts (McLeroy et al., 1988). Relevant examples could include weak referral systems or lack of trained healthcare professionals. The societal level includes factors that influence attitudes towards disability as well as factors that widen or reduce inequalities between different groups in society (Gregson et al., 2001). Examples could include social norms regarding individuals with disabilities or the provision of the disability grant from the state in order to reduce the financial hardships encountered by families of individuals with disabilities.

The following sections will focus on the most prominent themes that emerged during this study according to the different levels of the Social Ecological Model. For each level this will be achieved by discussing the themes that were identified as barriers to caring, followed by a discussion of the themes that served as facilitators to coping.

6.2.1 Individual factors. A number of individual concerns emerged as barriers to caring for a child with CP. Most of the interviews began with participants explaining how they felt when their child was diagnosed with CP. Fernández-Alcántara et al. (2014) found that parents experienced the most emotional distress at the time of their child's diagnosis, as most parents were not expecting their child to be born with a disability. Similar findings emerged in this study, as a number of participants recalled how their child's diagnosis had been an emotionally challenging time for them, as they were forced to accept their child's condition and their unexpected role as caregivers (Whittingham et al., 2013).

Furthermore, in many cases it has been found that parents display mixed feelings towards a diagnosis of CP, where they would either be relieved to find the cause for their child's condition or grieve the loss of the healthy child that they were expecting to have (Huang et al., 2010; Whittingham et al., 2013). This study found that most caregivers experienced the latter, especially in cases where a child was born healthy, but had sustained some form of trauma that had resulted in their diagnosis with CP. These caregivers found it difficult to accept that a child who had been born without complications would not be able to achieve the milestones that a healthy child would (Fernández-Alcántara et al., 2014).

From the outset of diagnosis, Whittingham et al. (2013) found that parents began to express concerns for their child's future, with specific worry centring on how their child would be integrated into school, work, and wider society. Contrary to such findings, the majority of participants noted that they had not given much thought to their child's future, as they were mostly focussed on managing their caregiving duties from one day to the next. It has been found that caregivers who focus on their present duties might be less prone to feeling overwhelmed by their caregiving tasks, which might be a vital coping mechanism to caregivers who reside in rural communities and receive little professional support (Akintola, 2008; Quinn et al., 2013). Since all of the caregivers were residing in rural communities, it is possible that they were more focussed on overcoming their daily challenges than they were on more long-term concerns (Parnes et al., 2009). However, the older caregivers in this study did express concern that they were aging and that they worried what might happen to their child when they are no longer able to care for them (Chakravarti, 2008; Murphy et al., 2006).

Although CP is a multifaceted condition that can range anywhere from an individual with impairment in a single limb to an individual who is completely immobile (Katz & Johnson, 2013), all of the participants in this study were caring for children who were immobile and dependent on assistive devices. This required caregivers to provide physical assistance to their children during the day and night; which involved lifting them, carrying them, bathing them, and feeding them. As a result, a number of caregivers experienced several physical concerns. One of these concerns included joint and back pain from lifting and carrying the child, which had become more difficult as the child aged. This is consistent with a findings by Murphy et al. (2006) that the physical demands of caregiving tend to have a greater impact on parents when their child grew and become heavier. Furthermore, due to the extended hours of their caregiving duties and the amount of energy consumed by these tasks (Murphy et al., 2006; Myers et al., 2009; Yantzi et al., 2006), a number of participants also reported that they experienced sleep disturbances and chronic fatigue.

One of the most prominent personal challenges that was associated with caring for a child with CP was the financial burden that caregivers experienced. Participants noted that items such as food, clothing, transport, and nappies were the most expensive to provide, which mirrors findings obtained by Davis et al. (2009) that the most basic items required for the care of a severely disabled child can be the most difficult to provide. This financial burden was often confounded by the fact that several caregivers had been unable to obtain employment. Previous studies have found that financial burden arises as many parents reduce their working hours dramatically or leave their jobs in order to care for their child (Murphy et al., 2006; Thrush & Hyder, 2014). The participants of this study indicated that financial burden mainly emerged when they were unable to obtain employment due to the amount of time that they were required to spend with their child on a daily basis (Bourke-Taylor et al., 2010).

Another prominent barrier was the difficulties that participants encountered in relation to the grant from the government. Saloojee et al. (2006) noted that the disability grant provided by the South African government is often underutilised by parents of children with disabilities due to long-waiting periods to receive the application form, lack of knowledge that their child qualified for a grant, and lack of necessary documentation. Contrary to such findings, caregivers in this study reported that it was relatively easy to apply for the grant; however, a number of participants found that the waiting period to receive the funds could take anywhere between three months to one year.

It is evident from the aforementioned findings that participants encountered a number of personal challenges that were often barriers to caring for a child with CP. It is vital to note that these caregivers also employed a variety of mechanisms that allowed them to cope with their caregiving duties. One of the most vital facilitators to caring was the acceptance of the child with CP. Although several participants felt that they had been forced to accept the unexpected news of their child’s diagnosis and their subsequent role as caregivers, they also noted how much easier their caregiving duties had become since they had accepted their child’s condition (Akintola, 2008). One possible reason for this is that when caregivers accept their child’s disability, they are able to develop a deeper emotional relationship with them, where they become more concerned about enjoying the time that they have with their child, as opposed to worrying about the tasks that they need to complete (Fernández-Alcántara et al., 2014).

The possession of faith also allowed caregivers to adjust to their caregiving duties and gave them strength during difficult periods. In many cases, participants noted how their faith had allowed them to make meaning of their child’s diagnosis, to learn to view their child’s condition as a blessing, and to perceive their child’s disability as part of a bigger plan (Zhang & Rusch, 2005). It has been reported that religious practices, such as faith, prayer, and a relationship with God, have been found to provide caregivers with the strength to overcome their daily challenges (Jonker & Greeff, 2009). Another mechanism that allowed participants to cope with their daily duties was to acquire information about CP and how to care for individuals with disabilities (Makoae et al., 2008). Since many caregivers often struggle to obtain information regarding their child’s care needs, where to obtain financial aid, and special education for their child (Golden & Nageswaran, 2012; McManus et al., 2006; Resch et al., 2010), a number of caregivers in this study took it upon themselves to obtain the information that they required. For some caregivers this was achieved by attending short courses so that they could learn more about home-based care; while others would attend workshops in their community where they were taught how to work with disabled children. This allowed participants to feel more in control of their situation and more empowered (Bee, Barnes, & Luker, 2009). Certain participants also noted that they had learnt how to care for their child through trial-and-error, where they would repeat certain techniques until they found methods that worked for them.

Finally, it has been found that individuals who volunteer to care for ailing patients are prone to obtain personal growth as well as psychological and emotional development (Akintola, 2010). A number of participants reported that they had changed for the better as a result of their caregiving duties, as several caregivers explained how they had developed improved patience, love, and compassion since they had started caring for a child with CP (Myers et al., 2009). These virtues often allow caregivers to become more appreciative and aware of those who are different (Bayat, 2007).

From the preceding discussion, it was evident that a multitude of individual factors emerged as barriers and facilitators to caring for participants in the present study. The following section will examine the themes that emerged as a result of the interpersonal processes experienced by caregivers.

6.2.2 Interpersonal processes. In addition to the personal challenges that they had to endure, participants also reported several interpersonal challenges that were primarily influenced by the relationship they had with their child. It has been reported that caregivers experience increased levels of anxiety, emotional strain, and diminished quality of life due to the physical and emotional burdens that accompany their roles (Davis et al., 2009; Minor, Carlson, Mackenzie, Zernicke, & Jones, 2006). Moreover, it has been found that a caregiver’s confidence in their ability to perform their caring duties is often deterred when they witness the pain, suffering, or death of the individuals in their care (Akintola, 2008). It has been argued that these challenges, combined with inadequate coping skills, can lead to burnout and compassion fatigue among caregivers (Minor et al., 2006).

In line with such findings, a number of participants reported that one of the most challenging aspects of caregiving was to witness negative aspects of their child’s condition. Caregivers recalled how traumatic it had been when a child in their care had suffered a neurological complication such as a seizure (Bax et al., 2005; Smith & Kurian, 2012). Furthermore, a number of caregivers also reported instances where they had struggled to feed their child due to chewing and swallowing difficulties that are often associated with CP (Aisen et al., 2011; Smith & Kurian, 2012; Tadema & Vlaskamp, 2009). This was challenging for caregivers to experience, as most of them had not been exposed to these kinds of symptoms and were thus not equipped with the knowledge to manage them. Minor et al.

(2006) found that a mindfulness-based stress reduction program, which allowed parents of children with chronic conditions to interact with more experienced caregivers as well as healthcare professionals, was an effective means to reduce stress levels and mood disturbances among caregivers. It is possible that a program of this nature could be beneficial to the caregivers in this study; however, the provision of such services is often lacking due to lack of funding being devoted to healthcare services and a lack of healthcare professionals who are trained to manage a child with CP (Davis et al., 2009; Donald et al., 2014; Thrush & Hyder, 2014). Furthermore, caregivers are often unable to find a break to attend such programs, as they spend most of their time caring for their child at home. This could indicate a need for programs that could provide these services to caregivers at their homes or community centres, and assist them to build their support systems so that they may become more equipped to manage their caring duties (Minor et al., 2006).

In addition to coping with the severity of their child's condition, participants also found it challenging to adjust to changes in their social life and personal relationships. It is often difficult for caregivers to maintain the social relationships that they formed prior to their child's diagnosis, as they find that others are unable to relate to their situation (Davis et al., 2009; Whittingham et al., 2013). In line with this, a number of caregivers noted how the diagnosis of their child had caused their priorities to change, as they had become more focused on their caring duties and meeting their child's needs than they were on activities that they had previously enjoyed. As a result, participants reported that they had become more distanced from their friends, as they felt that they no longer shared the same interests.

Due to the complex care needs that accompany a child with a disability; such as feeding, bathing, the administration of medication, the provision of physical therapy exercises, and assistance with mobility; it has been found that many caregivers do not have personal time to devote to social activities (Bourke-Taylor et al., 2010; Davis et al., 2009; Golden & Nageswaran, 2012; Whittingham et al., 2011). A number of participants in this study reported that the demands of their caregiving duties did not afford them the time or energy to socialise, which often resulted in feelings of isolation despite a desire to be surrounded by others (Davis et al., 2009). This lack of socialisation often became more challenging when a child had mobility difficulties that complicated a caregiver's ability to leave their home due to the amount of planning, physical work, and energy that were required when a caregiver desired to leave their home with their child (Yantzi et al., 2006).

Although participants experienced a number of barriers that were influenced by their interpersonal relationships and social lives, they also benefitted from their relationship with their child as well as their friends and family. A number of participants indicated that they received social support from a variety of sources, including their community members, healthcare professionals, and family members. It has been suggested that this resource is a vital means to facilitate coping among caregivers, as the presence of a support network has been shown to alleviate the stress that often accompanies the caregiving role (Davis et al., 2009; McManus et al, 2006). Participants reported that support from their family members was one of the pivotal facilitators that allowed them to adjust to their caregiving duties, as it prevented them from feeling overwhelmed when they were shorthanded at home or when they required assistance with their child. In line with previous findings, the presence of a child with CP often strengthened the bonds between a number of caregivers and their family members, as participants reported how their partners and their other children would assist them with their caring duties (Bayat, 2007; Jonker & Greeff, 2009).

Tangible assistance from community members, such as friends and neighbours, was also helpful for caregivers during challenging periods (Jonker & Greeff, 2009). Certain participants recalled instances where their friends and neighbours had provided them with meals when they were experiencing financial hardships; while others noted how their neighbours had watched over their child when they needed to leave the home. Since they had become caregivers, a number of participants had also befriended other parents of children with disabilities who provided them with advice and information that led to an improved understanding of their child's condition (Davis et al., 2009). Furthermore, support from healthcare professionals was also identified as an important resource by participants in this study. It is vital that caregivers have a comfortable relationship with their child's healthcare professionals, where they are able to communicate their experiences and are able obtain information about their child's condition as well as their caregiving duties (Van der Voort, Goossens, & Van der Bijl, 2007). Through this relationship caregivers are able to learn how to perform certain duties, such as bathing and feeding techniques, which allows them to develop confidence in their ability to fulfil their caring roles (Van der Voort et al., 2007).

Participants also felt that their ability to cope was influenced by their relationship with their child. Caregivers have noted that their child's inability to communicate is often a source of frustration for themselves and their child, as it becomes challenging when a child is unable to express their needs and feelings (Hartley et al., 2005). As participants interacted with their child over time, they were able to develop a greater understanding of their child's needs through non-verbal communication, and they began to adjust to their caregiving duties by treating their child as though they were any other able-bodied child. Learning to communicate with their child was a vital means for participants to develop secure, sensitive attachments with them and led to a deeper understanding of their care needs (Howe, 2006). Participants were more prone to develop this skill if they understood their child's limitations and frustrations, which allowed them to interpret whether their child's behavioural signals were expressions of happiness or distress (Howe, 2006).

Finally, a number of participants also reported that their daily interactions with their child had caused them to develop pride in their caregiving duties. Several caregivers noted how they had developed a passion for their caring duties, as they felt that there was real value in the work that they were doing with their child (Green, 2007). Furthermore, participants were also able to draw inspiration from their child's resilience and courage, as they felt that it was rewarding when their child reached certain developmental milestones (Davis et al., 2009).

It is evident that participants experienced a number of barriers and facilitators to caring that were influenced by their interpersonal relationships. It is also vital to examine the context in which these interactions took place. Therefore, the following section will focus on the community factors that served to aid or impede the caregiver experience.

6.2.3 Community factors. As noted by Parnes et al. (2009), the relationship between poverty, disability, and health is often influenced by the social and environmental contexts where individuals with disabilities as well as their families live. One of the greatest barriers that participants encountered was the harsh environmental conditions that they were living in. All of the participants were residing in or near informal settlements, where conditions such as overcrowding, inadequate sanitation, and limited access to water as well as healthcare services were prevalent (Oldewage-Theron, Dicks, Napier, & Rutengwe, 2005). Furthermore, individuals residing in informal settlements have also reported rodent infestation, rust, and damp in their homes (Oldewage-Theron et al., 2005). Participants found that the presence of these unhealthy environmental conditions in their respective communities were often detrimental to their child's health, and several caregivers desired to find a more suitable living environment for themselves as well as their child.

Since overcrowding is a prominent feature in many informal settlements, homes made of corrugated iron are often built close to one another, which leaves little space for individuals to walk between them (Oldewage-Theron et al., 2005). The lack of space between homes made it difficult for caregivers to transport their child, as their child's wheelchair could not fit such narrow spaces, and in many cases their child was too heavy to be carried (Bourke-Taylor et al., 2010). This also became problematic in times of emergency, such as floods and fires, as participants noted that it was a struggle to evacuate a burning or flooded home with a disabled child. Furthermore, participants also reported that the conditions of the roads in their communities did not always accommodate vehicles, which prevented transport services from accessing their homes (Barratt & Penn, 2009; Lucas, 2012). As a result of these physical barriers, caregivers and their children had limited access to certain private and public places, which contributed to their social isolation (Bourke-Taylor et al., 2010).

Participants also received a number of resources from the community which aided them in their caregiving duties. Murphy et al. (2006) highlighted the importance of informal support networks in order to improve the strength and resolve of caregivers. It has been suggested that acceptance from community members is an important facilitator for emotional well-being among caregivers for children with special needs (Altiere & von Kluge, 2009; Raz & Vizner, 2008). In line with such views, several participants in this study noted that when their child was accepted and included by members of their community, they felt more supported and were prone to less feelings of isolation. Participants argued that this acceptance accompanied a recent shift away from feelings of denial and shame towards disability due to an increased presence and awareness of disabled children in their community (Raz & Vizner, 2008).

Since many caregivers were unable to obtain employment due to the demands associated with their caring duties, the compounding effect of their unemployment status and financial burden often left them unable to provide the basic necessities for their child (Heymann & Kidman, 2008). Support from the community emerged as a vital means for caregivers to overcome these deficits and to improve their well-being (Heymann & Kidman, 2008). Participants who were employed as caregivers noted that private donations from community organisations, such as food, money, blankets, and assistive devices, were often vital to the maintenance of their care facilities.

The importance of religious institutions as a source of support have also been recognised in the literature (Jonker & Greeff, 2009; Makoae et al., 2008; Penman, Oliver, & Harrington, 2009). Interacting with members of the religious community has been identified as a vital source of emotional and spiritual support for caregivers during challenging periods (Jonker & Greeff, 2009; Makoae et al., 2008). In line with such findings, participants reported that they had been able to turn to their church groups in times of distress and members of their church would show concern, provide advice, and pray for them to overcome their challenges (Penman et al., 2009). Participants noted that this resource allowed them to feel loved and understood by others (Penman et al., 2009).

It is evident that participants encountered a number of barriers that were associated with their physical surroundings; however, they also received valuable support from their community members that aided the caregiving process. The next section will focus on the institutional factors that caregivers encountered in the public and private sphere.

6.2.4 Institutional factors. One of the greatest barriers that caregivers experienced was a lack of access to vital healthcare services (Barratt & Penn, 2009; Bourke-Taylor et al., 2010). A challenge that emerged among participants from the outset of their child’s diagnosis was a lack of access to adequate information. It has been argued that parents or caregivers usually expect information from healthcare professionals to help them understand their child’s condition (Gona et al., 2010). However, they are more likely to receive little or no information about CP, which can lead to feelings of mistrust towards healthcare professionals (Gona et al., 2010). In line with such findings, a number of participants reported how they were not informed of the extent of their child’s condition when they first sought out medical assistance for their child. Moreover, certain participants were only informed of the true extent of their child’s condition when they were referred to a care facility.

Caregivers also noted that they were not provided with information regarding their child’s care needs, their rights as caregivers, or where they might be able to acquire help with their child (McManus et al., 2006). This lack of information contributed to feelings of distress, frustration, and isolation among participants, as they felt that they were alone and had nowhere or no one to turn to for assistance (Davis et al., 2009). Owing to this lack of information, caregivers were often forced to take it upon themselves to obtain the relevant information regarding their child’s condition and care needs, which is a mechanism that was employed by a number of participants in this study (Davis et al., 2009; McManus et al., 2006).

Participants also noted that transport barriers prevented access to healthcare services for individuals residing in rural communities (Barratt & Penn, 2009). Common complaints among caregivers include having to travel long distances in vehicles that are often unreliable and expensive, which makes it challenging to attend follow-up appointments (Barratt & Penn, 2009). Similar concerns emerged among participants in this study, as their child's appointments at the clinic could take up to several hours and they would often need to hire public transport for an entire day (Boydell et al., 2006). The high cost of hiring public transport was thus one of the main contributors to the financial burden experienced by caregivers in this study.

In addition to the high costs of transport, participants were also inhibited from using public transport services due to the design of vehicles that did not accommodate individuals with disabilities as well as their assistive devices (Donald et al., 2014; Lucas, 2012; McManus et al., 2006). This became problematic for the caregivers who relied on public transport to attend their child's appointments, as they were often forced to carry their child to their nearest taxi rank or bus stop, or they would have to walk to the clinic and push their child in their wheelchair if their child was too heavy to be carried. This finding contributes to the argument that the task of caring for a disabled child in the context of a rural community can be more physically demanding than it would for caregivers in urban areas where healthcare services are centralised and more easily accessible (Geere et al., 2011). This could suggest that there is a need to improve the accessibility of public transport by fitting vehicles with the necessary aids to accommodate individuals using assistive devices. However, the cost of such an endeavour would be high and even with such provisions there is no guarantee that transport that has been wheelchair adapted will be wheelchair friendly (McManus et al., 2006).

Another prominent service-related barrier that caregivers experienced was a lack of access to respite care. The importance of respite services has been highlighted in the literature, as caregivers are often only able to take a break from their caring duties when their child attends a care facility or school for a few hours a day or a week (Yantzi et al., 2006). Since healthcare services are most likely to be located in urban areas, caregivers residing in rural communities do not have access to many vital support services such as out-of-home respite care (Yantzi et al., 2006). When there were care facilities available in their communities, certain participants felt that they did not always provide a disability-friendly environment due to the integration of both disabled and able-bodied children. As a result, caregivers became concerned that staff members were not equipped with the knowledge to provide the quality of care that their child required (Yantzi et al., 2006).

Caregivers were thus forced to seek alternative sources of respite, such as friends, family, or neighbours within their community (Yantzi et al., 2006). A number of participants were able to make use of unpaid respite from their family and community members; however, certain participants also experienced a lack of support from others (Resch et al., 2010). Caregivers explained how their family and friends did not possess the skills and knowledge that were required to meet their child's needs, which made them unable to cope with the caregiving role (Bourke-Taylor et al., 2010; Yantzi et al., 2006). However, in many cases participants had no choice but to rely on members of their community who had little caregiving experience, as there was no one else available to care for their child when they needed time away from home.

Although most participants found it challenging to access adequate respite services, there were certain caregivers who were able to find an appropriate care facility for their child in their community. These participants recognised the importance of their child's crèche, school, or day-care, as they valued the time off from their caring duties that these facilities afforded them (Yantzi et al., 2006). Furthermore, caregivers also valued the contributions that the staff at their child's care facility were making to their child's progress. A collaborative relationship is often developed between a parent, their child, and the staff at their care facility, as staff members share valuable knowledge that allows parents to understand the cause of their child's disability as well as the therapies that could be utilised in order to manage it (Leiter, 2004).

Participants also noted that their child would interact with a number of professionals through their care facility, which exposed them to a variety of resources that they would not have been able to obtain at home. One of these resources was the physical exercises and therapies that staff members would perform with the children at the care facility. The importance of physical activity has been recognised among both able-bodied and disabled children, as it is argued that physical activity contributes to improved physical, emotional, and social well-being among these children (Murphy & Carbone, 2008). Caregivers in this study recognised the importance of physical activity, as they reported how their child had progressed since they had begun to receive physical therapy at their care facility. Caregivers explained how their child's speech, dexterity, and mobility had advanced due to their daily activities and exercises. Caregivers felt at ease knowing that their child was receiving various therapies at their care facility, and they gained hope for their child's future by witnessing their improvements.

It is evident that although caregivers encountered a vast number of barriers that prevented them from accessing vital services that were necessary for their child's care, they were also exposed to several important resources when they were able to obtain these services. The following section will discuss the social policies, structures and systems that influenced caregivers at the societal level.

6.2.5 Societal factors. Participants experienced a number of barriers and facilitators that were influenced by broader social policies and norms regarding individuals with disabilities. One of these barriers concerned the negative perceptions that others held towards children with disabilities due to the prevailing social and cultural norms. Another common challenge experienced by participants was the cultural perception that their child's disability was the result of witchcraft practices, which often led to the rejection of disabled children in their families (Hartley et al., 2005). It has been found that these negative perceptions from others can make it difficult for parents to accept a disabled child (Wazakili et al., 2006); however, the caregivers in the present study were more prone to accept their child and became frustrated when others would suggest that their child's disability was the result of witchcraft practices.

These cultural beliefs also resulted in the stigmatisation of individuals with disabilities by members of the community (Akintola, 2008). In order to avoid stigmatisation from community members, many families develop a sense of denial that there is a disabled child in the home and resort to hiding the child away by locking them in a separate room (Akintola, 2008). In line with such findings, participants reported how other parents would often hide their disabled child away when others visited their home, which contributed to a greater lack of awareness of disabled children in their community. Although these perceptions had begun to shift as certain members of the community began to accept and integrate these children, certain participants reported that they still experienced negative reactions from others when they took their child out in public (Bourke-Taylor et al., 2010;

McManus et al., 2006). Caregivers noted that it was both frustrating and saddening when others would tease or stare at their child (McManus et al., 2006). This would suggest that there is still a need to promote awareness of children with chronic conditions and disabilities in these communities, as these negative reactions further contributed to the social isolation that many caregivers experience.

Participants also benefitted from several social policies that had been implemented to prevent inequality among individuals who are disabled. One of the most vital facilitators to caring that was identified by participants was the provision of financial aid from the government. In an attempt to improve access to healthcare, the South African government introduced a policy that allows pensioners, pregnant women, disabled individuals, and children under six year of age to access healthcare services for free (Barratt & Penn, 2009). In addition to this, a number of grants have been made available to individuals with special needs, including disability grants, child welfare grants, and care dependency grants (Barratt & Penn, 2009).

The majority of participants in this study relied on the care dependency grant as their primary source of income. If a South African citizen is the primary caregiver, parent, or foster parent to a child under the age of 18 years who has a disability that requires full-time care, they are eligible for the care dependency grant of R1350 per month (South African Government Services, 2014). Although a number of participants considered the grant to be a vital resource that often served as the only source of income for their household, they still experienced financial burden due to the immense expenses that their child and family incurred as a result of their child’s disability.

This section sought to examine the most prominent themes that were identified as barriers and facilitators to caregivers in the present study. The main themes and sub-themes were contextualised using the five levels of the Social Ecological Model - individual factors, interpersonal processes, community factors, institutional factors, and societal factors- and were discussed in relation to previous findings that have been identified in the literature. The limitations of this study, recommendations for future research, and concluding remarks will be presented in the following sections.

6.3 Limitations

The present study has several limitations. Firstly, although the sample comprised of individuals who resided in various areas of the Western Cape and who differed on demographic characteristics, such as the age of the child being cared for and the years of caregiving experience, the total participant group was not fully representative of the broader population of caregivers and the findings of this study are thus not generalisable. This limitation was further confounded by the fact that a small sample of predominantly female caregivers was used as the source of data collection. One means to overcome this limitation would be to extend the focus of the study to include more a more representative sample of caregivers across South Africa by sampling more male caregivers.

Secondly, the themes and sub-themes that were identified through thematic analysis were not verified. The preliminary results of thematic analysis could have been verified by sending the initial themes to the participants so that they could ensure that the themes were accurately deduced from the interviews. Moreover, focus groups could have been held with the participants in order to present and verify emergent findings with them. Although I was unable to make use of these measures due to geographic and time constraints, I made use of member checking during the interviews and clarified any misunderstandings with the social workers who were present. I was also unable to send the transcripts to participants to confirm their accuracy due to their personal circumstances.

6.4 Recommendations for Future Research

Given its exploratory nature, the present study has provided an avenue for future research of caregiver experiences in the context of a developing country such as South Africa. Since this study focussed on describing the barriers and facilitators that influence the caregiver experience, it is recommended that future studies build on these findings in order to develop and implement interventions for caregivers of children with CP.

In order to obtain more generalisable results, future research could expand the sample size to include female and male caregivers from different regions in South Africa. Furthermore, this study focused specifically on caregivers from rural communities, however, future studies could explore the differences between rural and urban caregivers in order to ascertain whether these groups differ in terms of the barriers and facilitators that they experience on a daily basis.

Through this research study, I was able to work with several community workers who regularly assist these caregivers and their families. It could be interesting to explore the experiences of these community workers in order to ascertain the barriers that these individuals encounter through their efforts to assist these families, as well as the resources that make their services easier to provide. Such findings could be used to inform policies of government branches, such as the Department of Social Development, in order to improve the services and interventions that are available to families of children with CP or even other disabilities.

6.5 Conclusion

This study aimed to explore the experiences of a group of caregivers for children with CP in various rural communities in the Western Cape, South Africa. This exploratory qualitative study revealed that caregivers encountered a number of barriers and facilitators that influenced their caring experience. A number of barriers to caring emerged including the personal consequences of caregiving, difficulty adjusting to caregiving duties, environmental conditions, lack of access to healthcare services, lack of respite services, and negative perceptions towards disability. Various facilitators to caring were also identified, namely personal coping methods, personal transformation, social support, relationship with one's child, community resources, child's crèche, and financial assistance. These themes were contextualised using the Social Ecological Model (McLeroy et al., 1988) and were compared to the existing literature on the caregiver experience. It was evident that most of these themes were consistent with those that have been identified in studies that have examined the experiences of caregivers for individuals with other chronic conditions, such as HIV/AIDS, autism, mental illness, cancer, and neurological disorders. This could suggest that there are similar barriers and facilitators shared by caregivers who reside in developing countries, regardless of the condition of the individual they are caring for.

Although most of the themes that were identified were consistent with previous findings on the caregiver experience, it was found that there were a number of service-related barriers that were particularly problematic for the caregivers in this study. Firstly, the lack of information regarding CP was a prominent barrier that was reported by participants. This challenge emerged from the time that a caregiver's child was diagnosed, as medical staff did not inform them of the extent of their child's condition, which resulted in much confusion and often a mistrust of healthcare professionals. Since the relationship between a child's caregiver and their team of healthcare professionals is often long-term, it is vital that there is trust and collaboration between these individuals from the start of their relationship. There is thus a need to ensure that caregivers receive an explanation of what their child's condition means, how it was caused, and how it can be managed at a level that they would understand.

Secondly, participants also found it difficult to adjust to their caring duties and were lacking adequate support networks. The findings of this study suggest that there is a need for programs that serve to provide caregivers with the support and education that will empower them to cope with their caregiving duties. Since caregivers are often unable to leave their home due to demands of their caring duties, there is a need for home- or community-based interventions that could accommodate caregivers who do not have the opportunity to leave their homes. Due to lack of funding and lack of trained professionals, these types of programs are not possible, which suggests that there is a need to improve the provision of these services. One means to do so could include programs where more experienced caregivers provide guidance about how to care for a child with a disability and how to manage one's role as a caregiver.

Thirdly, participants found that a lack of disability-friendly services was a prominent barrier that they encountered, especially when it came to accessing healthcare and respite services. Caregivers found that public transport was expensive and not equipped to accommodate their children. This suggests that there is a need to improve the accessibility of public transport by fitting vehicles with the necessary aids for individuals who are utilising assistive devices. Furthermore, participants also found that there were limited care facilities in their respective communities that were equipped to provide the quality of care that their child required. This was mainly influenced by the fact that both able-bodied and disabled children were enrolled in these facilities, which meant that the staff at these facilities were often not trained to care for individuals with disabilities. The provision of adequate respite services is a vital resource for caregivers, as it would provide them with time away from their caring duties that often left them unable to socialise or seek employment.

Although caregivers received support from a number of different sources that improved their ability to cope, it is evident that they still encountered a number of barriers that made it more challenging to perform their daily duties and it was found that these barriers were mainly service-related. There is thus a need to improve the provision of services to caregivers in this context, in order to ensure the well-being of both caregivers and the children in their care. This study is one of the first of its nature to be conducted in South Africa and the findings that were generated have served as a starting point for future research on this topic. It is hoped that these findings have illuminated the barriers and facilitators that these caregivers experience on a daily basis and that future research can explore the types of programs that can be implemented to generate greater awareness and support for children with disabilities as well as their caregivers.

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List of Appendices

The following documentation is attached and is included in support of this research project:

A. Ethical Clearance
B. English Biographical Questionnaire
C. Afrikaans Biographical Questionnaire
D. English Informed Consent Form
E. Afrikaans Informed Consent Form
F. English Semi-Structured Interview Questions
G. Afrikaans Semi-Structured Interview Questions
H. Participant Profiles
I. Turnitin Report

Appendix A: Ethical Clearance

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Approval Notice

New Application

09-May-2014

Steadman, Jacqui

Ethics Reference #: S14/03/061

Title: The experience of caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa.

Dear Ms. Jacqui Steadman,

The **New Application** received was reviewed by members of **Health Research Ethics Committee 2** via Minimal Risk Review procedures on **10-Apr-2014** and was approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **04-May-2014 -04-May-2015**
Please remember to use your **protocol number** (**S14/03/061**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.
Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval
Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard HREC forms and documents please visit: www.sun.ac.za/rds
If you have any questions or need further assistance, please contact the HREC office at 0219389207.

Sincerely,
Mertrude Davids
HREC Coordinator

Appendix B: English Biographical Questionnaire

Biographical information

Instructions: Please fill in your biographical information. Indicate your choices by circling the correct option.

Name and Surname: ………………………………………………………………………………

Age: ………………

Gender: Male/ Female

Ethnicity: White/ Coloured/ African/ Other*

If other, please specify: ………………………………………………………………………...

Marital Status: ………………………………………………………………......................

Home language: ………………………………………………………………………

Email address: ……………………………………………………………………………….

Contact number: ……………………………………………………………………………..

How long have you been a caregiver: ………………………………………………………….

Number of hours spent with child everyday: ………………………………………………..

Occupation: Part-time/ Full-time/ Unemployed

Age of the child being cared for: ……………………………………………………...

What type of Cerebral Palsy does your child have: ..……………………………………………

Appendix C: Afrikaans Biographical Questionnaire

Biografiese Inligting

Opdrag: Vul asseblief u biografiese inligting hieronder in. Dui u keuse aan deur die regte opsie te omkring.

Naam en van: …………………………………………………………………………….........

Ouderdom: ………………

Geslag: Manlik/Vroulik

Ras: Wit/ Kleurling/ Swart/ Ander*

Indien ander, dui asseblief aan ………………………………………………………….......

Huwelikstatus: …………………………………………………………...................

Huistaal: ………………………………………………………………………………..

E-pos adres: ……………………………………………………………………………

Kontaknommer: ……………………………………………………………………...

Hoe lank is u al ‘n versorger?: ……………………………………………………………

Aantal ure wat u daagliks met u kind spandeer : ……………………………………………..

Beroep: Deeltyds/Voltyd/Werkloos

Die ouderdom van die kind wat versorg word: ………………………………………………

Watter tipe serebrale verlamming het u kind?: ...…………………………………………......

Appendix D: English Informed Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: The experience of caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa.

REFERENCE NUMBER: S14/03/061

PRINCIPAL INVESTIGATOR: Jacqui Steadman

ADDRESS: 2 Woltemade Street, Die Boord, Stellenbosch, 7600

CONTACT NUMBER: 079 426 6160

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study aims to explore the experience of caring for a child with cerebral palsy (CP) on individuals who live in rural communities of the Western Cape, South Africa. For the purpose of this study, a primary carer of a child with disability has been defined as an individual who is responsible for the care and daily decision making of that child.
- Most of the studies that have been conducted on the caregiver experience have taken place in developed countries, while developing countries such as South Africa have received less focus. This study is significant because it is possible that caregivers encounter unique challenges and resources in rural areas that have not been identified in the literature from developed countries. A study of this nature has not been conducted in South Africa, and it is possible that the knowledge obtained from this study could be used to offer suggestions on how caregivers could attain more resources and how they could cope with the challenges they face.
- The study will be conducted at a time and place that suits you. Approximately 10-15 individuals will participate in this study. Data collection will commence with the completion of a biographical questionnaire. This will be followed by a semi-

structured interview, consisting of questions that relate to your experiences as a caregiver of a child with CP. The interviews will be conducted one-on-one and I (a Psychology Masters student) will be conducting the interviews. Each interview will be approximately 60-90 minutes long. With your permission, the interview will be tape-recorded so that it can be transcribed as verbatim for the data analysis.

Why have you been invited to participate?

- You have been invited to participate in this study because you have been identified as a primary caregiver of at least one child with CP and because you live in a rural community of the Western Cape.

What will your responsibilities be?

- *Y*our only responsibility in this study is that you partake in a once-off semi-structured interview that will last approximately 60-90 minutes, during which you will talk about the challenges and resources that influence your caregiving experience.

Will you benefit from taking part in this research?

- There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in South Africa, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the experiences of caregivers of not only children with CP, but caregivers of children with any disabilities in rural communities of South Africa and abroad.

Are there in risks involved in your taking part in this research?

- The only foreseeable risk for participants in the proposed study is that individuals might experience emotional discomfort or distress during the interviews, as they will be sharing personal details of their lives. However, a system is in place whereby my supervisor Dr. Chrisma Pretorius, a counselling psychologist, will refer any participants to the appropriate healthcare professional should they require any follow up services. Her contact details are: (021) 808 3453 or chrismapretorius@sun.ac.za

Who will have access to your medical records?

- Any information that is obtained in this study will be treated as confidential and any information that can be connected to a participant will not be disclosed without their permission. The identity of participants will be protected by assigning a code instead of using their names. Only the researcher and her supervisor will have access to the information obtained during the study. All the collected data will be kept secure in a locked cabinet in the supervisor’s office and it will be appropriately destroyed and discarded five years after the study is completed.

Will you be paid to take part in this study and are there any costs involved?

- ➢ You will not be paid to participate in this study; however, you will receive a meal voucher valued at R75 for your participation, and you will be compensated for any travel expenses.

Is there anything else that you should know or do?

- ➢ You can contact Dr. Chrisma Pretorius at tel. (021) 808 3453 if you have any further queries or encounter any problems.
- ➢ You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- ➢ You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I …………………………………..………… agree to take part in a research study entitled The experience of caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…........………… on (*date*) …………...……….. 2014.

....

Signature of participant   **Signature of witness**

Declaration by investigator

I *(name)* ……………………………………………..……… declare that:

- I explained the information in this document to …………………………………..

- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ....…........…………on (*date*) …………....……….. ………2014.

....

Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* ……………………………………………..……… declare that:

- I assisted the investigator (*name*) ……………………………………… to explain the information in this document to (*name of participant*) ……………..…………………………….. using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ....…........…………on (*date*) …………....………………..

....

Signature of interpreter **Signature of witness**

Appendix E: Afrikaans Informed Consent Form

DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK: Die ervaring van versorgers vir 'n kind met serebrale verlamming in landelike gebiede in die Wes Kaap, Suid-Afrika.

VERWYSINGSNOMMER: S14/03/061

HOOFNAVORSER: Jacqui Steadman

ADRES: 2 Woltemade Street, Die Boord, Stellenbosch, 7600

KONTAKNOMMER: 079 426 6160

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook enige tyd van die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch **goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).**

Wat behels hierdie navorsingsprojek?

- Die doel van die navorsing is om te kyk watter uitwerking die versorging van 'n kind met serebrale verlamming (SV), wat in landelike gebiede in die Wes Kaap, Suid Afrika bly, het op individue. Vir hierdie doel is u as die primêre versorger geïdentifiseer om aan die studie deel te neem aangesien u verantwoordelik is vir die versorging van, en besluitneming in belang van u kind.
- Meeste studies het gefokus op die versorging wat plaasvind in ontwikkelde lande, terwyl ontwikkelende lande soos Suid Afrika, min fokus ontvang. Hierdie studie is belangrik, omdat dit moontlik is dat versorgers unieke uitdagings en hulpbronne ervaar wat nie geïdentifiseer kan word in die literatuur van ontwikkelde lande nie. 'n Studie soos hierdie is nog nie vantevore in Suid Afrika uitgevoer nie en dit is moontlik dat die kennis wat tydens die studie verkry word, gebruik kan word om voorstelle te gee, en aanbevelings te maak, aan hierdie versorgers rakende hoe om meer hulpbronne tot hulle beskikking te kry en ook hoe om uitdagings wat hulle in die gesig staar te hanteer.
- Hierdie navorsingsprojek sal plaasvind op 'n tyd en plek wat vir u gerieflik is. Daar sal ongeveer 10-15 individue wees wat deelneem aan hierdie navorsingsprojek. Die data insameling sal aanvang neem na die voltooiing van 'n biografiese vraelys. Dit sal gevolg word deur 'n semi-gestruktureerde onderhoud wat sal bestaan uit vrae wat betrekking het op u as versorger van 'n kind met SV. Hierdie onderhoude sal individueel gedoen word en 'n meestersstudent in sielkunde sal die onderhoud met u

voer. Elke onderhoud sal ongeveer 60-90 minute lank duur. Met u toestemming sal dit op band opgeneem word, sodat dit getranskribeer kan word vir data analise.

Waarom is u genooi om deel te neem?

- U is genooi om deel te neem aan hierdie navorsingsprojek omdat u as die primêre versorger van ten minste een kind met SV gediagnoseer is, en omdat u in ‘n landelike gebied in die Wes Kaap woon.

Wat sal u verantwoordelikhede wees?

- U enigste verantwoordelikheid is dat u deelneem aan ‘n onderhoud wat ongeveer 60-90 minute sal duur. Gedurende die onderhoud sal ons praat oor die uitdagings en hulpbronne wat u ondervinding as versorger beïnvloed.

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

- Daar sal geen direkte voordele verbonde aan u deelname aan die studie wees nie. Hierdie studie word die eerste keer in Suid-Afrika gedoen, en daar is ‘n moontlikheid dat die bevindinge gepubliseer kan word in ‘n portuurbeoordeelde joernaal. Dit kan lei tot ‘n beter begrip van die ervarings van hierdie versorgers, nie net van kinders met SV nie, maar ook kinders met enige ander gebreke, in landelike gebiede in Suid-Afrika en oorsee.

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

- Die enigste voorsienbare risiko in hierdie navorsing is dat individue emosionele ongemak mag ervaar omdat hulle persoonlike inligting moet deel. Daar is egter ‘n sisteem in plek waar my studieleier, Dr Chrisma Pretorius,’n Voorligtingsielkundige, enige deelnemers sal verwys na die geskikte professionele gesondheidsorg werker, indien nodig. Haar kontak besonderhede is: (021) 808 3453 of chrismapretorius@sun.ac.za

Wie sal toegang hê tot u mediese rekords?

- Enige inligting wat deur middel van hierdie studie verkry word en wat geïdentifiseer kan word met jou sal vertroulik bly en geen inligting sal bekend gemaak word sonder u toestemming nie. Die identiteit van die deelnemers sal beskerm word deur ‘n kode, en u naam sal nie gebruik word nie. Slegs die navorser en haar studieleier het toegang tot u inligting. Alle data word toegesluit in ‘n kabinet in die toesighouer se kantoor en sal vernietig word sodra vyf jaar na die studie voltooi is.

Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

- U sal nie betaal word om aan die studie deel te neem nie, maar u sal wel ‘n R75 koskaartjie ontvang en ook vergoed word vir enige petrolkostes.

Is daar enigiets anders wat u moet weet of doen?

- U kan Dr. Chrisma Pretorius kontak by tel. (021) 808 3453 indien u enige verdere vrae het of enige probleme ondervind.
- U kan die **Gesondheidsnavorsingsetiek administrasie** kontak by 021-938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur u studiedokter hanteer is nie.
- U sal ’n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek, ……......................………........, om deel te neem aan ’n navorsingsprojek getiteld: Die ervaring van versorgers vir ‘n kind met serebrale verlamming in landelike gebiede in die Wes Kaap, Suid-Afrika.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in ’n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te *(plek)* ....…………. op *(datum)* …………....……….. 2014.

....

Handtekening van deelnemer **Handtekening van getuie**

Verklaring deur navorser

Ek *(naam)* ……………………………...……………… verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan ……………………….......................................………..

- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek ’n tolk gebruik het/nie ’n tolk gebruik het nie. (*Indien ’n tolk gebruik is, moet die tolk die onderstaande verklaring teken.)*

Geteken te *(plek)* ....………… op *(datum)* …………...………....2014

....

Handtekening van navorser **Handtekening van getuie**

Verklaring deur tolk

Ek *(naam)* ……………………………...……………… verklaar dat:

- Ek die navorser *(naam)* ……….........................…………………. bygestaan het om die inligting in hierdie dokument in Afrikaans/Xhosa aan *(naam van deelnemer)* …………………………........................ te verduidelik.
- Ons hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek ’n feitelik korrekte weergawe oorgedra het van wat aan my vertel is.
- Ek tevrede is dat die deelnemer die inhoud van hierdie dokument ten volle verstaan en dat al sy/haar vrae bevredigend beantwoord is.

Geteken te *(plek)* ....………….. op *(datum)* …………...………...2014

....

Handtekening van tolk **Handtekening van getuie**

Appendix F: English Semi-Structured Interview Questions

Questions for Participants

1. Can you tell me about your life and your experiences up until you became a caregiver?
    - How has your life changed since you became a caregiver?
2. How was your child diagnosed with Cerebral Palsy (CP)? What were you expecting to happen?
3. How did you feel when your child was diagnosed with CP? How do you feel about it now?
    - Did the doctor(s) explain to you what CP is?
    - Did they provide you with extra information about CP?
    - Could anything about that appointment have been different? If so, what?
4. Tell me about a typical day for you
    - How does your day begin?
    - What all do you do during the day and with whom?
5. How has the caregiving process affected your life in general?
6. Do you receive assistance from any persons or institutions? If so, who?
7. Tell me about your support systems?
    - Who or what assists you to cope with your caregiving role?
    - Who or what makes caregiving easier for you?
8. Do you receive any financial support?
    - If so, from where or whom?
    - What did this process entail?
    - If no, why not?
9. What are the main challenges that you have experienced as a caregiver?
    - Who or what makes caregiving difficult for you?
    - Are there any financial difficulties?
    - Are there any physical difficulties?
    - Are there any emotional difficulties?
10. When you are not caring for your child what do you do?
    - Does your child attend school during the day?
    - Are there special schools in your area?

Appendix G: Afrikaans Semi-Structured Interview Questions

Vrae vir deelneemers

1. Vertel vir my van u lewe en ervarings voor u ‘n versorger geword het.
    - Hoe het u lewe verander na u ‘n versorger geword het?
2. Hoe is u kind gediagnoseer met serebrale verlamming (SV)? Wat was u verwagtinge rondom wat gaan gebeur?
3. Hoe het u gevoel toe u kind met SV gediagnoseer is? Hoe voel u nou daaroor?
    - Het die dokter(s) SV aan u verduidelik?
    - Het hulle addisionele informasie oor SV aan u voorsien?
    - Kon daardie afspraak anders gewees het? Indien ja, hoe?
4. Wat behels ‘n tipiese dag vir u?
    - Hoe begin u dag?
    - Wat doen u gedurende die dag en met wie?
5. Ontvang u bystand van enige persoon of instansie?
6. Vertel my meer van u ondersteuningsnetwerk.
    - Wie of wat help u om u versorgingsrol te hanteer?
    - Wie of wat maak versorging vir u makliker?
7. Kry u enige finansiële bystand?
    - Indien wel, van wie en waar?
    - Wat behels hierdie bystand?
    - Indien nie, waarom nie?
8. Wat is die hoofuitdagings wat u ervaar het as ‘n versorger?
    - Wie of wat maak versorging vir u moeilik?
    - Is daar enige finansiële tekortkominge?
    - Is daar enige fisieke tekortkominge?
    - Is daar enige emosionele tekortkominge?
9. Wanneer u nie u kind versorg nie, wat doen u dan?
    - Woon u kind ‘n skool by gedurende die dag?
    - Is daar enige spesiale skole in u area?

Appendix H: Participant Profiles

The following section will provide a description of the participants that were interviewed during the present study. In order to ensure confidentiality, each participant was assigned a pseudonym. The following descriptions provide a brief summary of each participant’s demographic information, their living circumstances, as well as a reflection on my (the researcher’s) experiences of the interviews that were conducted with them.

Rosemary (F1)

Rosemary[4] is an unemployed, 62 year old African female with 12 years of caregiving experience who lives in Du Noon. Rosemary is a widower who had taken over guardianship of her granddaughter with CP after the mother of the child had passed away shortly after birth. Rosemary and her granddaughter were both living in a house which she had built with help from her neighbours while her husband was still alive.

Upon my arrival at the Resource centre in Du Noon, I was initially quite nervous to meet with the first batch of participants, as a number of residents in the community were staring at me when I drove into the informal settlement and some even knocked on my car window to ask me what a white woman was doing in an informal settlement. Despite feeling anxious about how I might be received by the community members that I would be meeting, Rosemary welcomed me into her home without hesitation and even hugged me upon my arrival. I could immediately tell that Rosemary took great pride in herself and her home, as one of the first things she told me was how she had laid the tiles and bricks in the house herself. During the interview with Rosemary I could tell that she took pride in her caregiving duties and that it had become a vital component of her life. Rosemary’s confidence and positive attitude were repeatedly reflected in her answers, and she exuded such enthusiasm that I felt thoroughly motivated when I left her house.

Lindiwe (F2)

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[4] Names have been changed to protect participants’ identities.

When I had initially arrived at the second participant's home, she was not there so the two social workers that accompanied me to Du Noon took me to see Lindiwe's child and her home while we waited to find out where she was. In the particular area where Lindiwe lives, the homes are built so close to one another that we had to walk sideways just to get from one home to another. This made me wonder how Lindiwe and other caregivers were able to transport their children from their homes to other destinations in the community. I left Lindiwe's home to go interview another participant until she was back. Lindiwe met with myself and the social workers at the Resource Centre in Du Noon, as she had recently returned from her outing. Lindiwe is an unemployed, 49 year old African female who shares a single-roomed informal house with her two sons, one of which was born with CP. An interesting aspect about Lindiwe is that she is also disabled. Her disability often prevents her from attaining work, but since she is a single mother, Lindiwe has to take on any job that she can to supplement her income from the grant she receives for her child, such as the cleaning of sheep heads once a week.

The interview with Lindiwe was interesting as she revealed aspects of the caregiving that I had not known about, such as the fear of leaving her child with neighbours when she needs to go out. Lindiwe was polite and very soft spoken. She put great thought into her answers to my questions and did not rush the interview, despite being concerned for her son whom she had left with a neighbour since the morning.

Lydia (F3)

For my third interview I met with Lydia at her daughter's day care centre in the Breede Valley, Worcester. This location was interesting because I was introduced to children with various disabilities who attend the day-care centre, as well as the caregivers that work with them on a daily basis. Lydia is a 29 year old Coloured female with 13 years of caregiving experience and lives with her daughter as well as her mother in her mother's home. Lydia is one of only four participants who work on a full-time basis. I could only meet with Lydia on one of her days off due to her work schedule, but we managed to find a time that was suitable for her. Due to transport difficulties Lydia arrived almost twenty minutes late for our interview, however, she was very polite and apologetic.

I conducted the interview with Lydia in Afrikaans, which is my second language, and I found that she was very patient with me. At first Lydia seemed hesitant to answer my questions and she responded in short, however, she became more comfortable and willing to share her experiences as the interview progressed. Due to having her child at a young age, Lydia was forced to accept her child and to love her regardless of her disability. I could tell that Lydia was interested in assisting me, but it seemed that she struggled to put her feelings into words at times. The topic also seemed to quite a difficult thing for her to speak about, however, she was compliant and assisted me to the best of her ability. I could also tell that Lydia had a great deal of pride in herself, as I offered to drop her off at home after the interview, but she insisted on walking.

Madeline (F4)

Madeline was the second participant that I interviewed at the day care in the Breede Valley. Madeline is a 62 year old Coloured female who adopted a child with CP. This was interesting because Madeline was the first non-familial caregiver that I interviewed. Although they have children of their own and were both retired, Madeline and her husband were in search of someone to care for since their children were grown up and had moved out of the house.

The interview with Madeline flowed very well, she spoke in-depth about her experiences and gave honest answers. I could tell that Madeline had much wisdom to share, as she had learnt a great deal on her own through her daily interactions with her child. For example, she spoke about how she taught herself to bathe her child and to feed her. Furthermore, Madeline also spoke about her child with pride even though she was not her biological mother. The interview with Madeline was quite effortless, as she was friendly and required little probing when she answered the questions.

Nesiwe (F5)

The fifth participant was a 33 year old African female living in Du Noon with her partner and her child with CP in a single-room informal home. This participant was one of only two cases where the father, mother, and child with CP were living in the same home. Nesiwe had come to the Western Cape to find work, however, being a caregiver for her child has become her full time job, and she has thus been unable to find work since having her child.

This particular interview was difficult to conduct because the social worker and I could not find the participant’s house since it was located in a part of the informal settlement that had burnt down in the beginning of the year. After walking around in search of her house in the rain and mud, we were able to find Nesiwe's house with help from another member of the community. Upon arrival at Nesiwe's home, it began to rain quite loud, and this made it quite difficult to hear what she was saying during the interview. The sound of the rain hitting the tin roof was quite frightening and it made me wonder what it must be like to experience this on a regular basis. In addition to this, the overall tone of the interview was solemn, it seemed that Nesiwe became quite soft spoken when she was talking about her experiences. Nesiwe answered the questions with very short answers and she seemed saddened to talk about her child.

Daniswa (F6)

The sixth participant was also interviewed at her home in Du Noon. Once again, the social worker and I struggled to find this participants home, and we eventually asked a community member for assistance after walking around the area for approximately 10 minutes. Daniswa is a 33 year old African woman who lives alone with her child with CP. Due to her caregiving duties; Daniswa has been unable to obtain full-time employment and has since tried to open a business in her home. Daniswa welcomed myself and the social worker into her home and even offered us some refreshments.

Although Daniswa was interested in speaking with us, it proved difficult to follow the interview, as there was a lot of noise in the house due to builders and music from the neighbours. The interview flowed well despite these distractions, and Daniswa answered the questions to the best of her ability.

Winona (F7)

The seventh participant met me at her child's day care centre in Wellington. At the day care centre, I was introduced to all of the children and caregivers who belong to the day care as well as several social workers who work with these individuals. Winona is a 41 year old Coloured female living with her husband and her mother near an informal settlement in Wellington. Her son had been healthy at birth, but had obtained an infection that spread to his brain when he was two months old and he has been disabled since.

On that particular morning, four participants had arrived at the day care centre at the same time for their interviews. As a result, interviews 7-10 all felt slightly rushed. However, the participants were patient and did not seem to mind waiting to be interviewed. I also had a social worker present who was familiar with the participants and who assisted me with

Afrikaans translations during these four interviews. Winona answered the interview questions in a very brief but to the point manner, even when she was asked to elaborate on certain points that she had made. It seemed that the topic was difficult for her to talk about, even with the presence of the social worker that she works with on a regular basis.

Sue (F8)

Sue is a 55 year old Coloured female caregiver who lives with her husband and fifteen year old child with CP. Sue had fallen pregnant at the age of 40 and had not found out about the baby until she was six months into her pregnancy. She had experienced intense pain and had to have an emergency caesarean to remove the baby. When she woke up in the hospital, the staff had informed Sue that the baby had to be taken to Tygerberg hospital because she had water on her lungs, and the doctors informed her that her child was disabled.

Sue was friendly and she seemed very interested in the topic of study. The interview with Sue was difficult to conduct because as many times as the social worker or I rephrased the questions, Sue did not understand them and was thus providing answers that did not make sense at times. This is a challenge that was repeated several times in the two interviews that followed. However, I still found that I gained valuable information from the participants despite these challenges. Although these interviews were difficult to conduct, I found that these challenges revealed something about the education levels of the participants and that it is possible that other caregivers in these types of communities might be facing similar circumstances.

Amy (F9)

Amy is a 48 year old Coloured female who lives with her 14 year old child with CP. Amy had had a difficult labour which resulted in the transfer of her child to Tygerberg hospital immediately after his birth. After her child was born and diagnosed with CP, Amy had stopped working to care for him full time. The father of the child visits once in a while, depending on whether he’s working or not, and Amy’s eldest daughter has moved out of the house.

This interview was quite challenging to conduct, as it was difficult to comprehend what she was saying although she spoke clearly and loudly. I found this was because she was speaking a form of Afrikaans that I (as an English speaker) was not familiar with. There were also loud noises in the background which made it more challenging to follow the conversation. However, despite these challenging aspects the social worker was able to interpret for me and I was still able to obtain some valuable information from the interview.

Brenda (F10)

Brenda is a 27 year old Coloured female who lives with her mom and two children just outside of an informal settlement. As the youngest participant to be interviewed, Brenda had given birth to a healthy baby boy when she was 19 years old. However, at the age of six months her son sustained a head injury and has been disabled since. Brenda expressed that neither she nor the doctors knew how this injury had happened, but she said that her son has not been the same since. At the time of the interview Brenda also had a new-born baby that she was caring for. Since she was caring for a disabled child as well as a new-born, Brenda was forced to stop working and now relies financial aid from the government and her mother.

Brenda spoke in a soft tone and gave short answers to the interview questions even when she was asked to elaborate further. This was one of the most difficult interviews to conduct, as Brenda seemed to struggle to talk about her experiences and she appeared sad especially when she spoke about the negative aspects of caregiving. Brenda also appeared to be fatigued, which could have been the result of her caring for two children who both require a substantial amount of care. After finishing this interview I felt slightly worried about the quality of the data collected on that particular day, as all four participants had relatively short interviews. It appeared that some of the caregivers interviewed also exhibited lack of comprehension possibly due to low-levels of education of their own, which felt like it might have had an impact. However, I still managed to obtain informative data from these participants in spite of these various challenges.

Zanele (F11)

Zanele is a 31 year old African female who is employed as a full-time caregiver at a day-care centre in Khayelitsha. This was a particularly interesting participant for me to interview, since Zanele was the first participant that was employed as a primary caregiver. Zanele is married and has a child of her own, but decided she wanted to devote her life to caring for individuals in need. She has been a caregiver for three years and cares for fifteen children with CP who range from the ages of 1 to 18 years.

Zanele was very welcoming and had much to say about her experiences. Zanele told me how much the job meant to her and how much she had experienced a personal transformation in the time that she has been working there. Zanele also told me that she had not known that she would be working with children who have CP, but she knew that she wanted to work with individuals with special needs. Through her caregiving experiences at the day-care centre, Zanele also told me how she has found her passion and that she is pursuing a career to become a teacher for children with special needs.

Phumla (F12)

Phumla is a 47 year old African female with 18 years of caregiving experience. Phumla had worked as a caregiver at several hospitals and homes before she opened up her own day-care centre in Khayelitsha where children with CP can stay from anywhere between five to seven days, or even permanently. Phumla had opened this centre due to the amount of children who had been locked away due to stigma towards disabled children in the community. At the time of the interview there were fifteen children with CP being cared for at the day-care centre and there were three caregivers working there.

Phumla was easy to listen to as she answered the interview questions with in-depth answers, which she told in a story-like manner. I was engrossed with what Phumla had to say since she had so many years of experience to share. Although Phumla has children of her own, she had adopted three of the children at the day-care because their parents were not able to care for them. In general, Phumla spoke about the children as if they were her own and expressed love for all of them. I truly felt that I could learn a great deal from Phumla due to her positive attitude and the wisdom she had to share. Meeting her and the children she cared for was an informative experience and I obtained important data from this interview.

Malusi (M13)

Malusi is a 54 year old African male who has 18 years of caregiving experience. Malusi lives with his wife and child in a house just outside of Khayelitsha. This was also an interesting participant to interview since he was the only male caregiver in this study. Malusi became the primary caregiver for his child since his wife is employed full-time as a teacher. Although Malusi is unemployed, he has been trying to start his own business, however, he is struggling to do so due to the amount of time that his child demands.

Walking around Malusi’s neighbourhood was quite intimidating, as his neighbours were staring at me and once again asked what I was doing there. The social worker who was with me had also informed me to hold on to my personal belongings, as there were frequently muggings in the area. Despite this anxiety, Malusi welcomed me into his home without hesitation and made me feel comfortable. Malusi was very polite and answered the questions to the best of his ability, although he struggled to recall the details of events such as his child's birth and her diagnosis with CP. I was interested in hearing a male's perspective regarding caregiving and I immediately noticed that although Malusi was willing to share his experiences, he did not have as much to say as some of the female caregivers did.

Pauline (F14)

Pauline is a 40 year old African female who has 18 years of caregiving experience. Pauline lives with her husband and two children in a house near Khayelitsha and she works as a teacher. Pauline had dropped out of school when she was in grade 10 due to family problems, however, she decided to go back to school after her child was born so that she could get a career and provide for herself and her child. After several attempts to earn her matric certificate, Pauline matriculated and began her tertiary studies.

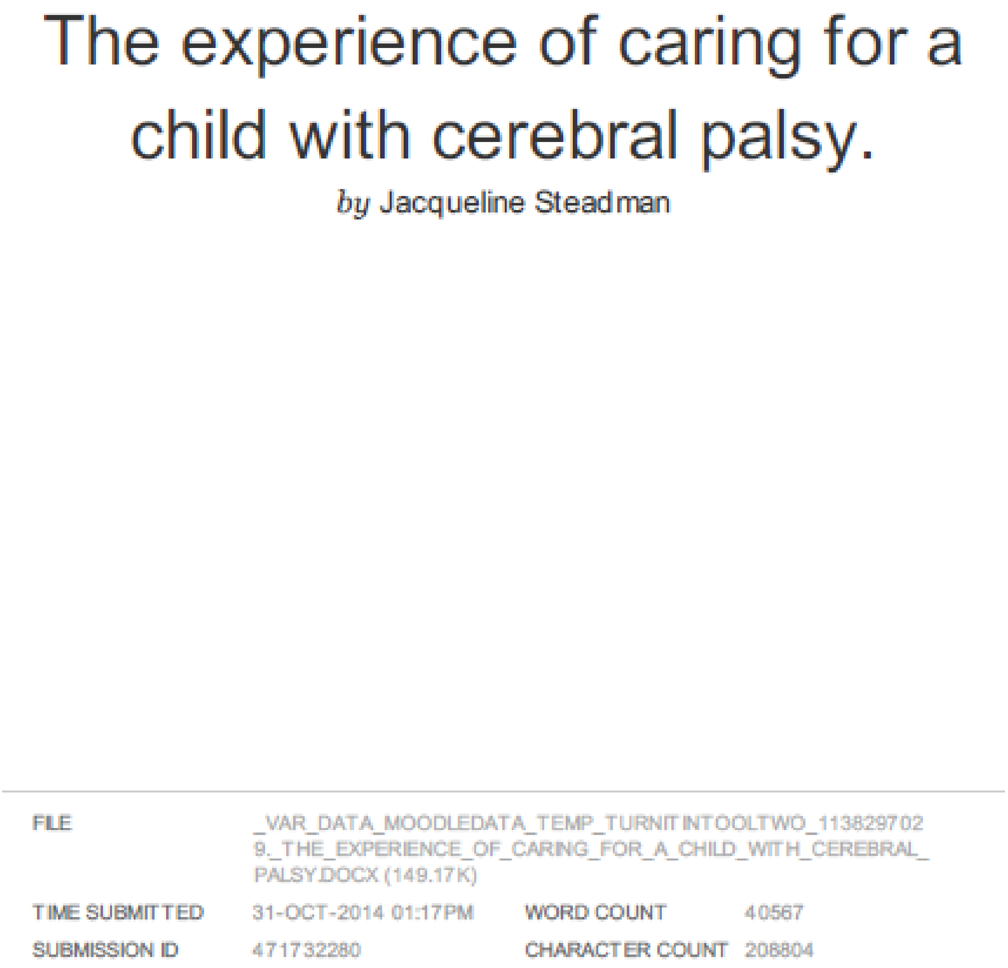
The interview with Pauline was very emotional, as she cried several times when she spoke about her family life and her early experiences as a parent. I asked Pauline numerous times if she wanted to stop the interview, however, she insisted on continuing and she had much to share. Pauline's child was also present in the room and she became quite upset when Pauline was crying. This was interesting because it shows that these children do have awareness of what is occurring around them, despite perceptions that they are incapable to do so. After the interview was over Pauline informed me that she became emotional because no one had ever asked to hear her story before. This was an inspirational participant to interview because she had overcome so much in her life and had become a successful mother and wife.

Bongi (F15)

Bongi is a 41 year old African female who gave birth to her first child when she was in grade 9 and thus had to leave school. This final participant is a mother of a child with CP who had taken the initiative to open a day-care centre for children with disabilities when she was 23, due to the lack of adequate care facilities in her area. Bongi now lives with her three children in her house in Philippi and runs the day-care centre out of her garage. During the day Bongi cares for ten children (including her own) with CP between the ages of 2 and 23 years of age.

Bongi was kind enough to meet with me at her home on a Sunday, so I already felt positive about this interview prior to my arrival at her home. Since it was a weekend, there were many noises in the background from the neighbours and even the other children in the home, which made it difficult for Bongi and I to hear one another. Despite these noises, the interview flowed well as Bongi was easy to speak to and she was able to share her insight as well as her experiences with me without hesitation. I was quite relieved when I left this interview, as the data collection process had been quite emotionally taxing. I do feel that this process was rewarding, as I was exposed to many new people and places that I would not have encountered had it not been for this research project. I was able to gain an understanding of the contexts that many of the participants live in, and this has definitely improved my awareness of the caregiver experience especially in the context of a rural community.

Appendix I: Turnitin Report



The experience of caring for a child with cerebral palsy.

by Jacqueline Steadman

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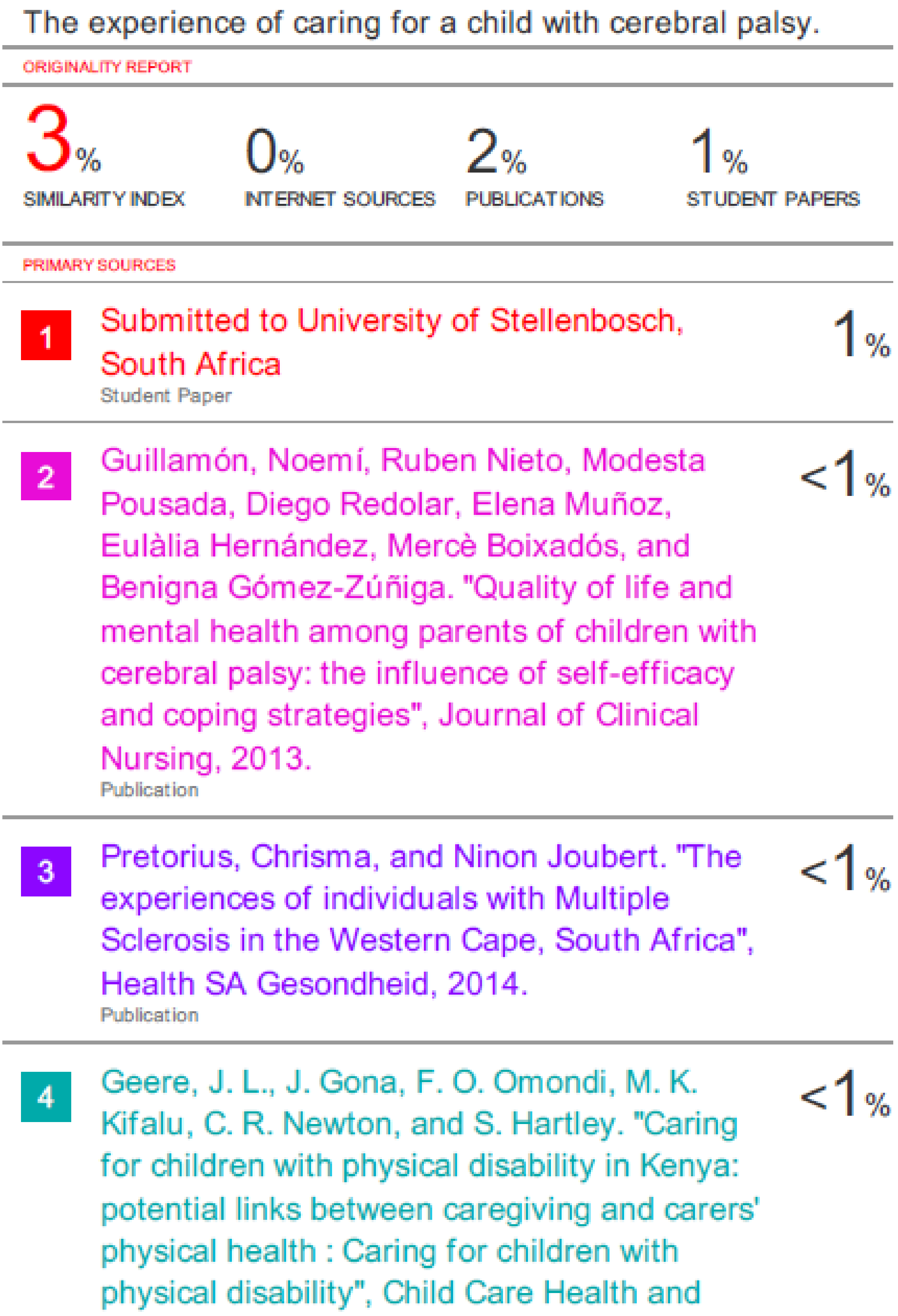

The experience of caring for a child with cerebral palsy.

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