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The hambisela programme's effect on stress levels and quality of line of primary caregivers of children with cerebral palsy in Mamelodi: a pilot study

Van Aswegen, Tami

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THE HAMBISELA PROGRAMME'S EFFECT ON STRESS LEVELS AND QUALITY OF LIFE OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN MAMELODI: A PILOT STUDY.

Tami van Aswegen

1010757

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.

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ABSTRACT

Cerebral palsy (CP) is a lifelong complex disorder that places multiple burdens on the caregivers. Caregivers of children with CP have high stress levels and poor quality of life which could have a detrimental effect on their children. Addressing the parents' needs is an important aspect when working with children with disabilities.

Sixteen participants from Mamelodi, a township in South Africa, participated in a quasi-experimental pilot study over eight consecutive weeks. The aim of the study was to determine if an educational intervention, Hambisela, could reduce caregivers' stress levels and improve their quality of life (QoL). Contributing factors such as parent's age and educational level, and the child's age and level of severity of CP were correlated to the caregivers stress levels and QoL. Participants completed the Parenting Stress Index – Short Form (PSI – SF), the Paediatric Quality of Life – Family Impact Module (PedsQL^{TM} – FIM), a demographic questionnaire and the Gross Motor Function Classification System was used to assess the child's level of severity.

No significant differences were found in the participants stress levels (p=0.7) and QoL (p=0.9) before and after completing the programme. A moderate negative correlation (r=-0.5) was found between caregiver's education level and stress and a moderate negative correlation (r=-0.5) was found between the caregiver's age and QoL.

An educational intervention alone, such as Hambisela, is not sufficient to reduce the stress of caregiver's of children with CP, or to improve their QoL. Stress is a complex multifactorial construct. In a developing country such as South Africa, social and environmental stressors are significant factors which play a role in these caregivers'

lives. Holistic interventions addressing all factors contributing to stress, especially social development, ought to be designed for this population.

DECLARATION

I, Tamryn Joy Van Aswegen, declare that this research report is my own unaided work except for the help given by the persons listed under the acknowledgements. It is being submitted in partial fulfilment of the requirements of the degree of Master of Science (Physiotherapy) at the University of the Witwatersrand. It has not been submitted before for any other degree or examination in any other university.

Signed this day in Johannesburg

_____

Signature

__ / __ / ____

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LIST OF ABBREVIATIONS

BDI-II	Beck Depression Inventory-II
BFMFS	Bimanual Fine Motor Function Scale
BPT	Behavioural Parent Training
CBT	Cognitive Behavioural Therapy
CHIP	Coping Health Inventory for Parents
CHQ	Child Health Questionnaire
CP	Cerebral Palsy
CVI	Cerebral Visual Impairment
DBC	Developmental Behaviour Checklist
DC	Difficult Child
DR	Defensive Responding
FCA	Family Centred Approach
FSI	Family System Interventions
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
HRQoL	Health Related Quality of Life
IFS	Impact on Family Scale
MACS	Manual Ability Classification System
MBI	Maslach Burnout Inventory

MBSR	Mindfulness Based Stress Reduction
MCT	Multiple Component Treatments
MITP	Mother-Infant Transaction Programme
NOSI	Nijmeegse Ouderlijke Stress Index
PCDI	Parent-Child Dysfunctional Interaction
PD	Parental Distress
PedsQL	Paediatric Quality of Life
PedsQL^{TM} – FIM	Paediatric Quality of Life – Family Impact Module
PSI - SF	Parenting Stress Index – Short Form
PSI	Parenting Stress Index
PSS	Perceived Stress Scale
QoL	Quality of Life
RCT	Randomised Controlled Trials
REM	Rapid Eye Movement
SPSQ	Swedish Parenthood Stress Questionnaire
STAI	State Trait Anxiety Inventory
WHOQOL-BREF	World Health Organisation Quality of Life Assessment

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CHAPTER 1: INTRODUCTION

“Cerebral Palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations. These disorders are attributed to non-progressive disturbances that occurred in the developing fetal or infant’s brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy and by secondary musculoskeletal problems.” (Rosenbaum *et al.,* 2007:9). When a child is diagnosed with CP, the whole family becomes involved. Majnemer *et a*l, (2012) states that the functioning of a family is seen as a fundamental environmental factor that influences the child's health and functioning. It is the factors inherent in caring for a child with CP that need to be managed as it is a permanent condition that will affect the family in the long term.

Stress can be described as the balance between external environmental factors and the ability to handle these factors and occurs when the external factors outweigh the ability to handle them (Eicher & Batshaw 1993; Blacher 1984). Parenting a child is somewhat stressful for any parent (Abidin 1995). Many factors are involved in determining what causes parental stress. The characteristics of the caregiver and child, the shared history between the two of them, social and economic factors as well as the cultural context will have an effect on the degree of stress (Raina et al., 2005). Parental stress has an impact on the relationship with the child and it can be detrimental to the child's development and well-being (Rodriguez & Green, 1997). It has been shown that parenting a child with CP is more stressful and has a negative impact on parents’ quality of life (QoL) than caring for a child without a disability (Abidin 1995; Ong *et al.,* 1998; Parkes *et al*., 2011; Rentinck *et al.,* 2007; Pousada *et al.,* 2013; Brehaut *et al.*, 2004; Park *et al*.. 2012; Butcher *et al*., 2008; Dehghan *et al*., 2014; Hammond *et al.*, 2014; Guillamón *et al*., 2013; Basaran *et al*., 2013). Conflicting results have been found

regarding the predetermining factors causing stress in parents of children with CP. In some studies the level of severity of CP has been found to affect stress levels (Lach *et al*., 2009; L. Ong *et al.,* 1998; Plant & Sanders 2007) but in other studies the results were not significant (Butcher *et al.,* 2008; Raina *et al*., 2005; Dehghan *et al*., 2014; Parkes *et al*., 2011; Magill-Evans *et al.,* 2001; Rentinck *et l.*, 2007). Child behaviour and cognitive problems have been found to be more consistent in causing stress and poor quality of life among caregivers (Pousada *et al.,* 2013). A few other factors that have been associated with increased stress levels include poor social support and lower levels of education of the caregiver (Ong *et al*., 1998). The Parenting Stress Index – Short form (PSI-SF) was designed to identify parent-child systems that are under stress. It includes 36 items which are divided into three sub-scales: parental distress, parent-child dysfunctional interaction and difficult child.

Ching-Fang Lee (2009) showed that parenting stress and QoL are related. A simple definition of QoL is “an overall assessment of well-being across various domains” (Bjornson & McLaughlin, 2001). These domains include health, emotional, cognitive and social well-being (Vila *et al*., 2003). Caregivers of children with CP have been found to have lower levels of QoL than the general population (Guillamón *et al*., 2013). As Ching-Fang Lee (2009) mentioned that parenting stress and QoL are interrelated, it can be assumed that if you decrease stress then QoL will improve. The Paediatric Quality of Life – family impact module (PedsQL^{TM} - FIM) questionnaire is composed of 36 items compromising eight dimensions. It gives a quantitative indicator of the caregiver's self-reported health-related quality of life (HRQoL) and how the family functions due to their child's health (Varni *et al.,* 2004). One domain of QoL and stress is social support. This can be addressed by forming a support group of caregivers of children with CP. The impact of group dynamics is known to have an influence on social support (Forsyth *et al.*, 2006).

Social support is but only one way of improving QoL and decreasing stress levels.

Caregiver knowledge of CP has been found to be inadequate (Karande *et al.*, 2008) and caregivers want information and counselling regarding their child's condition (Sen & Yurtsever 2007). Lower levels of education have also been shown to increase levels of stress (Ong *et al.,* 1998). Another key component in combating low levels of QoL and high levels of stress is by addressing self-efficacy. Self-efficacy can be explained as the "sense of competence and personal control over the care situation" (Guillamón *et al*., 2013:1580). By addressing self-efficacy one can empower caregivers of children with CP which will have a positive effect on QoL and stress (Guillamón *et al*., 2013).

Hambisela is a training programme that was developed by the CP association of the Eastern Cape. It consists of seven modules designed around the theme of "Getting to know CP": Introduction, Evaluating your child, Positioning your child, Communication, Everyday activities, Feeding your child and Play. The introduction teaches caregivers what CP is, the causes and how to identify it. A study completed in Turkey confirmed that caregiving activities such as feeding, dressing, bathing and carrying were among the difficulties experienced by caregivers with children with CP and this ultimately increased their stress levels (Sen & Yurtsever 2007). Hambisela addresses these issues by educating caregivers and providing alternative ways of carrying out these tasks. An added benefit of this programme is that it provides support to the caregivers due to the group dynamics of the programme. Hambisela was designed using groups of caregivers of children with CP to facilitate learning through personal experience.

Insufficient research has been published using educational interventions to see if something can be done about caregivers' high stress levels and low levels of QoL. Studies have been done to determine the level of knowledge on the condition, to determine what impact CP has on stress and QoL, as well as the efficacy of parenting interventions. However, few education interventions have been researched to determine if one can improve the caregivers' QoL and reduce their stress levels (Karande *et al.,* 2008; Whittingham *et al*., 2011).

Research Question

Does the Hambisela programme reduce stress levels and improve QoL of primary caregivers of children with CP?

Aim

To establish whether participation in the Hambisela programme will reduce the stress levels of primary caregivers of children with CP and whether it will improve their QoL.

Objectives

- To determine the change in primary caregivers' stress levels using the PSI-SF after participation in the Hambisela programme.
- To determine the change in primary caregivers QoL using the PedsQL™ – FIM questionnaire after participation in the Hambisela programme.
- To assess whether the child's age, primary caregivers' level of education, age and the level of severity of CP correlate with stress levels and QoL.

Significance of the study

Novak and Cusick (2006) stated that the family centred approach is the gold standard when treating children with cerebral palsy. Parents and primary caregivers have become an integral part in the treatment process. Many studies have proven that parents and primary caregivers of children with CP have higher levels of stress and poorer QoL than parents with typically developing children (Abidin, 1995; Ong *et al.*, 1998; Parkes *et al*., 2011; Pousada *et al*., 2013; Rentinck *et a*l., 2007). It has also been proven that the parents/primary caregiver's poor well-being can have a negative impact on the child's life (Rodriguez & Green 1997). Thus it is just as important to educate parents/primary caregivers and to provide them with support. Hambisela aims to educate parents/primary caregivers with respect to their child's condition, it also provides a setting for social support. As physiotherapists it is important to include the whole family when treating a child with CP and educating and providing support for the parents/primary caregivers may provide a more holistic approach which will ultimately add to the child's well-being.

Conclusion

Despite all the research which shows parents with children with CP have high levels of stress and low levels of QoL, few educational interventions have been done about it so far. Thus the aim of this study is to assess whether or not an educational intervention programme, Hambisela, will make a difference to these parents' QoL and stress levels.

CHAPTER 2: LITERATURE REVIEW

This chapter will discuss definitions of cerebral palsy (CP), its associated problems and the context of CP in Africa. Stress and quality of life (QoL) will be discussed as well as what factors cause stress and influence QoL. Available evidence regarding parenting stress and QoL of caregivers with children with CP will be evaluated. Possible interventions will be reviewed.

Pubmed, CINAHL, SCOPUS, Medline and ScienceDirect were the resources used to source the literature. English articles dated from 2000 were searched for and in-text citations dating back from 1983 were used.

Keywords: Cerebral palsy, education, interventions, parenting stress, quality of life.

2.1 Cerebral Palsy in the context of Africa

It has been estimated that children living in low-income countries under the age of five have an almost 16 times higher chance of dying than children in higher-income countries (World Health Organisation 2013). A major cause of death is due to neonatal complications. CP is one of the known neonatal consequences (Wilmshurst 2014). CP has been defined primarily as a disorder of movement and posture. It is often accompanied by problems with communication, sensation, perception, behaviour, cognition and epilepsy. It is a non-progressive disorder meaning that the insult has already occurred and therefore the lesion will not progress further. The insult occurs in the developing brain (Bax *et al*., 2005). The lesion itself does not progress but secondary musculoskeletal changes that occur are not static (Pruitt & Tsai 2009). Donald *et al.*, (2014) found that the leading causes of CP in Africa are kernicterus, neonatal infections and birth asphyxia. Malnutrition has been strongly associated with

fetal developmental complications and perinatal complications (Kerac *et al*., 2014). The exact prevalence of CP in low-income countries is unknown, however the estimated prevalence is expected to be 10 in 1000 births (Burton 2015).

People living in rural low-income areas are mostly concerned with surviving (Oakley & Marsden 1991). Thus basic needs such as food and water are the daily challenges that they face. Having a child with a disability adds to the challenges of living under these circumstances. Cultural contexts and beliefs make looking after children with disabilities complex. Some cultures believe that CP can be caused by witchcraft or that it could be a punishment from God (Olawale *et a*l., 2013). In Nigeria some Yoruba people believe that CP is caused by a curse or due to a punishment as a result of wrongdoings such as being involved in extramarital affairs (Hamzat & Mordi 2007).

A small study in South Africa found similar beliefs. They found that black South Africans perceive disability as a punishment for doing something wrong (Ross 2008). Disability is often seen as a curse which is triggered by angering the witches (Ross 2008). A qualitative pilot study in Gauteng, South Africa found that the people believe that eating or drinking incorrectly or being hit during pregnancy is the cause of CP (Penn *et al*., 2010). Another study conducted in the Western Cape, South Africa also supported the findings that some Africans believe that CP is caused by witchcraft and ancestral spirits (Masasa *et al.*, 2014).

The situation in South Africa is further complicated by the demands of a large population and the limited resources available. Clinics, especially in the rural areas, lack therapists and doctors with expertise in the field of CP. Often these clinics run out of the medication needed to treat spasticity and epilepsy (Donald *et al*., 2014). Families tend to travel far and public transport is a great hindrance for disabled people (Masasa *et al.*, 2014). Families often lose income when having to visit clinics as it usually takes the

whole day. Special equipment used to make life easier is hard to come by and expensive (Donald *et al*., 2014).

Olawale *et al*., (2013) studied the psychological impact of CP on the family. Although the study was a cross-sectional single centre study with a small sample size, they gathered some insight into how African families deal with the burden of CP. They found that the knowledge of CP amongst parents was inadequate, that society blamed them for their child's disability and that they relied on religious coping mechanisms to deal with their children. Masasa *et al*., (2014) and Ross (2008) reported that parts of South Africa use religion and traditional healers to deal with disability. An older study conducted in Nigeria found that caring for a child with CP had a negative impact on the caregivers' health when compared to caregivers without children with disabilities (Hamzat & Mordi 2007).

CP, especially in Africa is a disorder that is made even more challenging due to poverty and cultural challenges. To add to these challenges, CP is not only a motor disorder. The disability is complex and is associated with additional health and social problems. This further adds to the burden that is placed on these parents. The associated problems with CP are vast and widespread and should be managed by a multi-disciplinary team. These problems can influence the overall function of the child, their QoL and their life expectancy (Pruitt & Tsai 2009).

2.2 Cerebral Palsy and its associated problems

CP is classified according to the motor abnormalities, the accompanying impairments, the anatomical and neuro-imaging findings and the causation and timing of the incident. The motor abnormalities are classified according to the predominant tone that is

present. The three subtypes are spasticity, dyskinesia (choreoathetosis and dystonia) and ataxia. The Gross Motor Function Classification System (GMFCS) is the most widely used scale to assess the severity in terms of functional mobility and activity limitation. It has five levels, with level V being the most severe. The upper limb abilities can be assessed using the Bimanual Fine Motor Function Scale (BFMFS) or the Manual Ability Classification System (MACS). Neither has been as thoroughly studied as the GMFCS. The presence of associated impairments and how they impact on function influence the daily living of a child with CP. The distribution of motor abnormalities, neuro-imaging findings and if the causative agent is present, all add to the classification of CP (Rosenbaum *et al*., 2007).

The associated impairments are widespread and at times can produce greater activity limitations than the actual primary motor impairment. Problems with feeding and gastrointestinal functioning can place a greater burden on the caregiver. Vomiting, poor sucking, swallowing difficulties and choking are the consequences of a child with feeding difficulties (Reilly & Skuse 1992). This can lead to respiratory complications such as aspiration as well as nutritional deficiencies and growth problems. Children with a GMFCS of level IV and V are at a significant risk of swallowing problems (Calis *et al*., 2008). Often children with feeding difficulties also tend to eat slower. Feeding a child with CP can take up to two hours at a time (McCann *et al*., 2012). Research has shown that mealtimes that on average take longer than 30 minutes are an indication of dysphagia (Arvedson 2013). Prolonged feeding times as well as correct positioning to limit the risk of aspiration place more strain on the caregivers (Gisel 2008). As a result of feeding difficulties, parents are often limited as to what food they can give their children and they tend to follow a puréed or liquid diet. This together with limited mobility and prolonged supine positioning can cause constipation, reflux and nutritional problems (Park *et al*., 2004).

Constipation can cause great discomfort. Between 26% to 90% of children with CP suffer from constipation (Park *et al*., 2004). It can cause pain, an increase in spasticity and it can influence their appetites. If constipation is not dealt with effectively it can cause more serious problems such as bowel perforations. It is therefore important to monitor their bowel habits and put a bowel programme into place if necessary (Pruitt & Tsai 2009). Constipation can also contribute to reflux. Up to 75% of children with CP suffer from reflux (Sullivan 2008). Reflux can lead to erosion of the teeth as well as chronic aspiration (O'Sullivan *et a*l., 2003). Correct positioning is important when trying to prevent reflux. Medication is an option to relieve reflux and if it is severe then certain surgical procedures may be necessary.

Nutrition is often a serious problem in children with CP. Generally it is found that they are undernourished, although there seems to be an increasing trend in overweight ambulant children (Rogozinski *et al.*, 2007). This is also cause for concern as children can lose their ability to walk or walk with greater difficulty if they become too heavy. Children that are undernourished and that have problems with feeding often do well when fed via an enteric tube (Sullivan *et al*., 2005). Although, undergoing surgery places the child at risk. Certain complications such as fistula's and perforations can occur during surgery. Anaesthesia is also associated with risks such as respiratory depression and cardiovascular collapse (Sullivan *et al*., 2005).

CP is strongly associated with problems with vision, hearing and cognition. Visual problems can range from myopia to cerebral visual impairment (CVI). Poor vision can limit or prevent other skills from developing. Children may need to be assessed by an ophthalmologist to assist with visual management (Jones *et al.*, 2007). Hearing problems occur in 30-40% of children with CP and this will ultimately have an influence on their ability to communicate (Jones *et al*., 2007). In order to manage this problem an audiologist should be consulted. Cognition is a difficult concept to analyse in children with CP. Formal tests are not reliable as the motor impairment can influence the

success of certain outcomes. Children with dysarthria and severe motor impairment are often unable to get their message across and this can be interpreted as poor cognition (Fennell & Dikel 2001).

Another associated impairment with CP which can cause tremendous distress in parents and the child, is pain. Pain is often underestimated, yet it is found in almost half the CP population (Dodge 2008). Pain is very difficult to assess, especially in a child who is non-verbal. It can be the result of muscle spasms, deformities, hip dislocations, urinary tract infections, reflux or constipation. Revealing the source of pain often requires an in depth history and examination and it can take long periods of time and many investigations before the source is found (Dodge 2008). Research has shown that chronic pain in children can cause stress, anxiety and depressive symptoms in parents (Palermo & Eccleston 2009; Eccleston *et al*., 2004; Jordan *et al.*, 2008).

Sleep can be interrupted by pain as well as the inability to change position independently. Nearly 50% of children with CP show problems with rapid eye movement (REM) sleep as well as waking up frequently just after falling asleep (Newman *et al.*, 2006). Sleeping problems don't only affect the child but have an impact on the parents as they need to attend to the child during the night. Sleep deprivation can add to the caregivers and child's distress (Mörelius & Hemmingsson 2013).

Drooling is another problem seen particularly in more severely affected children with CP. Drooling can be affected by the oral motor tone. Low oral motor tone causes poor lip closure which results in drooling (Pruitt & Tsai 2009). Abnormal oral reflexes cause poor dentation which also affects lip closure and exacerbates drooling (Pruitt & Tsai 2009; Arvedson 2013). Drooling has a negative social stigma which could limit social outings and have a significant impact on the family's functioning (Hockstein *et al.*, 2004). Excessive saliva production can cause aspiration if swallowing problems exist.

One of the most dangerous complications associated with CP and often a cause of death, is respiratory complications. Due to the anatomical abnormalities as well as the biomechanical and musculoskeletal changes that occur over time, lung function can be affected. This makes them more prone to aspiration pneumonia, atelectasis and permanent lung disorders such as bronchiectasis (Pruitt & Tsai 2009).

Epilepsy is seen in between 15-55% of children with CP (Peduzzi *et al*., 2006). Due to the different brain areas that can be damaged in CP, epilepsy presents differently in all children. It can be difficult to identify epilepsy in children with CP. The management mainly involves pharmacology. There is little evidence to suggest that altering children's diet such as placing them on the ketogenic diet actually works (Pruitt & Tsai 2009).

CP is a complex disorder associated with a number of problems such as motor, sensory, nutritional and neurological impairments as described in the sections above. Together with the permanent nature of the resultant disability, parents have a lot to deal with. Therapy, medication, additional caregiving needs, hospitalisations and special education all add to the demands of daily living (Glenn *et al*., 2009). These demands can accumulate and cause stress.

2.3 Stress

Stress is described as an imbalance between the external environment and internal ability to respond to the stressor (Raina *et al*., 2005; Blacher 1984). Lazarus & Folkman (1984) explain stress as a continuous relationship between the environment and a person. They emphasize the emotion experienced when a situation is perceived as ominous and the person is unable to cope. Stress is comprised of emotional, physiological and behavioural responses that affect well-being (Bornstein 2002).

2.3.1 Parental Stress

Parenting in itself is a stressful job (Abidin 1995; Bornstein 2002). Parenting involves coping with minor hassles of daily functioning within a family, whether it be coping with behaviour or misbehaviour during activities of daily living or managing to juggle the daily care-giving tasks and responsibilities of running a household. This is generally seen as a normal process which is common to all parents. It is when these daily hassles become regular and intensify that adverse effects take place. These adverse effects can influence the quality of parenting which eventually will have a detrimental effect on the well-being of the child (Bornstein 2002; Abidin 1992). Each individual perceives stress in a different way (Glenn *et al.*, 2009) and that is one reason why some parents cope better than others.

Factors contributing to parenting stress can be divided into three subsections: parental factors, child factors and family system factors (Bornstein 2002). Parental factors depend on the parent's personality, their mood, how they usually experience stress in general, and their opinions on how to raise a child. Factors such as the child's temperament, how demanding he or she is, how easily they can adapt to changes and how busy or distractible they are, can all influence parenting stress (Bornstein 2002). The family system factors include the relationships between the parents and with the siblings and depends on the co-parenting skills (Bornstein 2002).

Ostberg & Hagekull (2000) used a structural modelling approach to understand parenting stress. They found that parents were more stressed if they had a high workload, inadequate social support, were older, experienced negative life events, had more children and perceived the child to be "difficult or fussy". Krech & Johnston (1992) mention that children with sleeping problems, excessive crying and feeding issues can influence the parent in the way they perceive their child. Perceiving your child as "difficult" is a negative perception which leads to stress. Britner *et al*., (2003) and

Respler-Herman *et al.*, (2012) found that high parenting stress levels were associated with poor marital satisfaction and insufficient social support. Good marital quality buffered parenting stress and high social support correlated to low levels of parenting stress. The above mentioned studies support Bornstein's (2002) theory regarding the factors associated with parenting stress. As stated in the literature, parenting in itself is stressful (Bornstein 2002; Abidin 1995). If the child has developmental complications, the role of parenting could be more taxing.

2.3.2 Parental stress associated with disability

Parenting children with disabilities is considered significantly more stressful than parenting children without disabilities (Brehaut *et al*., 2014; Park *et al.*, 2012; Parkes *et al*., 2011; Butcher *et al.,* 2008). Having a child with a disability is like suffering a loss in the family. The dream of having an 'ideal' child has been shattered (Schmitke & Schlomann 2002). Parents experience feelings of guilt, shock, denial, anger and even shame (Sen & Yurtsever 2007). The acceptance and inclusion of a disabled child into the family takes time and parents go through a myriad of hardships which contributes to their stress and overall well-being.

The stress experienced when parenting a child with a disability ranges from acute stressors, to transitional stressors to chronic stressors (Failla & Jones 1991). The acute stressors are usually present at the initial diagnosis or when specific surgical procedures are necessary. The transitional stressors occur when timely expectations such as walking or starting school are not met. Another example of transitional stressors are birthdays. As each year comes, certain normal developmental milestones are expected and the lack thereof causes more stress. The chronic stressors include worrying about the future, meeting the financial demands and the stigma often associated with disability (Failla & Jones 1991). Such stressors build up over time and

can lead to dysfunctional parenting. The additional caregiving needs such as special education, medication and therapy add to the burden placed on parents with children with CP. There are a wide range of therapeutic management approaches available (Novak *et al*., 2013) (See Appendix I) and many are timely and costly (McCann *et al.,* 2012). It can be daunting for parents to choose the treatment that best suits their family's needs.

As reviewed above, stress is a build-up of factors which influences how the parent copes. Families living with a child with a disability experience a wide range of factors which contribute to this stress. A multivariate model, the double ABCX theory supports this notion. It describes stress as a result of the interaction of the stressor, the way families deal with it and what resources they have available to help them cope with stress (Singer & Irvin, cited in Singer *et al*., 2007). Parenting, family, social environmental and child factors are reviewed to assess what stressors affect caregivers of children with CP.

2.3.3 Parental factors that contribute to caregiver stress levels

2.3.3.1 Self-efficacy

Self-efficacy refers to one's feelings of competence and control of a situation. It is a personal resource that parents can use to assist with care-giving activities (Guillamón *et al.*, 2013). Self-efficacy can determine how one examines a situation, how one deals with negative thoughts and feelings that are stimulated by care-giving activities (Márquez-González *et al*., 2009). It is the ability to ask for respite when needed and to have confidence in daily care-giving tasks. Self-efficacy is used as a coping mechanism for caregiving (Guillamón *et al*., 2013). It goes hand in hand with cognitive and behavioural efforts when trying to cope with stressful situations (Lazarus & Folkman 1984). Taanila *et al*., (2002) reported, in a qualitative study of parents with children with

intellectual and/or physical disabilities, that caregivers who had higher self-efficacy levels searched for information about their child's disability and sought emotional and social support. Not only did they turn to their families for support but they also turned to other parents of children with disabilities. Raina *et al*., (2005) validates this and showed that psychological health was improved by mastering self-care activities which also improved self-esteem. Márquez-González *et al.*, (2009) found that caregivers with low levels of self-efficacy showed higher levels of depressive symptoms. Thus self-efficacy can have an impact on one's mental health.

2.3.3.2 Health

2.3.3.2.1 Mental Health

Mental health refers to one's psychological and emotional well-being. Guillamón *et al.*, (2013) assessed the impact of caring for a child with CP on the caregiver's mental health and QoL. To measure mental health they used three different measurement tools, the mental health section of the World Health Organisation Quality of Life Assessment (WHOQOL – BREF), Beck Depression Inventory-II (BDI-II) and the Trait Scale from the State Trait Anxiety Inventory (STAI-Trait). They found that the general mental health amongst caregivers of children with CP was poor. Anxiety levels were similar to the general population but there was a high prevalence of depressed mood. This finding is confirmed by the works of Basaran *et al.,* (2013) and Lach *et al*., (2009). A study conducted in Ireland found that parents who spent more time "caring" for their child with CP had poorer mental health (Byrne *et al*., 2010). An interesting finding, as parents are encouraged to participate in the overall management of their child and thus end up spending lots of time with their child. Supporting caregivers of children with CP will have an impact on their mental health. Mental health is linked to one's physical health.

2.3.3.2.2 Physical Health

Physical health in this context refers to the condition of one's body. Good physical health is just one sphere of the overall health system and refers to living well despite illness and disability (Saylor 2004). When caring for children with physical disabilities such as CP, one's physical health can be affected. Brehaut *et al*., (2004) found caregivers of children with CP had more chronic health conditions compared to the general population. Pain was also reported to be more frequent in the caregiver group. The systematic review reported by Pousada *et al.*, (2013) confirmed these results as well as a study by Dehghan *et al.*, (2014).

2.3.3.2.3 Burnout

Caring for children with disabilities such as CP can be exhausting (Mörelius & Hemmingsson 2013). Over and above the daily caretaking tasks, children with disabilities experience greater sleeping problems than children without disabilities (Wright *et al*., 2006). Sleeping problems may be related to the actual diagnosis, such as the inability to turn in bed, seizures, breathing problems, pain and incontinence (Wright *et al*., 2006). Parents thus wake frequently at night to care for their children. Sleep deprivation was associated with poor health and psychological exhaustion in a study conducted by Mörelius & Hemmingsson (2013). Three hundred and seventy five children with disabilities were recruited, 47% woke frequently and needed night-time attention. They also found that unlike sleep problems in healthy children, children with disabilities' sleep patterns do not improve with age. This constant sleep deprivation over many years contributes to psychological exhaustion (Mörelius & Hemmingsson 2013).

Caregivers, after spending day in and day out with their children who require assistance with most activities of daily living can experience feelings such as exhaustion, being overextended and have feelings of uncaringness towards their children (Chiou & Hsieh 2008). Basaran *et al*., (2013) confirm this. They used the Maslach Burnout Inventory (MBI) and found that caregivers of children with CP had significantly higher MBI scores than their control group. Daily activities and sleeping problems are not the only contributing factors to parental stress, family and social environmental factors also play a role (Parkes *et al.*, 2011).

2.3.4 Family and social environmental factors

2.3.4.1 Social support

Social support as a factor influencing stress and well-being has been well researched over the years (Skok *et al*., 2006; Raina *et al.*, 2005; Guillamón *et al*., 2013; Pousada *et al*., 2013; Shilling *et al*., 2013). Social support has an impact on well-being in a direct as well as indirect way when dealing with stress. It can promote general well-being by providing a sense of belonging and improving one's self-worth regardless of stress. On the other hand social support can buffer the effects of stress by providing a solution or minimising the impact of the problem (Skok *et al.*, 2006).

Isa *et al*., (2013) studied the impact of children with disabilities on parent HRQoL and family functioning in Kelantan, Malaysia. Malay caregivers coped better than previously perceived, however, their QoL scores were still low. They have limited services and facilities for people with disabilities but they rely on religious coping strategies to assist with the adaptation of living with a child with a disability. These results cannot be generalised due to the lack of a control group as well as different social cultural aspects.

A study conducted in Turkey compared 143 caregivers of children with CP with 60 caregivers of typically developing children. The aim was to compare QoL, mental health and burnout between these two groups. They found that QoL was affected in all domains except for the relationship domain of the Turkish form of the WHOQOL-BREF. They found that their sample was not affected socially. They attributed their finding to the cultural lifestyle in Turkey which has strong family values and solid neighbourhood relationships that contributes to better social outcomes (Basaran *et al.,* 2013).

Guillamón *et al*., (2013) assessed social support by using the Coping Health Inventory for Parents (CHIP). This scale examines social support with the inclusion of family integration and communication with the healthcare team. Their results suggest that caregivers with higher social support had better mental health outcomes. Their sample size was however small and thus the findings cannot be generalised. Sen & Yurtsever (2007) found that 71,8% of their sample (mothers of 103 children with disabilities) wanted emotional support. More than half of the sample received some support from family members but many felt that this was insufficient. Support from professionals was requested to help with their stress.

Shilling *et al.*, (2013) conducted a systematic review of qualitative and quantitative studies assessing social support. The qualitative results provided consistent findings of the benefits of social support in combatting stress. However the quantitative findings were inconsistent. Generally the results were in favour of social support but strong quantitative evidence supporting the benefits of social support is lacking. Whether this is due to the different ways outcomes have been measured or not, further high quality research is needed. Nonetheless, Pousada *et al.,* (2013) reviewed 46 articles and found that low social support had a definite link to increased stress levels. The perception of support and the need for social support is experienced differently by all cultures. However, the impact that finances has on stress affects all cultures.

2.3.4.2 Financial impact

Finances can be an added burden on families with children with CP (Majnemer *et al*., 2012). Parents are often forced to stop working to take care of their child. This means that there is less income available. The associated impairments of CP often add to the financial strain. Medications, therapies, hospital admissions, special diets and education are examples of financial responsibilities (Sen & Yurtsever 2007; Brehaut *et al.*, 2004). Some families live very far from any services and occasionally need to hire specific cars to assist with transport. These visits can take the whole day which could indicate a loss of income (Nimbalkar *et al*., 2014). Forty nine percent of the families with children with CP investigated by Sen & Yurtsever (2007) were found to have financial difficulties. Twenty nine percent of them received financial support from close family members. If financial strain is apparent then everyone in the family needs to make sacrifices. This may cause conflict within the family, adding to the parental stress (Sen & Yurtsever 2007). Developing countries in Africa have a higher prevalence of CP than the developed countries in Europe and the United States (Donald *et al*., 2014). The poverty in developing countries can add to the perinatal complications such as neonatal infections and birth asphyxia, which can result in CP (Donald *et al*., 2014). These families already live in poor circumstances and being burdened by a child with CP creates further financial strain.

2.3.4.3 Environmental factors

The environment plays a huge role in everyday life. Stress due to the environment can be influenced either positively or negatively, depending on the circumstances. Maart *et al*., (2007) reported on the environmental barriers found amongst rural and urban disabled people in South Africa. They found that factors such as accessibility in homes, transport and facilities were major barriers especially amongst those living in urban

areas. Urban areas were described as more challenging as people with disabilities struggled with stairs, escalators and uneven terrain. However, the sample was derived from only the Western and Eastern Cape and convenience sampling was used. It is therefore impossible to generalise this information but it does give insight into what possible environmental factors could add to stress. Even in Europe where a formal public transport system exists, people with disabilities complain about public transport. Many European countries are able to provide families with alternative transport such as special cars to accommodate the disability. In Sweden the Government adapts houses specifically to the needs required (McManus *et al.*, 2006).

2.3.5 Child factors

2.3.5.1 Severity of disability

The severity of CP can be expressed by using the GMFCS. This scale is divided into five levels. The levels are graded according to the motor ability of the children i.e. walking, sitting, and initiating spontaneous movement. The quality of movement is not assessed but rather what the child can do at their particular age (Palisano *et al*., 1997). This scale is used regularly in this field of interest (Dambi *et al*., 2015; Yilmaz *et al.*, 2013; Skok *et al*., 2006; Park *et al*., 2012; Raina *et al*., 2005; Basaran *et al.*, 2013; Parkes *et al*., 2011)

Brehaut *et al*., (2014) found that caring for a child with CP demands more time spent with the child, this results in less time available for the caregivers themselves. The children's independent self-care tasks are limited due to the impact of the physical and intellectual disability. The higher the GMFCS level the more time the parent requires to take care of the daily tasks, as these children are more dependent on their parents. In this study they found that these demands influence the parent's well-being. This is supported by studies that depict that the more dependent the child is on the caregiver

the more stressful parenting is (Ong *et al.*, 1998; Plant & Sanders 2007). Other studies find no correlation between level of severity and stress *(*Butche*r et al., 2008; R*aina *et al*., 2005; Dehghan *et al.*, 2014). Parkes *et al*.,(2011) conducted a cross-sectional survey in nine different regions in Europe. Their population consisted of 818 parents of children with CP. They found no significant correlation between gross motor impairments and stress. They did find that children with intellectual problems, communication difficulties and pain had a significant impact on parent stress.

2.3.5.2 Behaviour, intellectual impairments and communication impairments

Many studies have found that problems with behaviour in children with CP contribute to parenting stress (Plant & Sanders 2007; Butcher *et al.*, 2008; Majnemer *et al*., 2012; Raina *et al.*, 2005). One tool used to assess behaviour is the Developmental Behaviour Checklist (DBC). Part of this checklist uses 6 subscales to assess behaviour. They look at disruptive behaviour, communication and anxiety disturbances, self-absorption, anti-social behaviour, depression and social relations (Taffe *et al.,* 2007).

Intellectual disabilities are associated with poor behaviour and poor communication (Parkes *et al*., 2011). Parent's stress levels increase when their children behave out of the norm. Banging of the head, shouting and repetitive behaviour are examples of poor social behaviour. Understanding and expressing are the two main branches of communication. Children with intellectual disabilities struggle with the interpretation of a message and children with CP can struggle with expressing themselves due to motor inabilities or they may struggle with the comprehension of a message.

The above factors contribute to caregiving stress. Measuring stress is important to determine a baseline of stress and to measure change in stress. Various tools have

been used to assess parenting stress. The Swedish Parenthood Stress Questionnaire (SPSQ) and The Nijmeegse Ouderlijke Stress Index (NOSI) are both derived from aspects of the Parenting Stress Index (PSI) (Ostberg *et al.*, 1997; de Brock *et al.*, 1992). Both tools were adjusted for the Swedish and Dutch population respectively. The Perceived Stress Scale (PSS) contains 14 items and assesses how stress causes people to feel overloaded, uncontrollable and unpredictable (Cohen *et al.*, 1983). The PSS was designed to be used for any population. A popular outcome measure used in many studies with children with disabilities, is the Parenting Stress Index (PSI) or the Parenting Stress Index – Short Form (PSI-SF) (Park *et al*., 2012; Majnemer *et al.*, 2012; Butcher *et al.*, 2008; Parkes *et al.*, 2011; Lee *et al*., 2009).

2.3.6 Parenting Stress Index

The PSI was developed to investigate the factors influencing parenting practices. It consists of 120 items which are divided into parent focused and child focused sections. The Parent Domain consists of seven subscales: Depression, Attachment, Role Restriction, Sense of Competence, Social Isolation, Relationship with Spouse and Parental Health. The Child Domain consists of 6 subscales: Adaptability, Acceptability, Demandingness, Mood, Distractibility/Hyperactivity, and Reinforces Parent. A further 19 items measure general life stressors. Although the PSI is a very comprehensive assessment, it has been found to be too time consuming (Abidin 1995). Thus the PSI-SF was developed. A factor analysis demonstrated three domains associated with the parent-child system, namely the parent, the child and their interactions. Hence, the tool was divided into three subscales. The ‘parent distress’ subscale assesses the stress that is caused by caring for the child, how the parent perceives their ability to parent and their perception of social support and depressed mood. The ‘parent-child dysfunctional interaction’ subscale assesses to what degree the child meets the parent’s expectations and how the relationship makes the parent feel. The ‘difficult child’ subscale assesses

the child's behavioural characteristics and the ease of managing their behaviour (Abidin 1995).

Abidin (1995) established reliability and validity of the PSI-SF. He found that the Total Stress Scores on the PSI correlated 0.94 to the PSI-SF total score. The subscales were also well correlated. Test retest reliability and internal consistency were demonstrated on 800 normal subjects. The psychometric properties of the PSI-SF were tested in a population of mostly African-American mothers with a low socio-economic status and the internal consistency and factor analysis remained high (Reitman *et al.*, 2002). This suggests that the PSI-SF can be used confidently among low socio-economic, non-Caucasian groups. In South Africa the PSI-SF has been translated into Sotho and Zulu and has been shown to have good test retest reliability (Potterton *et al.,* 2007).

Stress is not the only aspect that is affected by parenting children with disabilities. The impact of disability on caregivers has an influence on the QoL of the caregivers (Dehghan *et al.,* 2014; Hammond *et al*., 2014; Basaran *et al.,* 2013; Pousada *et al.,* 2013; Guillamón *et al.,* 2013).

2.4 Quality of life

A simple definition of QoL is "an overall assessment of well-being across various broad domains" (Bjornson & McLaughlin p183, 2001). These domains include health, emotional, cognitive and social well-being (Vila *et al*., 2003). The health domain is concerned with physical functioning: feeling tired, having headaches or body aches, stomach aches or feeling weak. Emotional functioning includes anxiety, sadness, and anger, feeling despondent or frustrated. Cognitive functioning involves thinking abilities, attention and memory. Social functioning addresses feelings of isolation, support

systems and socialising (Varni *et al.*, 2004). There is a vast amount of literature that shows that the QoL of caregivers of children with CP is poorer than the general population (Dehghan *et al.,* 2014; Hammond *et al.*, 2014; Basaran *et al.*, 2013; Pousada *et al*., 2013; Guillamón *et al.*, 2013). Lee *et al*., (2009) found that poor QoL is directly related to parenting stress. The factors causing stress that are discussed above also have an impact on QoL.

The type of disability was related to subjective well-being in a study conducted by Hammond *et al.*, (2014). They found that caregivers who care for people with multiple disabilities and intellectual disabilities had significantly lower subjective well-being. Isa *et al.*, (2013) confirmed that the more complex the disability the poorer the QoL. Behaviour problems, cognitive deficiencies, poor self-efficacy and isolation all contribute to poor QoL in caregivers of children with CP (Pousada *et al.*, 2013).

2.4.1 Quality of life instruments

Many QoL instruments are used to evaluate the impact of chronic conditions. The Impact on Family Scale (IFS) and the Child Health Questionnaire (CHQ) are frequently used to assess the impact a chronic disease can have on the rest of the family. The IFS measures the negative impact a paediatric health condition can have on the social and family systems. It gives insight into the psychological and social consequences a child's chronic condition can have on the family (Stein & Jessop 2003). It is however only one-dimensional. The CHQ measures the child's HRQoL and whether the child's health and behaviour influences family activities and dynamics. It also identifies the impact the child's health has on the parents worry or concern. Due to its ceiling effects in four subscales it has limited use in testing effects of interventions (Landgraf *et al*., 1996).

The Paediatric Quality of Life - Family Impact Module (PedsQL™ - FIM) is a multidimensional questionnaire. It assesses the parents' HRQoL and family functioning. It is able to detect numerous ways that a parent can be affected by their child's chronic condition. The internal consistency reliability was demonstrated for the PedsQL™ - FIM. The total scale score resulted in a 0.97. The test was able to distinguish between families with children in a long-term care facility and children who lived at home. Thus the PedsQL™ – FIM can be used for families with children with complex chronic health conditions (Varni *et al*., 2004). Medrano *et al*., (2013) assessed the psychometric properties of the PedsQL™ – FIM in a community sample. The results demonstrated that the PedsQL™ - FIM is a valid and reliable measure of family functioning and HRQoL. Thus this tool can be used in comparative studies.

Most studies examining stress and QoL in parents with children with disabilities recommend that interventions should be aimed at focusing on the parents and not only on the child (Basaran *et al*., 2013; Brehaut *et al*., 2004; Lach *et al*., 2009; Hammond *et al.*, 2014; Park *et al*., 2012; Plant & Sanders 2007). The literature needs to be explored to ascertain what evidence based practices are available to target interventions for parents with children with disabilities.

2.5 Interventions to reduce parenting stress

A systematic review of qualitative and quantitative data assessed the role of support in parents of children with chronic disabilities. Qualitative data reveals that peer support enhances a shared social identity, assists in supporting others, allows for personal growth and that people learn from the experience of others. The quantitative data reported positive effects of peer support on psychological health but this was not consistent. (Shilling *et al.,* 2013). The literature needs to be reviewed in order to see what evidence based interventions are available.

Mindfulness Based Stress Reduction (MBSR) is an intervention that uses meditation and discussions to enhance coping mechanisms and to help accept things the way they are. It includes breathing techniques and yoga movements to improve the awareness of one's body (Bazzano *et al*., 2015). A study used parents of 66 children with developmental disabilities to assess the impact the MBSR programme would have on parental stress. The sample was self-selected, predominantly female and married. Perceived and parental stress were significantly reduced. This shows that this type of programme can make a difference in their lives, however this programme needs to be tested amongst different cultural and socioeconomic populations to determine the success in a diverse population (Bazzano *et al.*, 2015). Benn *et al*., (2012) further supports that mindfulness reduces stress. They performed a randomised controlled trial (RCT) using mindfulness for parents with children with special needs and similar results were obtained. However, their sample did not include any children with CP.

Problem behaviour has been reported to be one of the greatest causes of parental stress (Bailey *et al.,* 2007; Plant & Sanders 2007; Butcher *et al.*, 2008; Majnemer *et al*., 2012; Raina *et al.*, 2005). Interventions for parenting stress are usually aimed at educating parents on social learning and coping skills using the cognitive behaviour approach. Cognitive behavioural therapy (CBT) has been used successfully in parents with children with intellectual disabilities to reduce levels of stress (Hastings & Beck 2004). Parent-led support networks are also recommended as a method of reducing stress (Hastings & Beck 2004). Singer *et al.*, (2007) conducted a meta-analysis to determine which interventions are evidence-based. Interventions using CBT, Family System Interventions (FSI), Multiple Component Treatments (MCT) and Behavioural Parent Training (BPT) were assessed. MCT's generally consisted of behavioural approaches, some form of education and a type of therapy for the child. Most of the MCT's were directed at children with Autism. They found that MCT's were the most effective in reducing stress levels, followed by BPT and CBT methods. This is true at least in the short term for middle class White American mothers. Similar research done in poverty stricken areas amongst diverse cultures is uncommon. Behavioural

interventions were further supported by a systematic review that assessed what interventions are available to target parenting stress. No RCT's were found. The three studies that were found suggest that parenting interventions focusing on parenting skills can make a difference to the child's behaviour (Whittingham *et al*., 2011).

A group music therapy programme was developed to assess the positive outcomes achieved by such a programme. Parenting stress itself was not measured but rather the impact of stress on the family. Significant improvements in parental mental health, positive parenting and key developmental areas were achieved (Williams *et al.*, 2012).

Karande *et al*., (2008) implemented a once off educational programme educating caregivers of children with CP about what CP is. They found that caregiver's knowledge of CP was inadequate and that with one session a significant improvement of their knowledge could be obtained. They mentioned that more sessions would be beneficial to educate the parents on more aspects of CP. Stress was however not an outcome assessed. No interventions known to date have used educating parents of children with CP with the aim of reducing stress. A study conducted in 2006, used an intervention to reduce stress in parents with premature infants. This population based RCT found significant reductions in parental stress using the PSI. The Mother-Infant Transaction Programme (MITP) was the intervention used. This programme has an element of educating the parents on how to handle premature babies (Kaaresen *et al*., 2006). A further study has shown that parents would like to be educated regarding CP to assist with the caregiving tasks and to cope better with the challenges that caring for these children presents (Olawale *et al*., 2013).

The Family Centred Approach (FCA) has been reported as the gold standard of treatment when working with children with CP (Novak & Cusick 2006). This approach takes a look at the child, the child's parents and siblings and their entire situation. The

professional and the family work together and the family chooses the goals. One part of the FCA is to address the needs of the parents (Caro & Derevensky 1991; King et al., 1999). Studies have found that the FCA reduces parents' anxiety, improves their mood and overall participation in the management of their children (Moxley-Haegert & Serbin 1983; King *et al.*, 1999; Caro & Derevensky 1991). Education is one field that forms part of this approach. However parental stress was not used as an outcome measure when this research was conducted.

The literature shows many interventions used to reduce stress and improve QoL in parents with children with disabilities but no education programmes aimed at educating parents on what CP is and teaching them how to handle their children has been used to reduce stress levels or to improve QoL.

2.6 Conclusion

The literature has shown definite high levels of stress and poorer QoL in caregivers with children with CP. A significant number of these studies recommend that interventions targeting education, social support and coping skills for caregivers should be made available to this population, all in an attempt to reduce the parent's stress and improve their QoL (Hammond *et al.*, 2014; Basaran *et al.,* 2013; Pousada *et al*., 2013; Krstic & Oros 2012).

CHAPTER 3: METHODOLOGY

This chapter will discuss the methodology of the study. It will focus on the setting, ethical considerations, study design and sample, the measuring instruments, procedure and data analysis.

3.1 Setting

The Hambisela training took place in Mamelodi at a venue suitable to all participants. Mamelodi is a rural township northeast of Pretoria, South Africa. This township is an under-resourced area with challenges arising from inaccessible health care, and a high prevalence of malnutrition and poverty.

3.2 Ethical considerations

Ethics for this study was obtained from the Human Research Ethics Committee of the University of the Witwatersrand (M140708). Participants were informed about the study and signed an informed consent form agreeing to participate in the study. Permission was granted from the Baby Therapy Centre to approach their patients.

3.3 Study Design

This study was a quasi-experimental pre-test – post-test design. A pilot study was decided upon to investigate the feasibility of conducting such research throughout the country.

3.4 Sample

A sample of convenience was used. Snowball sampling was applied to identify possible participants. The sample commenced with the parents/primary caregivers from the Baby Therapy Centre's outreach programme in Mamelodi and then it extended to people they knew and referred. The outreach programme provides therapy to children with disabilities. The parents of children with cerebral palsy (CP) were identified and recruited. Those parents then contacted other parents who fit the criteria of the study. A minimum sample size of 16 was decided upon, as at least eight participants and no more than 10 participants are required to run the Hambisela programme. Two eight-week programmes were decided upon. Eighteen participants from Mamelodi signed the consent form and agreed to participate in the study.

3.4.1 Inclusion criteria

The following inclusion criteria were used:

- Participants who were literate in reading and writing in English
- Participants who were the primary caregiver of a child with CP between the ages of six months and 12 years old.
- Participants who came from the Mamelodi area and were available for the training.

3.4.2 Exclusion criteria

The following exclusion criteria were used:

- Participants who completed the Hambisela training previously.

- Participants who belonged to a support group during the study period as this may have affected their levels of stress which would have affected the outcome of the study.

3.5 Measuring Instruments

3.5.1 PedsQL – FIM (Appendix IV)

The Paediatric Quality of Life – Family Impact Module (PedsQL^{TM} – FIM) was used to measure quality of life (QoL). This tool measures parent self-reported physical, emotional, social, and cognitive functioning, communication, and worry. The Module also measures parent-reported family daily activities and family relationships. The Module reflects the overall QoL. It consists of 36 items divided into eight categories. The items are scored on a 5-point Likert scale from 0 (Never) to 4 (Almost always) (refer to Appendix IV). The scores are then converted to a 0 to 100 scale. The scores were calculated before and after the intervention to determine if any change in QoL was observed. The higher the score the better the QoL. There are a further two sections, the Parent Health Related Quality of Life Summary score and the Family Functioning Summary score. These scores were also compared before and after the intervention. If more than 50% of a section was missing, the scores could not be calculated for that section. The tool was used to determine firstly the QoL of the caregivers and secondly to determine if there was a change in QoL after completing the Hambisela Programme.

3.5.2 Parent Stress Index – Short form (Appendix V)

Abidin (1995) designed the 36 item Parenting Stress Index – Short Form (PSI-SF). This is a shortened version of the 120 item Parent Stress Index (PSI) developed by Abidin in 1985. The PSI-SF was designed as a briefer measure of parenting stress and was

divided into three subscales. The Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI) and the Difficult Child (DC). Each subscale consists of 12 statements. The respondents were requested to respond on a Likert scale from one (strongly agree) to five (strongly disagree). The scores were then added together to form a score for each subscale. The three subscale scores were then added together to give a Total Stress Score. If their score is above the 90th percentile it is indicative that they are experiencing clinically significant levels of stress and they should be referred for further assistance. Items 1, 2, 3, 7, 8, 9 and 11 are added together to give a score for the Defensive Responding (DR) section. This section was designed to interpret if the respondent answered the statements with the intention to minimize problems with the parent-child relationship. If the score was 10 or below this showed an indication that the parent had few, if any parenting stressors, or the parent is disengaged from the parenting role or the parent is very competent in their role as parents and has excellent relationships with others.

The PSI-SF has been translated into Zulu and Sotho and it has good test-retest reliability (.84 for the Total Stress Scores and .68 to .85 for subscale scores) (Abidin 1995). It has not been validated in a South African population, however it has been previously used in a South African population and been found to be reliable (Potterton *et al*., 2007; Pugin 2007).

The PSI was completed before and after the intervention to determine the caregivers' initial stress levels and to determine any changes in stress levels after completing the Hambisela programme.

3.5.3 PedsQL Information Form (Appendix VI)

This Paediatric Quality of Life (PedsQL) demographic questionnaire was modified to include the level of severity of the child using the Gross Motor Function Classification System (GMFCS). The PedsQL Information Form gives information regarding their socioeconomic status, marital status, parent and child age, relationship and information of the child's health over the last 12 months.

3.5.4 Gross Motor Function Classification System (Appendix III)

Palisano *et al.*, (1997) developed the GMFCS to determine the level of severity of gross motor function in children with CP. It has been found to be valid and reliable and has been used widely in research (the high correlation (r=-.91) between GMFCS levels and Gross Motor Function Measure (GMFM) scores show construct validity) (Palisano et al., 2000). The classification is based on the child's self-initiated movement ability. The levels are differentiated by the child's functional limitations and the need for assistive devices. Quality of movement is not assessed using this scale. Level I demonstrates high functional levels and level V demonstrates low functional levels with much assistance needed.

3.6 Procedure

Identified participants were telephoned and invited to participate in the study. Participants met at the venue before the Hambisela training commenced and the benefits of Hambisela and the training requirements were explained. Participants were given an information form (Appendix VII) explaining the process. They completed the informed consent form (Appendix VIII) and participated in the programme that ran for

three hours, once a week for eight consecutive sessions. Participants brought their child along for the initial meeting so that the GMFCS level could be determined by a qualified physiotherapist.

Once participants signed consent the programme commenced. At the first session participants completed the following forms in English:

- PedsQL Information Form
- the PedsQL™ - FIM questionnaire and
- the PSI-SF

A research assistant helped the participants to complete the forms. The research assistant was trained prior to this session in order to be familiar with the questionnaires and procedure. The questionnaires remained anonymous and were coded with a number to ensure that the pre- and post- questionnaires of the same participant could be compared. The questionnaires were self-administered and took less than 45 minutes to complete. The researcher was not part of this process to avoid bias.

The Hambisela training took place over eight consecutive weeks. Each session was conducted in English and was approximately three hours long with a refreshment break half way through each session. The final session included a graduation ceremony. The sessions were group driven and participants were invited to take the lead and share experiences and advice. After each session a manual was given to each participant summarising the topic discussed. Table 3.1 gives an overview of the Hambisela programme.

Table 3.1 Hambisela Programme Content

Week	Theme	Contents	Materials used
1	Introduction	Discusses the definition of CP and the causes of CP. It furthermore explains associated problems and how the brain influences movement and posture. Participants are provided with opportunities to share their experiences about how they found out their children had CP.	Videos, pictures and group discussions.
2	Development	Provides an explanation of normal development. This theme furthermore explains how a parent may identify whether their child is developing typically by using a development chart. Participants are provided with information about milestones that can be expected in their own children in the future. The participants are provided with group tasks about typical development.	Pictures and charts.
3	Positioning	Practical session that teaches the participant how to position their child as well as how one may show others to position their child optimally. Participants assume the positions themselves to feel what an uncomfortable position is and how to change it. Equipment to enhance positioning is discussed.	Pictures and practical demonstrations.
4	Communication	Provides participants with an understanding of communication and the importance thereof. Participants are informed about what to do to	Pictures, activities, practical

		assist their child to communicate. Various methods of communication are discussed and an emphasis is placed on finding other ways to communicate besides talking such as signing, using communication boards and reading body language.	demonstrations and group discussions.
5	Everyday Activities	Explains how participants may use everyday activities such as bathing to assist their child to develop optimally.	Role play, activities, group discussions.
6	Feeding	Provides participants with an understanding of the possible feeding difficulties that children with CP have. Caregivers of children who are mainly dependent for feeding, will learn to find alternative ways to make feeding easier and more enjoyable. Caregivers of children who are almost independent will learn ways to make their child feed independently. This theme is a practical session in which participants practice spoon feeding and cup drinking with partners in the group. The importance of positioning whilst feeding is highlighted.	Pictures, activities, practical demonstrations and group discussions.
7	Play	Explains the importance of play for a child's development and will provide a caregiver with ideas on how to use play to promote development of communication, movement, social and emotional skills and learning.	Role play, activities, group discussions.
8	Graduation	Participants graduate from the programme and in this session they practice what they	Practical application of

		have learnt on their children and give feedback regarding their experiences.	acquired skills and knowledge.

At the final session the participants were asked to complete the PedsQL^{TM} - FIM and PSI-SF questionnaire again and a certificate of attendance was awarded. Participants were asked to fill in an informal questionnaire to consider their feelings about the training.

Participants were messaged the day before each session to remind them of the following day's training session.

Anonymised data was captured using an Excel spread sheet and the results were analysed.

The PSI - SF has a Total Stress Score. If the score was above the 90th percentile, indicating clinically significant stress levels, the participants were referred for counselling to the Itsoseng Clinic in Mamelodi East where free counselling is available.

3.7 Data Analysis

This study is a pilot study and thus due to the small sample size non-parametric statistics were used. The Mann-Whitney U test was used to determine the change between pre-test and post-test stress levels and QoL. Descriptive statistics, using means and frequencies were used to analyse the demographic data. The Spearman's Rank correlation test was used to correlate the demographic data to stress levels and QoL. Excel was used to determine the statistics and the p-Value was set at 0.05 to determine statistical significance.

A qualitative branch was added after receiving the data from the participant's feedback. No formal qualitative analysis of the feedback forms was conducted. Themes were derived from the participants' answers and then grouped together.

3.8 Conclusion

This chapter discusses the methodology used to determine whether the Hambisela programme reduces parent's stress levels and improves their QoL. It describes the setting, sample, inclusion and exclusion criteria, measuring instruments, procedure and data analysis. These results will be discussed in the following chapter.

CHAPTER 4: RESULTS

This chapter will present the results obtained from the study. The participants' stress and quality of life (QoL) levels will be reviewed as well as the change in these variables before and after the Hambisela Programme. The demographic information, particularly the caregiver's age and level of education and the child's age and level of severity, will be correlated to the caregivers' stress levels and their QoL. The information will be displayed in tables and figures. Descriptive statistics were used to describe the demographic data.

4.1 Subjects

Eighteen participants consented to participate in the study. Sixteen participants completed the Hambisela training programme. Two participants dropped out. One dropped out as her child was hospitalised and one was unable to get leave from work. The programme was well attended with 84.6% of sessions attended. All the primary caregivers were the mothers of their children except for one participant who was the grandmother. A large majority of participants were unemployed (82.4%) and 61% were single. The demographic information of the caregivers obtained from the Paediatric Quality of Life (PedsQL) information form is represented in Table 4.1.

Table 4.1 Demographic information of the caregivers (n=18)

Variable	Percentage % (n)
Marital Status (n=18)	
Single	61 (11)
Married	16.6 (3)
Living with someone	22.2 (4)
Educational Level (n=16)	
6th grade or less	12.5 (2)
7th-9th grade or less	0
9th-12th grade or less	25 (4)
High school graduate	25 (4)
Some college or certification course	18.8 (3)
College Graduate	6.3 (1)
Graduate or Professional degree	12.5 (2)
Employed (n=17)	
Yes	17.6 (3)
No	82.4 (14)

Participants were all from the Mamelodi area and their mean age was 32.1 years (±5.6 years). Qualifications higher than a school graduate were seen in 37.5% of the caregivers and 82.4% were unemployed.

Table 4.2 displays the demographic information of the children completed in the PedsQL information form.

Table 4.2 Demographic information of the children (n=18)

Variable	**Percentage % (n)**
Hospitalisations over last 12 months (n=15)	
Yes	60 (9)
No	40 (6)
Emergency room visit over last 12 months (n=15)	
Yes	46.7 (7)
No	53.3 (8)
GMFCS level (n=18)	
I	16.7 (3)
II	5.6 (1)
III	0
IV	11.1 (2)
V	66.7 (12)
Child's age in years (n=18)	
0 – 2	27.8 (5)
3 – 5	55.6 (10)
6 – 8	16.7 (3)
Gender	
Male	66.7 (12)
Female	33.3 (6)

All children were diagnosed with cerebral palsy (CP). The children's mean age in months was 36.5 (±6). All the participants were of African race. A Gross Motor Function Classification System (GMFCS) level V was the most prevalent with 66.7% of children falling into this category.

4.2 Parenting Stress

Parenting stress was measured using the Parenting Stress Index – Short Form (PSI-SF) and the results were analysed using the Mann Whitney U Test.

Table 4.3 Parenting Stress Index – Short Form results (n= 15)

	Mean (±SD)		
Elements measured	**Before**	**After**	**p-Value**
Total Stress Score	104.4 (18.8)	102.8 (19.4)	0.7
Parental Dysfunction	36.6 (11.3)	36.1 (11.1)	0.9
Parent Child Dysfunctional Interaction	33.2 (6.1)	33.8 (6.2)	1
Difficult Child	35.1 (5.7)	34 (6.9)	0.7

No significant differences were found before and after the intervention in any of the stress categories (Table 4.3). The Total Stress Scores were exceptionally high in this population.

4.3 Parent's Quality of Life

Parent's QoL was assessed using the Paediatric Quality of Life – Family Impact Module (PedsQL^{TM}- FIM) and was analysed using the Mann Whitney U Test.

Table 4.4 Paediatric Quality of Life – Family Impact Module results (n=16)

	Mean		
Elements measured	**Before intervention**	**After intervention**	**p-Value**
Total Score	55.5 (24.1)	56.2 (17.3)	0.9
Parent HRQL Score	31 (13.5)	32.8 (11.1)	0.8
Family Function Score	56.7 (29.3)	51.3 (19.3)	0.4

No significant differences were found in any categories of the parent's QoL before and after the intervention (Table 4.4). The Total Score is low indicating a poor QoL in these participants.

4.4 Clinical significance of results

The Total Stress Score was compared for all parents before and after the intervention. Figure 4.1 shows that before the intervention 87% of participants had a Total Stress Score of above 90 indicating clinically significant levels of stress. After the intervention 67% of participants had a Total Stress Score of above 90 (Figure 4.1).

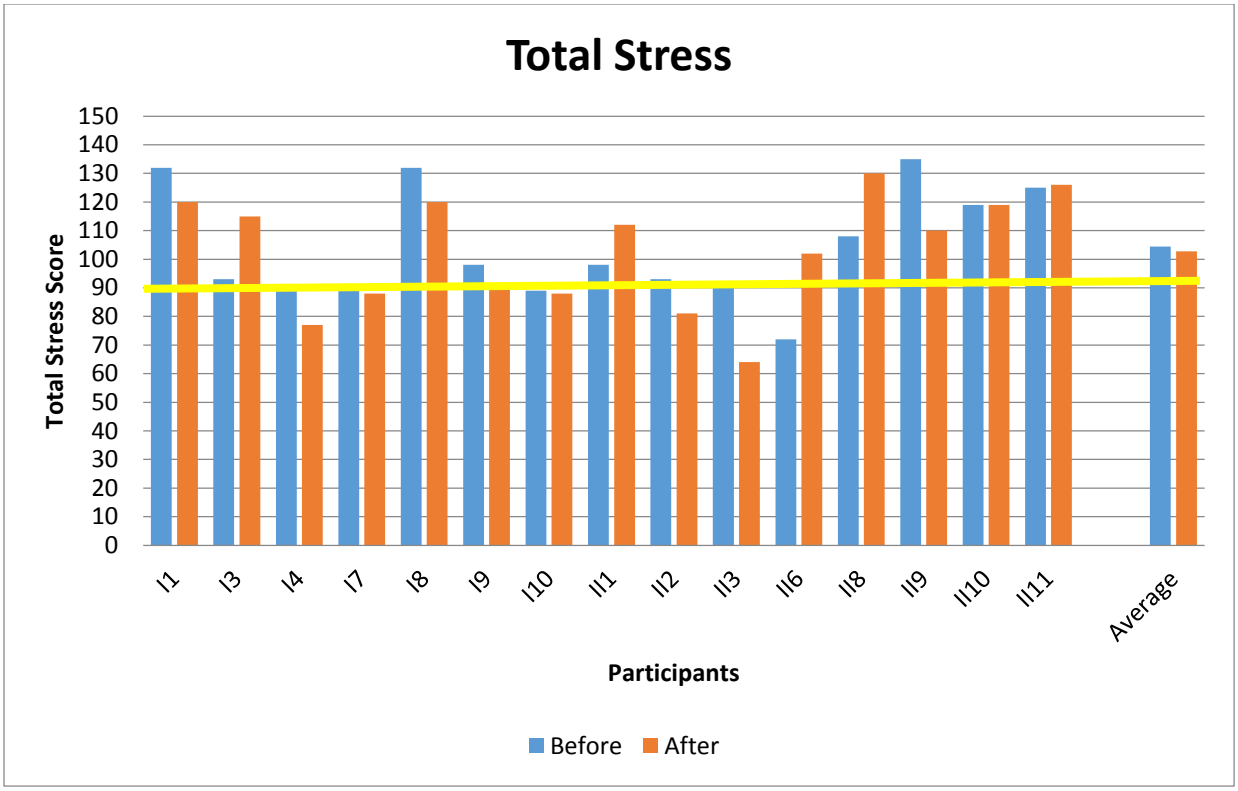


Figure 4. 1 Total Stress Score before and after the intervention

No statistical significance (p=0.7) was found in the Total Stress Score before and after the intervention. However clinically there was a decrease in stress to below the 90th percentile in 20% of participants.

4.5 Demographic variables and parenting stress

The relationship between the variables such as parenting stress, the caregiver's educational level and age and the child's age and level of severity were correlated using Spearman's rank correlation test. The results are shown in Table 4.5.

Table 4.5 Factors influencing parenting stress

Variables	R-value	P-value	Mean (SD)
Educational level	-0.5	0.03	-
Caregiver age (in years)	-0.1	0.8	32.1 (5.6)
Child's age (in months)	0.2	0.4	36.5 (6)
Level of severity	0.3	0.2	4 (1.5)

No correlations were found between the child's age, level of severity, participant's age and level of stress. A moderate negative correlation (r=-0.5) was found between the educational level and Total Stress Score, indicating that the higher educated the participants were the lower their stress levels were. This was found to be significant (p=0.03).

4.6 Demographic variables and parent's QoL

Table 4.6 Factors influencing parent's QoL

	R-value	P-value	Mean (SD)
Educational level	0.1	0.6	-
Caregiver age	-0.5	0.1	32.1 (5.6)
Child's age	0.2	0.4	36.5 (6)
Level of severity	-0.1	0.6	4 (1.5)

Table 4.6 shows that no correlation was found between parent's educational level, child's age, level of severity and parent's QoL. A moderate negative correlation (r= -0.5) was found between the caregiver's age and QoL. This indicates that the older the caregiver the poorer the QoL. This was not found to be statistically significant (p=0.1).

4.7 Qualitative comments received from the participants

On completion of the programme, participants commented on the effects of the programme. These comments were divided into themes. The themes are displayed in Table 4.7.

Table 4.7 Qualitative comments received from the participants

Theme	**Quotes**
Participants felt they gained knowledge about their children's condition	*"I learnt a lot of things…I learnt to position my son, to give my son attention, to communicate with him and to hold him correctly."* *"I learnt a lot from Hambisela….It did a lot for me…Now I can explain to anyone what is wrong with my child"* *"Hambisela meant everything you can think of…it helped me to understand my child more…it gave me knowledge, now I am more informed."* *"I came here not knowing what was wrong with my child, at the clinic they didn't tell me anything. Then I attended Hambisela and now I can tell you why he is like this, why he is slow to develop"* *"I learnt so much, things that I never knew… and that children with CP are like other children, you just have to help them so that they can try do things by themselves"*
Caregivers experienced an increase in self-efficacy	*"I am determined, I can conquer every situation that I come across with my child"* *"I learnt a lot…I learnt to accept my child like a normal child"* *"I know more about lots of things, positioning, playing with my kids and I am more confident"* *"Hambisela helped me to love my child and other CP children because now I understand all their challenges"*
Participants experienced an increase in self-	*"I am very happy to have been part of this group, I made lots of friends. The training made me realize that it is not only me that has problems with my child and I am a good mom to my*

esteem, they felt a sense of belonging	*child"* *"Hambisela taught me to look at my child in a different way, a better way"* *"No matter the challenges we come across every day, we can face them together and united as a whole"*

These comments reflect the positive effect that Hambisela had on the participants in this study.

4.8 Conclusion

The findings from this study show that the caregivers of children with CP from the Mamelodi area have clinically significant high levels of stress measured by the PSI-SF. No significant differences were found in their stress levels or QoL before and after the intervention. The only moderate correlation found between the variables and stress levels was the higher educated the caregivers were the lower their Total Stress Score. A moderate correlation was found between QoL and the caregiver's age. The older the caregiver was the poorer their QoL.

The implications of these findings as well as the limitations and recommendations are discussed in chapter five.

CHAPTER 5: DISCUSSION

This chapter will discuss the influence that the Hambisela Programme had on stress and quality of life (QoL) of caregivers of children with cerebral palsy (CP). It will also discuss how factors such as the child's age and level of severity as well as the parent's age and educational level, influence parenting stress and QoL. Previous research of a similar nature will be compared. The clinical implications will be highlighted and the limitations of the study will be mentioned. Further research recommendations will also be made.

5.1 Stress and Quality of Life

5.1.1 Parental Stress

No significant difference was found in stress levels before and after the intervention (p=0.7). A population of caregivers of healthy children with no neurological impairments, found a mean Total Stress Score of 62.6 (±15.6) amongst 87 parents (Respler-Herman *et al.* 2012). This shows that parenting in itself is stressful, let alone parenting a child with CP. In the current study a mean Total Stress Score of 104.4 (±18.8) was found amongst the participants prior to the intervention. This score is exceptionally high and falls above the 90th percentile. This score is high compared to other studies that have investigated parenting stress in populations of children with disabilities. Potterton *et al*., (2007) also found considerably high Total Stress Scores of 103.9 (±19.5) in a South African population of caregivers of HIV positive infants. A further two small pilot studies conducted in South Africa also tested the stress levels amongst parents with disabled children. Both studies found a mean Total Stress Score of 81 and 85.1 respectively (Haniff *et al.*, 2005; Pugin 2007). In Europe a cross-sectional survey across nine different regions, with a sample size of 785 caregivers of children with CP, found a mean Total Stress Score of 81.8 (±21.8) (Parkes *et al.*, 2011). All these studies used

either the Parenting Stress Index (PSI) or Parenting Stress Index – Short Form (PSI-SF) to measure stress. From this information it can be assumed that stress in South Africa, a developing country, is a significant problem for caregivers of children with disabilities. Looking more specifically within the socioeconomic construct of South Africa, the lower income groups suffered more from higher stress levels than the middle income groups (Pugin 2007; Potterton *et al*., 2007; Haniff *et al*., 2005). This suggests that poverty adds to the complex nature of stress when caring for children with disabilities. Many studies have found evidence to support this notion (Pugin 2007; Dambi *et al*., 2015; Ong *et al.*, 1998).

Of late, no educational interventions have been researched with the aim of reducing stress levels. Older research found that educating parents as part of a family centred approach (FCA) had a positive impact on their mood, anxiety and overall participation in the management of their children (Moxley-Haegert & Serbin 1983; Caro & Derevensky 1991; King *et al.,* 1999). The importance of educating caregivers about their child's condition is clear but the effect that it has on reducing stress is unknown. According to Abidin (1995), if the Total Stress Score is above the 90th percentile, parents are considered to have clinically significant high levels of stress. In this study 87% of participants had clinically significant stress levels prior to the intervention. After the intervention 67% had clinically significant stress levels. This indicates that 20% of participants were able to reduce their stress levels to below the clinically significant level. This suggests that the Hambisela Programme, an education programme, did have some benefit in reducing the participants' stress levels. Although not statistically significant, a plausible explanation for the fact that there were no statistically significant improvements in stress after the intervention could be that the participants live under poor socio-economic circumstances. Stress is a complex multifactorial construct that involves many different divisions such as environmental, social, psychological and biological stress (Porcelli 2010). This incorporates financial stress. Another way of looking at stress is looking at the objective and subjective burdens that stress causes. The objective burden of stress relates to social, environmental and financial causes

whereas the subjective burden relates more to the psychological/emotional impact of stress. Green (2007) found in her study that financial stress and time constraints were more prevalent than the emotional distress caused by parenting a child with a disability. Similarly in this study's sample, financial, social and environmental stressors may be more of a concern. They are more likely to worry about where to find food to put on their table than to worry about how severely affected their children are. These parents are trying to survive. Even if stress regarding their children is reduced, their stress due to circumstances remains unchanged. Popa *et al*., (2014) adds to this notion as they found that a certain amount of social support can make up for objective strains but it reaches a threshold and then does not make a difference anymore. To some extent the Hambisela programme offered social support to the caregivers but it was not enough to help them deal with all aspects of their stress.

Another possibility is that different cultures perceive disability, and thus stress, differently. Different cultures also cope with stress differently (Popa *et al*., 2014). Lazarus & Folkman (1984) explain dealing with stress by looking at the situation i.e. their perception of the stressful incident and then assessing what resources they have available to them to deal with the stress. Perhaps some cultures are more accepting of the situations that life has dealt them. Green (2007) determined that Caucasian's cope less well with stress than African Americans. She determined that African Americans are more positive and thus deal with stress in a better way.

5.1.2 Quality of Life

There was no significant difference found in the participants' QoL before and after the intervention. QoL was measured using the Paediatric Quality of Life – Family Impact Module (PedsQL^{TM} – FIM). This measurement tool has no 'cut-off' to determine what is clinically significant in terms of a poor or good QoL. Higher scores represent a better

QoL and lower scores represent a poorer QoL. In order to assess and compare QoL amongst different populations and cultures it is important to have a 'cut-off' measure. However, when this study's results were compared to other studies that used the PedsQL^{TM} - FIM, caregivers in South Africa presented with lower mean scores of Parent Health related Quality of Life (HRQoL). This sample's mean Parents HRQoL score was 31 (±13.5) in comparison to 72.2 (±13.9) in a Brazilian sample of 95 caregivers of children with malignant neoplasms (Scarpelli *et al.*, 2008) and 83.8 (±15.6) in a sample of 23 parents of children with CP and birth defects in San Diego (Varni *et al.*, 2004).

QoL is just as complex as stress. It includes domains such as health, emotional, cognitive and social well-being (Vila *et al.,* 2003). It could be reasoned that the Hambisela programme improved the participants' cognitive and social well-being, due to the knowledge that they gained and social support that they received from the nature of the group activities, as mentioned in their feedback comments. Empowering caregivers could influence their QoL but further interventions should be included to involve their emotional and health aspects in order to provide a more comprehensive service.

5.2 Demographics

Participants in this study were from the Mamelodi Township in Pretoria. Mamelodi is an under-resourced area with challenges arising from inaccessible health care, and a high prevalence of malnutrition and poverty. All participants were black African, which is a representative sample of this area. Seventeen of the participants were the mothers of children with CP while one was a grandmother of a child with CP. Fifteen of the 18 (83%) participants were unemployed and 11 (61%) were single parents bringing up their children on their own. Although the socioeconomic status of the participants was unknown, 83% were unemployed and were most likely living off a disability grant. A study in Zimbabwe, a country with similar resource limitations to South Africa, found a

60.9% unemployment rate amongst caregivers of children with CP (Dambi *et al*., 2015). Lv *et al*., (2009) researched a group of parents of children with Epilepsy in China. Only 22 of the 263 parents were unemployed, yet they found a significant correlation between those parents who were unemployed and poor QoL. In Turkey a study investigated the difficulties that families with disability experience. They found that amongst their CP sample, 92.8% were unemployed (Sen & Yurtsever 2007). This is similar to the unemployment rate of this current study and the impact that unemployment has on stress and QoL should not be underestimated.

5.2.1 Parenting stress and level of severity, child's age and caregiver's age

5.2.1.1 Level of severity

The level of severity of CP has been established by some researchers as a cause of stress (Ong *et al.*, 1998; Plant & Sanders 2007). However, level of severity across studies differ. Some perceive level of severity in terms of how dependent the child is on the parent (Byrne *et al.*, 2010). Others perceive the severity in terms of how demanding the child is or how much time is spent on taking care of the child (Brehaut *et al*., 2004). Others even perceive severity in terms of the number of disabilities a child has (Hammond *et al*., 2014).

In this study the severity of disability was evaluated using the gross motor function classification system (GMFCS) of the child. This measures the motor ability of a child at a certain age. The higher the GMFCS level the more dependent the child is on the parent for everyday tasks (Brehaut *et al.*, 2004). In this study there was no association found between the GMFCS level and Total Stress Score. However it must be mentioned that majority of the sample were classified as level V on the GMFCS. Thus majority of the sample were completely dependent on their caregivers for everyday tasks. The sample was not equally stratified amongst the five different GMFCS levels. Therefore it

is impossible to determine if caregivers with children with level I GMFCS classification experience less stress than those with children with level V GMFCS classification or vice versa.

Parkes *et al*., (2011) and Dambi *et al.,* (2015) also found no correlation between parenting stress and level of severity. Parkes *et al.,* (2011) had a large sample size of 785 children with CP. The sample was equally distributed between all five levels of the GMFCS. They however looked at level of severity differently. They correlated each sphere of severity, i.e. they looked at the motor ability, communication impairment and intellectual impairment individually. They found a significant correlation between parenting stress and communication and intellectual impairments but no correlation between GMFCS level and stress. Dambi *et al*., (2015) had a much smaller sample size of 46 Zimbabwean caregivers of children with CP. Their sample's GMFCS levels were mostly level I and level V and still no correlations were found. Plant & Sanders (2007) however found that the severity of disability as well as the child's behaviour contributed to parenting stress. They used a different tool to measure level of severity, the Vineland Adaptive Behaviour Scale – Survey Form. This tool investigated communication, daily living skills, socialisation and motor skills. Thus a wider definition of level of severity is interpreted. Majnemer *et al*., (2012) also reported a moderate correlation between parenting stress and motor abilities. They used the Gross Motor Function Measure (GMFM) to assess motor level of severity and not the GMFCS. They also found that behaviour was a greater cause of parenting stress than motor severity. The definition of level of severity may need to be further classified in order to compare results.

5.2.1.2 Child's age and Caregiver's age

The literature viewed when researching parenting stress found that a wide range of age amongst children with CP is used in the samples. Samples of parents with children with CP range from 15 months to 44 months (Britner *et al.*, 2003), two to seven years (Krstic

& Oros 2012), two to 18 years (Basaran *et al*., 2013), one to 14 years (Butcher *et al*., 2008), less than four years (Glenn *et al.*, 2009), six to 12 years (Majnemer *et al.*, 2012) and two to 13 years (Olawale *et al.*, 2013). This study used children from six months to 12 years. Children under six months are unlikely to be diagnosed with CP and the PSI-SF has been standardised for its use in parents with children under 12 years of age (Abidin 1995). Children older than 12 years become adolescents. Adolescents present with further challenges for parents. Often ambulant children with CP lose their ability to walk as they reach adolescence due to the sudden increase in body weight and height, adding to the list of challenges. Failla & Jones (1991) explain how parents go through different stressful stages as their disabled children grow up. Adolescence is one of the phases that presents as particularly stressful. Puberty starts and children with CP go through the same changes as children without CP (Jones *et al*., 2007). Dehghan *et al*., (2014) support the fact that adolescence is a stressful phase, as in their study they found that parents with children aged 12 to 18 years presented with higher stress levels than those with younger children. It was thus decided to keep the sample to 12 years and below. In this study no correlation was found between the child's age and stress (r=0.2). Neither was there a correlation between parents' stress and the parents' age (r=-0.1). This is similar to results found by Park *et al.*, (2012). No correlation was found between caregiver age and stress in their sample of 101 caregivers of children with CP in Korea, with the mean age of parents being 40.3 years. Plant & Sanders' (2007) sample of 105 mothers with children with a range of disability showed no correlation between age and stress. The mean age of the mothers was 35.2 years. Britner *et al.*, (2003) correlated maternal age (mean age of 29 years) with five different self-reported stress and coping scales in a population of 87 mothers of children with CP. No correlations were found. In this current study the parent's mean age was 36.4 years. The above viewed literature assessed mean maternal age between 29 and 40.3 years and no correlation was found between parental age and stress levels.

5.2.2 Parenting stress and parent education

A moderate negative correlation was found between this sample's parenting stress and level of education. The higher educated the parents were the lower the Total Stress Scores were. Ong *et al.*, (1998) found similar results amongst their Malaysian population. In their study they used the PSI to measure stress and found that as the parent's educational levels rose, their stress levels declined. Their sample was also from a resource limited area and participants were all parents of children with CP. In South Africa Potterton *et al*., (2007) found that a higher level of education was a predictor for stress to decrease over time. Their sample was different to this study in that they were caregivers of children with HIV. However the social circumstances and culture was similar to this current study. Green (2007) used both qualitative and quantitative research to examine daily hassles and emotional distress in caregivers of children with disabilities in America. She found that those parents who were more educated were less distressed as they were able to access resources to cope with their stress. Ong *et al.*, (1998) agreed with the above statement as they contributed their results to the possibility that the less educated the parent the more difficult it is to have access to social-educational and medical resources. The more educated parents are, the more chance they have of discovering ways to alleviate the burden of looking after children with disabilities. This is particularly true in developing countries as awareness and knowledge of disabilities is often lacking (Sharma & Sinha 2014; Masasa *et al*., 2014). In contrast Plant & Sanders (2007) found no association between parenting stress and caregiver education in their sample of caregivers of pre-school children with CP.

5.2.3 Quality of life and level of severity, child's age and caregiver's age

5.2.3.1 Level of severity

In this study no correlation was found between the level of severity of CP of the child and QoL of the caregiver. Level of severity of CP has been assessed by many researchers. Previous studies have found that the more severely affected the child, the worse the QoL of the parent (Basaran *et al.*, 2013; Dambi *et al*., 2015; Sen & Yurtsever 2007; Raina *et al.*, 2005). Isa *et al.*, (2013) found that the more complex the disability and the more disabilities that the child has, the poorer the parents' QoL. Their study looked at different types of disabilities and not only CP. However, they did find that the CP population placed more demands on their parents and thus their QoL was worse. In contrast to this Dehghan *et al.*, (2014) found no relationship between the mental health of the caregivers and the GMFCS level of their children, suggesting that the way mothers perceive mental health is not directly related to the caregiving demands required by the child. They did find that there was a correlation between the physical component of QoL and GMFCS level. This could be due to the fact that children with a GMFCS level V are more dependent on caregivers for all activities of daily living. The physical demands could therefore influence their QoL negatively (Raina *et al.*, 2005). Hamzat & Mordi (2007) also found no relationship between level of severity of CP of the child and QoL of the caregiver. They attribute this finding to the fact that their Nigerian population is very religious and that the positive belief system is what assists them to cope and thus the various levels of severity are insignificant. Skok *et al.*, (2006) looked at the association between level of severity and well-being in mothers of children with CP. They also used the GMFCS as the tool to measure level of severity. The level of severity had no impact on the well-being of the caregivers. However an important point was made as the GMFCS only measures the physical aspect of a child and therefore intellectual disabilities and behaviour were not included in the assessment. Thus severity of disability should be measured more comprehensively using a tool that investigates all spheres of severity such as cognitive, behaviour and motor impairments as well as the physical demands and time involved in caregiving. This needs to be

established before an accurate correlation between QoL and severity of disability can be attained.

5.2.3.2 Child's age

In this study no correlation was found between the caregivers QoL and the child's age. This corresponds to a study that investigated the impact of caring for a child with CP on the parent's QoL during childhood to adolescence (Davis *et al*., 2010). In their study no differences were found in the parent's QoL during the different stages of a child's life. This is possibly due to the fact that the basic caring required for a child with CP stays the same from childhood to adolescence (Davis *et al.*, 2010). They do mention that challenges during the different stages vary but ultimately it does not make a difference to the parent's QoL.

5.2.3.3 Caregiver's age

This study found a moderate negative correlation (r = -0.5) between the parent's age and their QoL, suggesting that the QoL of the parent can be affected by the increasing age of the parent. Huang *et al.*, (2014) found that older fathers caring for children with disabilities had poorer physical HRQoL than younger fathers. A study researching children with epilepsy also found that the older parents had poorer mental health related quality of life (HRQoL) (Lv *et al.,* 2009). Likewise lower satisfaction with family functioning was found in an increasing parental age in a study conducted by Failla & Jones (1991). However Mailick & Jan (2008) investigated the affect that caregiver age would have on well-being amongst caregivers with children with development and mental problems. They found that the negative impact that a child with a disability has on a caregiver reduces over time. They based their findings on Lazarus & Folkman's

(1984) theory which states that the more experience you have with distress the more the distress will decline over time. In other words, one adjusts over time. It seems as though research on how caregiver's age influences QoL is inconclusive.

A possible explanation for the correlation found in this study could be that the older parents have less energy than the younger parents and grow tired more quickly. One of the participants in Davis *et al.*'s (2010) study on the impact of caring for a child with CP expressed the following comment: "I'm getting older now and she plays havoc on my body, on things that I can do and can't do. I can't run anymore." A further possibility is the theory of wear and tear. The accumulation of stress, especially chronic stressors, builds up and thus the older the parent the more stress they would have dealt with (Failla & Jones 1991). Huang *et al*., (2014) found that perceived stress had a direct effect on the caregivers QoL rather than the actual disability having the effect on the QoL. This could explain why older parents with chronic stressors result in having poorer QoL.

5.3 Hambisela Programme

Although not a specific objective of this study, comments from the participants were collected at the end of the programme and divided into themes. Overall, the participants perceived the training as positive. Brehaut *et al*., (2004) found that caregiver stress can be reduced by providing social support, professional support services, improving self-esteem and assisting caregivers to master their caregiving situations. According to the comments made by the participants, Hambisela seems to have increased the participant's knowledge on CP, increased their self-efficacy and their self-esteem. Butcher *et al.*, (2008) suggested that interventions to reduce stress amongst caregivers of children with CP should focus on increasing the perceived competence of the parenting role and improve social isolation. Self-efficacy is associated with better mental

health and it is a tool that can be used to elicit empowerment (Guillamón *et al*., 2013; Márquez-González *et al.*, 2009). According to Karande *et al.,* (2008) parent knowledge of CP is inadequate and they recommend educating parents in order to empower them. Olawale *et al.,* (2013) supports this notion. The Hambisela Programme is a group programme that through its group activities provides social support amongst the group members. It educates caregivers with children with CP on how to handle daily caregiving tasks and it empowers them by improving their knowledge, self-efficacy and self-esteem.

5.4 Clinical Implications

Stress in this sample of caregivers with CP is extremely high and QoL is also considerably low. Further interventions to reduce stress and improve QoL must be identified to help alleviate this burden. Hambisela, the education programme used in this study should be explored using formal qualitative measures such as structured interviews. The informal feedback suggested that the participants may have experienced positive benefits such as improving knowledge, self-esteem and self-efficacy. Such constructs need to be explored in more depth. However, alone the programme is not enough to reduce caregivers' stress and improve their QoL. Perhaps in combination with other stress reducing methods, stress management and QoL may improve. A holistic approach which includes social development that focusses on security, employment, standard of living, relationships and nutrition are needed to alleviate structural strains experienced by caregivers living in low income areas. Other approaches such as emotional development, education and empowerment are also recommended for these families. Managing stress among caregivers therefore calls for a multidisciplinary and a multi-sectoral approach of which a programme such as the Hambisela programme could be a part of.

5.5 Recommendations

As this is a pilot study, further research should be undertaken in order to determine if these results could be generalised. Severity of disability should be investigated more holistically with all aspects being targeted i.e. motor ability, behaviour and cognition. It should then be tested to see if there is any impact on stress and QoL. A QoL tool should be developed with a standardised baseline level of clinically significant poor QoL. That way QoL would be better defined. It is recommended for further research that the PSI-SF and the PedsQL™ - FIM be validated in South Africa.

Stress and QoL are both such complex constructs that perhaps qualitative data would give a better idea of the cultural perception of stress and QoL and in this way more effective interventions could be designed and implemented.

5.6 Limitations

This study only targeted one cultural group in South Africa. CP affects all cultures and South Africa has a variety of cultures with 11 official languages. Further research should include different cultures to generate a more holistic picture of the burden that caregivers of children with CP experience in South Africa. The post-test evaluations were conducted immediately after the intervention, therefore the long term impact of the Hambisela programme is unknown. Future studies should focus on a longitudinal approach in order to test the knowledge transference and retention.

Although the assessment tools that were used are standardised tools, they have not been validated in South Africa. The cultural context is very important when delivering a tool as different cultures perceive things differently (Green 2007). The PSI-SF

psychometric properties were tested in a low socio-economic African-American population, however this test was conducted in a developed country where the environmental factors are very different to a developing country. Stress, QoL and parenting are all complex constructs and are perceived differently across cultures (Popa *et al.*, 2014). It is therefore important to validate these tools in order to compare results with other countries.

A further limitation to this study is the fact that the majority of this sample had children with a level V GMFCS. Thus a true reflection of how the GFMCS level affects parents stress and QoL could not be identified. Future research should compare the different GMFCS levels to stress and QoL.

5.7 Conclusion

Stress and QoL in this small population in Mamelodi are major problems. Using an education programme like Hambisela has positive benefits but does not significantly reduce the caregivers' stress levels. A more comprehensive approach needs to be developed, such as a holistic approach that includes other factors such as education, social and economic development, an approach that will look at all aspects of stress and QoL.

CHAPTER 6: CONCLUSION

Cerebral palsy (CP) is a complex disorder involving motor, sensory, nutritional and neurological impairments (Bax *et al*., 2005). The ramifications of the disorder add to the burden placed on the caregivers. Studies have shown that caregivers of children with CP have high stress levels and poor quality of life (QoL) (Brehaut *et al*., 2004; Park *et al.*, 2012; Parkes *et al*., 2011; Butcher *et al.*, 2008; Dehghan *et al*., 2014; Hammond *et al*., 2014; Basaran *et al*., 2013; Pousada *et al*., 2013; Guillamón *et al.,* 2013). The literature shows that knowledge of CP amongst caregivers of children with CP, especially in developing countries, is insufficient. Previous research investigating stress and QoL amongst caregivers of children with CP recommend interventions targeting education, social support and coping skills (Hammond *et al.*, 2014; Basaran *et al.*, 2013; Pousada *et al*., 2013; Krstic & Oros 2012).

The aim of this quasi-experimental pilot study was to determine whether participation in an eight week Hambisela Programme would reduce the stress levels in caregivers of children with cerebral palsy (CP). The education programme was also tested to see if it would improve the caregivers' QoL. Sixteen caregivers of children with CP between the ages of 6 months and 12 years participated in this study. The caregivers attended eight sessions, where learning was achieved through group discussions and sharing of personal experiences.

The majority of the children presented with a Gross Motor Function Classification System (GMFCS) of level V and were thus severely disabled. It was therefore not possible to assess the impact of severity of the disability on QoL and stress. A large portion of the caregivers were unemployed and single. The Hambisela programme alone, was unable to significantly reduce the caregivers' stress levels and improve their QoL. The caregivers' stress levels were exceptionally high (104.4 ± 18.8) and their QoL

levels were low (31 ± 13.5). A benefit of the programme however, is that it provided a social support group for the caregivers and comments from the participants suggest that it empowered them with knowledge.

The caregivers who participated in this study are in a very vulnerable situation, not only because they parent a child with a disability but also because of their social and economic circumstances. Both stress and QoL are complex multifactorial constructs. It is therefore difficult to assess stress levels due to CP in isolation. Future research should investigate tools to address this limitation and future interventions perhaps should look at a more comprehensive approach, one that includes social development, education, emotional support and poverty reduction.

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APPENDIX I: Therapeutic Interventions for children with CP

Alternative and Augmentative Communication (AAC)	An approach using technical devices to assist with communication.
Baclofen pump	A pump is inserted surgically into the abdomen and medicine is then pumped into the spinal cord to help reduce spasticity.
Bimanual training	Using two hands together during repetitive tasks.
Biofeedback	Electronic feedback that is supplied to the muscles to train voluntary control.
Botulinum toxin (BOTOX)	Botox is a medicine that is injected into the muscle to help block the spasticity.
Communication training	Using programmes such as Hanen and It Takes Two to Talk to train the partners to communicate effectively
Conductive education (CE)	Teaches movement using groups and routines and rhythmic intention.
Constraint-induced movement therapy (CIMT)	Preventing the dominant hand from participating in tasks to allow the non-dominant hand to perform the tasks.
Cranial osteopathy	Rhythmical movements of the skull bones to assist with reducing muscle tension and treats the central nervous system.
Dysphagia management	Facilitates safe swallowing by changing the consistency of food and paying attention to positioning.
Electrical stimulation	Using electrical currents to assist in strengthening muscles.

Goal directed/functional training	A motor learning approach that uses goals to achieve specific tasks.
Hippotherapy	Using horse riding to improve balance and alignment.
Hydrotherapy	Exercising in water.
Hyperbaric oxygen (HBO)	Using a special oxygen chamber to increase the oxygen in the blood.
Neurodevelopmental therapy (NDT)	NDT is a holistic, interdisciplinary approach that uses handling based on movement analysis to rehabilitate.
Orthopaedic surgery	Includes hip surgeries and musculoskeletal surgery to improve alignment and function.
Orthotics	Splinting, supporting and bracing used to improve alignment and function.
Seating and positioning	Equipment used to improve posture and assist with function.
Selective dorsal rhizotomy (SDR)	Surgical procedure whereby nerves causing spasticity are severed.
Sensory integration (SI)	Special exercises using the environment to strengthen and integrate the sensory system.
Therasuits	A full body suit that fits snuggly to improve proprioception and assist with alignment.
Vojta	Uses reflex points to stimulate automatic and involuntary complex movement.

APPENDIX II: ETHICAL CLEARANCE

R14/49 Mrs Tami van Aswegen

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140708

NAME: (Principal Investigator)	Mrs Tami van Aswegen
DEPARTMENT:	Physiotherapy Baby Therapy Centres Outreach Clinic, Mamelodi West-C4
PROJECT TITLE:	The Hambisela Program's Effect on Stress Levels and Quality of Life Primary Caregivers of Children with Cerebral Palsy in Mamelodi: A Pilot Study
DATE CONSIDERED:	25/07/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Joanne Potterton
APPROVED BY:	Professor Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	19/11/2014

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 Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX III: Gross Motor Function Classification System

CanChild Centre for Childhood Disability Research
Institute for Applied Health Sciences, McMaster University,
1400 Main Street West, Room 408, Hamilton, ON, Canada L8S 1C7
Tel: 905-525-9140 ext. 27850 Fax: 905-522-6095
E-mail: canchild@mcmaster.ca Website: www.canchild.ca

GMFCS – E & R
Gross Motor Function Classification System
Expanded and Revised

GMFCS - E & R © Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007
CanChild Centre for Childhood Disability Research, McMaster University

GMFCS © Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi, 1997
CanChild Centre for Childhood Disability Research, McMaster University
(Reference: Dev Med Child Neurol 1997;39:214-223)

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that **environmental** and **personal** factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the **child's or youth's present abilities and limitations in gross motor function**. Emphasis is on usual **performance** in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child's/youth's current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.

OPERATIONAL DEFINITIONS

Body support walker – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

Hand-held mobility device – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

Physical assistance – Another person manually assists the child/youth to move.

Powered mobility – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

Self-propels manual wheelchair – The child/youth actively uses arms and hands or feet to propel the wheels and move.

Transported – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

Walks – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

Wheeled mobility – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

GENERAL HEADINGS FOR EACH LEVEL

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

DISTINCTIONS BETWEEN LEVELS

Distinctions Between Levels I and II - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.

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Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)

BEFORE 2ND BIRTHDAY

LEVEL I: Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

LEVEL III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

LEVEL IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

LEVEL V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

BETWEEN 2ND AND 4TH BIRTHDAY

LEVEL I: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III: Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 4TH AND 6TH BIRTHDAY

LEVEL I: Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

LEVEL II: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

LEVEL III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

LEVEL IV: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

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BETWEEN 6TH AND 12TH BIRTHDAY

Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

BETWEEN 12TH AND 18TH BIRTHDAY

Level I: Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a hand-held mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when traveling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

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APPENDIX IV: PedsQL – Family Impact Module

PedsQL™

Family Impact Module

- Version 2.0

PARENT REPORT

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.

*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 Nev	**Some-times**	Often	Almost Alw

		er			ays
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

*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	0	1	2	3	4
4. I worry about how my child's illness is affecting	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

APPENDIX V: Parenting Stress Index – Short Form

PSI Short Form

Instructions

This questionnaire contains 36 statements. Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response that best represents your opinion.

Circle the SA if you strongly agree with the statement.

Circle the A if you agree with the statement.

Circle the NS if you are not sure.

Circle the D if you disagree with the statement.

Circle the SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA (A) NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Circle only one response for each statement, and respond to all statements. **DO NOT ERASE!** If you need to change an answer, make an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies. SA A NS (X) (SD)

SA = Strongly Agree	A = Agree	NS = Not Sure	D = Disagree	SD = Strongly Disagree

1.	I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
2.	I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
3.	I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4.	Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5.	Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6.	I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7.	There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8.	Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).	SA	A	NS	D	SD
9.	I feel alone and without friends.	SA	A	NS	D	SD
10.	When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11.	I am not as interested in people as I used to be.	SA	A	NS	D	SD
12.	I don't enjoy things as I used to.	SA	A	NS	D	SD
13.	My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14.	Sometimes I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
15.	My child smiles at me much less than I expected.	SA	A	NS	D	SD
16.	When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
17.	When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
18.	My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
19.	My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20.	My child is not able to do as much as I expected.	SA	A	NS	D	SD
21.	It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below.

22.	I feel that I am: 1. not very good at being a parent 2. a person who has some trouble being a parent 3. an average parent 4. a better than average parent 5. a very good parent	1	2	3	4	5
23.	I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
24.	Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
25.	My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
26.	My child generally wakes up in a bad mood.	SA	A	NS	D	SD
27.	I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
28.	My child does a few things which bother me a great deal.	SA	A	NS	D	SD
29.	My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
30.	My child gets upset easily over the smallest thing.	SA	A	NS	D	SD
31.	My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below.

32.	I have found that getting my child to do something or stop doing something is: 1. much harder than I expected 2. somewhat harder than I expected 3. about as hard as I expected 4. somewhat easier than I expected 5. much easier than I expected	1	2	3	4	5

For the next statement, choose your response from the choices "10+" to "1-3."

33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.	10+	8-9	6-7	4-5	1-3
34. There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35. My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
36. My child makes more demands on me than most children.	SA	A	NS	D	SD

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APPENDIX VI: PedsQL™ Family Information Form

ID#: ____ Date: __/__/__

GMFCS: _____ PedsQL™ Family Information Form

Who is completing this form? Please print your name: _____ (First Name) _____ (Last Name) ____ (Age)

What is your relationship to this child (please check and/or circle)?

☐ Mother, Step Mother, Foster Mother ☐ Grandmother ☐ Guardian
☐ Father, Step Father, Foster Father ☐ Grandfather ☐ Other _____

INFORMATION ABOUT THE CHILD

Name: *Date of Birth* (month/day/year): __/__/__ *Child is:* ☐ male ☐ female

Ethnic Group or Race: ☐ Black, Non-Hispanic ☐ Hispanic ☐ Native American or Alaskan Native ☐ Asian or Pacific Islander ☐ White, Non-Hispanic ☐ Other _____

INFORMATION ABOUT MOTHER	INFORMATION ABOUT FATHER
Marital Status: ☐ Single ☐ Living with someone ☐ Married ☐ Divorced ☐ Separated ☐ Widowed	*Marital Status:* ☐ Single ☐ Living with someone ☐ Married ☐ Divorced ☐ Separated ☐ Widowed
Highest Level of Education: ☐ 6th grade or less ☐ 7th-9th grade or less ☐ 9th-12th grade or less ☐ High school graduate ☐ Some college or certification course ☐ College Graduate ☐ Graduate or Professional Degree	*Highest Level of Education:* ☐ 6th grade or less ☐ 7th-9th grade or less ☐ 9th-12th grade or less ☐ High school graduate ☐ Some college or certification course ☐ College Graduate ☐ Graduate or Professional Degree
Occupation Or Job Title: _____	*Occupation Or Job Title:* _____

IMPACT SCALE

In the past 6 months, has your child...

Had a chronic health condition (defined as a physical or mental health condition that has lasted or is expected to last at least 6 months, and interferes with your child's activities)? ☐ NO ☐ YES

IF YES, What is the name of your child's chronic health condition? _____

In the past 12 months, has your child had...

Any OVERNIGHT VISITS to the hospital?	Any EMERGENCY ROOM/URGENT CARE visits?
☐ NO ☐ YES	☐ NO ☐ YES
IF YES, ... How many times? __	IF YES, ... How many times? __
What was wrong? _____	What was wrong? _____

In the past 30 days...

How many days did your child miss from school due to physical or mental health? __
How many days was your child sick in bed or too ill to play? __
How many days did your child need someone to care for him/her due to physical or mental health? __

IF YOU WORK OUTSIDE OF THE HOME, PLEASE ANSWER THE FOLLOWING QUESTIONS.

In the past 30 days, how many days have you missed from work due to your child's physical or mental health? __

In the past 30 days, has your child's health interfered with...	Never	Almost Never	Some-times	Often	Almost Always
Your daily routine at work	0	1	2	3	4
Your ability to concentrate at work	0	1	2	3	4

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APPENDIX VII: INFORMATION FORM

Dear Caregiver

My name is Tami van Aswegen and I am a physiotherapist. I am in the process of doing my Masters in physiotherapy and as part of the Masters it is required of me to do a research report.

I would like to invite you to participate in my study. I would like to include all primary caregivers of children with cerebral palsy (CP) between the ages of 6 months and 12 years old. That means that you are the person who mostly looks after your child.

I would like to investigate the influence of an education programme on primary caregivers' quality of life and stress levels. The programme I have chosen is Hambisela. This programme consists of 7 modules in which topics discussed are:

- What is CP and what causes CP?
- Good ways in which to position my child.
- Helpful ways to feed, dress and play with my child.

This programme uses groups of similar people to share experiences and advice among each other to assist with the understanding of CP.

Why am I doing this:
I would like to do this study to see if all primary caregivers in your situation would benefit from understanding more about the condition your child has,and to see if your quality of life and stress can be improved.

How am I going to do this:
I would like to invite you to participate in an 8 week training programme. The programme consists of 7 modules consisting of sessions of 3 hours. At the first session I would like you to fill in 3 questionnaires:

- an information questionnaire
- a stress questionnaire
- and a quality of life questionnaire

Each session will take place once a week at a convenient time for the group. Thus the programme will take 8 weeks to complete. The programme is just for you and not for your child, thus if possible your child can stay at home and if not possible, care for your child will be provided during the 3 hour session. At the 8th session I would like to invite you to a graduation ceremony where you will receive a participation certificate and ask you to fill in 2 questionnaires:

- a stress questionnaire
- and a quality of life questionnaire

The one questionnaire will ask you about your stress levels. This could make you realise how stressed you actually are. The questionnaire will come up with a score to determine your actual level of stress. If this score is above 90 then we recommend that you get some counselling to help you with your stress levels. The Itsoseng Clinic in Mamelodi East offers psychological counselling free of charge. It is a walk-in clinic that is open from Mondays to Thursdays 9:00 – 16:00.
Address: Corner of Hans Strijdom Avenue and Hinterland Street
Mamelodi East
Telephone no.: 012 842 3515

All that is required from you is your time and commitment for 8 weeks. Refreshments will be provided for you at each session and information booklets relating to each session will be supplied.

You have the right to decide to not participate in the study and you may withdraw from the study at any time.

Confidentiality will be highly respected at all times.

Contact information: Tami at 0822187988

_____

Signed and approved by Wits Physiotherapy Head of Department

Associate Professor Hellen Myezwa

APPENDIX VIII: CONSENT FORM

CONSENT FORM

Research problem: To assess the influence of the Hambisela programme on the stress levels and quality of life of primary caregivers of children with cerebral palsy.

I _____ understand the purpose of this study and give consent to participate in this research. I have read and understand the information and all my questions have been answered. I am fully aware of the procedure and I am aware that I may withdraw at any time without any prejudice towards myself or towards my child.

_____	_____
Caregiver	Researcher
_____	_____
Date	Date