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IMPACT OF CEREBRAL PALSY ON THE QUALITY OF LIFE OF THE FAMILY OF CHILDREN WITH CEREBRAL PALSY

Juanita Ferreira

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in Child Health (Neurodevelopment)

Johannesburg, 2018

DECLARATION

I, Juanita Ferreira, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Medicine in Child Health (Neurodevelopment) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signature_____

On this _____ day of _____

For my little flower of heaven, Teresa Judith Ferreira, forever and always.

27th October 1980 – 5th July 2016

ABSTRACT

CONTEXT: Caring for a child with cerebral palsy (CP) may have an impact on the quality of life (QoL) of the caregiver. The QoL of the caregiver may also be influenced by the severity of the gross motor functional impairment of the child with CP, and other demographic variables.

AIM OF STUDY: The aim of the study was to determine the impact of CP on the QoL of the primary caregiver (parents, guardians or caregivers) of children with CP, and to determine differences in QoL of caregivers of children of varying gross motor limitations e.g. children walking without limitations, in comparison to children requiring a wheelchair. The differences in gross motor limitations were observed between the different Gross Motor Functional Classification System (GMFCS) levels.

DESIGN, SETTING AND PARTICIPANTS: A prospective, observational and qualitative study design was used for descriptive and comparative purposes. There was no control group in the study. Data was collected from primary caregivers of, and living with children with CP, who attend routine clinic visits at the Neurodevelopmental Clinic of the Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) in Johannesburg, South Africa.

METHODS: 52 participants who consented to and were found eligible to participate in the study completed a Demographic Data Sheet and Peds QL™ Family Impact Module (Peds QL™ FIM) Questionnaire.

RESULTS: The overall QoL score of the research sample was 66.52. This is a score value out of 100. Following the interpretation guidelines using the Peds QL™ FIM, a higher score indicates a better QoL. As there was no control group in the study, there was no direct comparison to caring for a child without CP. This was a descriptive value. Of the demographic variables assessed, the only variable to prove a statistically

significant impact on the QoL of the caregiver was the gender of the child with CP ($p = 0.045$). Analysing the domains constituting the overall QoL as measured by the Peds QL™ FIM, a significant difference between the genders of the child with CP and the physical functioning ($p = 0.008$), cognitive functioning ($p = 0.027$) and family relationship functioning ($p = 0.015$) of the caregiver was identified. A significant difference between the age of the caregiver, and the social functioning ($p = 0.039$) and communication ($p = 0.003$) of the caregiver was also identified. No significant difference was found between the severity of GMFCS level of the child with CP and the QoL of the caregiver ($p = 0.255$).

CONCLUSION: CP was shown to not have a significant impact on the overall QoL of the caregiver of the child with CP. The severity of gross motor functional impairment did not have a significant impact on the overall QoL of the caregiver. However the gender of the child with CP and the age of the primary caregiver, were the only two variables that showed a significant impact on the overall QoL of the caregiver.

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ABBREVIATIONS

CP	cerebral palsy
QoL	Quality of Life
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital
Peds QL™ FIM	Paediatric Quality of Life™ Family Impact Module (Peds QL™ FIM)
GMFCS	Gross Motor Function Classification System
HRQL	Health Related Quality of Life
FFSS	Family Functioning Summary Score

CHAPTER ONE

INTRODUCTION

1.1 Background

Providing fundamental needs and care to a child without a disability entails many resources, yet caring for a child with disability supersedes those requirements in a completely other way. (1, 2, 3)

The burden of caregiving is well documented describing the extraordinary efforts caregivers undergo, in order to cope with the increasing demands specific to the child's needs. Particular challenges and demands are faced by caregivers of children with disabilities as compared to caregivers of children without disabilities. (4)

Cerebral palsy (CP) is the most common disabling motor impairment in childhood and describes a disorder of movement or posture; that results from some non-progressive lesion in the brain acquired early in life (prenatally, perinatally or in the first 3 years of life). (5, 6)

The incidence of CP in developing countries is between 2 - 2.5 per 1000 live births of which the majority of these children are cared for by their parents and families at home. (1)

The individual responsible for the caring and parenting of a disabled child is defined as the caregiver. The role may be fulfilled by a parent, or other member of the family. The profound effects of caregiving for a child with disability are experienced not only by the caregiver but the entire family. (4)

Managing the child's chronic health conditions and complex needs effectively while attempting to maintain the requirements of everyday living is one of the principal challenges faced by the caregiver. Demands of family life and family functioning, sibling adjustment, as well as income may all be affected. (1, 2, 3)

The permanent, dependent and long-term nature of CP requires supportive care services for that individual's lifetime. Co-morbid conditions often accompany CP, and may include cognitive impairment, visual and auditory impairment, communication difficulties, emotional and behavioural issues, and seizures. (3) Children with CP may also be limited in their self-care functioning, including their ability to feed and dress themselves. (2, 8)

The quality of life (QoL) of these caregivers is affected, as they may need to spend most of their time attending to the needs of the child. Often caregivers are exhausted mentally and physically, and also prevented from participating in other social activities. (7)

Existing literature strongly relays the concept that caring for a disabled child can have considerable implications on the health of the caregiver and that these caregivers are more likely to experience depression and distress, poorer emotional health, experiencing feelings of stress and pessimism about the future. (2)

Ongoing need for medical care, special education services, and assisted living services incur significant expenses to the family caring for the individual with CP. (2, 8)

The reason why some caregivers are able to cope whilst others do not, is not yet fully understood. (9)

Modifying factors of caregiver stress include:

- Characteristics of the caregiver (e.g. age, marital status, coping ability)
- Characteristics of the child (type and degree of disability)
- The shared history between the caregiver and the child
- Social factors (e.g. access to social networks and social support)
- Economic factors (e.g. socioeconomic status, ability to access care, employment)
- Cultural context. (9)

Each of these factors may impact the caregiver. The effect on the QoL of the caregiver is collectively influenced by multiple factors and the provision of care for a child with a physical disability. (1)

The hypothesis for investigating the topic “The Impact of CP on the Quality of Life of the Family of the Child with CP” is that the caregivers and family of children with CP will

experience a greater level of stress, than that of caregivers of children without any neurodevelopmental conditions. The burden of caregiving is presumed to impact the daily life of the caregiver, and is assumed to have an impact on the overall QoL of the caregiver. (10)

1.2 Aim, Objectives and Hypotheses

The aim of this study will be to determine and analyse the impact on the QoL of the primary caregiver (parents, guardians or caregivers) caring for and living with a child with CP, living in Gauteng, South Africa. Thus, the objectives of the study are:

1. To identify and describe the QoL of the primary caregiver of children with CP.

2. To determine if the QoL of the primary caregiver of children with CP is significantly different within the different severity groups of CP (according to the Gross Motor Function Classification System (GMFCS)), and to identify and describe the differences of QoL within these different groups.

3. To identify intervention services for the primary caregiver and community support services utilised by the primary caregiver, and deduce a correlation between caregiver support and QoL.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Cerebral palsy (CP) originally referred to as Little's Disease, was first described by William Little in 1862. It was described as a condition that affected children in their first year of life, significantly affecting the development of their skill progression, and which did not ameliorate over time. Little described the condition as resulting from a lack of oxygen at birth. (11)

Thereafter, it was proposed by Sigmund Freud that CP may result during the infant's brain development in the womb, and associated the resultant developmental disabilities with factors that may have influenced the developing fetus. (11)

Until the 1980's, birth asphyxia was considered the cause of CP. Extensive research now illustrates the aetiology of CP to be multi-factorial, and different for different individuals, and at different stages of development. (11)

Familiar to most healthcare and social-care providers, as well as the general lay public, CP is known as a physically disabling condition. (12) As children with CP have greater

care requirements than children of the same age without the condition, they often need greater participation from their caregivers. (1, 2)

Increased demand for resources results, when functional limitations due to disability are experienced by the child and that child depends on the caregiver long-term. (1, 2)

Poor physical health and emotional wellbeing is associated with caregivers of children with disability. (1, 2) The impact of CP on the individual and their family is profound, and continues throughout the lifespan of the child. (13)

2.2 Cerebral palsy (CP)

2.2.1 Definition

CP describes a disorder of movement or posture, of varying severity, and permanent in nature that may result in physical limitations. CP is attributed to a non-progressive lesion in the brain, acquired early in life (prenatally, perinatally or in the first 3 years of life). The damage to the central nervous system of the fetus/infant, may impact the neuromuscular, musculoskeletal and sensorial systems. (5, 6, 11)

In addition to motor impairments, disorders of sensation, perception, cognition, communication and behavior, epilepsy and musculo-skeletal problems may also accompany CP. (12)

2.3 Impact of CP on the Caregiver

Significant impairment to one or more organs or systems in the body relative to normal functioning defines disability. The growth and development of a child is greatly influenced by the family who too become affected, when a child with disability is born to a family. (1, 2)

Motor function impairment is the hallmark of CP. (1) Children with CP may also show limitations in sensory and intellectual functioning, and the ability to care for themselves. As a result independent functions such as feeding, dressing, bathing oneself and mobility, may be difficult or even impossible. The degree of dependency on the caregiver is proportionate to the severity of the CP, and may require the caregiver to support these functions. (10, 14) Long-term help from their families may be required. (14)

The reliance of the CP child on the caregiver may place far more demands on the primary caregivers, than that of primary caregivers of children without neurodevelopmental concerns or disabilities. The caregiver not only bears greater demand in relation to child care, but often has to adapt his/her lifestyle, working conditions and home space to suit and support the child with CP. (10, 14)

Data collected from surveys in the USA, Canada and Ireland, have illustrated that parents of children with CP, experience greater physical and psychological effects on their health that are deleterious in nature, than parents of children without CP. Many of the difficulties experienced by these parents are accordant with outcomes of the stress process model (theory to explain mental health outcomes) in which caring for an individual with CP can result in stress, which has an impact on the health of the parent directly or indirectly. (10)

The role of primary caregiving is often assumed by the mother of the child, often with little social support. (10)

Clinical research shows that mothers of children with developmental disorders, experience greater mental health distress and are at risk of developing stress-related mental, emotional and psychological disorders. (2, 10) Providing such intensive care on all parameters of daily functioning, may impact the physical and psychological health of the caregiver in an unfavorable manner. (10)

Furthermore, Bella et al (10) reports that a child born with a disability is commonly regarded by parents as a personal failure. They may feel pressured to accept a child that is different and who will place significant mental, emotional and physical demand on them. They may feel they are not prepared or, even able to meet these demands.

The World Health Organisation defines QoL as an “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” (13, 15)

Research has found that the more intensive the level of care required by the child, the lower the QoL and the poorer the psychological health experienced by the parent. As a result this may lower the quality of care offered by the parent, which may in turn have an effect on the health, well-being and QoL of the child. (2, 15)

The way in which caregivers of children with disabilities adapt to the demands of caregiving and the stressors associated with this, vary considerably. (4) Research investigating the impact of caring for a child with CP is varying. (16)

Most studies investigating the effect of caring for a disabled child have focused on the challenging factors that impact negatively on the QoL of the caregiver, rather than the positive aspects (4), resources and facilitating factors that may assist the caregiving experience. Positive approaches and attitudes of the family, adequate support systems, religion, and financial aid have been identified as factors encouraging of caregiving. (9)

Okurowska-Zawada et al (16) assessed QoL of parents of children with CP utilising the WHOQOL-BREF questionnaire (an instrument assessing QoL in physical and psychological health, social relationships and the surrounding environment). The study found that parents of children with CP described their QoL as good. Parents adjusted to the chronic nature of CP, and accepted the long-term dependency required by the child with CP.

2.4. Epidemiology

2.4.1 Prevalence of CP

The prevalence of CP is variable, and dependent on definitions, classifications and case ascertainment. (11) Literature however indicates that CP, the most common disabling motor impairment in childhood (12, 14) has a prevalence of 2 -2.5 per 1000 live births, of which the majority of these children are cared for by their parents and families at home. (2, 11) In particular, CP affects two to three out of every 1000 live births in Europe and Canada; and up to seven live births per 1000 in Brazil. (10)

In understanding the prevalence rates, it is worthy to note that converse to perinatal mortality rates which have declined over time, the birth prevalence of CP (incidence of CP at birth) since the 1950's has not declined. With the advent of neonatal intensive care units and improvements in neonatal intensive care, the proportion of children with

CP born very prematurely has increased (i.e. mortality decreased, CP rates remain). (11)

For children born to term, the prevalence rate of CP is one per 1000 live births. Increased gestational age contributes to significantly reduced CP rates: (11)

Table 2.1 Prevalence of CP relative to gestational age (11)

Gestational Age	**Prevalence of CP**
22-27 weeks	14.6%
28-31 weeks	6.2%
32-36 weeks	0.7%
Term infants	0.1%

Gestational age also influences the type of CP developed as illustrated in Table 2.2 below. (11)

Table 2.2 Type of CP developed relative to the gestational age (11)

Term infant	Non-spastic CP is more prevalent than in the preterm infant
Preterm infant	Spastic CP is predominant
Moderately preterm infant (32-36 weeks)	Spastic CP six to ten times higher than the term infant
Very preterm infant (less than 32 weeks)	Spastic CP ten times higher than in moderately preterm infants

The prevalence of CP is significantly influenced by the birth weight of the child. For infants of birth weights less than 1000 grams (as compared to birth weights of between) 1000 and 1499 grams) CP prevalence rates are lower, due to the high number of infants who do not survive and thus do not contribute to the prevalence rate. (11)

Highest prevalence rates (59.18 per 1000 live births) have been identified in infants of 1000 – 1499 grams birth weight; whilst lowest prevalence rates (1.33 per 1000 live births) have been identified in infants weighing over 2500 grams at birth. (11)

Perinatal and neonatal mortality rates accelerated up until the 1960's, with a huge decline in rates until the late 1980's, when there was then an increase in the absolute number of children with CP. Mortality rates have plateaued from the 1990's, however with a declining trend in the CP rate. Moderate and very low birth weight being the primary contributors to the CP numbers identified. (11)

2.4.2 Aetiology

Risk and aetiological factors of CP are extensive, and CP can result from the influence of one or many risk factors, at any stage of the individual's development, not excluding the stage before conception to infancy. The precise cause of an insult to the central nervous system resulting in CP may be difficult to determine in all cases. (11)

Two principal factors identified as having a significant impact on the aetiology of CP include the gestational age and birth weight of the individual. (11) Additionally multiple pregnancies, maternal genitourinary infections and socioeconomic factors contribute significantly to the development of CP. (17)

In the last 40 years there has been little change in the total number of children developing CP, despite the progress in antenatal and perinatal care. Outcomes of pregnancy would have been expected to improve, due to advances in maternal health, improved management of premature and difficult deliveries and improvement in neonatal care. (17)

In developed countries there have been some changes in patterns of CP yet with no reduction in the frequency of CP. Due to the greater survival of children to an age where CP can be diagnosed, the numbers of children with more severe forms of CP are increasing, mainly in the group of children born prematurely. Children born with a lesser degree of prematurity (28-32 weeks gestation) have an improved outcome. (17)

Variations in prevalence and aetiology exist due to differences between developed and developing countries. The European Collaboration of CP Registers (SCPE) keep CP registers and using similar methods of ascertainment have comparable CP rates. However in developing countries there is a relative lack of information. In areas where health services are poorly developed it is likely that children not well at birth, severely premature or small for gestational age will not survive. Conditions such as meningitis, cerebral malaria or severe neonatal jaundice or maternal rhesus immunisation contribute more so to postnatal cases. (17)

2.4.3 Life Expectancy

Literature estimates that 65-90% of individuals with CP will survive into their adult years, due to the progress of medical care and rehabilitation, and the advancement of assistive mobility devices. (3) There is an 87% rate of survival to reach the age of 30 years. (11) Consequently parents assume long-term responsibilities as caregivers of their children with CP. (3)

2.4.4 Classification of CP

An appropriate classification system for CP is required in order to provide the most adequate treatment. Variance in the clinical presentation of the condition exists and difficulties of sensation, perception, cognition, communication and behavior by epilepsy, and by secondary musculoskeletal complications commonly partner the motor disorders of CP. Description of the nature and severity of CP can provide information to the healthcare team that may support the existing and future requirements of the individual with CP. (12)

The degree of functional motor impairment determines the severity of CP of the individual. The Gross Motor Function Classification System (GMFCS) is a classification system describing the ability of a child with CP to move within 5 ordinal scales, and is most often used to describe the degree of motor impairment. (17, 18) The GMFCS was developed in order to have a standardised system of classifying the severity of gross motor function in individuals with CP. The GMFCS has been evaluated for reliability and validity, and has become the principal way to describe the severity of motor disability in children with CP. (12)

The GMFCS measures the movement ability of children with CP across four age bands, namely:

Less than 2 years

2 to 4 years of age

4 to 6 years of age

6 to 12 years of age. (12)

Severity of gross motor function progresses over the levels, from 1 to 5. (12)

Table 2.3 below describes the GMFCS levels: (18)

Table 2.3 GMFCS Level I-V (18)

Level I	Walks without limitations
Level II	Walks with limitations
Level III	Walks using a hand-held mobility device
Level IV	Self-mobility with limitations; may use powered mobility
Level V	Transported in a manual wheelchair

Traditional approaches to the classification of the individual with CP, divides CP into two major physiological classification groups indicating the site of the brain lesion. The two groups are the pyramidal (spastic) and extra-pyramidal (non-spastic) groups. Damage to the pyramidal tracts, responsible for voluntary movements, describe spastic CP, whereas damage outside of the pyramidal tracts, in the basal ganglia or the cerebellum describe non-spastic CP. (11)

Spastic CP accounts for 70-80% of all CP cases, as opposed to non-spastic CP accounting for 15-20% of all cases. (11) Extra-pyramidal (non-spastic) CP is further sub-divided into dyskinetic and ataxic CP. (11, 17)

According to the predominant motor characteristics, CP may also be classified as spastic, hypotonic, dyskinetic and ataxic CP. (11)

Topographical classification of CP classifies CP according to the pattern of limb involvement, namely monoplegia, diplegia, triplegia, hemiplegia, and quadriplegia. (11)

Classification documentation should include the age of the individual with CP, the nature of the information utilised (e.g. examination notes, screening tools, maternal recall etc.), and the metabolic and neuroimaging investigations performed. (12)

A classification system that is reliable and complete is valuable. The research and science underlying the approach to the classification of CP, has evolved over the years, and continues to progress with the emergence of data and technology. These developments will lead to improved precision and accuracy of classifying and describing the clinical picture of CP. Baxter et al (12) advises four major scopes to be used in the classification of CP, namely motor abnormalities, accompanying impairments, anatomical and neuro-imaging findings, and causation and timing. (12)

2.5 The South African Context

2.5.1 The Prevalence of CP in South Africa

In developing countries, little is known about the prevalence of childhood disability, including CP. (19, 20)

As previously stated, the prevalence of CP globally is estimated at 2-2.5 per 1000 live births. However the prevalence of CP in Africa is not as clearly defined, as little research has been conducted in developing countries. (9)

Higher rates of prevalence have been noted in rural and less developed communities. Donald et al (9) reported CP rates to be higher than global estimates, with an average prevalence of two to ten cases per 1000 live births.

Within the South African context specifically, inconsistencies regarding findings of prevalence rates have been found. (9)

Couper et al (19) conducted a descriptive study in the Manguzi sub-district of KZN in SA, in order to determine the prevalence of disability in children under ten years of age. Results of the study found the prevalence of disability among children to be high, the diagnosis of CP (prevalence of ten per 1000) being secondary to perceptual disability (disability impairing sight or hearing) (seventeen per 1000). (20) The study found that the overall rate of childhood disability was comparable to rates for other similar rural areas in SA, which suggest the accuracy of the result. (19)

In the above mentioned study, the prevalence rate for CP was five times higher than in developed countries namely Ireland 1.7/1000, USA 2/1000 and Sweden 2.3/1000. The reason for this comparably higher rate is suggested by Dowding and Barry to be related in part to socio-economic factors. (19)

Furthermore, other studies conducted in South Africa (SA), namely KwaZulu Natal, Mpumalanga, and the North West province reported far higher prevalence rates consisting of 33 per 1000, 64 per 1000, and 52 per 1000 respectively. (9)

Literature has suggested that poor antenatal care may increase the risk for complications during any stage of pregnancy, which could ultimately increase the risk of CP in the unborn child. (9, 21)

In SA, 85% of the population relies on the public health system for healthcare, (20) however healthcare facilities are usually located in urban areas, leaving rural and outlying areas devoid of healthcare professionals and services. (9, 21)

Transport to the hospital is costly due to the distances involved, and timeous transport is not always available, often forcing individuals to give birth at home. Due to the absence of healthcare support in the home, the risk of complications at birth is increased. (9)

Due to the logistics of healthcare service availability and the rate of children with CP born outside of healthcare facilities, it is possible that the prevalence of CP is not entirely accurate due to CP cases not being recorded. Furthermore methods of collecting CP prevalence data (primarily surveys and hospital records) vary significantly which could potentially lead to discrepancies in prevalence rates in SA. (9)

2.5.2 Aetiology from a South African Perspective

The Community Agency for Social Enquiry (as part of the Department of Health) conducted a research study, and identified the primary causative factors of childhood disability and impairments in SA. These include: (20)

- Illness
- Prenatal problems (e.g. genetic disorders) and peri-natal problems (e.g. trauma at birth)
- Injuries
- Accidents
- Violence and trauma
- Poverty
- Unhealthy lifestyle
- Poor medical/healthcare services
- Environmental factors, such as epidemics, natural disasters, the impact of pollution. (20)

In the above-mentioned study it was also found that individuals living in rural areas (as opposed to urban areas) are more likely to be reported disabled. Absent physical and financial access to healthcare and antenatal services, poorer education, inadequate nutrition and other poverty-associated factors may contribute to disability. (20)

Up to 40% of the causes of disability are reported by the department of social development as preventable. (20)

As compared to global aetiology (Section 2.3) poverty is a differentiating and significant factor contributing to the development of disability in SA. (20)

Statistics South Africa reported, in 2014, that 20% of South Africans (total approximate population 56 million) live in severe poverty. Healthcare services and amenities are often limited in rural areas of which, 40% of the population lives. As a result, many children, including those with disabilities live in a disabling environment. (22)

The ability of health and social services to address the factors that contribute to disability is compromised due to the lack of accurate information pertaining to prevention and management of disability, and the impact of targeted provision services in SA. (20)

In order to develop a targeted and effective prevention and intervention program for children with disabilities in SA, the challenge posed by causative factors needs to be overcome. (20)

2.5.3 Challenges accessing suitable healthcare for individuals with CP

Notwithstanding personal circumstance, socioeconomic status, family dynamics and living environments, living with CP presents a broad range of daily challenges. (9)

Living in the more rural and poorer areas of SA, children with CP are especially neglected and deprived of appropriate service provision, as in many cases healthcare facilities are primarily located in urban areas. (9)

As healthcare facilities required by individuals with CP are not always accessible, due to long distances, an unaffordable transport expense may be incurred. Time required to travel further distances often requires the accompanying caregiver to take time off work. Additional challenges impacting the child and caregiver may include the transportation of assistive devices, which may be bulky and difficult to transport. (20, 21)

Hospitals in SA are often understaffed, which translates into long waiting periods. Children with CP may find these waiting times difficult. Available healthcare facilities near home are usually not specially- or well trained and experienced in the management of paediatric CP. (20, 21)

In SA, children with CP qualify for support from the state in the form of a Care Dependency Grant (CDG), however this money is sometimes the only source of income for the family of the child with CP, and thus is often not entirely used to look after the CP child, who already due to their condition, incur many additional costs. Routine visits to clinics, additional therapy, particular food, medication, walking devices, and disposable nappies may incur costs that the CDG does not cover. (21)

2.5.4 The primary caregiver of the child with CP

As children with CP are often limited in their ability to take care of themselves, they are often dependent on a caregiver to support them with their most basic needs. This however can place an increased and burdensome demand on the caregiver. (21)

Literature has reported that caregivers, particularly mothers, may feel isolated, lonely and depressed in managing everyday living. Availability and accessibility of support services for the families of the child with CP are often absent or minimal. (21)

2.5.5 Care and interventions for individuals with CP

Although CP is a permanent disability spanning a lifetime there are numerous interventions available that may support the individual with CP and their QoL. An intervention is an amenity that improves the state of CP and the overall experience of the individual with CP. Children with CP should be supported by health professionals and community based support services who work as a team to support the child and family. (23)

The approach to the medical management of CP is complex. While the main focus is primarily on the motor disorder, management of both the motor disorder and existing co-morbidities require a team of multi-disciplinary professionals working together to improve the comfort, functioning, self-confidence, and independence of the individual with CP. (21)

Access to healthcare services required by the individual with CP is entirely dependent on its availability, and differs between provinces. Studies have shown that less than 30% of children who require rehabilitation in SA actually obtain it. (21)

2.5.6 Non-Governmental Organisations (NGO's) in South Africa

Disability in SA is represented by SADA, the South African Disability Alliance, comprised of representatives from 12 national organisations. Formerly known as the Federal Council on Disability, the SADA is defined as "a body of consensus, and the voice of the disability sector in SA". Of disabled South Africans, 8% are represented by SADA. (21)

The National Council for Persons with Physical Disabilities in South Africa, NCPPDSA, works with a key affiliate, the National Association for persons with CP, NAPCP. The NAPCP hosts many specialized schools for children with CP; and the provincial associations for individuals with CP. CP associations provide an essential function of intervention to individuals with CP, through involvement in the care and rehabilitative services required locally. (20, 21)

2.6 Conclusion

The majority of studies investigating the impact of caregiving of a child with a disability have been conducted in developed countries of middle and high income. In developing countries, like SA, limited research exists. (9)

Thus there is a need to explore the impact of caregiving for a child with disability, such as CP, to describe the effect on the caregiver and identify what the factors are that contribute to the QoL and caregiving experience. (9)

This study assesses the impact of living with a child with CP and thus is important for the identification and description of the QoL of primary caregivers of children with CP.

CHAPTER THREE

METHODS AND MATERIALS

3.1 Introduction

This chapter presents the methodology used in conducting the research study, and includes the study design, the population and sample, the pilot study, method of data collection, and the procedure of the study. The measurement tool used, the PedsQL™ Family Impact Module (PedsQL™ FIM), is also described.

3.2 Study Design

This research study was a prospective, observational and descriptive study conducted to determine and describe the impact of cerebral palsy (CP) on the quality of life (QoL) of the family of children with CP. As the research study did not include a control group, there is no direct comparison. The research study variables are described and the QoL of caregivers caring for children of different gross motor functional impairment (CP severity) is described, by using the GMFCS levels 1-5.

3.3 Study Population and Sample

The research study was conducted between September 2016 and July 2017, at the Neurodevelopmental Clinic for children with CP at the Charlotte Maxeke Johannesburg Academic Hospital (CMJAH), a state hospital in Johannesburg, Gauteng (South Africa).

The population of the study included the parents (mother or father), guardians or primary caregivers of, and living with children with CP, who attend routine clinic visits at the Neurodevelopmental Clinic of the CMJAH. The type of sampling used in the research study was convenient sampling.

The sample of the study included the parents (mother or father), guardians or primary caregivers of, and living with a child with CP who accepted the invitation and were eligible to participate in the study, according to the inclusion and exclusion criteria. Should both the mother and father be deceased or absent in the life of the child with CP, the primary caregiver or guardian living with and caring for the child with CP was invited and included to participate in the study.

The sample of the study included 52 participants. One parent (mother or father), guardian or primary caregiver of each family (living with the child with CP) participated in the study.

3.4 The Research Study Tool: The PedsQL™ Family Impact Module (PedsQL™ FIM)

The PedsQL™ Family Impact Module (PedsQL™ FIM) (Appendix I) is a parent-reported, multi-dimensional instrument, designed to assess and measure the impact of paediatric chronic health conditions on the parents and caregivers of children with the condition. The questionnaire is a 36-item instrument assessing 8 groups or domains of functioning in the last seven and last thirty days, as reported by the parent. (24, 25) In this research study the PedsQL™ FIM measuring the impact on the QoL of the caregiver in the last thirty days was utilised.

The first 6 domains are focused on self-functioning (parent or caregiver) and include physical functioning (6 items), emotional functioning (5 items), social functioning (4 items), cognitive functioning (5 items), communication functioning (3 items), worry functioning (5 items). (24)

The remaining 2 domains are focused on family functioning and include family daily activity (3 items) and family relationships (5 items). (24)

In order to score each item of the questionnaire, a 5-point response Likert scale is utilised (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = always a problem). (26)

In order to obtain statistical data the scores acquired from the completed PedsQL™ FIM were transformed using the PedsQL™ FIM scoring instructions. The items are reverse scored and linearly transformed to a 0-100 scale, for ease of interpretation. The extension of the scoring scale ranges from 0 to 100. Higher scores indicate better

functioning and less negative impact on the QoL of the parent or caregiver (out of 100). (26)

To reverse score, the scale items of 0-4 are transformed to values of 0-100 as follows:

0 = 100; 1 = 75; 2 = 50; 3 = 25; 4 = 0

To generate the PedsQL™ FIM Total Scale Score (descriptive of QoL), the mean is calculated as the sum of items over the number of items answered (this accounts for missing data). (26) These values provide the outcome variables that describe QoL of the participants in the study. (24, 25)

Focus groups, cognitive interviews, and pre-testing measurement development protocols, as well as previous research and clinical experiences with children with chronic health conditions, and their families and caregivers were used to develop the groups / domains and items of the questionnaire . Research results prove reliability and validity of the PedsQL™ FIM in families caring for children with chronic health conditions. (25)

Table 3.1 below summarises the PedsQL™ FIM domains and describes their respective items (25)

Table 3.1 The Domains and General Content of the PedsQL™ FIM (25)

Parent Functioning Domain	**Items in each Domain**	**General Content / Description**
Physical Functioning	6	Problems with physical functioning, including feeling tired, getting headaches, feeling weak, and stomach problems
Emotional Functioning	5	Problems with emotional functioning, including anxiety, sadness, anger, frustration, and feeling helpless or hopeless
Social Functioning	4	Problems with social functioning, including feeling isolated, difficulty getting support from others, and finding time or energy for social activities
Cognitive Functioning	5	Problems with cognitive functioning, including difficulty maintaining attention, remembering things, and thinking quickly
Communication	3	Problems with communication, including others not understanding the family's situation, difficulty talking about child's health condition, and communicating with health professionals
Worry	5	Problems with worrying, including worrying about child's treatments and side effects, about others' reactions to child's condition, about the effect of the illness on the rest of the family, and about child's future
Family Functioning Domain	**Items in each Domain**	**General content / description**
Daily Activities	3	Problems with daily activities, including activities taking more time and effort, difficulty finding time and energy to finish household tasks
Family Relationships	5	Problems with family relationships, including communication, stress, and conflicts between family members, and difficulty making decisions and solving problems as a family

3.5 The Pilot Study

As the PedsQL™ FIM instrument had not been validated for a South African population, (24, 25) a pilot study was completed (prior to the research study) in order to ensure validity of the PedsQL™ FIM for a South African study group. Based on the pilot study findings, adjustments were made to the questionnaire in order to accommodate variances specific to the South African population. These adjustments included the translation of the questionnaire into two additional official languages used in SA.

The pilot study was conducted over two CP clinic days at the Neurodevelopmental Clinic. Six participants completed the PedsQL™ FIM on the 5th September 2016, and an additional five participants completed the PedsQL™ FIM on the 9th September 2016. In total, the pilot study included 11 participants (primary caregiver from each family of, and living with a child with CP).

3.5.1. PedsQL™ FIM Translation

Subsequent to the completion of the pilot study, it was found on administering the questionnaire to the participants that the questionnaire was fairly well understood. However, it was observed that the English language used in the questionnaire was not entirely comprehended, and that some of the participants struggled with understanding the following questionnaire phrases:

- I feel sick to my stomach (Physical Functioning Section)
- I feel anxious (Emotional Functioning Section)
- I feel frustrated (Emotional Functioning Section)
- I feel isolated from others (Social Functioning Section)

- It is hard for me to keep my attention on things (Cognitive Functioning Section)

After consultation with Professor Lorna Jacklin and Professor John Pettifor, it was decided to professionally translate the questionnaire into Zulu and Xhosa. According to the Census 2011: Census in Brief document released by Statistics South Africa (27) the most commonly spoken languages in SA includes Zulu (22.7%) and Xhosa (16%). English is the fourth most commonly spoken language in SA (9.6%). (27)

The professional translation services of N & N Language Consultancy Services were employed (Appendix II). The PedsQL™ FIM was translated from English into Zulu by language practitioner, Yvonne Malindi (Appendix III). The PedsQL™ FIM was translated from English into Xhosa, by language practitioner, Thozamile Sikosana and edited by Yvonne Malindi (Appendix IV). Both language practitioners are accredited members of the South African Translators Institute (Appendix V). For ease of comprehension, the entire questionnaire was translated.

3.6 The Research Study Procedure

The day before each clinic day, the researcher visited the Neurodevelopmental Clinic in order to review the patient details of patients attending appointments at the clinic the following day. This was done in order to identify patients with CP attending the clinic.

On the clinic day, patients and their accompanying primary caregiver attending routine clinic visits at the Neurodevelopmental Clinic of the CMJAH, were invited to participate in the study. The Neurodevelopmental Clinic is held and attended by patients every first

and third Monday of the month, with the clinic being attended by approximately 20 patients each day (three hour session). Not all patients were eligible to participate in the study.

The study was explained to the caregivers of the child with CP. The caregivers of the child with CP who accepted the invitation to participate in the study were asked to complete the Participant Eligibility Sheet (Appendix VI). This form allocated a file number to the participant in order to ensure confidentiality.

Should the caregiver of the child with CP, have been eligible to participate in the study, the PedsQL™ FIM was assessed for comprehension of the questions, and ease of completion of the questionnaire by the participant. The participant was able to choose from the English, Zulu or Xhosa version of the PedsQL™ FIM.

The participant was then taken to a private room in the clinic where they were asked to complete the Participant Information and Consent Form (Appendix VII), the Demographic Data Sheet (Appendix VIII) and the PedsQL™ FIM (Appendix I). Completion of the questionnaire was done between 5 and 10 minutes.

The researcher completed the GMFCS level of the participant's child with CP, using the GMFCS guidelines by Palisano et al. (18)

This identified the severity of CP patients included in the study, with the purpose that the results of the study would be reflective of the range of Gross Motor Functional

Classification System (GMFCS) level, and not skewed to represent only one class of severity of CP patients.

The Gross Motor Functional Classification System (GMFCS) for CP (18) is a clinical classification system of 5 levels, describing the gross motor ability of individuals diagnosed with CP. Distinctions between the different levels of motor functional classification are based on functional limitations, the requirement of assistive technology such as mobility devices, and the quality of the individuals movement. The different levels of classification are specific to different age categories, appropriate to different levels of neurodevelopment. The primary objective of the GMFCS is to determine the individuals present motor function abilities and limitations. (18)

The participant was thanked for their participation in the study. There was a short debriefing and should the participant have required psychological support or counselling, the participant would have been referred to the social worker within the department. None of the participants in the study reported emotional distress, and therefore counselling and support from the department social worker was not required.

3.7 Data Collection

The tool used to measure and determine the impact of CP on the QoL of the caregivers of children with CP was the PedsQL™ FIM (Appendix I).

The method of data collection was paper and pen. The PedsQL™ FIM was administered to determine the impact of CP on the QoL of the caregivers of, and living with children with CP.

3.8 Outcome Measures

3.8.1 The PedsQL™ FIM

The PedsQL™ FIM is designed to measure the impact of paediatric chronic health conditions on the parents and family of the child with the chronic health condition. The questionnaire measures physical, emotional, social and cognitive functioning, communication and worry in the last seven days, and the last thirty days, as reported by the parent. Additionally parent-reported family day activities and family relationships are measured by the questionnaire. (24)

The GMFCS scoring guidelines were utilised in order to determine the GMFCS level of each child with CP. This was completed by the researcher and the GMFCS level was recorded in the Demographic Data Sheet (Appendix VIII). (18)

Permission to use the questionnaire was requested and obtained from Professor James W. Varni, author of the PedsQL™ FIM via email (Appendix IX).

3.8.2 Demographic Variables

Demographic data of the participants was collected using the Demographic Data Sheet (Appendix VIII). The following variables were investigated:

- Gender
- Date of birth / Age of the participant
- Marital / Relationship status
- Length of time caring for the child
- Presence of fathers, other siblings, grandparents (living with the child with CP)
- Level of education
- Employment status
- Health status

The demographic data of the participants was collected in order to determine whether a comparison between the categorical and continuous variables existed (e.g. marital status (single, married or widowed)), gender (male and female)) etc.

3.9 Consent

3.9.1 The Study Location / Site

In order to attend the Neurodevelopmental Clinic within the CMJAH to conduct the research study, permission from the senior paediatrician of the Neurodevelopmental clinic, Dr. Thomson was sought and approved (Appendix X). In order to conduct the research study in the CMJAH, permission from the CEO of the hospital, Mrs. Gladys Bogoshi, was sought and approved (Appendix XI).

3.9.2 Participant Consent Forms

The consent of each participant was sought, and approved before their participation in the study. Consent was provided through the completion of the following forms / appendices:

- Participant Information and Informed Consent Form (Appendix VII)

3.10 Inclusion and Exclusion Criteria

The following criteria were used for the admission of the participants to the study:

3.10.1 Inclusion Criteria

Families: Parents, guardians and caregivers of children with CP, who are living with the child. Either the mother or father participated in the study. Participants needed to be proficient in Zulu, Xhosa or English as a first or second language.

Children: Children aged between 3 and 12 years, previously diagnosed with CP.

3.10.2 Exclusion Criteria

Family members: Parents, legal guardians, caregivers or other family members who do not live with the child; have a previous psychological diagnosis, or physical disability (that occurred before care-giving for the child).

Participants not proficient in Zulu, Xhosa or English as a first or second language.

Older children who attend the clinics on their own, without a parent, guardian or caregiver present were not able to participate in the study.

3.11 Limitations

1. A disadvantage of the PedsQL™ FIM is that the questionnaire has not been validated for a South African population.

2. The PedsQL™ FIM is in English, and although participants using English as their second language were included in the study, it would be ideal to include only participants using English as a first language, so as to avoid any confusion if the questions were not entirely understood.

3. The severity of CP was only assessed by GMFCS scales, and should have included additional aspects of everyday independent functioning such as feeding, going to the toilet, bathing, and mobility.

3.12 Ethics

Informed consent was obtained from every participant. Due to the nature of the population (families of children with CP) included in the study, confidentiality, sensitivity and empathy was maintained throughout the course of the study.

A file number was allocated to every participant of the research study. The file number was allocated in the Participant Eligibility Sheet (Appendix VI) and was used to complete the Demographic Data Sheet (Appendix VIII) and the PedsQL™ FIM (Appendix I). This was done in order to ensure the confidentiality of the participant and the child with CP.

Ethical clearance for the research study was obtained from the Human Ethics Research Ethics Committee (Medical) of the University of the Witwatersrand: Ethics Clearance Certificate M160495 (Appendix XII).

3.13 Statistical Analysis

3.13.1 Software

Statistical analysis and management of the data was performed in Stata/IC version 14.1. Data from the Participant Information and Informed Consent, and Demographic Data sheets (Appendices VII and VIII) was captured by the researcher into excel, and then imported into Statistica version 13.2 (28) The data was checked for any missing or duplicated data. Some of the data was categorised.

3.13.2 Level of Significance

A 5% level of significance was used when analysing the statistical significance of the results obtained from the research study.

A p-value of 0.05 was considered as statistically significant. Should the p-value have been less than 0.05 (at a confidence level of 95%) then the variables being assessed would be significantly different from one another ($p < 0.05$) and the null hypothesis rejected. Should the p-value have been greater than 0.05 then no statistically significant difference existed between the variables assessed, and the null hypothesis accepted.

3.13.3 Normality

QoL was tested for normality using the Shapiro-Wilk test. The study data was normally distributed, with a p-value of 0.42 ($p > 0.05$). Thus the mean and standard deviation calculated for.

The findings of the research study are presented in Chapter 4: Results.

CHAPTER FOUR

RESULTS

4.1 Introduction

The findings of the research study are presented in Chapter 4. Graphical representation by means of tables will be used to describe the data.

The variables of the caregivers, and children with cerebral palsy (CP), as well as the socio-demographic variables will be described in detail.

The objectives of the research study tested are presented in the following order:

The identification, analysis and description of the impact of CP on the quality of life (QoL) of primary caregivers of children with CP on the family of children living with CP, in Gauteng, SA.

The effect of the severity of CP (according to the Gross Motor Function Classification System (GMFCS)) on the quality of life of primary caregivers of children with CP, and the identification and description of the differences of the quality of life within these different groups.

4.2 Study Population

A total of 71 primary caregivers of children with CP were screened for eligibility to participate in the study.

In order to confirm eligibility to participate in the study the Participant Eligibility Sheet (Appendix VI) was utilised. Inclusion and exclusion criteria outlined in Section 3.10 supported eligibility to participate in the study or not. In this manner, 19 participants were excluded from participating in the research study, and 52 participants were found eligible to participate in and complete the research study.

Table 4.1 Participant (Caregiver) Gender Figures

Participant Gender	**n**	**%**
Female	45	86.54
Male	7	13.46

Table 4.2 Participant (Caregiver) Age Range Figures

Participant Age Range	**n**	**%**
< 25 years	3	5.77
25 to 34 years	24	46.15
35 to 44 years	19	36.54
45 to 54 years	3	5.77
> 55 years	3	5.77

The study population included females (n = 45) and males (n = 7), of whom their ages ranged between 20 and 65 years of age. Participants included mothers, fathers and grandparents of, and living with children with CP.

4.3 Demographic Variables

Demographics pertaining to the child with CP and the caregiver of the child with CP were investigated in order to determine whether these factors impacted the QoL of caregivers of children with CP. Factors evaluated in the Demographic Data Sheet (Appendix VIII) were categorised and abbreviated as follows:

Table 4.3 Demographic Variables of the Child with CP and the Caregiver of the Child with CP and the Respective Abbreviations

Demographic variable	**Abbreviation**
GMFCS of the child with CP	CHS
Age of the child with CP	CHA
Gender of the child with CP	CHG
Length of time diagnosed with CP	CHL
Age of the primary caregiver	CGA
Gender of the primary caregiver	CGG
Relationship Status of primary caregiver	CGM
Length of time caring for the child with CP	CGC
Support in the home	CGS
Level of education of the primary caregiver	CGE
Employment status of the primary caregiver	CGW

The demographics of the child with CP that are described include:

GMFCS, age, gender, and length of time diagnosed with CP.

The demographics of the caregiver of the child with CP (participant) that are described include:

Gender, age, relationship status, length of time caring for a child with CP, support, education and employment status.

4.4 Summary Statistics

Summary statistics are detailed for the quality of life (QoL) for the total group of caregivers (participants) in Table 4.4. The mean and its standard deviation, as well as the frequency are shown for the demographic variables and their data captured.

Table 4.4 Table Summarising the Statistics for the Quality of Life (QoL) of Different Demographic Variables

Characteristic	Level	Mean (SD)	Frequency
Overall		66.52 (18.47)	52
GMFCS of the child with CP			
	Level 1	69.77(14.4)	12
	Level 2	75.26(18.76)	7
	Level 3	60.26(22.47)	6
	Level 4	69.32(21.73)	5
	Level 5	63.04(18.76)	22
Age of the child with CP			
	2-4 years of age	72.41(18.71)	8
	4-6	60.25(17.13)	14
	6-12	66.55(19.53)	30
Gender of the child with CP			
	Female	72.98(16.20)	20
	Male	62.48(18.89)	32
Length of time diagnosed with CP			
	< 3 years	68.85(13.27)	10
	3-6	65.20(18.06)	24
	7-9	68.96(20.50)	10
	>9	64.50(24.90)	8
Age of the primary caregiver			
	<25 yoa	68.73(28.48)	3
	25-34	59.59(18.61)	24
	35-44	72.10(14.56)	19
	45-54	77.25(25.47)	3
	>55	73.62(14.85)	3
Gender of the primary caregiver			
	Female	65.97(18.53)	45
	Male	70.09(19.10)	7
Relationship Status of primary caregiver			
	Single	60.91(19.66)	24
	Married	72.51(13.92)	20
	Co-habiting	69.81(22.61)	6
	Widowed	83.11(0)	1
	Divorced	45.04(0)	1
Support in the home			
	Yes	66.29(18.88)	45
	No	68.03(16.83)	7
Level of education of the primary caregiver			
	Did not complete primary school	77.49(2.39)	2
	Primary School	67.51(17.48)	18
	Secondary	63.37(20.07)	25
	Tertiary	72.62(18.94)	6
	Currently a tertiary student	68.8(0)	1
Employment status of the primary caregiver			
	Unemployed	62.20(20.6)	19
	Part-time or temporary employment	65.95(16.46)	10
	Employed	69.91(18.53)	19
	Retired, pensioner	82.03(4.03)	2
	Unemployed because currently a student	62.65(1.03)	2

The QoL of the caregiver as measured by the PedsQL™ FIM was highest in the caregiver age group of 45–54 years of age, and lowest in the caregiver age group of 25-34 years of age, as shown above in Table 4.4.

Table 4.5 Results from Linear Regression to Assess Association Demographic Variables of the Caregiver with the Domains Assessed in the PedsQL™ FIM

Chara	**Level**	**QoL (Overall)**		**D1**		**D2**		**D3**		**D4**		**D5**		**D7**		**D8**	
		Coef	**P-v**	**Coef**	**P-v**	**Coef**	**P-v**	**Coef**	**P-v**	**Coef**	**P-v**	**Coef**	**P-v**	**Coef**	**P-v**	**Coef**	**P-v**
CHS	1	Ref															
	2													18.25			
	3													-18.05	0.059**		
	4													-13.88			
	5													-22.22			
CHA	1	Ref						-30	0.06*								
	2							0.37									
	3																
CHG	1	Ref															
	2	-10.49	0.045**	-14.3	0.008**	-13.12	0.062**			-13.1	0.027**					-18.45	0.015**
CGA	Per unit increase	0.557	0.054*					0.91	0.039			0.883	0.03**			0.805	0.057*

Symbols and abbreviations utilised in Table 4.5 above include:

***** : p-value of < 0.1 (marginal or some evidence of association)

** : p-value < 0.05 (statistically significant)

CHS: GMFCS of the child with CP

1: Level 1

2: Level 2

3: Level 3

4: Level 4

5: Level 5

CHA: Age of the child with CP

1: 2- 4 years of age

2: 4-6 years of age

3: 6 -12 years of age

CHG: Gender of the child with CP

1: Female

2: Male

CGA: Age of the primary caregiver

1: < 25 years of age

2: 25-34 years of age

3: 35-44 years of age

4: 45-54 years of age

5: > 55 years of age

Domains of the PedsQL™ FIM: **D1** Physical Functioning

D2 Emotional Functioning

D3 Social Functioning

D4 Cognitive Functioning

D5 Communication

D6 Worry

D7 Daily Activities

D8 Family Relationships

Coef: Regression Coefficient: Describes the relationship between how the dependent variable (y) may change in response to changes in the independent variable (x). The coefficient is the value / constant that represents the rate of changes of one variable as a function of the other variable. (29)

P-v: p- value: Calculated probability. The level of marginal significance representing the likelihood of the given event. (29)

Ref: Reference: For the particular demographic, the reference value quantifies how much the groups within the demographic differ (comparison group for that particular variable). (29)

In Table 4.5 above no data is included for Domain 6 as the results of this domain were not statistically significant, or near statistical significance ($p > 0.05$).

4.4.1 Age

4.4.1.1 Age of the Child with CP

The mean age of the child with CP in the research study was 6.4 years.

Caregivers of children with CP aged between 2 and 4 years reported the highest mean QoL score, 72.41. The lowest mean QoL score was 60.25, reported by caregivers of children with CP between the ages of 4 and 6 years of age as shown in Table 4.4.

Univariate linear regression conducted on the data provided a non-significant result for all domains of the PedsQL™ FIM. The *Social* domain, which was most affected, provided the most significant statistical difference for the age classes of children with CP of 0.06, in the age class of 4-6 years of age illustrated in Table 4.5. This p-value is however not statistically significant ($p > 0.05$).

Thus the age of the child with CP does not significantly impact the QoL of the caregiver.

4.4.1.2 Age of the Caregiver of the Child with CP

The mean age of the caregiver was 36.2 years.

Univariate linear regression conducted on the data provided statistically significant results for the overall PedsQL™ FIM. Thus the overall QoL is significantly impacted by the age of the caregiver. The *Social*, *Communication* and *Family Relationships* are the domains of the PedsQL™ FIM most significantly affected, however only the *Social* and *Communication* domains provided statistically significant p-values of 0.039 and 0.03 respectively ($p < 0.05$). (Table 4.5)

The age of the caregiver is thus a factor that may contribute significantly to the QoL experienced by the caregiver, especially with regards to *Social* and *Communication* domains of QoL.

4.4.2 Gender

4.4.2.1 Gender of the Child with CP

Table 4.6 Children with CP Gender Figures

Gender of the Child with CP	**n**	**%**
Female	20	38.46
Male	32	61.54

Of the children with CP whose caregivers participated in the research study, 20 children were female (38.46%), and 32 children were male (61.54%).

Table 4.4 illustrates the overall QoL score as measured by the PedsQL™ FIM, was higher in caregivers of female children with CP (72.98) as compared to caregivers of male children with CP (62.48)

Univariate linear regression conducted on the data, provided statistically significant results for the overall PedsQL™ FIM score for the gender of children with CP ($p = 0.045$). Thus QoL of the caregiver is significantly impacted by the gender of the child with CP. In particular, the *Physical*, *Cognitive* and *Family Relationships* domains which were most affected, provided the p-values of 0.008, 0.027 and 0.015 respectively as shown in Table 4.5.

This may indicate that the QoL of caregivers of male children with CP is more affected than caregivers of female children with CP. This may not be conclusively deduced as being a result of CP, but may include other factors such as general neurodevelopmental differences between genders.

4.4.2.2 Gender of the Caregiver of the Child with CP

Of the caregivers of children with CP, 45 caregivers were female (86.54%), and 7 caregivers were male (13.46%).

QoL as measured by the PedsQL™ FIM was higher in male caregivers (70.09) than in female caregivers (65.97). Assessing whether the difference in gender of the caregiver significantly impacts the QoL of the caregiver, a p-value of 0.588 was generated. Thus although the QoL value was higher in male than female caregivers, the difference was not statistically significant.

The gender of the child with CP may impact the QoL of the caregiver, however the gender of the caregiver does not significantly impact the QoL of the caregiver.

4.4.3 Gross Motor Functional Classification System (GMFCS) Levels of the Child with CP

Table 4.7 GMFCS Levels of the Child with CP

GMFCS Level	Number of children	Percentage of children
1	12	23.08
2	7	13.46
3	6	11.54
4	5	9.62
5	22	42.31

Pertaining to the severity of CP, as classified by the GMFCS, Table 4.7 above shows most children with CP were classified with a GMFCS level of 5 (42.31%).

QoL scores of the different GMFCS levels were analysed to determine if the GMFCS impacted the QoL of the caregiver significantly.

Table 4.8 QoL Scores of Caregivers of Children with CP According to Gross Motor Function Classification System (GMFCS) Levels of Children with CP

GMFCS	Mean Overall QoL Score	SD
1	67.81	15.5
2	80.42	14.08
3	60.26	22.47
4	69.32	21.73
5	63.04	18.76

Caregivers of children with CP with a GMFCS level of 2, had the highest mean QoL score for the PedsQL™ FIM (SD = 14.08) whereas caregivers of children with CP with a GMFCS level of 3, had the lowest mean QoL score for the PedsQL™ FIM QoL (SD = 22.47).

Using linear regression, the p-value between the GMFCS levels 1-5 was 0.255, illustrating no association between the GMFCS levels of children with CP, and the QoL score of the caregivers of children with CP.

Univariate linear regression conducted on the data provided a non-significant result for all domains. The *Daily Activities* domain, which was the most affected domain, provided the most significant statistical difference for the GMFCS level 3 of 0.059 as shown in Table 4.5. This p-value is however not statistically significant ($p > 0.05$).

The severity of CP may impact the QoL of the caregiver with regards to the management of daily activities.

Furthermore the impact of the GMFCS level of the child with CP, on the Health Related Quality of Life (HRQL) and family functioning aspects of the PedsQL™ FIM were explored. This is discussed in detail in Section 4.5.10.

4.4.4 Duration of Diagnosis of the Child with CP

The QoL of the caregiver as measured by the PedsQL™ FIM, was not significantly different between the lengths of time the child is diagnosed with CP ($p = 0.62$; $p > 0.05$). Whether the child has been diagnosed with CP for less than 3 years, as compared with the child diagnosed with CP for more than 7 years did not significantly affect QoL scores of the caregiver.

4.4.5 Relationship Status

Caregivers were categorised into single, married, co-habiting, widowed or divorced groups as shown in Table 4.4. Most caregivers of children with CP were single (n= 24; 46.15%).

Divorced participants provided the lowest quality of life as measured by the PedsQL™ FIM (45.04). Widowed participants (83.11) and married participants (72.5) provided the highest quality of life as measured by the PedsQL™ FIM.

The quality of life between the caregivers of different relationship statuses was not statistically different ($p > 0.05$), producing a p-value of 0.295 between the different relationship statuses.

4.4.6 Caregiver Support

The Demographic Data Sheet (Appendix VIII) captured support of the caregiver by investigating the presence of the other parent (mother or father), presence of other siblings, grandparents or other individuals living with the caregiver and the child with CP.

86.54% of the caregivers responded with support, and 13.46% of the caregivers responded with no support. Table 4.4 illustrates the QoL as measured by the PedsQL™ FIM was higher in caregivers receiving no support (people) than in caregivers with support (people resources).

Referring back to notes made in participants research study files, caregivers with no support, discussed how despite not having support of family or friends, their faith in God gave them strength to cope, and they viewed the child with CP as a blessing.

The DDD Sheet (Appendix VIII) did not investigate religious views or cultural outlooks of participants which may have provided insight into the caregiving and coping ability, or lack thereof in the population studied. This is discussed as a limitation (5.2 Limitations of the Study).

A p-value measuring statistically significant difference of 0.82 for support showed no significant difference between the QoL of caregivers with and without support respectively.

4.4.7 Caregiver Education

Most of the caregivers had completed secondary school (completed grade 12 / standard 10) (48.08%). The remainder of caregivers: did not complete primary school (3.85%), completed primary school (completed grade 7 / standard 5) (34.62%), and completed tertiary education (11.54%) respectively. One caregiver /participant was currently a tertiary education student (1.92%) (Table 4.4).

The QoL mean scores did not reflect any pattern of consistency for the variable of caregiver education. The QoL as measured by the PedsQL™ FIM was higher in caregivers who did not attend, or who did not complete primary education (77.49), whereas the QoL as measured by the PedsQL™ FIM was lowest in caregivers who did attend and complete secondary education (63.37) (Table 4.4).

There was no significant difference between the QoL of caregivers with different education backgrounds. The p-value measuring statistical difference between the levels of education of the caregivers in the study was 0.849, and not statistically significant ($p > 0.05$).

4.4.8 Caregiver Employment Status

Reference to Table 4.4 shows a significant percentage of the caregivers were unemployed (36.54%) and 19.23% of the caregivers had only part-time or temporary employment. 36.54% of the participants were employed, and 3.85% of the participants were retired (pensioners) and 3.85% were unemployed because they were currently studying.

The QoL as measured by the PedsQL™ FIM was highest in caregivers who were retired, and no longer working as they are now on pension (82.03), whereas the QoL was lowest in caregivers who were unemployed (62.20).

The resulting p-value of 0.206 ($p > 0.05$) for the employment status of caregivers of children with CP showed no statistically significant difference between the caregivers employment status. The results of this research study show that employment status does not significantly impact the QoL of the caregiver of the child with CP.

4.4.9 Overall / General QoL

Table 4.9 Summary of Total Scale Scores Across the 8 Domains of the PedsQL™ FIM

Domain	**Mean**	**Standard Deviation**
Physical Functioning	63.7	19.2
Emotional Functioning	59.42	24.73
Social Functioning	64.18	28.2
Cognitive Functioning	77.69	20.92
Communication	74.84	26.07
Worry	59.06	21.77
Daily Activities	53.53	34.63
Family Relationships	77.15	27.01

In order to obtain statistical data the scores acquired from the completed PedsQL™ FIM questionnaires were transformed using the PedsQL™ scoring instructions as described in Section 3.4 (The Research Study Tool: The PedsQL™ Family Impact Module (PedsQL™ FIM)).

After transforming the scores into a 0-100 scale, the mean for the different domains, *Physical Functioning, Emotional Functioning, Social Functioning, Cognitive Functioning, Communication, Worry, Daily Activities* and *Family Relationship* domains, was calculated for the 52 participants resulting in values of 63.7 for the *Physical* domain, 59.42 for the *Emotional* domain, 64.18 for the *Social* domain, 77.69 for the *Cognitive* domain 74.84 for the *Communication* domain, 59.06 fort the *Worry* domain, 53.53 for the *Daily Activities* domain, 77.15 for the *Family Relationships* domain.

According to the Scaling and Scoring of the PedsQL™ Family Impact Module Guidelines higher scores indicate better functioning of the caregiver, and greater QoL. The lower the PedsQL scores the poorer the functioning of the caregiver and poorer QoL. (26)

The data demonstrates in this study population, the *Daily Activities* domain is the most affected domain (lowest QoL), and the *Cognitive Functioning* domain is the least affected domain (highest QoL).

4.4.10 Health Related Quality of Life (HRQL) and the Family Functioning Summary Score (FFSS)

Health related quality of life (HRQL) and family functioning are elements of, and significant contributors to QoL. QoL related to health is primarily determined by the individuals health status, and may be changing / evolving (dynamic), subjective and encompass multiple dimensions inclusive of physical, social, psychological, cognitive and spiritual factors. (30)

HRQL is a multidimensional concept that represents the QoL from the perspective of the individual's health status. (30) The PedsQL™ FIM measures the impact of chronic medical conditions on the HRQL and family functioning of the caregivers of children with CP. (31)

Additionally the impact of chronic disease is a significant factor on family functioning, as the role of the family in the adaptation to disease is essential. (26) Perceptions and dynamics of the family unit as a whole describe the family functioning. (4) The impact on the family functioning on the family caring for the child with CP is assessed through the Family Functioning Summary Score (FFSS).

The PedsQL™ FIM yields data from which the HRQL and FFSS of the caregiver of the child with CP is calculated. The HRQL score encompasses multiple domains of physical and psychological health, measuring the impact of caring for a child with CP on physical, emotional, social and cognitive functioning of the caregiver. The FFSS measures the impact on the daily activities and family relationships of the family of the child with CP. (31)

Table 4.10 The Overall Mean Caregiver HRQL Score and FFSS

	Mean Caregiver HRQL	**Mean Caregiver FFSS**
Overall	66.23	68.40

The QoL score calculated from the PedsQL™ FIM is essentially an average score out of 100. The higher the values score, the greater the health-related quality of life and family functioning of the caregiver and family of the child with CP. (26, 27)

The overall HRQL score was calculated as 66.23. The overall FFSS was calculated at 68.40.

Table 4.11 The Mean Caregiver HRQL Scores and FFSS of the different GMFCS Levels

GMFCS Level	Mean Caregiver HRQL	Mean Caregiver FFSS
1	67.08	75.26
2	81.25	80.8
3	63.13	54.69
4	66.25	66.46
5	61.82	64.73

The HRQL and FFSS were greatest in the caregivers and family of children with CP with a GMFCS level of 2.

The HRQL was lowest in the caregivers of children with CP with a GMFCS level of 5. This result seems probable as the GMFCS level of 5 is the highest, indicating greatest degree of disability of the CP. (18)

The FFSS was lowest in the families of children with CP with a GMFCS level of 3.

Linear regression, calculated the p-value of the HRQL between the GMFCS levels 1-5 as 0.14 illustrating no significant influence of the GMFCS levels of children with CP on the HRQL of the caregiver of the child with CP. Alternatively stated, in this research study the severity of gross motor functional impairment does not significantly influence the health related quality of life of the caregiver of the child with CP.

Assessing the impact of GMFCS on the FFSS, linear regression yielded, the p-value of the FFSS between the GMFCS levels as 0.167 illustrating no significant influence of the GMFCS levels of children with CP on the QoL of the family functioning of the family caring for the child with CP. Thus in this research study, the severity of gross motor functional impairment does not significantly influence the family functioning of the family caring for the child with CP.

4.5 Test of Hypotheses (Objectives / Aim of Research Study)

4.5.1 Objective 1

To determine the impact of cerebral palsy (CP) on the quality of life (QoL) of primary caregivers of children with CP.

The results of the research study do not support the hypothesis (objective 1). Thus the null hypothesis is accepted.

In order for CP to have an impact on the QoL of primary caregivers of children with CP, the overall QoL score, once transformed, should be significantly lower. With reference to Table 4.4 the overall QoL of the 52 participants in the study was calculated to be 66.52. As there was no control group in this research study, there is no comparative QoL score, and thus no p-value can be calculated to determine significant differences between caring for a child with CP and caring for a child without CP.

The study investigated the varying demographic variables that may impact caregivers of CP children, and determines whether the different variables impact QoL significantly or not.

The only demographic variable to have a statistically significant effect on the overall QoL of the caregiver was the gender of the child with CP ($p = 0.045$) as shown in Table 4.5.

Analysing the impact on the QoL of the individual domains of the PedsQL™ FIM, the QoL of the *Physical Functioning*, the *Cognitive Functioning* and the *Family Relationships* domain were significantly affected by the demographic of the gender of the child with CP being cared for, producing p-values of 0.008, 0.027 and 0.015 respectively (Table 4.5).

Additionally, the *Social Functioning* and *Communication* domains of the PedsQL™ FIM were significantly impacted by the age of the caregiver of the child with CP, producing p-values of 0.039 and 0.03 respectively (Table 4.5).

4.5.2 Objective 2

To determine if the QoL of primary caregivers of children with CP is significantly different within the different severity groups of CP (according to the GMFCS) and to identify and describe the differences of the QoL within these different groups.

The results of the research study do not support the hypothesis (objective 2). Thus the null hypothesis is accepted.

Linear regression illustrated the p-value between the GMFCS levels 1-5 was 0.255, illustrating no association between the GMFCS level of the child with CP, and the QoL of the caregiver. The severity of CP (according to the GMFCS levels) did not illustrate a statistically significant difference between the different levels of CP severity.

The severity of CP (as indicated by GMFCS level) did not significantly affect the overall QoL of the caregiver, however the *Daily Activities* domain of the PedsQL, which was the most affected domain, provided the most significant statistical difference for the GMFCS 3 of 0.059 (Table 4.5). This illustrates that the severity of CP impacts QoL of the caregiver of the child with CP most significantly in daily activity functioning.

Severity of functional motor impairment (represented by the GMFCS levels in this study) did not significantly impact the health related QoL of the caregiver, or the family functioning of the family involved in caring for the child with CP.

4.5.3 Objective 3

To identify caregiver intervention, and or community support services utilised by the caregivers of the children, and deduce a correlation between caregiver support and QoL.

This objective was not completed in the research study. The PedsQL™ FIM did not investigate this parameter, nor did the Demographic Data Sheet (Appendix VIII) cover this aspect. The only near parameter that looked at the caregiver intervention, and or community support services, was the question in the Demographic Data Sheet (Appendix VIII) that questioned the presence of spouse or mother or father; other siblings; grandparents (living with the child with CP) that supported the primary caregiver of the child with CP.

Identification of caregiver intervention, and or community support services will be listed and described as a recommendation for future research studies and research reports conducted in the condition of CP

CHAPTER FIVE

DISCUSSION

5.1 The Impact of cerebral palsy (CP) on the Quality of Life (QoL) of Parents, Guardians or Primary Caregivers of Children with CP

The primary objective of this research study was to investigate the effect of CP on QoL of primary caregivers of children with CP. The findings of this research study were not that which may have been anticipated, as the results of the study did not support the hypothesis.

Caregivers of children with disabilities, as compared to those of children without disabilities, face particular challenges and demands. Parenting a child with a disability goes beyond the requirements of parenting a child without disability, as parents have to accommodate the specific demands related to the needs of their child. (32)

The birth of a disabled child has a long term impact on the family (32).

Evidence shows that how families cope and adapt to caring for children with disabilities may vary significantly. The different adaptations to children with disabilities may result in different impacts on the health, well-being and QoL of the primary caregivers.

The demands of caregiving contribute directly to the health of caregivers. Behaviour and day to day needs of the child creates challenges for the caregiver, and strongly influences the psychological and physical health of caregivers. Child behaviour problems are an important predictor of caregiver psychological health, both directly and indirectly, through their effect on self-perception and family function. (1)

Research predominantly shows a negative impact on the overall well-being and QoL of the caregiver and family of children with CP. (32)

The caregiver of the child with disability exhibits poorer outcomes than caregivers of normo-typical developing children. (33)

Research evidences that caring for a child with a disability may be stressful, often having a negative impact on the health of the caregiver and family. Consistently studies report higher levels of psychological concerns, which may include perceived stress, depression, and feelings of reduced well-being amongst caregivers of children with disabilities. (33)

Health risk behaviours such as poor sleep quantity and quality, lack of physical exercise and lack of leisurely activities, are behaviours that albeit support the ability of the caregiver to manage caring for a child with CP, is detrimental to their health. (33)

Despite the evidence illustrating the negative impact on the QoL of caregivers of children with CP, some evidence illustrates how primary caregivers adapt to the greater demand of their child with CP, develop a positive attitude to their child with disability, and achieve homeostasis in the caregiving environment that is most suitable for them as the caregiver and the child. (2, 7, 33)

This research study has not shown a significant impact on the overall QoL of the primary caregiver of the child with CP. No direct comparison can be made, as the study did not include a control group.

Results of this research study may be due to the instrument used to collect data, lack of a control group, and variation in the severity of disability of the children cared for by caregivers in the study.

Previous research studies investigating the impact of CP on the QoL of caregivers of children with CP have utilised several instrument tools, exploring overall health and well-being, physical and psychological health.

Furthermore this research study did not investigate whether the participant received a Care Dependency Grant (CDG), and it is suggested as a recommendation for future research studies investigating similar fields of interest.

The high unemployment rate of the participants in the research study (59.55%) (unemployed 36.5%; part-time or temporary employment 19.2%: and unemployed due to studies 3.85%) (Table 4.4), and the receipt of the grant (CDG) should be investigated, to determine whether these factors make a difference to the QoL of the caregiver of the child with CP.

5.2 Limitations of the study

1. As the PedsQL™ FIM has not been validated for a South African population, a pilot study was completed (prior to the research study) in order to ensure validity of the PedsQL™ FIM for a South African study group.

   Based on the pilot study findings, adjustments to the questionnaire were made only in respect of language comprehension to accommodate the South African population of participants.

   Although the questionnaire was fairly well understood by the participants of the pilot study it was noted that the English language used in the questionnaire was not entirely comprehended. The questionnaire was professionally translated into Zulu and Xhosa, as these are the most commonly spoken languages in SA (Zulu (22.7%) and Xhosa (16%)). English is the fourth most commonly spoken language (9.6%) in SA. (28)

2. The PedsQL™ FIM is in English, and although participants using English as their second language are included in the study, it would be ideal to include only participants using English as a first language, so as to avoid any confusion in the comprehension of the questionnaire. The translation of the PedsQL™ FIM questionnaire into Zulu and Xhosa supported participants using English as their second language.

3. Due to the nature of caring for a child with CP, the investigator of the research study was required to support the participant more so than would usually be required. If the participant attended the CP clinic on his/her own, the child with CP would accompany the participant.

   To support completion of the questionnaire, either the participant supervised the child with CP and the investigator assisted in completion of the questionnaire, or the investigator supervised the child with CP so that the participant could

complete the questionnaire. If the participant attended the CP clinic with a family member the child with CP remained with the family member outside of the interview room.

When the investigator supported the participant, no assumptions were made, and only direction from the participant was recorded. Despite attempts to assist with questionnaire completion in a completely objective manner, it must be noted that observer bias may have been introduced. Recommendations for future research studies may include utilizing assistance from clinic staff so as to avoid any observer bias.

4. The research study did not include a control group. The inclusion of a control group in the study would have provided a comparison for the overall QoL of the caregiver of the child with CP, and provided further insight as to whether caring for a child with disability as compared to caring for a child without disability, significantly impacted the QoL of the caregiver.

5. The population studied in the research study was of varying socio-economic status, in terms of financial and employment status. No formal measurement of socio-economic status was recorded. However due to the participants attending a government hospital, the Charlotte Maxeke Hospital, without access to private health care, it was presumed that participants could be matched for socio-economic status. Household income (including grants) may have provided a more accurate representation of financial status.

6. The research study did not confirm or deny the diagnosis of CP of the children cared for by the participant. The diagnosis, as recorded in the child's medical file, was assumed correct as this was previously done by the respective paediatric professional of the neurodevelopmental clinic. An incorrect diagnosis of the child with CP may have been possible and is acknowledged.

7. The investigator of the research study utilised the GMFCS criteria in order to classify the severity of CP of the child cared for by the primary caregiver. This was done, as the GMFCS was not available in every child's medical file in the neurodevelopmental clinic. This was not verified by an additional paediatric professional.

8. The Demographic Data Sheet (Appendix VIII) did not investigate the religious or cultural outlooks of the participants, which may have provided insight into the caring and coping ability, or lack thereof in the population studied.

9. The Demographic Data Sheet (Appendix VIII) did not investigate whether a grant (CDG) was received by the participants of the study, and whether the unemployment rate and grant made a significant impact on the QoL of the caregiver of the child with CP.

10. The research study did not investigate caregiver intervention, and or community support services utilised by the caregivers of the children. This data may have provided a possible correlation between caregiver support and QoL.

Early intervention is advised for families at risk of experiencing severe distress, and caregiver interventions and support should be initiated for the whole family living with a child with CP (32). Comprehending the dynamics of the factors influencing the QoL of families is necessary for the development of effective interventions. (4) Secondary to the immediate family providing caregiving, the influence of social support provided by extended family and friends contributes to the QoL of the caregiver. (1)

5.3 Recommendations for Future Research Studies

1. Due to time and resource deficiencies, the research study did not include a control group of participants caring for children without CP, that either were without any form of chronic disease and normally developed, so to speak, or that did have a chronic condition (that still may have posed an impact on the QoL of caregivers of children with a chronic condition, such as asthma).

2. The aim of the research study was to achieve a sample group of at least 100 participants, in order to analyse the data.

Due to the following factors:

- Fewer CP patients attending the CP clinic than estimated
- Failure of caregivers to participate in the research study, due to not meeting eligibility criteria of the population screened for participation in the study
- Time constraints of the investigator to continue data collection of the research study for a longer period of time, in order to recruit more participants.

Only 52 participants were recruited to participate in the research study. Future research studies investigating the impact of CP on the QoL of participants should consider a greater sample size in order to achieve a greater power to detect statistically significant differences, when analysing the data.

In order to recruit a greater number of participants, the research study should have continued for a longer period of time. Additionally utilization of additional CP clinic sites, such as the Chris Hani Baragwanath Hospital (CHBH) and the Rahima Moosa Mother and Child Hospital (RMMCH) may have been utilized to recruit more participants which may have resulted in more statistically significant results.

CHAPTER SIX

CONCLUSION

The primary aim of the research study was to determine and analyse the impact of cerebral palsy (CP) on the quality of life (QoL) of primary caregivers of children with CP on the family of children living with CP, in Gauteng, South Africa (SA).

The identification and description of the QoL of the caregivers of children with CP was investigated and recorded. Identification and description of differences in QoL of caregivers within the different severity groups of CP (according to the Gross Motor Function Classification System (GMFCS)), was secondary to the primary aim of the research study.

The conclusions of the research study are summarised below:

The impact of CP on the overall QoL of primary caregivers of children with CP in Gauteng, SA was not statistically significant. The study found that caring for a child with CP does not significantly impact the overall QoL of the caregiver.

Additionally, the physical and psychological health of the caregiver (as defined by the health related quality of life) and family functioning of the family involved in caring for the child with CP is not significantly impacted by caring for a child with CP.

This was a surprising and unexpected finding, as this is contrary to the majority of clinical evidence documented illustrating the impact on the QoL of caregivers of children with CP as significant.

The impact of CP on the QoL of primary caregivers of children with CP did not vary significantly with respect to gross motor functional impairment, as measured by GMFCS in this research study.

The most significantly impacted aspect of the QoL of the caregivers of children with CP was the *Daily Activities* domain. The GMFCS level 3 group proved to have the greatest impact on managing the *Daily Activities* aspect of QoL of the caregivers of children with CP.

Severity of disability of CP of the child, did not significantly impact the physical and psychological health of the caregiver, or the family functioning capacity of the family caring for the child with CP.

Gender of the child with CP cared for by the caregiver, was the variable of the child that impacted the QoL of the caregiver most significantly.

CHAPTER SEVEN

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APPENDICES

APPENDIX I	PedsQL™ Family Impact Module (PedsQL™ FIM) *English Version (original)*
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APPENDIX I

ID#_____

Date:_____

PedsQL™

Family Impact Module

Version 2.0

PARENT REPORT

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DIRECTIONS

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for **you**. Please tell us **how much of a problem** each one has been for **you** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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In the past ONE month, as a result of your child's health, how much of a problem have you had with…

PHYSICAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel tired during the day	0	1	2	3	4
2. I feel tired when I wake up in the morning	0	1	2	3	4
3. I feel too tired to do the things I like to do	0	1	2	3	4
4. I get headaches	0	1	2	3	4
5. I feel physically weak	0	1	2	3	4
6. I feel sick to my stomach	0	1	2	3	4

EMOTIONAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel anxious	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I feel frustrated	0	1	2	3	4
5. I feel helpless or hopeless	0	1	2	3	4

SOCIAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel isolated from others	0	1	2	3	4
2. I have trouble getting support from others	0	1	2	3	4
3. It is hard to find time for social activities	0	1	2	3	4
4. I do not have enough energy for social activities	0	1	2	3	4

COGNITIVE FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4

COMMUNICATION *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel that others do not understand my family's situation	0	1	2	3	4
2. It is hard for me to talk about my child's health with others	0	1	2	3	4
3. It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4

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In the past ONE month, as a result of your child's health, how much of a problem have you had with…

WORRY *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I worry about whether or not my child's medical treatments are working	0	1	2	3	4
2. I worry about the side effects of my child's medications/medical treatments	0	1	2	3	4
3. I worry about how others will react to my child's condition	0	1	2	3	4
4. I worry about how my child's illness is affecting other family members	0	1	2	3	4
5. I worry about my child's future	0	1	2	3	4

DIRECTIONS

Below is a list of things that might be a problem for **your family**. Please tell us **how much of a problem** each one has been for **your family** during the **past ONE month.**

In the past ONE month, as a result of your child's health, how much of a problem has your family had with…

DAILY ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. Family activities taking more time and effort	0	1	2	3	4
2. Difficulty finding time to finish household tasks	0	1	2	3	4
3. Feeling too tired to finish household tasks	0	1	2	3	4

FAMILY RELATIONSHIPS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. Lack of communication between family members	0	1	2	3	4
2. Conflicts between family members	0	1	2	3	4
3. Difficulty making decisions together as a family	0	1	2	3	4
4. Difficulty solving family problems together	0	1	2	3	4
5. Stress or tension between family members	0	1	2	3	4

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APPENDIX II

N&N Language Consultancy Services

Confirmation letter

To: J. Ferreira
(WITS student number: 578677)
082 260 5711
35A Van Buuren Road,
Bedfordview
2008

From: Yvonne Malindi (Language Practitioner)
Address: PO Box 5516
Vanderbijlpark
1900

My ref: Conf.01/2017

Date: 11/04/2017

To whom it may concern

Re: TRANSLATION/EDITING/PROOFREADING/TRANSCRIPTION: English/IsiZulu.

I/We hereby confirm that a **Questionnaire_20170320 PEDS** was translated into IsiZulu by Yvonne Malindi, a language practitioner with MA degree in languages and IsiXhosa by Thozamile Sikosana and edited by Yvonne Malindi.

Kind regards

Ms NY Malindi
Cell: 0827048636
Fax: 0865171141
Email: nokuthula@vodamail.co.za/yvonne.malindi@gmail.com

APPENDIX III

IsiZulu

ID#: _____
Usuku: _____

PedsQL™ Imojuli emayelana nomthelela kumndeni

Ushicilelo 2.0

UMBIKO WOMZALI

IMIYALELO

Kwesinye isikhathi imindeni yezingane iba nokukhathazeka okukhethekile noma izinkinga ngenxa yesimo sempilo yezingane. Ekhasini elilandelayo kunohlu lwezinto ezingaba yinkinga **kuwe**. Sicela usitshele ukuthi lokho nalokho **kube yinkinga kangakanani** kuwe **enyangeni EYODWA edlule** ngokukokelezela:

0 uma **kungakaze** kube yinkinga

1 uma **kucishe kungakaze** kube yinkinga

2 uma kube yinkinga **kwesinye isikhathi**

3 uma **bekuvame** ukuba yinkinga

4 uma **cishe ngaso sonke isikhathi** kube yinkinga

Azikho izimpendulo ezishaya khona noma ezingashayi khona. Uma ungawuqondi umbuzo, sicela ucele usizo.

Enyangeni EYODWA, ngenxa yempilo yengane yakho, **ube** nenkinga engakanani ngalokhu:

UKUSEBENZA KOMZIMBA (izinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Ngizizwa ngikhathele emini	0	1	2	3	4
2. Ngizizwa ngikhathele uma ngivuka ekuseni	0	1	2	3	4
3.Ngizizwa ngikhathele kakhulu ukwenza izinto engithanda ukuzenza	0	1	2	3	4
4. Ngiba nekhanda elibuhlungu	0	1	2	3	4
5. Ngizizwa ngibuthakathaka emzimbeni	0	1	2	3	4
6. Ngizizwa ngiphathwa yisisu	0	1	2	3	4

INDLELA ENGIZIZWA NGAYO (izinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Ngizizwa ngisaba	0	1	2	3	4
2. Ngizizwa ngidangele	0	1	2	3	4
3. Ngizizwa ngithukuthele	0	1	2	3	4
4. Ngizizwa ngikhungathekile	0	1	2	3	4
5. Ngizizwa ngingenalusizo noma ngingenathemba	0	1	2	3	4

UKUXHUMANA NABANTU (izinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Ngizizwa ngiqhelile ebantwini	0	1	2	3	4
2. Ngiba nenkinga ekutholeni ukwesekwa ngabanye abantu	0	1	2	3	4
3. Kulukhuni ukuthola isikhathi sokwenza izinto zokungcebeleka	0	1	2	3	4
4. Anginawo amandla anele okwenza izinto zokungcebeleka	0	1	2	3	4

UKUSEBENZA KWENGQONDO (nginezinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Kulukhuni kimina ukuthi ngihlale nginake izinto	0	1	2	3	4
2. Kulukhuni kimina ukukhumbula lokho engikutshelwa ngabantu	0	1	2	3	4
3. Kulukhuni kimina ukukhumbula lokho engisanda kukuzwa	0	1	2	3	4
4. Kulukhuni kimina ukucabanga masinyane	0	1	2	3	4
5. Ngiba nenkinga ekukhumbuleni lokho ebengisanda kukucabanga	0	1	2	3	4

UKUXHUMANA (izinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Ngizizwa sengathi abanye abantu abasiqondi isimo somndeni wami	0	1	2	3	4
2. Kulukhuni kimina ukukhuluma ngempilo yengane yami nabanye abantu	0	1	2	3	4
3. Kulukhuni kimina ukutshela odokotela namanesi ngendlela engizizwa ngayo	0	1	2	3	4

Enyangeni EYODWA, ngenxa yempilo yengane yakho, **ube** nenkinga engakanani ngalokhu…

UKUKHATHAZEKA (izinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Ngiyakhathazeka ngokuthi ingabe ukwelashwa kwengane yami kuyasebenza yini	0	1	2	3	4
2. Ngiyakhathazeka ngemithelela emibi yemithi yengane yami/yokwelashwa kwengane yami	0	1	2	3	4
3. Ngiyakhathazeka ngokuthi ingabe abanye abantu bazosithatha kanjani isimo sengane yami	0	1	2	3	4
4. Ngiyakhathazeka ngendlela ukugula kwengane yami kuba nomthelela ngayo kumalungu omndeni wami	0	1	2	3	4
5. Ngiyakhathazeka ngekusasa lengane yami	0	1	2	3	4

IMIYALELO

Lapha ngezansi kunohlu lwezinto ezingaba yinkinga **kumndeni wakho**. Sicela usitshele ukuthi lokho nalokho kube yinkinga kangakanani kumndeni wakho **enyangeni EYODWA edlule**

Enyangeni EYODWA, ngenxa yempilo yengane yakho, **umndeni wakho** ube nenkinga engakanani ngalokhu…

IMISEBENZI YANSUKU ZONKE (izinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Imisebenzi yasekhaya ithatha isikhathi sami futhi iyangisinda	0	1	2	3	4
2. Kulukhuni ukuthola isikhathi sokuqeda imisebenzi yasekhaya	0	1	2	3	4
3. Ngizizwa ngikhathala kakhulu ukuqedelela imisebenzi yasekhaya	0	1	2	3	4

UBUDLELWANE NOMNDENI (izinkinga ngalokhu…)					
	Akukaze	Cishe akukaze	Kwesinye isikhathi	Kuvamile	Cishe ngaso sonke isikhathi
1. Ukwesweleka kokuxhumana phakathi kwamalungu omndeni	0	1	2	3	4
2. Izingxabano phakathi kwamalungu omndeni	0	1	2	3	4
3. Kulukhuni ukuthatha izinqumo ngokubambisana nomndeni	0	1	2	3	4
4. Kulukhuni ukuxazulula izinkinga zomndeni ngokubambisana	0	1	2	3	4
5. Ingcindezi noma ukukhathazeka phakathi kwamalungu omndeni	0	1	2	3	4

APPENDIX IV

IsiXhosa

ID#: _____
Umhla: _____

PedsQL™ Imodyuli Echaphazela Usapho

Uhlelo 2.0

INGXELO YOMZALI

IMIYALELO

Iintsapho zomntwana ngamanye amaxesha ziba nenkxalalbo okanye ubunzima ngempilo yomntwana. Kwiphepha elilandelayo siza kudwelisa izinto ezinokuba yingxaki **kuwe**. Nceda usixelele ukuba ziyingxaki kangakanani nganye kuzo kwinyanga ENYE edlulileyo ngokwenza isangqa:

0 ukuba **ayizange** ibe nengxaki

1 ukuba **phantse ayizange** ibe nengxaki

2 ukuba **ngamanye amaxesha** iba nengxaki

3 ukuba **isoloko** iyingxaki

4 ukuba **phantse isoloko** iyingxaki

Akukho zimpendulo zichanileyo neziphosakelelyo. Ukuba akuwuqondi umbuzo, cela uncedo.

Kule **nyanga INYE,** ngenxa yempilo yomntwana wakho, ukhe wanengxaki kangakanani **wena**:

UKUSEBENZISA UMZIMBA (ingxaki …)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Ndiva ndindiniwe ebudeni bosuku	0	1	2	3	4
2. Ndiva ndidiniwe xa ndivuka kusasa	0	1	2	3	4
3. Ndiva ndidiniwe ukwenza izinto endizithandayo	0	1	2	3	4
4. Ndiba nentloko ebuhlungu	0	1	2	3	4
5. Umzimba uba buthathaka	0	1	2	3	4
6. Ndigula kakhulu	0	1	2	3	4

UKUSEBENZA KWEEMVAKALELO (ingxaki …)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Ngokuziva ndixhalabile	0	1	2	3	4
2. Ndiziva ndidakumbile	0	1	2	3	4
3. Ndiziva ndinomsindo	0	1	2	3	4
4. Ndiziva ndididekile	0	1	2	3	4
5. Ndiziva ndingenakuzinceda ndingenathemba	0	1	2	3	4

UKUSEBENZA KWEZENTLALO (iingxaki…)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Zokuziva ndizikhetha kwabanye	0	1	2	3	4
2. Zokufumana inkxaso kwabanye	0	1	2	3	4
3. Lokufumana ixesha lokwenza izinto zasekuhlaleni	0	1	2	3	4
4. Yokuba namandla okwenza izinto zentlalo	0	1	2	3	4

UKUSEBENZISA INGQONDO (ingxaki…)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Kunzima kuma ukugcina ingqondo ezintweni	0	1	2	3	4
2. Ndiyazilibala izinto endizixelelwa ngabantu	0	1	2	3	4
3. Kunzima ngam ukukhumbula into endisandul' ukuyixelelwa	0	1	2	3	4
4. Kunzima ukucinga ngokukhawuleza	0	1	2	3	4
5. Kunzima ukukhumbula into endisandul' ukuyicinga	0	1	2	3	4

UNXIBELELWANO (ingxaki…)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Abanye abayiqondi imeko yosapho lwam	0	1	2	3	4
2. Kunzima kum ukuthetha ngempilo yomntwana wam	0	1	2	3	4
3. Kunzima ukuxelela oogqirha noonesi indlela endiziva ngayo	0	1	2	3	4

Kule **nyanga INYE** idluleleyo, ngenxa yempilo yomntwana wakho, ibingakanani ingxaki **kuwe** oye waba nayo …

UKUKHATHAZEKA (ingxaki …)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Ndikhathazwa yinto yokuba unyango lomntwana wam luyasebenza na	0	1	2	3	4
2. Ndikhathazwa yimiphumo yonyango lomntwana wam	0	1	2	3	4
3. Ndikhathazwa yindlela abanye abaya kusabela ngayo kwimpilo yomntwana wam	0	1	2	3	4
4. Ndikhathazwa yindlela ukugulla komntwana okuchaphazela ngayo abanye kusapho	0	1	2	3	4
5. Ndikhathazwa likamva lomntwana wam	0	1	2	3	4

IMIYALELO

Ngezantsi kukho uludwe lwezinto ezinokuba yingxaki **kusapho lwakho.** Nceda sixelele **ubungakanani bengxaki** nganye ekuyo kwayiyo **kusapho lwakho** kule **nyanga INYE idluleyo**.

Kule **nyanga INYE** idluleyo, ngenxa yempilo yomntwana wakho, **intsapho yakho** ibe nengxaki kangakanani …

IMISEBENZI YOSUKU (iingxaki…)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Imisebenzi yosapho ithatha ixesha namandla	0	1	2	3	4
2. Kunzima ukufumana ixesha lokugqiba imisebenzi yekhaya	0	1	2	3	4
3. Ukudinwa kunokugqiba imisebenzi yekhaya	0	1	2	3	4

UBUDLELWANE BOSAPHO (ingxaki…)					
	Ayizange	Phantse Ayizange	Ngamanye Amaxesha	Kusoloko	Phantse Kusoloko
1. Ukungancokoli phakathi kwamalungu osapho	0	1	2	3	4
2. Iingxabano phakathi kwamalungu osapho	0	1	2	3	4
3. Kunzima ukwenza izingqibo silusapho	0	1	2	3	4
4. Kunzima ukulungisa iingxaki zosapho	0	1	2	3	4
5. Uxinezeleko okanye ukujongana ngezikhondo zamehlo namalungu osapho	0	1	2	3	4

APPENDIX V



South African Translators' Institute
SATI — Bridging Language Barriers

South African Translators' Institute | Suid-Afrikaanse Vertalersinstituut | Umbutho wabaGuquleli waseMzantsi Afrika | Inhlangano yaBahumushi yaseNingizimu Afrika | Sebopeqwa sa Bafetoledi sa Afrika Borwa | Mokgatlho wa Bafetoledi wa Afrika Borwa | Inhlangano Yebahumushi YaseNingizimu Afrika | Tshimiswa tsha Vhapindudzi tsha Afurika Tshipembe | Vandlha ra Vahundzuluxi ra Afrika Dzonga

SATI MEMBERSHIP CERTIFICATE

Name	Ms Nokuthula Yvonne Malindi
Membership Number	1000557
Membership Year	2017
Membership Validity	1 January to 31 December 2017
Accreditation Status	Not accredited
Further comments	

Issued by the South African Translators' Institute on 10 April 2017.
Should any further information be required, please contact the Institute at office@translators.org.za.

011 803 2681
0866 199 133
office@translators.org.za
www.translators.org.za
PO Box 1710, Rivonia, 2128

APPENDIX VI

Participant Eligibility Sheet

PARTICIPANT DETAILS (COMPLETED BY RESEARCHER)	
DATE	
PARTICIPANT NAME AND SURNAME	
*FILE NUMBER	

*The file number will be issued to the participant, and will be used to complete the Demographic Data Sheet (Appendix VIII) with the purpose of ensuring the confidentiality of the participant and the child with CP.

PARTICIPANT ELIGIBILITY (COMPLETED BY RESEARCHER)		
You are a parent (mother / father), family member, legal guardian or caregiver of the child	TRUE	FALSE
You live with the child		
You attend the Cerebral Palsy Neurodevelopment Clinic at the Charlotte Maxeke Hospital, Johannesburg		
You are able to read, and understand English		
You are not pregnant		
You are currently well without a diagnosis of physical or psychological origin		
The child with CP, whom you care for, and who lives with you, has been previously diagnosed with CP		
The child with CP, whom you care for, and who lives with you, is aged between 3 and 12 years of age		

Should the participant answer TRUE to all the above statements, they are eligible to participate in the research study, and will complete and sign the Participant Information and Consent Form (Appendix VII) and Demographic Data Sheet (Appendix VIII) before the administration of the PedsQL™ Family Impact Module (Appendix I).

APPENDIX VII

Participant Information and Consent Form

IMPACT OF CEREBRAL PALSY ON THE QUALITY OF LIFE OF THE FAMILY OF CHILDREN WITH CEREBRAL PALSY

Dear Parent / Caregiver / Guardian,

My name is Juanita Ferreira; I am completing my research study at the University of Witwatersrand. I am doing a research study to help me understand how caring for a child with cerebral palsy affects your life and the life of your family.

To collect the information I am going to ask you to answer some questions, using a question form (PedsQL™ Family Impact Module). You will complete the form in a private room. All the information you provide for this study will not be told to anyone that is not involved in the study; and your name and the name of the child with cerebral palsy will not be used in the study reports.

The question form (PedsQL™ Family Impact Module) that you will complete does not involve risks to you or the child you care for, during participation of this research study. No costs to you as a participant in the research study, is expected from participation in the research.

Taking part in this study is voluntary and you are free to refuse to take part in the study or to withdraw your permission and to discontinue participation at any time. Such refusal or discontinuance will not affect your regular treatments or medical care in any way. A signed copy of this consent form will be given to you.

When the study is finished I, the researcher will write a report about what was learned.

Name and Surname of participant: _____
File number: _____
Child with CP GMFCS level: _____
Contact number: _____
Address: _____

I, Juanita Ferreira (researcher) have fully explained the procedures of the study and questionnaire. I have asked whether any questions have arisen regarding the procedures and have answered these questions to the best of my ability. If you should have any questions during the study, please contact me on 082 260 5711.

_____ _____
Juanita Ferreira Date

I, _____ (Name and Surname of participant) have been fully informed of the processes to be followed, and have been given a description of the research I am taking part in.

In signing this consent form as I agree to take part in the study and I understand that I am free to withdraw my permission and stop taking part in this study at any time. I understand that if I have any questions at any time, they will be answered.

_____ _____
Participant Date

APPENDIX VIII

Demographic Data Sheet

PLEASE COMPLETE THE FOLLOWING (TO BE COMPLETED BY THE PARTICIPANT). <u>NO NAME AND SURNAME OF THE PARTICIPANT AND CHILD WITH CP TO BE RECORDED ON THIS SHEET</u>	
Participant File Number:	
Information recorded is that of the participant	
Gender (Male / Female)	
Date of birth / Age	
Marital / Relationship status (Are you married, living with someone or in a relationship?)	
Length of time caring for the child with CP	
Presence of mother or father; other siblings; grandparents (living with the child with CP)	
Level of education (Did you complete school? What standard or grade of school did you complete? Did you study after school?)	
Employment status (Do you have work? Is this temporary or permanent?)	
Health status (Are you diagnosed with any diseases or medical conditions?)	

DETAILS OF CHILD WITH CP (TO BE COMPLETED BY THE PARTICIPANT)	
Information recorded is that of the child with CP	
Participant GMFCS level	
Date of birth / Age	
Gender (Male / Female)	
Date of diagnosis of CP	

APPENDIX IX

Permission to use the PedsQL™ FIM from the author of the tool, Prof JW Varni

Dear Professor Varni,

I hope you are well on receiving this mail.

My name is Juanita Ferreira, and I am currently completing my Master's Degree (MSC. Medicine) in Child Health: Paediatric Neurodevelopment option, at the University of Witwatersrand in South Africa. The topic of my research report is the "Impact of Cerebral Palsy on the Quality of Life of the Family of Children with Cerebral Palsy".

In my research study I would like, with your permission, to please make use of the PedsQL™ Family Impact Module to measure the impact of disease on the quality of life of families with children who have cerebral palsy (CP). Children with CP will be classified according to the functional classification of CP using the Gross Motor Functional Classification System (GMFCS). The PedsQL™ Family Impact Module questionnaires will be classified / grouped accordingly, to determine the impact on the quality of life of families of children with CP according to the functional classification of the CP. The study will take place at the Neurodevelopmental Clinic for children in the Charlotte Maxeke Johannesburg Academic Hospital (CMJAH), a state hospital in Johannesburg, Gauteng (South Africa).

I would like to ask for permission to please make use of the PedsQL™ Family Impact Module in the research study.

It would be a great help, and an honour to make use of this tool in my study. I would include all referencing and due credit.

Looking forward to your response,

Juanita Ferreira

Please go to www.pedsql.org and click on conditions of use. There is no license fee. You can download the PedsQL™ from the Mapi website.

Thank you.

James W. Varni, Ph.D.

Professor and Vice Chair for Research

Department of Pediatrics, College of Medicine

Julie and Craig Beale ’71 Endowed Professor

Center for Health Systems + Design

Department of Landscape Architecture and Urban Planning

College of Architecture

Texas A&M University

3137 TAMU

College Station, Texas 77843-3137

jvarni@tamu.edu

APPENDIX X

Permission to use the Neurodevelopmental Clinic in the research study (Head of the Neurodevelopmental Clinic)

Dear Dr Heather Thomson,

I hope you are well on receiving this mail.

Dr Thomson I am completing my study titled "The Impact of Cerebral Palsy on the Quality of Life of the Family of Children with Cerebral Palsy". In this study I will be measuring the impact on the quality of life of parents and primary caregivers of children with cerebral palsy (CP) [using the PedsQL Family Impact Module], and then comparing the different classes of severity of CP (as classified by the Gross Motor Function Classification System (GMFCS)).

I would like to ask for permission to please attend the CP clinic you run, every first and third Monday of the month in order to recruit participants to the study.

Doctor Thomson, should you agree, I will invite parents and primary caregivers of children with CP, who attend the Neurodevelopmental Clinic, at the Charlotte Maxeke Johannesburg Academic Hospital, to participate in the study. Should the participants agree to participate in the study, I will explain the outline of the study and questionnaire; administer the questionnaire accordingly; and thank the participants for their participation.

I look forward to your response,

Kind regards,

Juanita Ferreira

Dr Thomson agreed to the use of the Neurodevelopmental clinic verbally.

APPENDIX XI

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Mr. J. Maepa
Office of the Clinical Director
Tell: (011) 488-3365
Email:johannes.maepa@gauteng.gov.za
08 February 2016

Dear Dr. Juanita Ferreira

STUDY TITLE: Impact of Cerebral Palsy on the quality of life of the family of children with Cerebral Palsy.

Permission to conduct the above mentioned study is provisionally approved. Your study can only commence once Ethics approval is obtained. Please forward a copy of your ethics clearance certificate as soon as the study is approved by the Ethics committee for the CEO's to give you the final approval to conduct the study.

Supported / ~~not supported~~

Dr. M. Mofokeng
Clinical Director
DATE: 8/02/2016

Approved / not approved

Ms. G. Bogosi
Chief Executive Officer
Date: 9.2.2016

APPENDIX XII

R14/49 Miss Juanita Ferreira

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160495

NAME: (Principal Investigator)	Miss Juanita Ferreira
DEPARTMENT:	Paediatrics Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Impact of Celebral Palsy on the Quality of Life of the Family of Children with Cerebral Palsy
DATE CONSIDERED:	06/05/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Lorna Jacklin
APPROVED BY:	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	24/05/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. I **agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of clearance meeting where the study was initially reviewed. In this case, the study was initially review in April and will therefore be due in the month of April each year.

Principal Investigator Signature

Date 2 September 2016

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES