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THE LEVEL OF STRESS OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfillment of the degree of Master of Science in Medicine in Child Development.

Johannesburg, 2018

DECLARATION

I, Mmathuto Mandy Molokomme-Radebe, declare that this research report is my own unaided work and I have acknowledged all sources. This research report is being submitted in partial fulfillment of the degree of Master of Science in Medicine in child development at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

Signature: _____

_____day of _____2018

ABSTRACT

Introduction: The knowledge concerning the level of stress that caregivers of children with cerebral palsy (CP) experience is very important to health care professionals caring for these children. It is knowledge that will alert the health care professionals on how to intervene in the management of parental stress and in return, will equip the caregivers of CP children with strength, resources and help provide them with the maximum care for their disabled children.

Aims and objectives: The aim of this study was to assess the amount of stress that primary caregivers experience from caring and raising their children with CP. The objective was to identify the socioeconomic factors leading to parental stress. The association between parental stress and the severity of the CP child's motor function and their communication function disability were also assessed.

Methodology: A prospective, cross-sectional, descriptive study of primary caregivers of CP children between ages of 1 to 14 years, who attended the CP clinic at Chris Hani Baragwanath Academic Hospital (CHBAH), South Africa, from October 2017 to January 2018, was conducted.

A convenience sample, of the first ten caregivers per Tuesday CP clinic were chosen and were given two questionnaires to complete (a demographic and the Parent Stress Index (PSI) forms), facilitated by a trained research assistant. The researcher, herself, classified the CP child's motor function disability using the gross motor function classification system (GMFCS) and their communication function disability using the functional communication classification system (FCCS).

Results: Eighty caregivers participated in the study with the median age of 36(31-44) years. The marital status and employment status of the caregivers and their partners significantly affected their stress levels. Married caregivers had less stress levels (PSI score=102 (87-109)) compared to single caregivers with high levels of stress (PSI score=111.5 (101-121)) ($p<0.01$). The stress levels were higher when the primary caregiver alone was employed compared to when both

primary caregiver and partner were either unemployed (p=0.02) or employed (p=0.01). Caregiver's stress levels were not affected by the severity of the levels of GMFCS or FCCS of the CP child.

Conclusion: This study on parental stress in parents or primary caregivers of children with cerebral palsy has concluded that the severity of cerebral palsy (assessed by GMFCS and FCCS) does not affect the level of parental stress in their parents or primary caregiver. The parental stress levels are greater in a single parent and if the primary caregiver alone is employed as opposed to both parents being employed or unemployed. Financial and family support is potential factors that are important to address to improve the parental stress levels in parents or primary caregivers of CP children.

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ABBREVIATIONS

CP: Cerebral palsy

CHBAH: Chris Hani Baragwanath Academic Hospital

FCCS: Functional communication classification system

GMFCS: Gross motor function classification system

IQR: Interquartile range

NGOs: Non-Governmental organizations

PSI-SF: Parenting stress index-short form

SA: South Africa

SANDTA: South African Neurodevelopmental Therapy Association

SOWETO: South Western township

CHAPTER 1

LITERATURE REVIEW

1.1 Background

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behavior; and further complicated, by epilepsy and secondary musculoskeletal problems (1).

Every young child deserves maximum care from their parents but the role of care giving becomes difficult to cope with when a child has severe neurodevelopmental impairments and long term care-dependency (2, 3). Parents of such children experience high amount of stress (4, 5), impaired mental health (6), sense of devaluation and self-blame (7), minimal physical functioning and constant fatigue (8, 9).

Increased parental stress and depression has been linked to the worsening severity of the motor function and cognitive problems of the CP child, poor caregiver self-efficacy and low levels of social support for the child (10). In addition to the child's underlying CP condition; compromised or poor socioeconomic factors also contribute to the stress level of the family.

These factors may help us understand the extent to which the parents are affected and how they are coping with their child's condition (11).

There is a correlation between the gross motor function classification system of the CP patient to the parental stress index (PSI) of the caregiver, (the higher the GMFCS level, the higher the PSI of the caregiver) (12). In this study, the GMFCS is used to classify the severity of CP in the different types which directly correlates to the parental stress. The spastic diplegic child is mainly affected in their lower limbs. Most of these children can walk with limitations; and may need a manual device to help them walk. They can be less dependent and achieve all other aspects of their development fairly well thus needing less assistance from their parents. The spastic quadriplegic child has all four limbs and trunk

affected thus most of them cannot sit nor walk. The ones who cannot sit nor walk are totally dependent on their caregivers for activities of daily living. They are immobile and spend most of their days in bed or on the floor waiting to be turned to prevent bed sores and contractures and are wheelchair bound. Much physical strength is applied daily by parents of the totally dependent CP children thus these parents have more body pains than those parents of less dependent CP children (13).

It was also found that the speech and cognitive impairments in the spastic quadriplegics (14) (15) were also important factors adding to parental stress. On the other hand, dystonic quadriplegic patients may have relatively normal cognition and dysarthric speech which parents learn to understand and that is an important factor because even though the patients struggle physically, they are able to communicate their needs which alleviate parental stress. The functional communication classification system (FCCS) for individuals with cerebral palsy is used to classify the communication ability of patients with cerebral palsy and it was utilized in this study.

In terms of intervention, social support is very important in alleviating parental stress. Most parents especially mothers of CP children were found to have a much improved wellbeing if supported socially (16).

Parent support groups are created as a platform for these parents to share emotional issues, relevant information and practical resources (17). Health services are important as an intervention for a CP child and their entire family. Any parent reaching out to a health service should receive social support. The hospital multidisciplinary team of doctors, therapists, social workers, dieticians and counselors are the first line of health workers to provide medical and psychosocial support to the CP child and their parents.

Therapy associations in South Africa (SA):

- The South African Neurodevelopmental Therapy Association (SANDTA) is aimed at preparing therapists to effectively assess, treat and manage children with CP within a public setting. SANDAT has branches in the following provinces of SA: Northern Gauteng, Southern Gauteng, Kwa-Zulu Natal, Free State, Western Cape and the Eastern Cape.

- The Malamulele Onward-Outreach, to caregivers of children with CP, consists of a team of volunteer therapists who travel to the under-resourced areas of SA. They aim to improve the lives of the children with CP and their caregivers by teaching caregivers daily skills of how to handle and provide proper home and rehabilitative care to their children. They also provide support to local rehabilitation staff responsible for providing services to the CP children and their families.

1.1.1 The definition of cerebral palsy and parenting stress

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behavior; and further complicated, by epilepsy and secondary musculoskeletal problems (1).

The motor disabilities in cerebral palsy are usually classified according to the predominant motor disability into spasticity, dyskinetic (athetosis and choreoathetosis), ataxic and a mixed group (combination of dystonia, spasticity and/or truncal hypotonia) (1).

CP begins in early childhood and the developmental delay persists throughout their lifespan. Many changing demands of a CP child are due to their developmental delay thus they are dependent on their caregivers for activities of daily living (18, 19).

The concept of parenting stress revolves around the child's and parent's characteristics. When the parent's capacity to take care of their child is exceeded by the disabled child's demands on them, they experience stress (20). These parents perceive their child's disability and needs as exceeding the resources they have to raise the child.

The child's underlying CP condition is not the only factor resulting in parental stress. Other factors include child's temperament, caregiver's age, education level and marital status. Family related factors are employment status of parent and their spouse, family income and the availability of social support (9, 11, 15).

The results of parental stress are: poor mental health (6), a sense of devaluation and self-blame (7). The depression these parents experience inversely leads to worsening severity of the child's disability and cognition due to poor social support to the child.

1.2 Factors resulting in parental stress

1.2.1 Child related factors: severity of cerebral palsy

The severity of the CP child's disability is the most common variable to be analyzed and the commonly used tool to assess this is, is the GMFCS (21). There were studies which illustrated that the quality of life and mental health of the caregivers were not related to this variable (14, 16).

In South Africa, a study was conducted in 2007, to assess the relationship between severity of CP in children and the level of stress experienced by their caregivers. A population sample of 35 caregivers participated in the study and the outcome was that the level of parenting stress experienced by the caregivers was not influenced by the severity of the CP child's disability (19).

There are studies that found a correlation between the well-being of the caregiver and the severity of the CP child's motor disability. One study illustrated that the severity of motor disability was related to the total score of the Parental Stress Index (PSI) (12). Another study was done in which the different levels of CP were compared according to their degree of severity and the outcome of the study showed that the parents of more dependent children had more severe bodily pains compared to parents of independent children (13).

Other studies looked into the presence of behavioral problems of the CP child in addition to their motor disability and they found that these caregivers had higher levels of stress and worse general wellbeing (2, 17). The CP child's cognitive impairment was found to be affecting their parent's psychological health thus classified as one of the important predictors of the level of stress of caregivers (15). Associated with the child's cognitive impairment are their speech problems which correlated with their caregiver's depression (14).

1.2.2 Caregiver related factors

- **Caregiver's marital status and social support**

  Over years researchers have looked into the importance of social support to the primary caregiver of disabled children, with the aim to correlate social support to lessen levels of stress of primary caregiver's.

Many studies have shown that social support is an important factor, which through a direct or an indirect way, contributed to the wellbeing of primary caregivers (2, 15-17). There are researchers who concluded that perceived social support was a direct reflection between stress and well-being of mothers of CP children (16). It was also found that social support had indirect effects on psychological and physical health of the primary caregiver (2).

A study that investigated single mothers had found that these mothers had difficulty in involving their CP children in activities and they were not optimistic about their children's future and family situation compared to married mothers. The researcher postulated that single mothers were less able to cope with their disabled children, due to lack of a supportive partner with whom to share the burden of the child's daily care, personal concerns and issues around management of family life. The sample population was largely Caucasian thus these findings did not include other ethnic groups where single mothers may rely on extended social networks for support such as the child's grandparents (22).

Button et al, stated that mothers who take on a bulk of childcare activities were dependent on their spouses or partners for both emotional support and practical assistance (15). The majority of mothers in this study reported a greater need for practical assistance than emotional support while in contrast; mothers of severely impaired children said practical assistance from partners disrupted their already established care-giving routines. Mothers of the severely impaired child reported to be functioning better when partners were less involved with the direct care giving duties to their CP children (15).

- **Caregiver's level of education**

  A randomized controlled trial was done in a large population of Chinese families who were raising mentally handicapped children. The researchers found a correlation between the parent's level of education and parenting stress, with the less educated mothers experiencing high levels of stress. There was also a link between the mother's low level of education and low income which suggested that these two factors are intertwined (23).

1.2.3 Family related factors

- **Family Adaptation**

  Studies have investigated the whole family with the objective to analyze the effects of caring for the CP child on family functioning and the family's adaptation to having a child with CP.

  Button et al, investigated the influence of partner support on maternal stress and found that mothers as primary caregivers experienced high levels of stress when their CP children had cognitive impairment irrespective if they received their partners support or not. The study concluded that family functioning with a disabled child will be effective if the mother as a primary caregiver receives an extended network of social support in addition to her partner's support (15).

  The health status of the CP child depends on the wellbeing of their primary caregiver who relies on good family support and functioning. A study by Raina et al reported higher levels of family functioning to be associated with better psychological and physical health of the primary caregiver (2).

- **Family income and employment status**

  Families caring for children with CP are faced with an increased financial burden. Researchers looked at the impact of employment and low family income on parenting stress, in an effort to motivate for government policies which pays attention to social welfare issues of families caring for physically disabled children.

  The American Task force on the family's income created in 2003, found that the lack of employment and poverty were the dominant factors correlating to poor parenting and child outcomes. Poor American families were mostly residing far from health care facilities and they struggled with transport to be able to take their children for health management. These families had limited day-care centers for their disabled children and they lacked employee benefits such as health insurance and sick leave thus the mothers are forced to quit their jobs, placing more strain on the financial state of the family (24).

  Some researchers looked more on the impact of employment for mothers of children with CP. They found that working provides the mothers with time away from stressors associated with caring for their disabled children. The mother's self-esteem is improved due to development of a separate identity from the mothering role. When working, the

mothers are no longer socially isolated and that imposes a normal life structure which their children can fit into rather than the children being the unhealthy constant focus (23). In contrast, a study done in Bangladesh found that the amount of family income had no impact on parenting stress (25). Another study that confirmed this outcome, illustrated a negative correlation between family income and parenting stress in families of disabled children (26).

1.3 Outcome measures

The following tools were used in this study:

1. The Parenting Stress Index- Short Form (PSI-SF)
2. The Gross Motor Functioning Classification System (GMFCS)
3. The Functional Communication Classification System (FCCS)

1.3.1 Parenting Stress Index – Short Form (PSI-SF)

In 1985, Abidin created the PSI as a screening and diagnostic tool, designed to yield a measure of the relative magnitude of stress in the parent-child system (27). It consists of 120 items of parent self-report questionnaire that picks up a wide range of potential influences on parenting practices. The domains are 54 parent-focused items, 47 child-focused items and 19 items covering general life stressors.

The Parent Domain comprises of the following seven subscales: depression, attachment, role restriction, sense of competence, social isolation, relationship with spouse and parental health. The child domain comprises of six subscales: adaptability, acceptability, demandingness, mood distractibility/hyperactivity and reinforces parent domains. Abidin's conceptualization of parenting stresses consists of a total of these 13 subscales (27).

Abidin's model is comprehensive with proven reliability and validity but researchers and clinicians found it to be too time consuming to administer and use for screening (23).

1.3.1.1 Development of the PSI-SF from the original PSI

In 1995, Abidin developed a 36 item (three factor short form where each factor has 12 items) PSI-SF as a derivative of the full length PSI (27). The three subscales of the PSI-SF:

- Parental Distress (PD)

  This subscale was derived from the parent domain scales of the full length PSI and it determines the stress experienced by the parent as a function of personal factors linked to parenting. It includes different stressors such as impaired sense of parenting competence, stresses caused by restrictions placed on other life roles, conflict with the child's other parent, lack of social support and presence of depression.
- Parent Child Dysfunctional Interaction (PCDI)

  This subscale contains items from acceptability and it reinforces parent and attachment subscales of the full length PSI. It gives an indication of the parent and child bond and it illustrates the extent to which the parent feels alienated from the child.
- Difficult Child (DC)

  This subscale was derived from the child domain of the full length PSI; it dwells on the behavioral characteristics of the child that defines them as either easy or difficult to manage. The child behavioral characteristics includes temperament and learned patterns of defiant, non-compliant and demanding behaviors (27).

1.3.1.2 The scoring and interpretation of the PSI-SF

The PSI-SF is used widely by researchers as a screening tool for the identification of parent-child systems. It reveals systems which are under stress thus at risk of developing into dysfunctional parenting behaviors or child with behavioral problems.

The three subscales of the PSI-SF (PD, PCDI and DC) each have 12 items which the parent is required to rate from 1 (strongly disagree) to 5 (strongly agree). The item scores for each subscale are then added to give a resultant figure ranging from 12 to 60. The results of the subscales are added and the researcher ends up with the total parenting stress score (Total PSI-SF) ranging from 36 to 180.

The total parenting stress score indicates the level of stress a parent experiences from her parenting role and it does not include other additional life stressors. A high total score means that the subscales had high scores and that the parent has high stress levels. When interpreting the

scores, parents with a raw score of 90 and above are experiencing clinically significant stress levels and they should be referred for further professional management.

Analyses of the subscales scores, gives an indication of the probable causes for the high stress levels and assists in choosing the appropriate management for each parent as follows:

- High PD scale score means that the parent is in distress thus therapeutic services designed to improve the parent's self-esteem and level of adjustment is provided.
- High PCDI scale score means that the parent-child bond has not been established or it is weak and this poses as a risk for child abuse of which intervention is then urgently needed.
- High DC scale score means that the child has behavioral problems which the parent cannot cope with or the child has severe physical disabilities that the parent cannot handle. This type of parent-child system needs professional assistance.
- A parent who has a total score within the normal range but a single high subscale score also needs professional assistance (27).

It is also possible that the total PSI-SF score can be extremely low and that may be related to a dysfunction in the parent-child system. The PSI-SF Defensive Responding scale assesses the angle at which the parent approaches the questionnaire. Some parents portray themselves as coping very well with their disabled children thereby minimizing any indication of stress. A score of less than 10 on the defensive responsive scale suggests that there is one of the following possibilities:

- The parent is dishonest; they make themselves appear highly competent and free of stress.
- The parent is not invested in the role of parenting thus they do not experience the stressors associated with parenting a disabled child.
- The parent might be very competent in taking care of their disabled child due to a strong support system from the family and from extended support.

1.3.1.3 Conclusion

The PSI-SF derived from the full length PSI can be used by researchers and clinicians as a tool to identify parental stress in the parent-child system (27).

1.3.2 Gross Motor Function Classification System (GMFCS)

1.3.2.1 Development of the GMFCS

The GMFCS was produced for classification of motor disability of children with cerebral palsy between the ages of one to 14 years. CP children are classified up to five levels according to their self-initiated movements assessing their function of sitting and walking. The levels were classified based on their functional limitations, the need to use assistive technology for mobility (crutches, walkers or cranes) and the use of wheeled means of mobility.

This classification was meant to be easy and quick to use by reporting brief descriptions of each level and summarizing between each pair of levels. The researcher does not have to go through a long standardized assessment; they can just observe or use the reported motor functioning of the CP child. The child's development is not assessed in depth and only their gross motor function is classified into one of the five levels.

The classification of motor function is dependent on the age; especially in early childhood and for this reason a separate description for children in different age bands was done for each level (Appendix F). The classification should be evaluated according to the child's usual function in their daily environment (home, school and community). It should not be based on their best capacity (21).

1.3.2.2 Reliability and Validity

Modified nominal processes and Delphi survey methods were used to establish content validity on 28 physiotherapists and occupational therapists from three treatment centers in Ontario as well as on professionals in the field of developmental disability and CP from North America, Europe and Australia. These international groups of experts were unanimous in their agreement of a need for a classification system for children with CP based on their construct of disability and functional limitation. Their emphasis was on a classification that will describe the child's current

functional abilities to be able to assist families and professionals in planning for the child's needs and recommendations for the use of assistive technology. After the second round of the Delphi survey, there was a consensus agreement concerning the classification using levels and distinctions between them, including the age group of children suitable for the classification system (21).

Reliability ratings of children from five different treatment centers in Ontario were compared by two different therapists using inter-rater reliability. Kappa statistics were calculated as a measure of chance-corrected agreement. The kappa was 0.75 for children of two to 12 years, establishing moderate support for the overall reliability of the classification system (21).

1.3.2.3 Conclusion

The GMFCS was accepted as a valid and reliable tool in classifying the severity of motor disabilities of children with CP. It provides health care professionals with a consistency in terminology for CP disabilities and assists in the implementation of treatment outcome measures in research.

1.3.3 Functional Communication Classification System (FCCS)

1.3.3.1 Development of the FCCS

The FCCS was developed with a purpose to classify how children between the ages of 4 and 6 communicate daily. It focuses on how the child communicates rather than on how they should communicate. It is used for the following purposes:

- To share accurate information between parents of disabled children and health care providers.
- To identify communication resources, training and support services.
- To plan effective and specific training for the caregivers and teachers of disabled children.
- For research purposes, tracking the outcomes of interventions, educational programs and care plans (28).

Disabled children have factors which affect their ability to communicate of which these are: poor muscle control and strength, hearing and vision impairments, poor expressive and receptive skills, cognitive impairment and lack of motivation. For these reasons, they communicate with people they spend most of their time with and with people who understand their limited communication skills. Moreover, there is a high possibility that strangers might not understand their communication skills. In the same way, some disabled children communicate effectively when using Augmentative and Alternative Communication (AAC) strategies. AAC strategies include pictures, communication devices and signing systems.

As mentioned above, disabled children prefer using their unique communication systems with familiar people. The FCCS should reflect what the child usually does, even if the child can perform at a higher level with familiar people. When using the FCCS, the support the disabled child requires from the person they communicate with, is very important. The person they communicate with can be the caregiver, friend, peer, teacher or others. Some will need a lot of support while others will not need support.

The FCCS levels reflect the types of support from people communicating with the disabled children (Appendix G). It ranges from no support required (level 1) to total support required (level 5). A CP child who is classified as level 1 will have minimal or no difficulties when compared to normally developing children while a level 5 CP child needs total support.

1.3.3.2 Conclusion

The FCCS was established as valid and reliable tool to classify the communication ability of the CP child. It is used for research purposes, the development of care plans and implementation of interventions (28).

1.4 Problem statement

Few studies were done to measure the level of stress experienced by caregivers of children with cerebral palsy in SA.

It will be beneficial for the multidisciplinary team working with CP children, to know the level of stress experienced by their caregivers especially those with low socioeconomic status. This knowledge will guide us in providing maximum care to our CP children while equipping their caregivers with adequate resources and strength.

CHAPTER 2

METHODOLOGY

2.1 Aim of study

This study aimed to assess the stress levels experienced by primary caregivers from caring and raising their CP children.

2.1 Study objectives

- To assess the severity of CP in the different types, utilizing the GMFCS
- To assess the communication ability of a CP child, utilizing the FCCS
- To assess the stress levels of caregivers of children with CP, utilizing the PSI-SF
- To assess the association between the severity of CP, communication ability of the CP child and the stress levels of caregivers

2.3 Research design

The study was designed as a prospective, cross-sectional and descriptive study.

2.4 Location of study

The study was conducted at Chris Hani Baragwanath Academic Hospital (CHBAH) which is the largest hospital in Africa. The hospital is situated in the South Western Townships (SOWETO) of Johannesburg. It provides health care services for people of different socioeconomic status, with the majority of people from the low socioeconomic backgrounds.

2.5 Ethical clearance

Ethical clearance to conduct this study was approved unconditionally by the Human Research Ethics Committee of the University of the Witwatersrand. Clearance Certificate Number: M140407 (Appendix A). Permission to conduct the research at CHBAH was granted by the chief executive officer (CEO) of the hospital. Informed consent was signed by the study participants before starting with the data collection.

2.6 Study population

The study population includes caregivers who brought their children to the paediatric CP clinic at CHBAH on Tuesdays. It was a convenience sample of the first ten caregivers per clinic and their CP children between the ages of 1 and 14 years. The study was conducted over a period of three months from November 2017 to January 2018. The caregivers and their children were invited to participate in the study and they were given an information sheet. Those who agreed to participate in the study had signed consent forms.

2.7 Inclusion and Exclusion criteria

2.7.1 Inclusion criteria

The subjects were caregivers and their children who were:

- Between 1 and 14 years of age.
- Diagnosed as having CP by a paediatric neurologist.
- Attending the children's CP clinic at CHBAH.

2.7.2 Exclusion criteria

Subjects who were excluded from the study:

- Those who refused to participate.
- Adults who were not primary caregivers.
- The questionnaires were incompletely or incorrectly answered.

2.8 Study procedure

Each caregiver was seen individually by the researcher and research assistant nurse and informed about the study. They were given a document package labeled with a numerical code to preserve their confidentiality.

The document package included; an information sheet describing the details of the study, a consent form (translated in IsiZulu and Sesotho), a demographic questionnaire (Appendix B), a parenting stress index (PSI) sheet (Appendix C), a GMFCS questionnaire (Appendix D), a FCCS questionnaire (Appendix E), a GMFCS form (Appendix F) and FCCS form (Appendix G).

The caregivers who agreed to be study participants and had signed consent forms were encouraged to be relaxed and to be sincere in filling the questionnaires.

The researcher went through the questionnaires with the caregiver to make sure they understood everything in order to be able to complete the forms correctly.

The researcher assessed the CP children and classified the severity of motor function using the GMFCS questionnaire (Appendix D) and their communication functioning level was classified using the FCCS questionnaire (Appendix E).

2.9 Outcome measures

1. **The Demographic Questionnaire**

   The demographic questionnaire (Appendix B) was designed to provide details about the caregiver's marital status, education level, employment status and income per month. It further explored the involvement of family members; the number of other children in the family and the presence of other chronically ill members of the family. Other aspects looked at were; the employment status of the caregiver's partner, presence of a helper and availability of medical aid for the CP child.

2. **The Parent Stress Index- Short Form (PSI-SF)**

   The completed PSI form questionnaires (Appendix C) were scored and analyzed according to the PSI manual (27). The scores of each subscale (PD, PCDI, DC) were calculated for each of their 12 items and the values were added. Each participant then had a total score (PSI-SF Total) of the three subscales added. Interpretation according to the manual is that scores above 90 (raw score) for the Total PSI-SF should be indicative of clinically high level of stress within the parent-child system thus requiring professional intervention. Participants who scored above 90 raw score were referred to the CHBAH child and family unit (CAFU) in the Paediatric Psychiatry department for counseling and guidance in coping with stress.

3. **The Gross Motor Function Classification System (GMFCS)**

   The GMFCS was developed by Palisano et al in 1997 to classify the severity of the motor function of the CP child (Appendix F) and it has been used by researchers since then. The

researcher used it to classify the severity of the motor function of the children in this study, into level 1 to 5 as per their severity. It's a quick and easy to use classification based on the child's self- initiated movement during their daily functioning in their environment. The children's functional limitations, their need for assistive technology and mobility devices are the basis for the distinctions between their levels (21).

4. **The Functional Communication Classification System (FCCS)**

   It focuses on how the child communicates rather than on how they should communicate. The CP children have delayed speech compared to their healthy peers. The FCCS (Appendix G) thus classify the CP children based on the way they express themselves. They have limited communication skills and for this reason they tend to mostly communicate with people they are close to like family members of friends and they might not communicate with strangers. People familiar to the CP child learn to support them during their conversations and that level of support is the one used in the classification using the FCCS. It ranges from no support required (level 1) to total support (level 5). A CP child who is classified as level 1, will have minimal or no difficulties when compared to normally developing children while a level 5 CP child needs total support (28).

2.10 Statistical Analysis

Frequencies or percentages and means with standard deviations or medians with interquartile ranges were used to describe the demographic data. Medians with interquartile ranges were used to report the GMFCS and the FCCS data. The Chi-squared, Fischer exact or Mann-Whitney U test were used to compare the demographic variables, GMFCS and FCCS data with the levels of stress of caregivers (PSI). A p value of < 0.05 was considered significant.

CHAPTER 3

Results

There were a total of 80 participants and the median age of their primary caregivers was 36 (31 - 44) years.

As shown in table 3.1 below, the majority of caregivers (80%) had moderate degree of stress according to their parent stress index (PSI) scores and only 5 (6%) of the caregivers had severe PSI scores.

The majority of children (56%) were mixed type of cerebral palsy. The total number of quadriplegic (spastic, hypotonic and mixed) patients were 64 (80%) which was greater compared to diplegics and hemiplegics who were only 16 (20%).

The primary caregiver was the mother (90%) of whom more than half were single parents and majority had achieved a secondary level of education. Most of the caregivers were unemployed (77.5%) but majority received an income of R1500-R3000 from grants and other sources.

Only 4% of CP children were on medical aid and 5% had a helper at home to assist.

Table 3.1 Demographic information and characteristics of CP children and their caregivers

The different types of CP	**n (%)**
Spastic diplegic	7 (9)
Spastic hemiplegic	9 (11)
Spastic quadriplegic	9 (11)
Hypotonic quadriplegic	4 (5)
Dystonic quadriplegic	6 (7.5)
Mixed quadriplegic	45 (56)
Caregivers	
Mothers	72 (90)
Grannies	7 (9)
Aunts	1 (1)
Marital status	
Single	42 (53)
Married	17 (21)
Live in Partner	21 (26)
Educational level of caregiver	
Primary	6 (7.5)
Secondary	70 (87.5)
Tertiary	4 (5)
Employment status of the caregiver	
Fulltime	10 (12.5)
Part time	8 (10)
Unemployed	62 (77.5)
Employment status of the partner	
Fulltime	18 (22.5)
Part time	9 (11)
Unemployed	13 (16)
Missing	40 (50)
PSI (Mild, moderate, severe)	
Mild <90 (<50%)	11 (14)
Moderate 90-119 (50-66%)	64 (80)
Severe 120-180 (67-100%)	5 (6)
Income per month	
< 1500	1 (12)
1500-3000	54 (67.5)
3000-6000	16 (20)
6000-12000	7 (9)
>12000	2 (2.5)
Does the caregiver have other children? (YES/NO)	
Yes	66 (82.5)
No	14 (17.5)
Other family members with chronic diseases (Yes/No)	
Yes	21 (26)
No	59 (74)

Is the CP child schooling? (Yes/No)	
Yes No	45 (56) 35 (44)
Day scholar/Border?	
Scholar Border	40 (89) 5 (11)
Is there a helper?(Yes/No)	
Yes No	4 (5) 76 (95)
Is the CP child on medical aid? (Yes/No)	
Yes No	3 (4) 77 (96)

The median PSI score for all 80 caregivers was 108.5 (100.5-119.5). As shown in Table 3.2 below, there was no significant change in the PSI score as the GMFCS level increased however due to the small number of patients with FCCS levels; a meaningful comparison could not be made.

Table 3.2 GMFCS and FCCS levels of CP child and caregiver's PSI scores

GMFCS level	**Number of children** **n**	**PSI Score** **Median (IQR)**
I	0	0
II	16	105 (101-116)
III	8	114 (107-124)
IV	32	102 (94-119.5)
V	24	112 (106-118.5)
FCCS level		
I	1	108 (108-108)
II	2	94.5 (87-102)
III	3	90 (74-100)
IV	4	100.5 (83-117)
V	5	111 (109-119)

Table 3.3 below shows the factors affecting the PSI scores. The marital status of the caregiver was a significant factor influencing PSI scores. Married caregivers had lower stress levels (lower PSI scores) compared to single caregivers with higher PSI scores (p=0.01).

The caregiver and partner combined employment status was also a significant factor influencing PSI scores. When the primary caregiver alone was employed, they had higher stress levels (high PSI scores) compared to when both the primary caregiver and partner where either unemployed ($p=0.02$) or employed ($p=0.01$). However, the numbers of caregivers in each of these groups were small to suggest that this is a meaningful comparison.

The other factors such as education level of caregiver and partner, caregiver's income per month, whether the caregiver has other children or not and whether the CP child attends school or not had no impact on the stress level of the caregiver.

Table 3.3 Factors affecting PSI scores

Factors	n	PSI Score Median(IQR)
Marital status		
Single	42	111.5 (101-121)*
Married	17	102 (87-109)
Live in partner	21	111 (103-117)
Educational level of caregivers		
Primary	6	104 (93-120)
Secondary	70	109 (101-119)
Tertiary	4	114.5 (94.5-128.5)
Educational level of partner		
Primary	3	113 (112-120)
Secondary	30	103 (95-111)
Tertiary	5	110 (109-126)
Caregiver Employed		
Yes	18	104.5 (97-115)
No	62	109 (101-120)
Partner employed		
Yes	27	104 (98-112)
No	13	102 (95-117)
Employment status		
Partner only employed	21	108 (103-113)
Both unemployed	9	100 (82-111)**
Both caregiver and partner employed	6	96 (87-103)***
Caregiver only employed	4	114 (106-130)
Income per month		
< 1500	1	105 (105-105)
1500-3000	54	110.5 (101-119)
3000-6000	16	105.5 (88.5-119)
6000-12000	7	103 (98-126)
> 120000	2	94 (78-110)
Caregiver's other children		
Yes	66	108 (99-120)
No	14	111 (103-119)
Is the CP child schooling		
Yes	45	105 (98-117)
No	35	111 (101-120)

*p<0.01 between single and married

** p=0.02 between caregiver employed only and both caregiver and partner unemployed

*** p=0.01 between caregiver employed only and both caregiver and partner employed

CHAPTER 4

Discussion

Factors that significantly affected the high stress levels of primary caregivers of CP children are marital and employment status. Other socioeconomic factors such as caregiver education level, income level and the presence of other siblings in the family had no additive effect on increasing parenting stress levels. Married caregivers were found to have less stress compared to single caregivers. When the primary caregiver alone was employed they had high stress levels compared to when both caregiver and partner were either employed or unemployed. The severity of the child's cerebral palsy was found to be a non-significant confounding factor to levels of stress in primary caregivers which is in contrast with what was expected.

A large percentage of primary caregivers in this study, 86% had high stress levels. This is an important outcome which confirms that most primary caregivers of CP children are significantly affected by caring and raising their children. This study had a total study sample size of 80 caregivers and their CP children who were attending the paediatric CP clinic at CHBAH. This study sample size was greater in number to yield more meaningful results compared to Pugin's study which was done at the Frances Voorweg School in Southern Gauteng in South Africa, with a study sample size of only 35 caregivers and their CP children (19). In Pugin's study, the outcome was similar but a lower percentage (42.8%) of primary caregivers had high stress levels possibly due to a higher socioeconomic status (19). This study population was black caregivers residing in the township areas surrounding CHBAH. They were unemployed (78%) and represented the lower socioeconomic income group as 88.5% earn less than R6000 per month. These parents emphasized that their inability to support their children financially in the way they wished to, increased their levels of stress. In comparison to Pugin's study; which included all the racial groups and represented the broad urban population of South Africa; the study population consisted of a combination of the lower and middle working class groups (19) thus the majority of them had no stress from financial burdens.

.

This study illustrated that married caregivers had less stress levels (lower PSI scores) compared to single caregivers with high stress levels (higher PSI scores) (p=0.01). The possible postulated reasons for married caregivers to have a lower stress level was that they had constant support from their partners in all aspects of their lives (emotional, practical and financial) and this made the task of caring for their CP child much easier. In contrast, the single caregivers lacked support from their partners. Some of them mentioned that they sometimes get assistance with their CP children from their extended family members (grandparents and aunts) but the absence of constant support from a partner impacted on their stress and increased their stress levels. McCubin et al. also conducted a study that concluded that single mothers of CP children had high levels of stress due to lack of support from a partner (22).

Married caregivers were content with themselves and at peace with raising and taking care of their CP children. Single caregivers reported that they felt worthless and unwanted along with their CP children because they were rejected by their partners. A few single caregivers had suicidal thoughts and felt that they were not coping in raising their children. These caregivers were immediately referred for parental counselling in the psychiatry department. The limitation of this study is that the above reasons for the differences in the levels of stress between single and married caregivers were not qualitatively assessed.

The caregiver and partner's combined employment status was also a significant factor affecting parenting stress levels. When the primary caregiver alone was employed, they had high stress levels compared to when both the primary caregiver and partner where either unemployed (p=0.02) or employed (p=0.01). The employed primary caregiver was faced with a task to run the day to day functioning of their family, ensuring that basic needs are met while taking care of their CP child. They also had to prove to be productive at work by performing at their utmost best then return home daily to resume the caregiver's duties alone. That was a heavy task for one person to fulfill. Some of them mentioned that they were thinking of leaving their jobs to stay at home to relieve the stresses related to work. On the other hand, when both the primary caregiver and partner were employed, they shared the responsibility of managing their families and the household; ensuring that basic needs are met in addition to taking care of their CP child. The primary caregiver did not feel overwhelmed and burdened by facing all these responsibilities alone. When the primary caregiver and partner were both unemployed, the constant presence of

the partner was a relieving factor to the primary caregiver. Knowing that they are not alone in raising their CP children irrespective of being unemployed, gave them peace and contentment.

Dambi et al. conducted a study which concluded that unemployed caregivers of CP children had lower levels of stress (30). They found that unemployed parents have more contact time with their CP child and thus increases their bonding and subsequently these parents felt that care-giving their CP child is a blessing and not a burden (30).

The GMFCS was used to classify the CP child's motor function severity and the children were classified into five levels, with increasing severity from level one to five. The median PSI score for all 80 caregivers was 108.5 (100.5-119.5) and there was no significant change in the stress levels (PSI scores) as the GMFCS level increased. The severity of the CP child's function did not increase parental stress as would be expected.

The caregivers of severe CP children reported that knowing and understanding their children's condition empowered them to accept and manage their children to the best of their abilities. They appreciated the input of the multidisciplinary team for teaching them about CP and involving them as primary decision makers in the management of their children. This important factor alleviated their stress, which they reported to be significantly greater before they knew their children's condition.

Pugin also investigated the relationship between the severity of cerebral palsy functioning in these children and the level of stress experienced by their parents (19). The GMFCS was also used as a tool to measure the severity of CP and PSI scores used to measure parents stress levels. Level one to three of the GMFCS was of minimal severity, grouped as group one and level four and five was of maximum severity, grouped as group two. The parents' PSI scores in the two groups were compared and similarly to this study; there was no significant difference between the two groups ($p=0.73$) (19). The outcome in both studies is that the severity of motor disability in CP children, measured by the GMFCS does not affect parental stress. Pugin attributed the results to the fact that the study sample was small with the very severe CP children (levels 5) being only 3 and had to be combined in one group with level 4 children who were also 3 children thus a total of 6 children(19). Although the study population size was higher in this study, the findings were similar with no differences noted in PSI scores and severity of GMFCS levels.

The FCCS was used to classify the communication ability of the CP child according to the level of support the child needs from the person they converse with. The FCCS is used in children between the ages of 4 to 6 years and unfortunately this age group of CP children collectively was a small number of the study sample (17 children); thus a meaningful comparison could not be done.

Virella et al. conducted a study and looked into the classification systems of communication for use in an epidemiological surveillance of children with cerebral palsy (29). Three systems were used to classify communication: the communication function classification system (CFCS), the Viking speech scale (VSS) and the FCCS. These systems were used in 155 children aged 4 to 13 years with cerebral palsy from eight European countries. Test-retest stability was moderate to high for VSS (k=0.66-0.88), CFCS (k=uncomputed-0.910) and FCCS (k=0.52-0.91). The overall outcome was fair to very good for every classification system, with the FCCS covering the 4 to 6 year olds however; the VSS was considered the easiest instrument to use (29). In retrospect, the VSS would have been a more suitable tool to use to assess the communication ability of the children in this study because it covers a broader range of children from 4 to 13 years of age.

Some caregivers of the children who had no expressive speech at all and no use of gestures to express themselves, were asked how they knew if their children's needs were met. They reported that they had developed a well-regulated routine of taking care of their children. They said that they feed, bath, give medication and perform other parental duties routinely and they believed that their children were satisfied with the care they received.

Implications of the study findings for clinical practice

Primary caregivers involved in this study appreciated the benefits of understanding CP and being engaged by the multidisciplinary team in managing their children. They felt empowered and in charge of taking care of their disabled children. This is a call for all health care providers working with CP children to keep improving their knowledge and to be up to date with CP management to be able to keep imparting their knowledge to the caregivers.

Single caregivers had high levels of stress irrespective of them being employed or not, this calls for social support for them. Skok et al. concluded that the caregivers who received social support experiences lower levels of stress (16). Social support can be through support groups locally

where the caregiver can access them easily and home- based therapists who visit the homes to render family centered therapies for the CP child can also be very helpful.

Limitations encountered in the study

- The study population consisted of caregivers of the black ethnic group only. This means that the researcher had no perspective of how other ethnic groups cope with their CP children. From this study, it appeared that black caregivers who had extended families received a substantial amount of social support from their extended family network and whether the same applies to other ethnic cultures is not known.
- Most participants were from a low socioeconomic background. Majority of the primary caregivers (78%) were unemployed and only 18 (22%) employed in the lower and middle working class. There is no data from primary caregivers of the higher working class and whether they have any stressors related to caring for a CP child.
- The majority of CP children in the study consisted of quadriplegics (80%) and a smaller percentage of diplegics and hemiplegics (20%). This imbalance of the types of CP might have led to the poor correlation between motor severity of the CP child or GMFCS and parental stress levels.
- The FCCS as a communication measuring tool which only covered the 4 to 6 year olds was used instead of the VSS which would have covered the broader age range from 4 to 13 years and would have been more beneficial to utilize.

Recommendations based on findings

Larger studies including the different ethnic and cultural groups of South Africa will be beneficial in detecting varying parental stress levels and should also include participants from different socioeconomic backgrounds thus the impact of these different factors can be more reliable.

It will also be beneficial to have a balanced group of all types of CP children to be able to assess the impact of severity of the CP child on parental stress levels rather than having only the severe types of CP children to report on. Future researches might elicit significant results if they use the VSS as a communication measuring tool rather than using the FCCS.

CHAPTER 5

Conclusion

This study investigated the level of stress experienced by primary caregivers of children with cerebral palsy. The severity of the motor function and communication function of the CP child were assessed in comparison to the parental stress levels.

The following conclusions were drawn from the results of the study:

1. The parenting stress levels (assessed by PSI-SF) were generally higher in a majority of caregivers of children with CP (86%) attending the CP clinic at CHBAH.
2. The stress level of primary caregivers is not influenced by the motor or communication severity of the CP child, as assessed using the GMFCS and the FCCS.
3. Marital status is one of the demographic variables that impacts on parental stress as married caregivers were found to be less stressed compared to single caregivers.
4. When both the primary caregiver and their partner were employed or not; they had lower stress levels than compared to when the primary caregiver was the only one employed.

Family centered approach of the management of a child with CP is the best way to help minimize parental stress. Primary caregivers need social support to be able to maintain their physical and mental wellbeing and that is evident in the results of this study illustrating that married caregivers have less stress than their single counterparts.

REFERENCES

1. Morris C. Definition and classification of cerebral palsy: a historical perspective. Developmental Medicine & Child Neurology. 2007;49(s109):3-7.
2. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics. 2005;115(6):e626-e36.
3. Raina P, O'Donnell M, Schwellnus H, Rosenbaum P, King G, Brehaut J, et al. Caregiving process and caregiver burden: conceptual models to guide research and practice. BMC pediatrics. 2004;4(1):1-13.
4. Blacher J. Severely handicapped young children and their families: Research in review. Print book : English ed: Orlando: Academic Pr; 1984. 449 p.
5. Schieve LA, Blumberg SJ, Rice C, Visser SN, Boyle C. The relationship between autism and parenting stress. Pediatrics. 2007;119(Supplement 1):S114-S21.
6. Weiss SJ. Stressors experienced by family caregivers of children with pervasive developmental disorders. Child Psychiatry & Human Development. 1991;21(3):203-16.
7. Holroyd J, Brown N, Wikler L, Simmons JQ. Stress in families of institutionalized and noninstitutionalized autistic children. Journal of Community Psychology. 1975;3(1):26-31.
8. Hedov G, Annerén G, Wikblad K. Self-perceived health in Swedish parents of children with Down's syndrome. Quality of life research. 2000;9(4):415-22.
9. Emerson E. Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. Journal of intellectual disability Research. 2003;47(4-5):385-99.
10. Pousada M, Guillamón N, Hernández-Encuentra E, Muñoz E, Redolar D, Boixadós M, et al. Impact of Caring for a Child with Cerebral Palsy on the Quality of Life of Parents: A Systematic Review of the Literature. Journal of Developmental & Physical Disabilities. 2013;25(5):545-77.
11. Guyard A, Fauconnier J, Mermet M-A, Cans C. Impact sur les parents de la paralysie cérébrale chez l'enfant: revue de la littérature. Archives de pédiatrie. 2011;18(2):204-14.
12. Wang H-Y, Jong Y-J. Parental stress and related factors in parents of children with cerebral palsy. The Kaohsiung Journal of Medical Sciences. 2004;20(7):334-40.
13. Byrne M, Hurley D, Daly L, Cunningham C. Health status of caregivers of children with cerebral palsy. Child: care, health and development. 2010;36(5):696-702.

14. Unsal-Delialioglu S, Kaya K, Ozel S, Gorgulu G. Depression in mothers of children with cerebral palsy and related factors in Turkey: a controlled study. International Journal of Rehabilitation Research. 2009;32(3):199-204.
15. Button S, Pianta RC, Marvin RS. Partner support and maternal stress in families raising young children with cerebral palsy. Journal of Developmental and physical disabilities. 2001;13(1):61-81.
16. Skok A, Harvey D, Reddihough D. Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. Journal of Intellectual and Developmental Disability. 2006;31(1):53-7.
17. Wanamaker CE, Glenwick DS. Stress, coping, and perceptions of child behavior in parents of preschoolers with cerebral palsy. Rehabilitation Psychology. 1998;43(4):297-312.
18. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. Developmental medicine and child neurology Supplement. 2007;109:8-14.
19. Pugin A. The relationship between severity of cerebral palsy in children and the levels of stress experienced by their parents. Johannesburg, South Africa: University of the Witwatersrand; 2007.
20. Abidin RR. The Determinants of Parenting Behavior. Journal of Clinical Child Psychology. 1992;21(4):407-12.
21. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Developmental Medicine and Child Neurology. 1997;39(4):214-23.
22. McCubbin MA. Family stress and family strengths: A comparison of single- and two-parent families with handicapped children. Research in Nursing & Health. 1989;12(2):101-10.
23. Pearson V, Chan TWL. The relationship between parenting stress and social support in mothers of children with learning disabilities: A Chinese experience. Social Science & Medicine. 1993;37(2):267-74.
24. Schor EL. Family pediatrics: report of the Task Force on the Family. Pediatrics. 2003;111(6 Pt 2):1541-71.
25. Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H. Predictors of Stress in Mothers of Children With Cerebral Palsy in Bangladesh. Journal of Pediatric Psychology. 2000;25(6):427-33.

26. Manuel J, Naughton MJ, Balkrishnan R, Paterson Smith B, Koman LA. Stress and adaptation in mothers of children with cerebral palsy. Journal of Pediatric Psychology. 2003;28(3):197-201.
27. Abidin RR. Parenting Stress Index: Professional manual. Lutz, FL: Psychological Assessment Resources, 1995.
28. Barty E, Caynes K, Johnston LM. Development and reliability of the Functional Communication Classification System for children with cerebral palsy. Developmental Medicine and Child Neurology. 2016;58(10):1036-41.
29. Virella D, Pennington L, Andersen GL, Andrada Mda G, Greitane A, Himmelmann K, et al. Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy. Developmental Medicine and Child Neurology. 2016;58(3):285-91.
30. Dambi JM, Jelsma J, Mlambo T. Caring for a child with Cerebral Palsy: The experience of Zimbabwean mothers. African Journal of Disability. 2015;4(1):168.

APPENDICES

Appendix A Ethics Approval Certificate

R14/49 Dr Mmathuto Mandy Molokomme-Radebe

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140407

NAME: (Principal Investigator)	Dr Mmathuto Mandy Molokomme-Radebe
DEPARTMENT:	Paediatrics Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	The Level of Stress of Caregivers of Children with Celebral Palsy and Autistic Spectrum Disorders
DATE CONSIDERED:	25/04/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Kebashini Thandrayen and Prof John Rhoda
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	30/10/2017

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review April and will therefore be due in the month of April each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date 31/10/2017

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B: Demographic questionnaire

DEMOGRAPHIC QUESTIONNAIRE

Study number: _____

Please circle the appropriate response where applicable:

1) Sex: Female Male
2) Age: _____Years
3) Marital status? Single Married Divorced Live in Partner
4) Highest education level achieved by:

Yourself :		Your partner/spouse :	
Matric Certificate		Matric Certificate	
Diploma		Diploma	
Degree		Degree	
Other		Other	

5) Are you employed? Yes No
   is your partner employed? Yes No
6) If your answer is yes do you work: part-time or full-time
   If your partner works does he/she do so: part-time or full-time
7) What is your occupation? _____
   What is your partner's occupation? _____
8) What is the approximate household income for the month?

R1500 – R3000	
R3000 – R6000	
R6000 – R12000	
Other	

9) Do you have any other children? Yes No
   If your answer is yes please provide their ages and medical conditions if they have any

Age	Medical Condition

10) Does your child who has cerebral palsy suffer from any other medical conditions for example asthma or epilepsy? Yes No

If your answer is yes please specify: _____

11) Is your child on any chronic medication? Yes No

If your answer is yes please specify :

Chronic Medication	Number Of Times Per Day

12) Do you or anyone else in your family suffer from any chronic illness or disability: Yes No If your answer is yes please specify :

Family Members	Chronic Illness / Disability

13) Are you and your family members of a medical aid? Yes No

14) Does your child go to school? Yes No

How far from school do you live? _____

15) Do you have your own transport or do you rely on public transport? _____

16) Is your child in the hostel or a day scholar? _____

17) Do you employ someone to help care for your disabled child's needs on a regular basis?

Yes No

Appendix C Parenting Stress Index-Short Form

Parenting Stress Index-Short Form

Study number: _____

Child's gender: _____

Child's age: _____

Today's date: _____

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 this child'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 this 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 this child has caused more problems than I expected in my relationship with my spouse (or male friend/ 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) This child rarely does things for me that make me feel good**.**

SA A NS D SD

14) Does this child understand you and others?

SA A NS D SD

15) a. My child smiles at me much less than expected and communicates much less.

SA A NS D SD

16) b. When I do things for my child, I get the feeling that 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) There are activities your child can do.

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 choice "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.

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 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.

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

Think carefully and count the number of things which your child does that bother you.

10+ 8-9 6-7 4-5 1-3

For example: dawdles, refuse to listen, overactive, cries, interrupts, fights, whines, etc.

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 expected.

SA A NS D SD

36) My child has more demands on me than most children.

SA A NS D SD

Appendix D GMFCS questionnaire

Gross Motor Functional Classififcation System

The GMFCS Questionnaire

Level 1 (Walks without limitations)		
	YES	NO
1. Does your child have any limitation when walking?		
If yes :-		
Level 2 (Walks with limitation)		
	YES	NO
1. Does your child get tired when walking long distances?		
	YES	NO
2. Does he/she have a problem with balance?		
	YES	NO
3. Does he/she need a hand-held device or was it used previously while learning to walk?		
	YES	NO
4. Does he/she have a problem walking up and down stairs?		
	YES	NO
5. Is he/she capable of good running and jumping?		
Level 3 (Walks with hand held devices)		
	YES	NO
1. Can your child sit on his/her own without help?		
	YES	NO
2. Does he/she request some external support to sit?		
	YES	NO
3. Can he/she stand indepedantly?		
	YES	NO
4. Does he/she use a hand-held mobility device?		
level 4 (Sits supported , uses a wheelchair or powered mobility)		
	YES	NO
1. Does your child function only in a supported seated position?		
	YES	NO
2. Do you have to carry your child to move your child?		
	YES	NO
3. Does he/she us a normal wheelchair?		
	YES	NO
4. Does he/she use powered mobility?		
level 5 (Transported in a wheelchair)		
	YES	NO
1. Does your child have control over head and trunk?		
	YES	NO
2. Do you always have to carry your child to move them?		
	YES	NO
3. Does your child use a wheelchair?		
	YES	NO
4. Does your child need extensive assisted technology?		

Appendix E FCCS questionnaire

Funtional Communication Classification System

Prompt Question to Help Discrimination Between Levels

Level 1

	YES	NO
1. Do others ***easily understand*** the child?		
2. Does the child ***begin a conversation*** with a peer/friend orb adult without help or prompting?		
3. Does the child get their messege across ***without*** extra help?		
4. Is the child ***aware*** of the listener's understanding and do they repeat themselves and try again when not understood?		
5. Does the child communicate independently about things or events that are not present?		
6. Does the child communicate a ***variety of meanings*** ?		
7. Does an ***unfamiliar person*** need to ask prompting questions to understand the child's meaning?		

Level 2

	YES	NO
1. Does the child use a ***means of communication*** that others ***easily understand*** mostly ***independently*** ?		
2. Does the child communicate about things ***that have happened or will happen*** (not present) with some support?		
3. Does the child ***have another try when they are not understood*** ?		
4. Does an ***unfamiliar person*** need to ***rely partially*** on a ***familiar person*** to understand a child's meaning?		
5. Do the child's friends/peers need help from a familiar person to interpret the child's meaning?		

LEVEL 3		
	YES	NO
1. Is the child ***beginning to use a means of communication*** with ***some ability*** that is readily understood by others who know the system or can work it out?		
	YES	NO
2. Does the child have a ***means of communication*** that others can figure out from the environment or the situation?		
	YES	NO
3. Does the child use a reliable yes/no response?		
	YES	NO
4. Does the child indicate their ***immediate needs, wants, likes/dislikes,for things/activites happening*** around them?		
LEVEL 4		
	YES	NO
1. Does the child ***attempt to initiate or respond*** to conversation with another person?		
	YES	NO
2. Does the child ***focus their attention on the other person*** when they are communiacting?		
	YES	NO
3. Does the child give a ***response*** that can ***mostly be understood*** when given ***choices*** between objects or activities?		
	YES	NO
4. Does the child use body movement, facial expression, vocalisation and/or gesture to show they understand conversation relating to daily activities and settings, family members and news?		
	YES	NO
5. Does the child show potential to use, a "means of communication" that can be understood by others which has not yet been established due to accessing difficulties? Or has the child started to learn butis successful mostly with familiar people?		
LEVEL 5		
	YES	NO
1. Is the child an "Unintentional Communicator"?		
	YES	NO
2. Does the child show happiness or sadness/discomfort but rely totally on a familiar person to interpret more specific needs based on that person's knowledge of the child, the environment and child's usual routine?		
Does the listener need to know:		
	YES	NO
* The child's usual daily activities and/or changes to these to figure out the child's needs and/or behaviour?		
	YES	NO
* The child's likes and dislikes to figure out the child's responses and behaviour?		
	YES	NO
* What has recently occurred to help problem solve what the child may be communicating?		
	YES	NO
* The child's physical status and movement patterns to interprete the child's responses or behavior?		

Appendix F GMFCS Form

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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Appendix G FCCS Form

Cerebral Palsy League

the centre for cerebral palsy

Functional Communication Classification System

Prompt Questions to Help Discriminate Between Levels

Level I

- Do others ***easily understand*** the child?
  The child may stutter or have some speech errors but others can understand them without extra help.
- Does the child ***begin a conversation*** with a peer/friend or adult without help or prompting?
  The other person may either be familiar or unfamiliar with the child. Familiar people include friends and family. Unfamiliar people include people in the community such as doctors, nurses, and receptionists who don't know or see the child often.
  For example: The child without prompting starts a conversation with a kindy teacher or another child to tell about their birthday.
- Does the child get their message across ***without*** extra help?
  It is okay if they are successful even if they stutter or say one or two sounds wrong but are still understood; it is not okay if these minor difficulties mean the listener loses interest, for example if it takes too long, or needs help to understand.
- Is the child ***aware*** of the listener's understanding and do they repeat themselves and try again when not understood?
  For example: The child repeats, talks louder, gives extra information and/or persists enough to get the message across.
- Does the child communicate independently about things or events that are not present?
  *For example: The child communicates about things or events **other than** what is happening **immediately** around them. This includes topics such as their favourite TV show or DVD, friends/family/pets, as well as places they have recently been or are going to such as child care, birthday parties.*
- Does the child communicate a ***variety of meanings***?
  For example: The child makes comments, describes things, asks question, gives directions and uses speech in pretend play.

If "no" to ANY, go to Level II →

- Does an ***unfamiliar person*** need to ask prompting questions to understand the child's meaning?
  For example: The listener looks to a parent or friend to confirm or clarify what the child is saying, or check a topic.

If "yes", go to Level II →

Level II

- Does the child use a ***means of communication**** that others ***easily understand*** mostly ***independently***?
  The child may need some help to set up the device. This help could be to put the device/book or switch in front of the child for a conversation, or to programme an electronic device, add pictures or words to a communication book.
  The child may be a competent signer but require assistances to interact with an unfamiliar person.
- Does the child communicate about things ***that have happened or will happen*** (not present) with some support?
  For example: The child uses gesture/picture board/SGD to refer to a person who is not present; The child tells the teacher, after prompting from their parent, about the party on the weekend; The teacher asks the child "leading" questions to get the child started.
- Does the child ***have another try when they are not understood***?
  For example: The child may repeat or persist to get the message across. They may need questions or prompts by the listener.

If "no" to ANY, go to Level III →

- Does an ***unfamiliar person*** need to ***rely partially*** on a ***familiar person*** to understand a child's meaning?
- Do the child's friends/peers need help from a familiar person to interpret the child's meaning?

If "yes", go to Level III →

**The "means of communication" could be speech or alternative and augmentative*

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Level III

- Is the child ***beginning to use a means of communication**** with ***some ability*** that is readily understood by others who know the system or can work it out?
  The listener may need to hold or set up the system. The listener may need to help by saying the child's message out loud.
  For example: A child makes a rocking motion with her arms, which means different things depending on the situation. At preschool this may indicate a desire to play with a doll but at the health centre it may be to draw her mother's attention to a mother holding a baby.

- Does the child have a ***means of communication**** that others can figure out from the environment or the situation?
  The child may use some speech sounds, words, or vocalising, facial expressions, body movements, and gestures, including pointing using hand or eye gaze, and/or some hand signs.
  For example: The child raises a hand to gain attention. The child looks at the teacher and at the drink at lunch time to indicate that they want the drink first. The child raises their fist to their mouth to indicate that they are hungry or thirsty.

- Does the child use a reliable yes/no response?

- Does the child indicate their ***immediate needs, wants, likes/dislikes, for things/activities happening around them***?
  The child may communicate about things in the "here and now" such as that they are thirsty, hungry, finished, that they want more, or that someone is doing something funny or naughty.
  For example: The child draws attention to something happening in the classroom by vocalising and pointing, but they do not retell the event later without support from another person who was also there.

If "no" to ANY, go to Level IV →

- Does an ***unfamiliar person*** need ***to rely mostly on a familiar person*** to interpret the child's meaning?

If "yes", go to Level IV →

Level IV

- Does the child ***attempt to initiate or respond*** to conversation with another person?
  This may be a social greeting or about things happening around them. The child may use methods such as vocalisations, facial expression and/or body movements.

- Does the child ***focus their attention on the other person*** when they are communicating?

- Does the child give a ***response*** that can ***mostly be understood*** when given ***choices*** between objects or activities?
  The child's response may be an emerging way to indicate "yes or no", and be given in response to the person offering the choice.
  *For example: The child may use facial expression, body gesture or movement, happy versus upset vocalisation, or a smile versus turning away in **response to being offered** a drink.*

- Does the child use body movement, facial expression, vocalisation and/or gesture to show they ***understand conversation*** relating to daily activities and settings, family members and news?
  (The conversation relates to familiar daily routines and in familiar settings such as home, child care and/or preschool)

- Does the child show potential to use, a "means of communication" that can be understood by others which has not yet been established due to accessing difficulties? Or has the child started to learn but is successful mostly with very familiar people?
  (Familiar people will be a parent and/or those introducing the system such a therapist, or teacher who has knowledge of both the child and the developing system.)

If "no" to ANY, go to Level V →

- Does an unfamiliar person need to rely totally on a familiar person to interpret the child's meaning?
  The listener needs specific knowledge of the child's communication, general skills and daily activities.

If "yes", go to Level V →

Level V

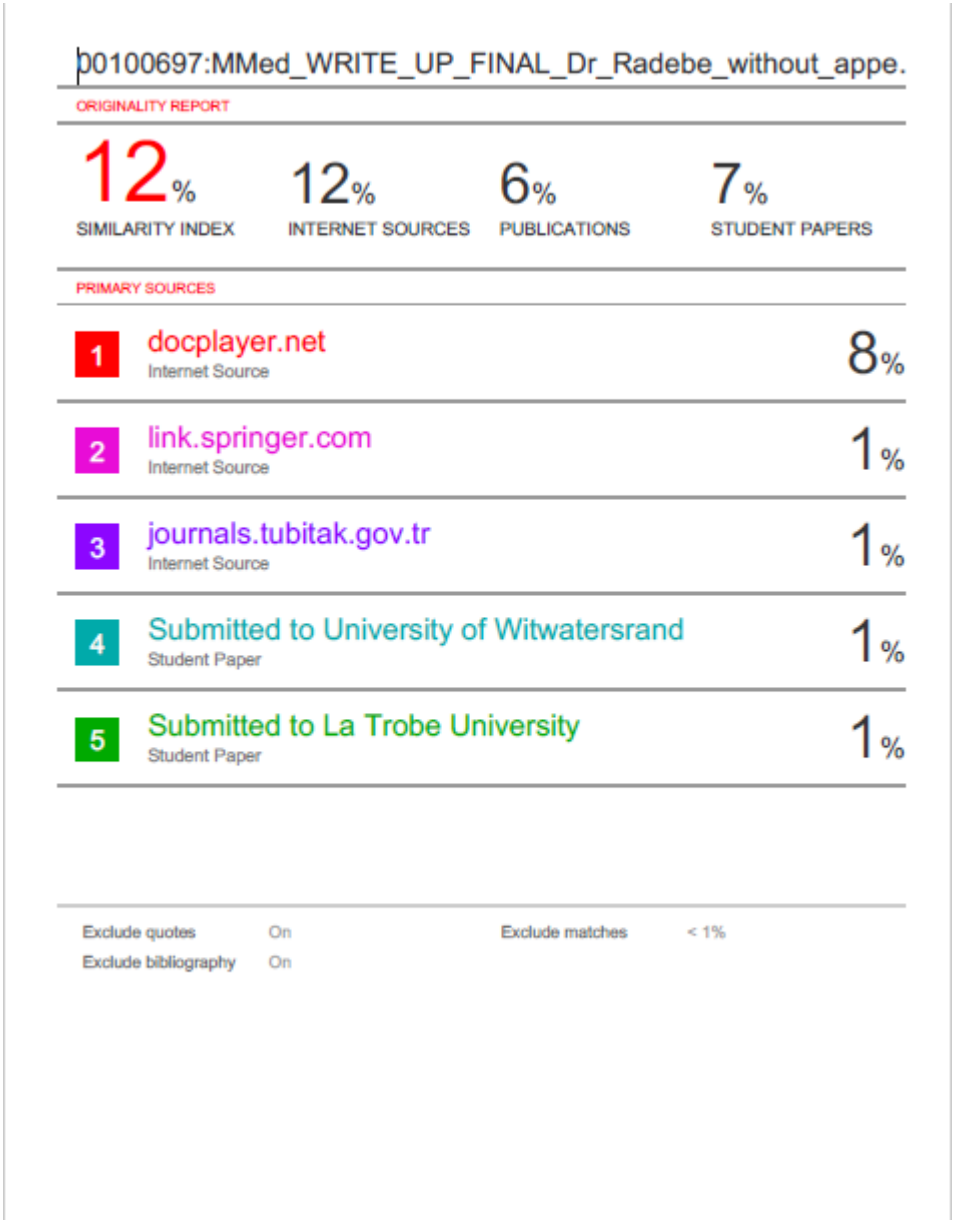
- Is the child an "Unintentional Communicator"?

- Does the child show happiness and sadness/discomfort but rely totally on a familiar person to interpret more specific needs based on that person's knowledge of the child, the environment and the child's usual routine?
  The child may react to things that happen to them such as experiencing movement, pain or hunger, and sometimes things that happen around them.
  For example: The child is restless, and vocalising, while looking generally around the room, at 11:30am so the teacher knows she is probably hungry, and at 3:00 in the afternoon so her carer knows to reassure that her drink is on the way.

- Does the "listener" need to know:
  - the child's usual daily activities, and/or changes to these to figure out the child's needs and/or behaviour?
  - the child's likes and dislikes to figure out the child's responses or behaviour?
  - what has recently occurred to help problem solve what the child may be communicating?
  - the child's physical status and movement patterns to interpret the child's responses or behaviour?

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Appendix H Turnitin report



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ORIGINALITY REPORT

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