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PARENTS'/CAREGIVERS' AND REHABILITATION PROFESSIONALS' PERSPECTIVES OF OCCUPATIONAL PERFORMANCE OF CHILDREN WITH CEREBRAL PALSY: A COMPARATIVE STUDY

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A research report submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy

Johannesburg,

April 2017

Declaration

I, Beniginer Chigonda declare that this research report is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



18th April 2017

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Dedication

I dedicate this research report to all the children with disabilities, for whom I strive to make a difference to their quality of life through lessons learnt from this research.

Acknowledgments

I would like to express my heartfelt gratitude to the following individuals and organizations who contributed immensely to this research in various ways:

Mrs Denise Franzsen for her supervision and mentoring.

All children with cerebral palsy who participated together with their

Mr Henry Mandishona of Premier Rehabilitation Services for granting permission for me to carry out part of the data collection at their institution.

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All occupational therapists and physiotherapists who participated by assessing and completing the Paediatric Evaluation of Disability Inventory for the participating children.

My husband Tatenda and daughters Shingirai and Yanai for their love and support throughout the course of my studies.

Abstract

The study sought to compare the caregivers' evaluation of the occupational performance and assistance needed by children with cerebral palsy (CP) to that of treating therapists to ascertain agreement about the children's strengths/weaknesses so goals for intervention can be set. The Paediatric Evaluation of Disability Inventory (PEDI) parent/caregiver and therapist scores of 50 children with CP in Harare aged four to six and half years were analysed. The association between PEDI scores and the Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) levels as well as the internal consistency of the PEDI for this sample were also determined.

Correlations for the caregivers' and therapists' scores on the PEDI were strong to excellent. A marked decrease in functional skills on the PEDI was noted in relation to the GMFCS and MACS levels with a negative moderate correlation between the PEDI scores and the GMFCS levels for self care, a negative strong correlation for mobility but a negative weak correlation for social function. The similarity of scores indicates positive correlation that allows for collaborative goal setting and Family Centred Therapy with these children. Internal consistency was excellent for all functional skills domains and caregiver assistance.

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Definition of Terms

Cerebral palsy- “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 foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum, Paneth, Leviton, Goldstein, Bax, Damio *et al*., 2007:8).

Functional Skills- refer to a child’s ability to perform essential activities of daily life in the child’s natural environment (Haley, Andrellos, Coster, Haltiwagner & Ludlow, 1992:6).

Caregiver- Relatives, friends and neighbours who assist with activities of daily living and complex health care needs that were once the domain of trained hospital personnel (Levine, Reinhard, Feinberg, Albert, Hart (2003). In the current research this refers to parents either mother or father or any person who normally cares for the child with CP at home

Caregiver assistance- is the amount of help children with CP need to carry out functional activities in typical daily situations. Caregiver assistance provides a general assessment of independence (Haley, Andrellos, Coster, Haltiwagner & Ludlow, 1992:15)

Gross Motor function- is self initiated movement with particular emphasis on sitting, trunk control and walking (Palisano, Rosenbaum, Bartlett, & Livingston, 2007).

Mobility- is the ability to move in one’s environment with ease with or without the use of adaptive equipment (Haley,Andrellos, Coster, Haltiwagner & Ludlow, 1992:11).

Social skills- are the skills and behaviours concerned with the way people live with others in the community and they are relevant and necessary for participation in one's family and culture (Haley,Andrellos, Coster, Haltiwagner & Ludlow, 1992:12).

Personal activities of daily living - are the day to day tasks typically performed for self care (James, Ziviani, & Boyd, 2014).

Abbreviations

ADL	Activities of Daily Living
CP	Cerebral Palsy
FCFT	Family-Centred Functional Therapy
FIM	Functional independence Measure
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
IADLs	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
MACS	Manual Ability Classification
OTPFIII	Occupational Therapy Practice Framework III
PADL	Personal Activities of Daily Living
PEDI	Paediatric Evaluation of Disability Index

CHAPTER 1: INTRODUCTION

1.1 Introduction

Occupational performance is the process of carrying out all tasks that form the basis of what an individual does in their day-to-day lives (Miller, 2003). It is highly dependent upon the setting and social expectations (Haley, Andrellos, Coster, Haltiwagner & Ludlow, 1992). For children with disabilities, Activities of Daily Living (ADL) skills are delayed and do not occur at expected ages because they follow different developmental trajectories in response to the disturbances that they have suffered (Ketelaar, Gorter, Westers, Hanna, & Verhoef, 2014).

"(CP) is the most common physical disability of childhood with a prevalence of approximately 2 cases per 1000 live births" (McAdams and Juul, 2011:564). Affected children often rely on caregivers for participation in their occupational performance including basic everyday self care activities like washing and dressing as well as functional mobility. They need special care, training and support in order for them to learn to function and become as independent as possible. Other occupational performance areas including play and social participation are also affected (Yalon-Chamovitz, Selanikyo, Artzi, Prigal, & Fishman, 2010). The GMFCS (Palisano, Rosenbaum, Bartlett, & Livingston, 2007) and the MACS (Eliasson, Krumlinde-Sundholm, Rösblad, Beckung, Arner, Öhrvall, & Rosenbaum, 2006) are two scales commonly used to classify the severity of the mobility and hand function deficits of children with CP respectively. Developmental patterns differ for children at different disability levels as measured by the GMFCS (Ketelaar *et al*., 2014).

The GMFCS and MACS functional classifications have been recommended as good indicators of mobility and manual function of children with CP respectively (Chagas, Defilipo, Lemos, Mancini, Frônio & Carvalho, 2008). Chagas *et al*. (2008) suggested that it is necessary to identify and compare the information made available by the classification systems to that by functional tests to ascertain if they show any relationship which can be utilised in intervention planning. Majority of the studies done

so far regarding this relationship have been done in developed countries and none have been done in the context of the current research.

These classifications allow therapists and caregivers to take the severity of CP into account and work as a team for effective management of children with CP to achieve the best outcomes in terms of independence in occupational performance for each child (Rich, Rigby, & Wright, 2013). It has been noted in a previous study that mothers and therapists may disagree on the evaluation of performance of children with CP (Elad, Barak, Eisenstein, Bar, Givon, & Brezner, 2013) but the importance of caregiver involvement in the evaluation of children cannot be ignored especially considering the importance of Family Centred Functional Therapy (FCFT) where caregivers and therapists have to work in collaboration to come up with child's strengths and weakness, analyse the tasks that the child is expected to perform and also understand the environment's effect in enabling or hindering the child's performance (Lammi & Law, 2003).

Family Centred Functional Therapy can be viewed as a step further from client-centred occupational therapy which emphasised the importance of respect for clients' strengths, experiences, and knowledge, their right to make choices concerning their lives and fostering respectful and supportive relationships with clients (Hammell, 2013).

Understanding caregivers' perceptions is important for setting goals aligned to their needs and expectations for the children (Löwing, Hamer, Bexelius, & Carlberg, 2011). Therapists have to reconcile differences in ratings of independence in occupational performance by caregivers and themselves before coming up with intervention programmes (Rich *et al*., 2013). Caregivers are important members of the treating team and need to be incorporated in developing goals for the child with the therapists as it is the caregivers' responsibility to carry through with correct intervention at home on a day- to - day basis.

1.2 Statement of the Problem

From the researcher's experience there appears to be a lack of insight among caregivers of children with CP attending outpatient clinics in Harare about how much their children can do for themselves. Caregivers tend to give assistance rather than encouraging independence in ADLs to improve the children's occupational performance. There also appears to be a lack of awareness among these caregivers about their role in children's rehabilitation and they seem not to take the initiative to become involved. There seems to be a tendency by families to think that clinicians know it all hence caregivers take a passive role waiting to be told what to do.

Therapists may also be unaware of the exact circumstances in a child's home environment that impact on their occupational performance and thus evaluate the child's capacity in a clinic rather than their actual capability or performance in carrying out the activity when at home or their motivation to perform these activities at home (Holsbeeke, Ketelaar, Schoemaker, & Gorter, 2009). Misalignment of goals for intervention can also result when caregivers, who have social and cultural expectations about the way children should develop, are not aware of what a child can achieve and do not give input in the evaluation and subsequent goal setting (Rich *et al*., 2013).

1.3. Purpose of Study

The purpose of this study was to compare the evaluation of the occupational performance of children with CP by caregivers to that of occupational therapists and physiotherapists using the PEDI (Haley *et al*., 1992) in three domains namely self care, mobility and social participation. The association between occupational performance of children with CP attending clinics in Harare, Zimbabwe and the different GMFCS and MACS levels was confirmed as well as the amount of assistance they need to carry out these activities.

1.4. Research Questions

Is there a difference between caregivers' and therapists' evaluation of occupational performance and the assistance needed by children with CP in Harare when evaluated using the PEDI?

Is there association between PEDI scores for children with CP and levels on the GMFCS as well as levels on the MACS?

1.5. Aim of Study

The aim of the study was to compare the caregivers' evaluation of the occupational performance and the assistance needed by children with CP to that of treating therapists when using the PEDI and to determine if there was an association between PEDI scores for children with CP and levels on the GMFCS as well as levels on the MACS.

1.6. Research Objectives

1. To determine and establish the correlation of the caregivers' and therapists' evaluation of the self care, mobility and social domains and the assistance needed using the PEDI for children attending therapy at CP clinics in Harare.
2. To determine the association between the PEDI scores for children attending therapy at CP clinics in Harare and levels III, IV and V of the GMFCS
3. To determine the association between the PEDI scores and the levels on the MACS for children attending therapy at CP clinics in Harare
4. To determine the reliability of the PEDI when used with caregivers and therapists at CP clinics in Harare using internal consistency.

The first objective considers the correlation between caregivers' and therapists' scores on the PEDI for this sample while the fourth objective considers the reliability of the PEDI when used with this sample.

1.7. Null Hypotheses

1. There is no correlation in evaluation of self care, mobility and social domains and the assistance needed using the PEDI between therapists and caregivers of children attending CP clinics in Harare.
2. There is no correlation between level of disability and perceived level of occupational performance measured by the PEDI and the levels on both the GMFCS and MACS.

1.8. Significance/Justification of Study

The researcher set to gain insight into caregivers' views on occupational performance of children with CP and how their evaluation of the children may differ from that of therapists. Significant differences or similarities in the way caregivers rate children's performance compared to therapists have a bearing on the use of FCFT for intervention. The information is expected to help therapists when setting priorities for intervention in collaboration with caregivers (Law, Hanna, King, Hurley, King, Kertoy, & Rosenbaum, 2003). If therapists and caregivers are able to agree on the children's performance, it becomes easier for the caregivers to participate in the child's therapy and prioritise occupational performance outcomes for the children. Differences in self care, mobility and social participation between children on levels III, IV and V of the GMFCS and the MACS were confirmed and expectations of what independence can be expected at each level for this population can be further explored.

1.9 Layout of the Research Report

Chapter 1 - Introduction to the research report is presented in this chapter. The statement of the problem, purpose of study, research question and aim of study are discussed. The research objectives and hypothesis drawn are also presented and the last section spells justification to carrying out the study.

Chapter 2 - This chapter critically discusses literature related to the topic under study. Literature reviewed include occupational performance of children with CP,

the association between occupational performance and assistance and the severity of CP. Assessment tools used to evaluate occupational performance of children with CP are reviewed as well as the caregivers experiences with completing the PEDI. Family centred Functional Therapy is also discussed.

Chapter 3 - The methodology used to carry out the research is described in this chapter. The study design, sample size and selection are described. Appropriateness of the instruments used in sample selection and data gathering are discussed. These include the demographic questionnaires, GMFCS, MACS and the PEDI. The procedure used to carry out the research is described starting with seeking ethical clearance from the Human Research Ethics Committee (HREC) at the University of the Witwatersrand and study institutions. Selection of participants with informed consent, caregivers' reports and therapists' assessment procedures are described. Data analysis methods used as well as ethical consideration taken are also covered.

Chapter 4 – Results of the study are presented in this chapter. The first section presents results of caregivers' and therapists' evaluation of the self care, mobility and social domains and the assistance needed using the PEDI. The second section presents result of the comparison of the PEDI scores of the caregivers to those of therapists. The third section presents results on the association between the PEDI scores and levels of disability as assessed by the GMFCS and the MACS. The last section presents results on internal consistence of the PEDI when used by caregivers and therapists in Harare.

Chapter 5 – This chapter presents the discussion of the findings in relation to demographics and the treatment context. The evaluation of the occupational performance and the assistance needed by children with CP rated on the PEDI by caregivers and therapists will also be discussed. The association between PEDI scores and levels on the GMFCS as well as levels on the MACS will be discussed.

Chapter 6 – Conclusion to the study and recommendations for future research are spelt out in this chapter.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The review of the literature will briefly consider CP and occupational performance and the association between the severity of CP in relation to the execution of self care, mobility and social participation. The importance of family centred therapy and the caregivers' understanding of the effect of CP on function and their involvement in goal setting in therapy for their child with CP will be included. The assessment of function in self care, mobility and social participation by therapists and caregivers will be reviewed as well as the standardised assessments used for children with CP including the PEDI (Eliasson *et al*., 2006).

Literature for this review was sourced from Google Scholar, Ovid, EBSCO Host, Science Direct, Biomed central, Medline and Pubmed. To include all keywords the literature search covered articles and books from the last 10 years with some iconic primary sources for parent report being more than 20 years old.

2.2. Occupational performance and Cerebral palsy

Cerebral Palsy is characterized by musculoskeletal problems with associated sensory, perceptual, cognition, communication and behaviour performance skill deficits which limit occupational performance and restrict participation in life situations (Malheiros, de Mello Monteiro, Da Silva, Torriani-Pasin, De Andrade, & Valenti, 2013). Disabled children, especially those with motor and cognitive deficits due to CP have difficulty in achieving independence in occupational performance with their self care, social participation and mobility being of the greatest concern in the younger child (Fauconnier, Dickinson, Beckung, Marcelli, McManus, & Michelsen, 2009).

Health is related to participation in activities as well as environmental and personal factors (World Health Organization, 2001). Therefore according to the

Occupational Therapy Practice Framework III (OTPFIII) the outcome of the occupational therapy process is “achieving health, well-being, and participation in life through engagement in occupation” (American Occupational Therapy Association, 2014:S2). Hence goals related to the occupational performance of a child with CP has become an important area of research, as researchers and occupational therapy clinicians shift from focusing on the child’s neurological deficits to focusing on the consequences of CP in daily functioning (Ketelaar *et al*., 2014).

The OTPFIII which is based on the International Classification of Functioning, Disability and Health (ICF) considers amongst other things both Personal Activities of Daily Living (PADLs) and instrumental activities of daily living (IADLs) as well as social participation, leisure, sleep, rest and education (American Occupational Therapy Association, 2014). Instrumental ADLs which need higher cognitive and physical functioning than PADLs, are oriented towards sustaining independence in the home (James, Ziviani, & Boyd, 2014) and therefore do not apply to younger children. Only PADLs which mainly constitute self-care activities like washing, bathing, functional mobility and safety as well as social participation which are assessed in the PEDI will be considered in this study. It has been found that children with CP often fall behind expected performance levels in functional skills because of their motor and associated difficulties (James *et al*., 2014). Social participation is also an important area to consider when assessing occupational performance in young children as this occurs in all contexts they function in including home, community and school (American Occupational Therapy Association, 2014).

An important concept related to functional well being in children with CP is to understand what the child is capable of doing and what they are actually doing in their context. Therefore occupational performance should be measured by assessing an individual’s capacity, capability or performance. “Capacity describes what a person can do in a standardised environment while capability describes what an individual can do in his or her daily environment and performance describes how a person actually performs in his or her daily environment”

(Holsbeeke *et al*., 2009:849). Both capacity and performance are important for children with CP and their caregivers because they form the base for goal setting for therapy for the child's independent functioning in all contexts (Rosenbaum & Gorter, 2012). Clinicians have however been reported to often focus on motor rather than occupational performance capacity when assessing and treating children with CP to improve performance (Levitt, 2009).

It is also necessary to consider the child's intrinsic factors and contextual factors which mediate the relationship between capacity, capability and motor performance because social and physical environments are known to affect the way in which children learn motor skills (Levitt, 2009). The child's internal drive should also not be underestimated as it greatly influences the association between capacity, capability, and performance. A holistic approach which analyses the child, the task and the environment should therefore be employed when planning the focus of intervention to achieve the best independent functioning for children with CP (Holsbeeke *et al*., 2009).

In a study across eight regions in Europe, Fauconnier *et al*. (2009) found that demographic and social factors did not influence participation. It was clear however that regulation and legislation and the provision of resources can influence participation of children with CP. No published study could be found on the effects of socio-demographic factors on participation in occupational performance of children in developing countries, where these factors may have any influence. A striking finding in the study by Fauconnier *et al*. (2009) was the significant differences in participation between the eight regions in Europe that they assessed. The consistently higher participation of children with CP in occupations in one region was attributed to governmental policies. This study also found that the participation in areas of occupation of children with CP was influenced by client factors (American Occupational Therapy Association, 2014) such as pain, severity of impairment in mobility, hand function, social function, and intellect (Fauconnier *et al*., 2009). Pain, in particular, was linked to poor quality of life in areas of self-perception, psychological and physical functioning while gross motor function and Intelligence Quotient level were independently

related to quality of life and greater severity of impairment of these client factors was found not to always indicate poorer quality of life. Children with mild to moderate disabilities are prone to score poorly on quality of life in the social acceptance, self-perception, school environment and in the moods and emotions domains (Arnaud, White-Koning, Michelsen, Parkes, Parkinson, Thyen, *et al*., 2008).

Spastic quadriplegia, dystonia and athetosis forms of CP are considered to affect functional skills more than the others. Children with other forms of CP (diplegia, hemiparesis, hypotonic) are more likely to have better functional skills. For example, the children with hypotonic CP often get stronger as they grow older, and those with hemiparetic and diplegic CP compensate with their unaffected limbs to achieve considerable functional skills (Accardo & Hoon, 2008).

2.3 Association between Severity of the Cerebral Palsy and Occupational Performance

The Gross Motor Function Classification System (Palisano *et al*., 2007) and the MACS (Eliasson *et al*. 2006) are two scales commonly used to classify severity of mobility and hand function deficits of children with CP respectively. The Gross Motor Function Classification System is associated with the mobility domain while MACS is more associated with the self care domain on the PEDI. Researchers have used the GMFCS and MACS scales in conjunction with the PEDI to ascertain the relationship between severity of CP and occupational performance of children with CP. However, neither the GMFCS nor the MACS are associated with the social domain of the PEDI. Some of the findings are discussed in this section.

Research has shown a moderate association between the severity of CP as measured on the GMFM-66 and the mobility domain of an occupational performance assessment for children with disability measured by the PEDI Functional Skills Scale (Han *et al*., 2011). Öhrvall, Eliasson, Löwing, Ödman and Krumlinde-Sundholm (2010) investigated the acquisition of self-care and mobility skills using PEDI in children with CP in relation to their manual ability MACS

scores as well as their gross motor function GMFCS levels. Children at MACS and GMFCS levels I or II were found to score higher than those at levels III to V on the self-care as well as the mobility domain of the PEDI. Self-care ability also increased as children at MACS levels I or II got older while mobility got better with age for children at GMFCS level I. Children with CP at MACS levels I and II and GMFCS level I achieved independence in self-care and mobility although at an older age than children who did not have CP. Children at higher GMFCS and MACS levels showed minor progress relative to their age and remained dependent, needing assistance from caregivers. This research is helpful and provides guidelines for goal setting for clinicians and when discussing expectations with caregivers of children with CP (Öhrvall *et al*., 2010).

The findings of Öhrvall *et al*. (2010) were confirmed by Brandäo, Gordon and Mancin (2012) in a study which further analysed the association between gross motor function, fine motor skills and occupational performance in children with CP. An association was established between MACS levels and self-care skills and also between GMFCS levels and mobility skills (Brandão *et al*., 2012).The association was further established by Kwon, Kim, Chang and Kwon (2013). The study revealed that the severity levels of CP and Bimanual Fine Motor Function levels moderate the association between the GMFM-66 and the self-care domain of the PEDI Functional Skills Scale. An association was also found between the occupational performance skills of children with CP and caregiver assistance required on the PEDI. These researchers however, attribute the outcome to the most participants in their study group with quadriparesis and GMFCS levels IV and V, which resulted in lower PEDI scores in all categories. All these factors should be considered in intervention planning when working with children with CP (Kwon *et al*., 2013).

“The GMFM-66 and the PEDI Functional Skills Mobility domain are complementary assessments that may be used interchangeably when it is not possible to administer both.....an important distinction is that the GMFM scale measures the child’s capacity and the PEDI measures the child’s capability or performance” (Han *et al*., 2011:402).

Although all the studies referred to so far in this section had large samples of above 100 participants in each, all of them were cross sectional thus change and other aspects such as the rate of change which can only be assessed over time could have been missed (Öhrvall *et al*., 2010; Brandão *et al*., 2012; Kwon *et al*., 2013).

To remedy the shortcoming in other studies Ketelaar *et al*. (2014) carried out a longitudinal study with a sample of 100 participants. This study concluded that functional skills are acquired faster in children with lower GMFCS levels, indicating better gross motor function. For mobility, differences in the rate of development are most likely between GMFCS level I to III and GMFCS level IV/V. These developmental differences for GMFCS levels can be helpful when discussing expectations and planning intervention with families (Ketelaar *et al*., 2014).

Chagas *et al*. (2008) in Brazil confirmed strong and significant negative correlations between the functional classifications and the results from the PEDI and GMFM-66 tests. These results suggested that the MACS and GMFCS functional classifications are good indicators of the manual function abilities and mobility of children with CP respectively. These authors noted that although the GMFM and the PEDI tests are well-known in the international literature; the classification of Brazilian children and those from other less developed countries on the GMFCS and the MACS still need to be further researched.

2.4 Assessment of Occupational Performance in Children with Cerebral Palsy

2.4.1. Assessments tools

There are a number of assessments available for use in paediatric rehabilitation to measure performance of children with CP. The GMFCS and MACS are specific tools for CP. The PEDI is a commonly used functional assessment for children and is described as a gold standard assessment for children with disabilities (Law, 2003; Ziviani, Ottenbacher, Shephard, Foreman, Astbury, Ireland, 2001).These assessment tools are described below:

2.4.1.1 Gross Motor Function Classification Scale

"The GMFCS has become the international standard for describing subgroups of children with CP across the severity spectrum" (Ketelaar *et al*., 2014:2). It is based on movement that happens spontaneously especially movement that is essential for walking and trunk control. The GMFCS was developed to classify the level of gross motor movement for children with CP or limitations thereof. The five levels of motor function on the scale are used to establish a child's occupational performance with or without assistive devices or use of a wheelchair (Palisano *et al*., 2007).

2.4.1.2 Manual Ability Classification System

The Manual Ability Classification System is used to describe how a child handles day-to-day objects. It spans across five levels from ease use of hands to unable or very limited ability to handle objects. MACS levels usually remain the same over time even with intervention. A caregiver report is usually used to classify a child's performance (Eliasson *et al*., 2006)

2.4.1.3 Paediatric Evaluation of Disability Inventory (PEDI).

The PEDI is "used to determine functional capabilities and performance, monitor progress in functional skill performance and evaluate therapeutic or rehabilitative program outcome in children with disabilities. It is appropriate to use with children aged between six months and seven years and a half years. It assesses two hundred and seventy-one items divided into three subtests: i.e. Functional Skill Scale: Self care (eating, grooming, dressing, bathing, and toileting), mobility (transfers, indoors, outdoors mobility) and social function (communication, social interaction, household, community tasks); ii. caregiver assistance that the child gets and iii. the environmental modifications done for the child to function" (Kothari, Haley, Gill-Body, & Dumas, 2003:777). For very young children basic skills like getting in and out of bed are included. For all age groups, body transport activities include locomotion in and out doors and the ability to manipulate objects during locomotion (Haley *et al*., 1992).

The social function domain in the PEDI is concerned with skills that are relevant and necessary for participation in one's family, community and culture depending

on age (Haley *et al*., 1992:12). These skills include communication, problem solving, interpersonal relationships, as well as aspects of play and instrumental ADL in the form of safety in and outside of the home (Coster & Gleeve, 2008). The PEDI can be used as caregiver observation report or by therapists observing and assessing children with disabilities for both intervention and research purposes (Rich *et al*., 2013). Use of the PEDI by caregivers and therapists supports the FCFT approach used in treatment of children with CP. Caregivers are best positioned to observe children's occupational performance and hence they can be involved in intervention for this aspect.

2.4.2 Caregivers' experience with Paediatric Evaluation of Disability Inventory

Using the PEDI has been met with mixed feelings by caregivers of children with CP. These feelings may have both positive and negative implications on children screening, assessment and the rehabilitation process.

A study by Rich *et al*. (2013) with mothers of children with CP revealed the following advantages that caregivers experience with completion of the PEDI for their children:

i) PEDI completion is enlightening and provides a reflective experience of how caregivers have been viewing and handling the children

ii) PEDI has an educational value on both knowing what to expect from the child as well as highlighting what needs to be worked on

iii) After completing the PEDI, caregivers gain confidence in setting goals and get involved with planning for intervention

iv) PEDI completion makes caregivers aware of unnecessary assistance they may have been giving their children hence opening room for them to start involving and encouraging the child to participate in own care.

Participants also expressed negative feelings that they experienced during and after completing the PEDI. Mothers, especially of severely affected older children, reported unpleasant emotions when they realise that their children are not able to perform what they should otherwise be performing had it not been of the CP.

They felt overwhelmed and discouraged (Rich *et al*., 2013). Although the study by Rich *et al*. (2013) cannot be generalised due to a small sample size of only 12 participants who were engaged in semi structured interviews, it gives an indication of what caregivers of children with CP could be experiencing.

Worth, Darrah, Magill-Evans, Wiart and Law (2013) investigated the stability of items on the PEDI. The study revealed general stability of most items but also the need for clear explanation and assistance for caregivers to fully understand the rating descriptors (Worth *et al*., 2014).

2.5 Family centred functional therapy

“Family-Centred Functional Therapy is a comprehensive approach to paediatric occupational therapy that considers and addresses the skills of the child, the requirements of functional tasks and the elements within the tasks environment, including family goals and preferences”(Lammi & Law, 2003: 285). The model addresses intervention for the child’s occupational performance by considering contextual factors and caregivers’ and the child’s functional goals in to account (Darrah, Law, & Pollock, 2001).

Family-therapist collaboration is crucial in the rehabilitation of children with CP if positive outcomes are to materialise (Brandão, Oliveira, & Mancin, 2014). Intervention approaches in FCFT are centred not only on the child but also on analysing the task to be completed and the environment in which the task is to be completed. Adjusting these three components is key to intervention and change in performance may either be gradual or immediate depending on the state of the three components (Lammi & Law, 2003)

An advantage of FCFT is that it is useful in raising caregivers’ awareness of children’s abilities which facilitates realistic goal setting for improving functional performance (Lammi & Law, 2003). It encourages collaboration between health care providers and family ensuring that families take part in all aspects of their children’s rehabilitation and caregivers have reported satisfaction with care and

improved child performance as well as decreased anxiety on their part when they get involved (Law *et al*., 2003).

Caregivers' satisfaction with services is subject to their perception of involvement and the view that their needs and wishes are addressed (Law *et al*., 2003). King, Teplicky, King and Rosenbaum (2004) agreed that FCFT takes cognizance of the child, parent/caregiver, family and service system outcomes. It focuses on interventions that occur in the child's own environment and strongly promotes the psychosocial well-being of disabled children and their families leading to contentment with service (King *et al*., 2004).

Decision making in paediatric rehabilitation therefore should involve rehabilitation personnel and caregivers working together to set goals and plan intervention as well implementing the programmes. The combined effort provides motivation for the caregivers to carry out the intervention for the child at home and is usually accompanied with improved outcomes. It increases caregivers' feelings of competence and achievement. Goals based on family concerns and preferences and their input in ongoing therapy encourages them to carry through with functional tasks training in the home (Øien, Fallang & Østensjø, 2010).

Over the last ten years the emphasis in providing services for children with CP has been on FCFT and the collaboration between health care professionals and family. Evaluation of children, goal setting and intervention planning should be done together with all team players agreeing on what is to be focused on in therapy (Hanna & Rodger, 2002). For caregiver–therapist collaboration to work effectively, therapists need to take into account and be able to handle issues that arise. Handling caregivers' needs and views, which differ greatly because they are all unique, is an important part of the collaboration. Therapists need to continuously foster and develop effective professional relationships with caregivers, facilitating the formulation of shared priorities and goals, planning intervention and establishing services that support collaboration (Hanna & Rodger, 2002).

Egilson (2011) carried out a study in Iceland to find out the views of parents with disabled children on service provision. Many parents think that they are poorly informed of therapy priorities and the whole process of rehabilitation. They long for mutual-respect, involvement in goal setting for intervention and they want to be regarded as key players in their children's rehabilitation process. Parents of children attending therapy over the years tend to be more dissatisfied with the services and they wish for empowerment and support to continue with therapy at home, especially if they have to travel far to access services (Egilson, 2011). Egilson concluded that needs and wants of caregivers and children with CP need to be respected for effective rehabilitation to take place. Environment and peculiar circumstances of the children must be considered by therapists over and above the existing impairments (Egilson, 2011).

Caregivers' goals and priorities are however diverse as shown by Knox (2008) who explored parents' functional and occupational performance priorities for their children with CP. Differences were recorded per age difference of the children, type of CP and severity of CP implying that caregivers have particular concerns for their children based on the three factors hence therapists must take this into account (Knox, 2008). Brandäo *et al*. (2014) confirmed these differences in a study to ascertain prioritised goals by caregivers of children with CP. Self-care related activities were viewed as the most important for all caregivers while caregivers of children with severe motor dysfunction were concerned about play behaviour more than those whose children had better motor function. Younger children were reported by their caregivers to need more assistance in play and mobility compared to older children. These findings can assist rehabilitation health workers in orienting the rehabilitation process for children to address goals and priorities identified by caregivers in order to strengthen caregiver-therapist collaboration and improve treatment outcomes (Brandão *et al*., 2014). However caregivers and therapists do need to agree on the child's abilities and deficits in client factors and their occupational performance if collaborative goals are to be set and achieved.

2.6. Caregivers' versus health professionals' evaluation of children

Research on professional and parent correlation of scores started in the 1980s and current research developed based on the findings. Caregivers and professionals agreed significantly on observed language behaviour (Rescorla, 1989; Dale, Bates, & Morisset, 1989) and more correlation was observed in studies where caregivers have been involved to assist with initial screening of the children (Bricker & Squires, 1989). Information from both caregivers and professionals should hence be used because they each add valuable information necessary for goal and priority setting and the intervention planning process (Diamond & Squires, 1993).

As Diamond and Squires (1993) point out however it is not necessary that professionals and caregivers agree completely in terms of the child's occupational performance. In terms of evaluation it has been shown that the average correlation between caregivers' and professionals' scores is found on 75%-95% of the items from standardised tests. The differences in the items may reflect skills the child is just beginning to develop seen either by the caregivers or therapists in settings that differ (Diamond & Squires, 1993; Squires, Nickel, & Bricker, 1990).

In a study in Israel Elad *et al*. (2013) found significant differences between mothers' and rehabilitation professionals' scores using the PEDI on capability and performance in self -care of children with CP. The biggest discrepancies were found in the caregiver assistance self-care and mobility domains of the PEDI. Mothers rated their children lower as they perceived their children needing more assistance in performing everyday self care activities and in moving around than did the rehabilitation professionals. These differences could be due to the fact that mothers understood their children better, particularly regarding performance in the home environment (Elad *et al*., 2013).

Differences could also have been a reflection of average performance in different settings and the observation over time by the mother, whereas rehabilitation professionals do a snapshot objective measure (Palisano, Rosebaum, Bartlett, &

Livingston, 2008; Vargus-Adams, Martin, Maignan, Klein & Salisbury, 2011). For example, children may use different forms of mobility in different contexts and over different terrains, which cannot always be observed in the clinic (Tieman, Palisano, Gracely & Rosenbaum, 2004).

Because of the psychological and emotional aspects, mothers can be overprotective towards their children with disabilities and this has a potential influence on their perception of children's capabilities and function (Duncan & Caughy, 2009). Overprotection may cause children to manifest problem behaviours and this may provide caregivers with inappropriate feedback hence they rate their children differently from the rehabilitation professionals (Ungar, 2009).

Besides these assumptions caregivers are experts on observing the children and hence are important partners in the collaborative goal setting process (Bamm & Rosenbaum, 2008; Rich *et al*., 2013). It therefore becomes mandatory for therapists to collaborate with caregivers about the child's capacity, capabilities and performance in order to reach an agreement for setting goals for intervention (Löwing *et al*., 2011; Rich *et al*., 2013) so that FCFT can be implemented.

The PEDI completion by caregivers is useful in implementing FCFT as it is associated with the following advantages:

i. caregivers become more aware of child development patterns, ii. caregivers become aware of unnecessary assistance that they give to their children, iii. caregivers gain insight on areas that they need to prioritise for intervention of their children and iv, they become more confident to teach their children new skills (Rich *et al*., 2013). It has also resulted in the introduction of the necessary assistive devices and then enhancing children's quality of life by allowing them to experience the feeling of being useful in their own care (Rich *et al*., 2013). Caregivers themselves value the opportunity to be involved in the goal setting process which should be guided by the rehabilitation professionals depending on the severity of the child's impairments. These goals must however take the severity of the child's condition into account (Egilson, 2011).

In a study to investigate correlation between parents' and physicians' scores in rating performance of children with juvenile idiopathic arthritis parents and physicians showed fair positive correlation in their scores. Over-rating by parents was linked to higher pain experienced by the child and a worse child health association score as parents perceive their children to be in more pain than physicians. The over-rating by physicians was linked to more severe joint damage and inflammation as they understand these aspects better (Palmisani, Solari, Pistorio, Ruperto, Malattia, Viola, Buoncompagni, ...Ravelli, 2007)

2.7 Caregiver reports

Family reports offer cheap practical ways of measuring children's activities and participation. Family have a good knowledge of children's behaviour in different environments unlike health professionals who may only have a limited interaction with the children in standardised environments (Elad *et al*., 2013; Morris & Wates, 2006). However, caregiver attributes may have an impact on how they rate performance of the children. In a study by Arnaud *et al*. (2008) family psychosocial characteristics were reported to have a bearing on the way caregivers view their children's quality of life. Parent's levels of anxiety and stress were inversely proportional to reported quality of life (Arnaud *et al*., 2008).

Caregivers are the best people to report on observable behaviours that occur frequently in all settings but this is not possible during observation or standard testing in a clinical setting (Elad *et al*., 2013; Diamond & Squires, 1993). Use of caregiver reports is cost effective as less time and human resources are required. It however, comes with its own shortfalls. Recalling behaviour that occurred may be problematic hence there is need for a reliable way for caregivers to rate their children. They may be given an opportunity to observe certain behaviours and comment on them immediately. For this reason caregiver report can be considered most useful as a screening tool rather than an assessment tool itself (Diamond & Squires, 1993)

Caregiver characteristics may affect or influence the behaviour of the children with disabilities including those with CP. If the caregivers are overprotective, they

are more likely to cause behavioural dependence and poor psychological adaptation on their children (Holmbeck, Johnson, Wills, McKernon, Rose, Erklin& Kemper, 2002). Children, if perceived to be vulnerable by their caregivers, have a high likelihood of behavioural problems which may also affect their performance. As a result parental perceptions can influence children's occupational performance at home and in other settings. If caregivers underrate what the child can do, they may never allow the child to attempt tasks and the child will perform at a lower level than their capabilities (Duncan & Caughy, 2009).

Anxieties of parenting children with disabilities often lead to reduced child participation in the community (Parkes, McCullough& Madden, 2010) and overall mothers tend to be more overprotective than fathers (Holmbeck *et al*., 2002). All these factors need to be explored and taken into account when collaborating with caregivers in order for therapists to handle the situation and direct the process appropriately.

2.8 Developing countries

In a study by Chagas *et al.* (2008) in Brazil, there were strong and significant negative correlations between the functional classifications and the results from the PEDI and GMFM-66 tests. These results suggested that the MACS and GMFCS functional classifications are good indicators of the manual function abilities and mobility of children with CP. These authors noted that although the GMFM and the PEDI tests are well-known in the international literature; the classification of Brazilian children with the GMFCS and the MACS was still under developed as is the case in all developing countries.

In a systematic review done by Donald, Samia, Kakooza-Mwesige & Bearden (2014) on paediatric CP in Africa, it was highlighted that most research published on ADLs is on developed countries and very little literature was available from research done in developing countries. This review suggests several gaps of knowledge regarding CP in Africa. Qualitative or mixed-methods studies assessing patient and family understanding of CP are virtually absent in Africa. There is need for longitudinal studies that would assess outcomes over time for

patients with CP as well as for randomized controlled trials of community-based treatment strategies that would be appropriate in an African setting (Donald, Samia, Kakooza-Mwesige & Bearden, 2014).

2.8 Summary

Cerebral Palsy is a childhood disease that affects function in all areas of self care, mobility and social function. Affected children may need assistance from caregivers to perform these activities. In rehabilitation programmes, it is important to help the children to be as independent as possible. Therapists and caregivers need to understand what the child is capable of doing and what they are actually doing in their context in order to make realistic plans and intervention programmes for rehabilitation of these children.

Severity of CP has been proven to be associated with mobility and developmental differences for GMFCS levels can be helpful when discussing expectations and setting goals with families regarding both mobility and self-care domains of children with CP. The PEDI can be used as parent observation report or by therapists observing and assessing children with disabilities for both intervention and research purposes. Use of the PEDI by caregivers and therapists supports the approach used in treatment of CP with FCFT. An advantage of FCFT is that it is useful in raising parent's awareness of their children's abilities which facilitates realistic goal setting for improving functional performance.

Family reports offer cheap practical ways of measuring children's activities and participation. Family have a good knowledge of children's behaviour in different environments unlike health professionals who may only have a limited interaction with the children in standardised environments.

CHAPTER 3: METHODOLOGY

3.1. Study design

The research design for this study was quantitative, comparative and descriptive in nature. The study was carried out to determine the caregivers' and rehabilitation professionals' scores on the PEDI for children attending CP clinics in Harare and these were compared. The association between the children's occupational performance measured by the PEDI and their level of function on the GMFCS and MACS was also established. Although the researcher interviewed caregivers about their children's performance, scores were recorded as numbers (see Appendix D) and analysis was based on the numerical scores hence the study was quantitative (Kielhofner, 2006).

3.2. Study population

Three treatment contexts were selected for the study. These are the main treatment contexts found in Zimbabwe and the researcher wanted to have a representative sample. The first (Harare Hospital Children's Rehabilitation Unit) was a hospital based outpatient setting in a public hospital, the second (Premier Rehabilitation Centre) was private outpatient rehabilitation centre and the third (Ruvheneko) was an outreach point where therapists go to attend to the children at a community centre. Outreach programmes are organised and run by Harare Hospital Children's Rehabilitation Unit.

At the two outpatient based settings caregivers bring the children for one on one occupational therapy and physiotherapy sessions. The therapist would perform hands on treatment techniques and involve the child in therapeutic activities based on therapist's preferred treatment approaches. Home programme of handling techniques, activity participation by the children as well as caregiver hands on exercises, for example daily stretches are demonstrated to caregivers who are given an opportunity to try out with the child together with therapist.

In the public hospital children with CP are identified and referred from the hospital's maternity ward and paediatric unit and also from surrounding council clinics. Children may commence therapy while they are still admitted and they have to continue therapy at the children's rehabilitation unit once discharged from hospital (Dambi & Jelsma, 2014). Caregivers and the children who come for therapy are attended to on a first come first served base hence they all have to come early in the morning to join the queue and may spend several hours at the hospital. There were two occupational therapists, two physiotherapists and three rehabilitation technicians but for purposes of this study only therapists were eligible to participate. Several therapists and technicians work with the children in one big room where there are lots of distractions. Average patient to therapist ratio was 8:1 and children were seen in therapy once per month.

In the private rehabilitation centre the children are identified and referred mainly from the surrounding private paediatricians, maternity hospitals and paediatric wards in the private hospitals where occupational therapists and physiotherapists may start therapy while the children are still admitted and they will continue therapy as outpatients when discharged from the wards. There were two occupational therapists and three physiotherapists and only one occupational therapist participated in the study. Children and their caregivers come for therapy at specific booked times hence working parents find it flexible for them since they can book times that do not disturb work schedules too much. Frequency of therapy sessions varies for different children and is determined by the therapists in liaison with the caregivers based on the child's abilities and limitations and also affordability of services. The average patient to therapist ratio was 8:1 per day.

At outreach children and their caregivers converge at a local community centre on a set date once per month where therapists and rehabilitation technicians come to attend to them. Children attend short one-on-one sessions with the rehabilitation professionals. They together with their caregivers may attend group based activities, demonstration sessions on taught home programmes, educational sessions and group discussions on any important issues that may arise (Dambi & Jelsma, 2014).

3.2.1. Sample selection

Participating children and their caregivers were selected from three centres namely: Harare Hospital Children's Rehabilitation Centre, Premier Rehabilitation Centre and Ruvheneko outreach point. The researcher used hospital/centre paediatrics department patient records to identify potential participants for the study using the inclusion criteria outlined in section 3.2.2 below. Children from these centres were selected in order to make the sample representative of all children with CP in Harare. All identified children were listed per age range. The children with CP were selected using stratified random sampling per age range every six months from four years to six years six months. There were supposed to be ten children were selected per age range. There were five age ranges and caregivers for the selected children per age range were selected for the study with a total of 50 children being selected. The researcher arranged with centres' therapists in charge to meet with caregivers and the children to seek for permission to include them in the study after explaining to them about the research and informed consent. If a selected caregiver/child did not consent/assent to participating in the study, another child was selected to replace the one who did not consent. In cases where the caregiver was not the parent or legal guardian of the child, an information pack was sent to the parent/legal guardian for them to give consent for the child to be included in the study. Children were asked to assent only if they were able to communicate. For the children who were not able to give assent the parent's/guardian's consent was used to include them in the study.

Comparison focused on occupational performance scores by occupational therapists/physiotherapists and caregivers as well as between different levels of disability. Socioeconomic status was not considered as a variable in this study.

Inclusion criteria

The following criteria were used to select participating children:

1. Child had to be in the age range of four to six years 6 months. This ensured applicability of all instruments that the researcher was going to use namely GMFCS, Manual Ability Classification System for Children with

Cerebral Palsy (MACS) and PEDI. It is also normally expected that at age four and above children are less dependent on the caregiver for function hence caregivers can report more clearly on children's performance than they would for younger children (Öhrvall *et al*., 2010).

2. Child had to fall in grade III, IV or V of the GMFCS. Those on levels I and II are expected to be independent (Palisano *et al*., 2007) hence they were not suitable for this study.
3. Child had to be living in a home setting and had to be attending outpatient occupational therapy and physiotherapy sessions at time of study. The child had to have attended at least three sessions of either occupational therapy or physiotherapy or three sessions of each.
4. Caregiver (either mother or father or any person who normally cares for the child at home) had to be willing to participate in the research and answer to questions for the researcher to complete the PEDI.

3.2.2. Sample size

A sample size of 50 preschool children and their caregivers was selected for the study based on the difference of 3 with a standard deviation of 5.4 for scores between caregivers and rehabilitation professionals for mobility in children with moderate disability as reported by Elad *et al*. (2013). This ensured significance set at ≤0, 05 with power of 80% between the two sets of scores.

3.3. Instrumentation

Three instruments that had been tested for validity and reliability for use with children and caregivers were used. These are discussed in the following subsections:

3.3.1 Demographic Questionnaire

Demographic information (Appendix A) was collected through use of a demographic questionnaire. The information included child's name, age, gender and information pertaining to their attendance of therapy. Caregivers names and contact details were also documented. These forms were kept separate and used

when necessary for example, to follow up caregivers to bring their children for assessment.

3.3.2. Gross Motor Function Classification Scale

"The Gross Motor Function Classification System (Appendix B)has become the international standard for describing subgroups of children with CP across the severity spectrum It is based on self-initiated movement with emphasis on trunk control and walking" (Ketelaar *et al*., 2014:2) . The purpose of the GMFCS is to classify the level of gross motor movement for children with CP or limitations thereof. The five levels of motor function on the scale are used to determine a child's mobility performance with or without assistive devices or use of a wheelchair. The GMFCS was proven to have good validity and a kappa inter-rater reliability of 0.75 (Palisano *et al*., 2008).

Wood and Rosenbaum (2000) studied the reliability and stability of the GMFCS when used with children with CP over time. The study was based on a retrospective chart review of 85 children with CP followed from when they were two years or younger until they were twelve years of older. The GMFCS was applied to clinical notes by two blinded raters four times throughout the study. High interrater and test-retest reliabilities of 0.93 and 0.79 respectively were recorded.

Mayson, Ward & Davies (2013) assessed the reliability of previously assigned GMFCS scores. One group of children with CP had GMFCS previously assigned and the other group had no GMFCS score assigned. Using database information, two physiotherapists independently determined GMFCS scores for children from both groups. Between-therapist correlations were kappa = +0.84 for GMFCS previously assigned group and +0.95 for no GMFCS assigned group. Kappa correlation between direct assessment and retrospectively assigned scores for the GMFCS previously assigned group was +0.79. The authors concluded that previously assigned GMFCS scores are reliable to use.

3.3.3. Manual Ability Classification System

The Manual Ability Classification System (Appendix C) is used to describe how a child handles day-to-day objects. It spans across five levels from ease of use of hands to unable or very limited ability to handle objects and the MACS levels usually do not change over time or as a result of intervention. A caregiver report is used to classify a child's performance (Eliasson *et al*., 2006).

Reliability was tested between pairs of therapists for 168 children with CP between 4 and 18 years and between 25 parents and their children's therapists. The results demonstrated that MACS has good validity and reliability. The intraclass correlation coefficient between therapists was 0.97 and between parents and therapist was 0.96 indicating excellent corellation (Eliasson *et al*., 2006).

In Brazil Silva, Funayama and Pfeifer (2014) examined the inter- and intra-rater reliability of the Portuguese-Brazil version of the MACS by comparing the classifications given by therapists and parents of children with CP between the ages of 4 and 18. Therapists classified manual ability through direct observation and information provided by parents. An almost perfect positive correlation resulted among therapists [K=0.90 (95% CI 0.83-0.97); ICC=0.97 (95%CI 0.96-0.98)] and intra-rater reliability for therapists of Kappa ranging between 0.83 and 0.95 and ICC between 0.96 and 0.99 for the evaluator with more and less experience in rehabilitation, respectively. There was fair positive correlation between therapists' and parents' scores [K=0.36 (95% CI 0.22-0.50); ICC=0.79 (95% CI 0.70-0.86)].

3.3.4. Paediatric Evaluation of Disability Inventory (PEDI)

The PEDI is a widely used measure in CP clinical assessment and research (Elad *et al*., (2012). It samples key capabilities, function and environmental modifications in three domains of self care, mobility and social function (Haley *et al*., 1992). For the purposes of this study, Part I which assesses discrete PADL tasks through self-care, mobility as well as social function was used. Skills are rated as 0 (unable, or limited in capability) or 1 (able to perform the skill, or beyond the level). Part II which assesses caregiver assistance, with 20 complex

functional activities rated on a scale between 0 (total assistance) and 5 (independent) was also completed (Appendix D).

The PEDI was tested by the developers and the following reliabilities were reported for the six scales in the instrument. Internal reliability Cronbach's coefficient alpha values ranging from 0.95 to 0.99.and inter-rater reliability for clinical sample had intraclass correlation coefficient ranging from 0.84 to 1.00. Reliability of respondents had intraclass correlation coefficients ranging from 0.74 to 0.96 with only one problematic score of 0.3 in the Social Function Modifications section. This section was then modified and the child oriented category was removed for some items (Haley *et al*., 1992). The instrument was validated by a panel of experts for content, construct, concurrent, discriminant and evaluative validity (Haley *et al*., 1992:63).The PEDI has several advantages over other activities of daily living measures for elementary school age children (Rich *et al*., 2013). The advantages include availability of Rasch analysis software for scores analysis, strong psychometric properties and a broad item content which make it a measure of choice for research (James *et al*., 2014). It has a few limitations that include a narrow age range and response format which may limit its ability to detect minor functional changes on items (James *et al*., 2014). Numerous studies support PEDI's psychometric properties and its applicability to use in diverse cultures (Rich *et al*., 2013). It is recommended for use with parent report using a questionnaire or structured interview format (Kwon *et al*., 2013).

Other versions of the PEDI have also proven good reliability and validity for example the Dutch version reliability was recorded as: on scale level 0.90, self-care domain 0.89, mobility domain 0.74 and social function domain 0.87 (Wassenberg-Severijnen, Custers, Hox, Adri Vermeer, & Helders, (2003).
The Norwegian version of the PEDI has also been proven to be a reliable instrument for evaluation of young children. Inter-rater reliability ranged from ICC 0.95-0.99 for all domains, and all ICCs observed in intra-rater reliability were equal to or greater than 0.99 (Berg, Jahnsen, Frøslie & Hussain, 2004).

3.4. Procedure

Ethical clearance was obtained from the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (Appendix E). Permission to do the study was obtained from the ethics committee of Harare Central Hospital and the operations manager of Premier Rehabilitation Centre (Appendix F). A pilot study was carried out with two children and their caregivers to ascertain the amount of time needed by the researcher to complete the PEDI interviewing the caregivers and completion of the assessment by the therapists. This helped the researcher to plan appropriately for the main study interview sessions. The pilot also helped to discover potential problems that needed to be rectified before embarking on the actual study for example ascertaining before hand the parent/caregiver's preferred language when the researcher asked them about their children completing the PEDI.

3.4.1. Recruitment of participants

The researcher selected participants for the study. Children were recruited by the researcher if the CP diagnosis had been confirmed from the children's medical record which the caregivers are given at the hospital when the children are assessed by a paediatrician. In cases where the caregivers had lost this record, the master file kept at the hospital was consulted.

Caregivers were then invited to participate in the study. They were provided with an information sheet and the researcher also explained verbally what the research was all about. They were asked to sign informed consent (Appendix G) to participate and for their child to be assessed on the PEDI by the treating occupational therapists or physiotherapist. Children who were able to communicate were asked to give informed assent (Appendix G) before being assessed by the treating therapist. Those who were not able to communicate were still assessed per their parents'/guardians' consent. In cases where the caregiver was not the child's guardian, an information pack and consent form was sent to the guardian for them to sign and give consent for the child to participate in the study.

The researcher confirmed the severity of disability of the children using the GMFCS in order to exclude those that were not eligible for the study. For those selected after the GMFCS, the MACS assessment was done to determine the levels of hand use in handling objects.

The GMFCS and MACS functional classifications were done because they have been deemed good indicators of mobility and manual function of children with CP and hence they may be useful in the processes of evaluation and intervention planning (Chagas *et al*., 2008). It is necessary to identify and compare the information made available by these classification systems to that by the functional tests to ascertain if they show any relationship which can be utilised in intervention planning (Chagas *et al*., 2008). Research on their use is not yet developed in the context of the current study.

3.4.2. Caregivers assessment of children

After the MACS scores were determined for the children, the researcher then interviewed the children's caregivers and used the PEDI evaluation form to score their responses. The researcher used the English version of the PEDI but, where necessary, explained items in vernacular for participants to understand. Translation of the PEDI was not possible for two reasons: formal translation of the PEDI had not been permitted and also the type of study was small it being a research report.

Interviewing of caregivers was scheduled for the days that they would have been booked to bring the children for therapy sessions and they were given transport fees by the researcher for the particular visit so that they would not miss the appointment due to lack of bus fare. Scheduling of interviews on same day as therapy appointment was done to help minimise the hassle for caregivers transporting children as well as to accommodate some caregivers especially mothers who had to arrange for time off work to bring children for therapy sessions.

3.4.3. Therapists assessment of children

Occupational therapists/physiotherapists at the relevant centres were invited by the researcher to participate in the study if they had been working in the department for at least three years and had at least a bachelor's degree in their field of work. They were provided with an information sheet and were asked to sign informed consent to participate (Appendix H). The treating therapists were trained by the researcher to use the PEDI evaluation scale. They then assessed the same children whose caregivers were interviewed by the researcher and filled out the PEDI evaluation forms. The therapists had to complete the PEDI evaluation form for the children that they have had at least three sessions with and were already familiar and had already built rapport with.

3.5. Data analysis

Descriptive statistics were used to describe demographic information and the scores on PEDI from participants' and therapists' reports. Frequency distributions, means, medians, lower and upper quartiles and standard deviations were used.

The Spearman's non-parametric correlation coefficients for data that is not normally distributed and logistic regression were used to test for correlation between the caregivers' and the therapists' PEDI scores. The sample size was small (50) therefore it was assumed that data was not normally distributed.

The association between the severity of the CP on the GMFCS and the MACS was correlated with the domain scores and assistance score on the PEDI using Spearman's correlation coefficients and logistic regression.

The Conbach's Alpha was used to test for internal consistence of the PEDI when used by caregivers and therapists in Harare.

3.6. Ethical considerations

Once ethical clearance and permission to carry out the study was obtained the researcher recruited the participants. The researcher explained verbally to all

participants as well as in the consent letters what the research was all about and participants signed informed consent (Appendix G and H). Participants were given the right to choose to participate or withdraw from participating in the research at any time without fear of any consequences of withdrawal.

Autonomy

The researcher explained to participants that taking part in the study was completely voluntary and not taking part in it, or withdrawing from it, carried no penalty of any sort. Caregivers were provided with an opportunity to give informed consent to participate. Parents/guardians were also given an opportunity to give informed consent for their children to participate and children who were able to communicate were given an opportunity to assent to participating in the study.

Confidentiality and anonymity was maintained by the use of a code instead of names on all evaluation forms such that a participant's information or responses could not be linked to them in any way. Only the researcher had a list of names and codes to enable the code to be linked to a particular child/caregiver. All identifying information was kept by the researcher in a secure location.

Beneficence

The researcher explained to participants that the results of the study may be made available for academic and clinical purposes to improve rehabilitation services especially FCFT but information pertaining to individual participants would not be disclosed.

The researcher explained that the participants were not going to get any direct benefits for participating in the study but caregivers may benefit by having increased awareness of developmental patterns and greater insight into levels of assistance that they give children, and also how to facilitate children's independence in activities.

Non-maleficence

The researcher ensured that no distress was inflicted on the participants. Caregiver interviews and assessment of children by therapists were carried out in familiar paces where they usually come for usual therapy sessions. Caregivers

were reimbursed the transport fees for themselves and their children to avoid financial stress. Children were assessed by therapists that they were already familiar with hence no stranger anxiety was inflicted.

Justice

All information gathered on the PEDI from participating caregivers and children assessments was considered and used when completing the study.

CHAPTER 4: RESULTS

4.1. Introduction

Results for the study are presented in this chapter. The first section presents demographic information of the 50 participating children, caregivers, therapists and study locations. The second section presents descriptive information of the PEDI results on functional activities by both the caregivers and the therapists. The third section presents descriptive information of the PEDI results on caregiver assistance by both the caregivers and the therapists. In the fourth section results on differences in PEDI scores for children at different GMFCS levels and differences in PEDI scores for children at different MACS levels are presented. The last section presents results on the relationship between level of disability and perceived level of occupational performance.

4.2 Demographics

4.2.1. Personal demographics

4.2.1.1. Gender Distribution

Table 4.1- Gender frequency distribution n=50

Gender	n	percentage
Male	25	50
Female	25	50
Total	50	100

Fifty children participated in the study. Both sexes constituted 50 percent each of the total sample (Table 4.1).

4.2.1.2 Age

Of the fifty children who participated, the biggest age group (46%) was between 4 years and 4 years 5 months. The age groups divided into six month intervals from 4 years 6 months to 5 years 11 months had a similar number of children in them with slightly more in the 6 years to 6 years 6months age group. Although the

researcher wanted to have an equal number of children per age band participating, this was not possible due to limited numbers of children in age ranges above 4 years 6 months in the study population (Table 4.2).

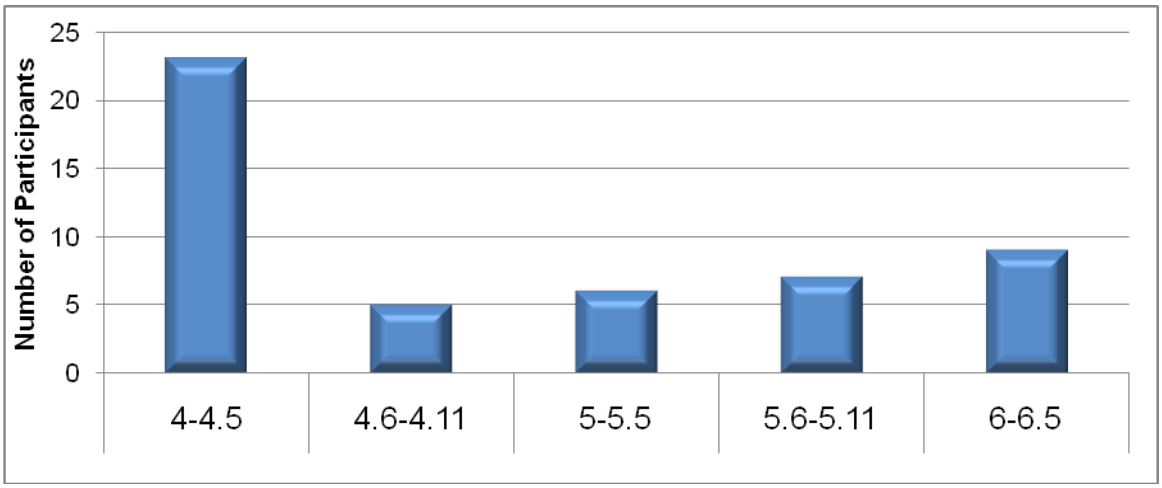


Figure 4.1- Age distribution

Table 4.2- Age frequency distribution n=50

Age range	n	percentage
4years to 4 years 5months	23	46
4years 6 months to 4 years 11 months	5	10
5years to 5years5months	6	12
5years6months to 5 years 11 months	7	14
6years to 6years6months	9	18
Total	50	100

4.2.2 Medical and Functional History

4.2.2.1. Diagnosis

Children with different forms of CP participated in the study. The highest percentage for one diagnosis was 22% with dystonia while 20% presented with

spastic quadriplegia and another 20% had athetoid CP. The smallest percentage presented with hypotonic CP (Table 4.3).

Table 4.3- Diagnosis frequency distribution n=50

Diagnosis category	n	percentage
Spastic Quadriplegia CP	10	20
Dystonia CP	11	22
Athetoid CP	10	20
Diplegia	6	12
Hypotonic	5	10
Hemiparesis	8	16
Total	50	100

4.2.2.2. Gross Motor Function Classification System scores

Recap of descriptions of GMFS levels for four to six year olds

Children with GMFCS scores III to V participated in the study. The majority (48%) of them was at GMFCS level V while only seven (14%) were at level IV (Table 4.4).

Table 4.4- Gross Motor Function Classification System score frequency distribution n=50

GMFCS score	n	percentage
III	19	38
IV	7	14
V	24	48
Total	50	100

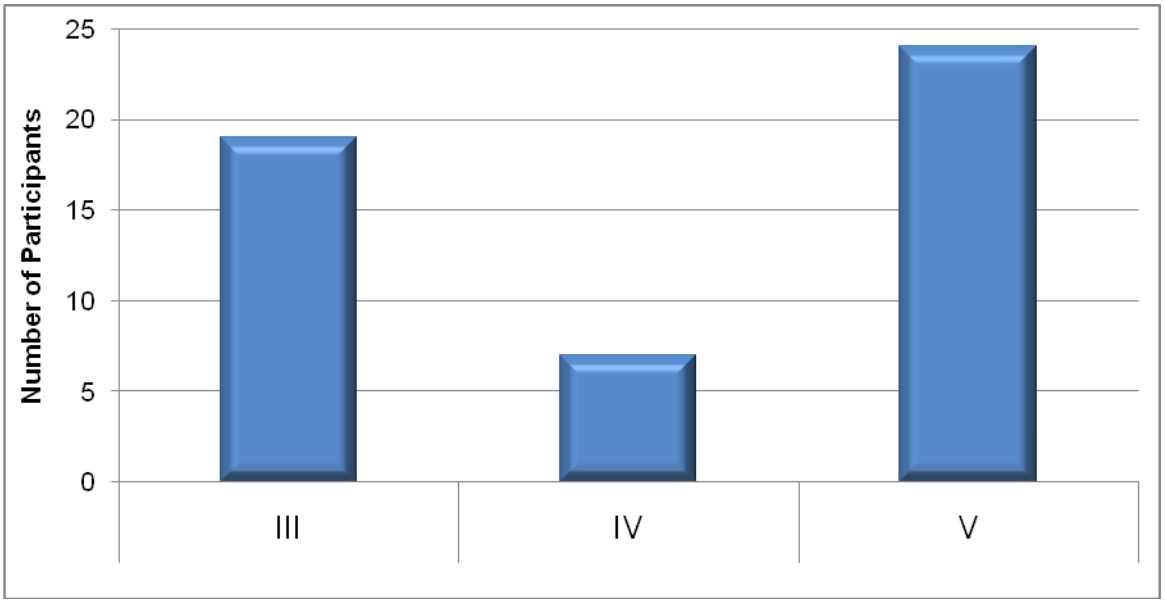


Figure 4.2 Gross Motor Function Classification System Level Distribution

4.2.2.3. Manual Ability Classification System scores

Children with hand function at all MACS levels participated in the study.

A similar percentage of the children (34%) children were at MACS level III and (32%) MACS level II, while a small percentage (8%) was at MACS level IV and MACS level I (2%) (Table 4.5).

Table 4.5- Manual Ability Classification System score frequency distribution n=50

MACS score	n	percentage
I	1	2
II	16	32
III	17	34
IV	4	8
V	12	24
Total	50	100

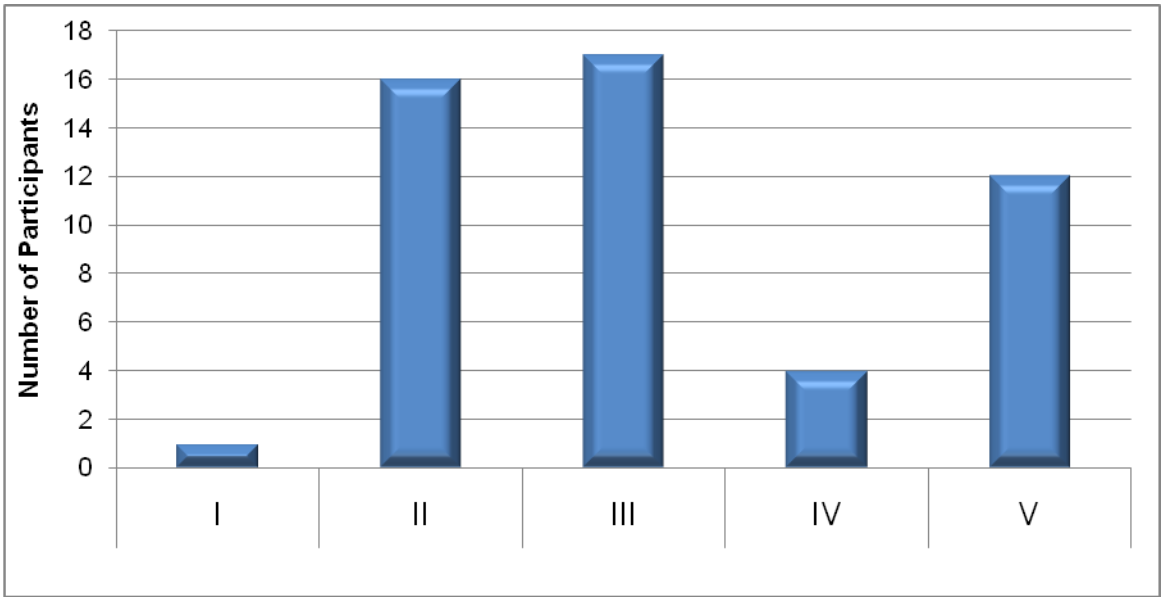


Figure 4.3 Manual Classification Scale Levels

4.2.3 Treatment context

4.2.3.1. Place where children were treated

Participants were sampled from three locations which provide occupational therapy and physiotherapy services for children with disabilities (Table 4.6).

Table 4.6- Number of participants per location frequency distribution n=50

Location	n	percentage
1-Harare Hospital Children's Rehabilitation Centre	15	30
2-Premier Rehabilitation Centre	23	46
3-Ruvheneko Outreach Point	12	24
Total	50	100

The majority of children (76%) were selected from location 1 and 2 where they attended as outpatients. Only 24% were selected from location 3 which was an outreach point where therapists go to a community centre to provide therapy in the community.

4.2.3.2 Treating therapist

Four therapists participated in the study and completed the PEDI questionnaires on the children they have been treating. Therapists 1and 4 were physiotherapists and therapists 2 and 3 were occupational therapists. Nearly an equal number (54%) of the children were assessed by physiotherapists and by occupational therapists (46%) (Table 4.7).

Table 4.7- Treating therapist frequency distribution n=50

Treating therapist	n	percentage
1-Physiotherapist	15	30
2-Occupational Therapist	9	18
3- Occupational Therapist	14	28
4- Physiotherapist	12	24
Total	50	100

4.2.4. Caregiver Demographics

The respondent for each PEDI questionnaire was the person who usually cared for the participating children at home.

Table 4.8- Respondents frequency distribution n=50

Respondent	n	percentage
Mothers	30	60
Domestic Helpers	11	22
Sisters	4	8
Aunts	3	6
Grandmothers	2	4
Total	50	100

The majority (60%) of the respondents were mothers, while 22% were domestic helpers. A small percentage were (8%) were sisters to the participating children, aunts (6%) or grandmothers (4%) (Table 4.8).

4.3. The Paediatric Evaluation of Disability Index scores

4.3.1 Functional Skills Assessed by Caregivers and Therapists

The means, medians, lower quartiles and upper quartiles for PEDI Functional Skills scores from both caregivers and therapists are shown in Table 4. 9. The Spearman's non-parametric correlation coefficient and the Cronbach's Alpha are also shown. Results pertaining to the three domains are presented separately under Sub Sections 4.3.1.1.to 4.3.1.3. The Spearman's non-parametric correlation coefficient was used to test for correlation between raters' scores for data that is not normally distributed. Non parametric tests were used as it was assumed that due to small sample sizes the data was not normally distributed. The Spearman's non-parametric correlation was also used for testing the correlation between level of disability and hand use against PEDI scores.

The Cronbach's Alpha was used to test for internal consistence. Internal consistence describes the extent to which all the items in a test measure the same concept hence it is connected to the inter-relatedness of the items within the test. If the items in a test are correlated to each other, the value of alpha is increased (Tavakol & Dennick, 2011).

Table 4.9- The correlation and internal consistency for the Paediatric Evaluation of Disability Index functional skills scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile)		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Functional Skills/ Self Care score	24.30 (14.08)	22.92 (13.95)	23.50 (14-33)	23.00 (12-31)	0.91	0.89	0.90
Functional Skills/ Mobility score	11.72 (6.87)	11.22 (6.61)	11.00 (6-18)	10.50 (4-17)	0.93	0.92	0.92
Functional Skills/ Social Function score	26.92 (14.66)	27.54 (13.90)	23.00 (14-42)	28.00 (16-39)	0.92	0.90	0.89

4.3.1.1. Functional Skills Self-Care domain scores

Table 4.10-Correlation and internal consistency for the Functional Skills/Self Care domain scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Functional Skills/ Self Care score	24.30 (14.08)	22.92 (13.95)	23.50 (14-33)	23.00 (12-31)	0.91	0.89	0.90

The mean, median, lower quartile and upper quartiles for self care domain were all higher for caregivers' scores than on therapists' scores indicating caregivers scored the children as a little more independent in self care (Table 4.10). There was excellent correlation between the caregivers' and therapists' scores with a rho of 0.91. Internal consistency for this domain was also excellent for both caregivers and therapists.

Figure 4.4 shows a scatter plot showing the linear relationship between caregiver and therapists scores of self-care functional skills. It appears that the scores of therapists can be used to predict scores of caregivers which means that whether the PEDI is done by the caregivers or therapists the results can be used for treatment planning in rehabilitation. The coefficient of determination (R2) was 0.85 indicating a good fit at $p(F) \leq 0.0001$

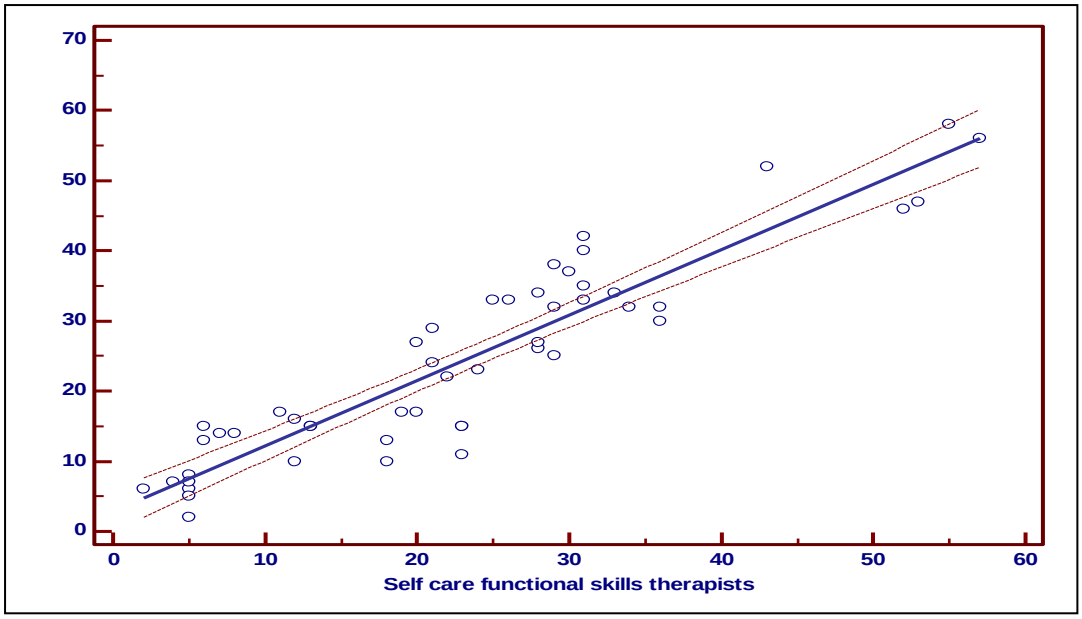


Figure 4.4 Linear relationship between parent/caregiver and therapists - self-care functional skills scores

4.3.1.2. Functional Skills Mobility domain scores

Table 4.11-Correlation and internal consistency for the Functional Skill/Mobility domain scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Functional Skills/ Mobility score	11.72 (6.87)	11.22 (6.61)	11.00 (6-18)	10.50 (4-17)	0.93	0.92	0.92

The mean, median and lower and upper quartiles for the functional skills category scores were all slightly higher for the caregivers' than the therapists (Table 4.11).

Spearman's rho of 0.93 was achieved between caregivers' and therapists' scores for this domain indicating excellent correlation.

The linear relationship between caregiver and therapists scores for mobility functional skills is shown on Figure 4.5.It appears that the scores of therapists

can be used to predict scores of caregivers. The coefficient of determination (R2) was 0.86 indicating a good fit at p (F) ≤ 0.0001

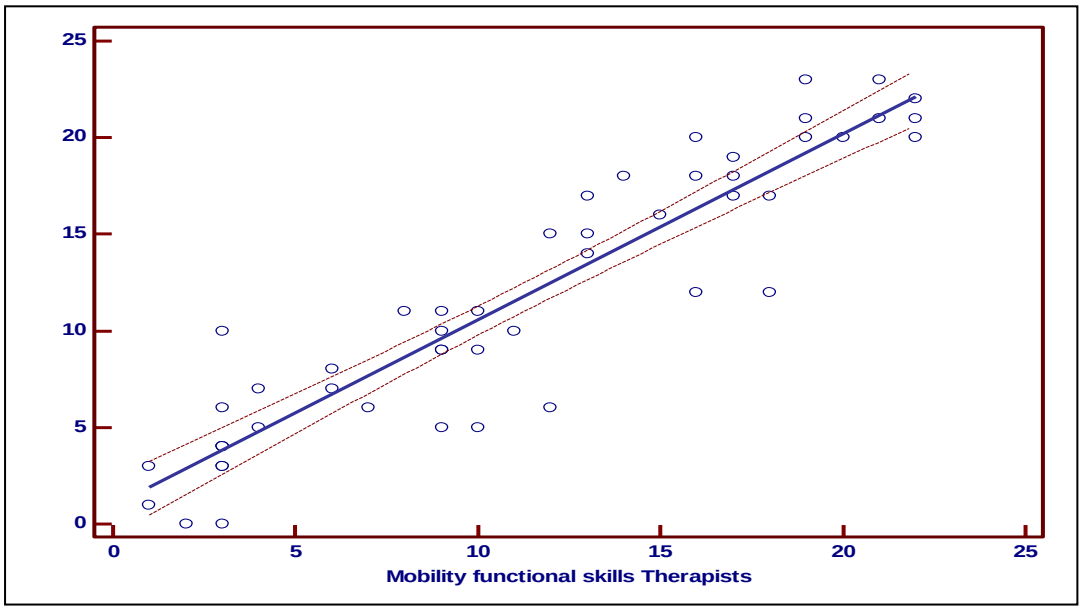


Figure 4.5 Linear relationship between parent/caregiver and therapists – mobility functional skills scores

4.3.1.3 Functional Skills Social Function domain scores

Table 4.12-Correlation and internal consistency for the Functional Skills/Social Function domain scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Functional Skills/ Social Function score	26.92 (14.66)	27.54 (13.90)	23.00 (14-42)	28.00 (16-39)	0.92	0.90	0.89

Means, medians and lower quartiles for the social function category were higher on therapists' scores than on caregivers' scores. The median for therapists was 28.00 and that of caregivers was 23.00 (Table 4.12).

There was a Spearman's rho of 0.92 showing excellent correlation between caregivers' scores and therapists' scores for this domain. The linear relationship between caregiver and therapists scores for social function functional skills is shown on Figure 4.6 and it also appears that the scores of therapists can be used to predict scores of caregivers. The coefficient of determination (R2) was 0.84 indicating a good fit at p(F) ≤ 0.0001 which means that whether the PEDI is done by the caregivers or therapists the results can be used for treatment planning in rehabilitation.

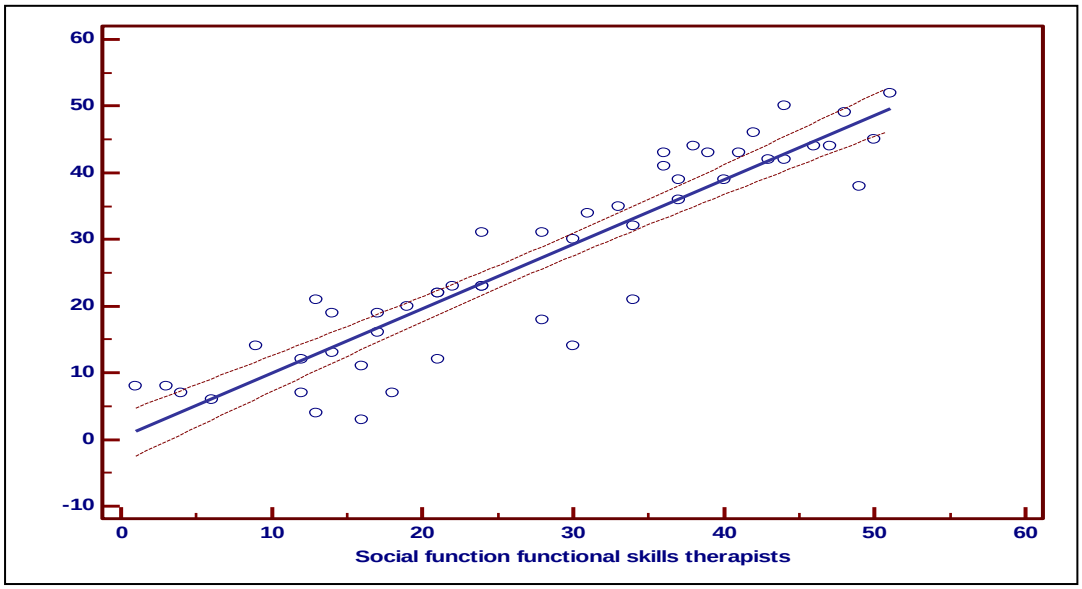


Figure 4.6 Linear relationship between parent/caregiver and therapists-social function functional skills scores

4.4. Care giver Assistance on the Paediatric Evaluation of Disability Index

4.4.1 Caregiver Assistance Assessed by Caregivers and Therapists

The medians, lower quartiles and upper quartiles for PEDI caregiver assistance scores from both caregivers and therapists are shown in Table 4.13. Results pertaining to each domain are presented separately in subsections 4.4.1.1 to 4.4.1.3. The correlations for scores between the caregivers were strong to excellent as was the internal consistency for both groups.

Table 4.13- The correlation and internal consistency for the Paediatric Evaluation of Disability Index functional skills scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Caregiver Assistance/ Self Care score	13.60 (6.39)	13.80 (6.56)	13.50 (0-24)	16.00 (0-23)	0.85	0.90	0.90
Caregiver Assistance/ Mobility score	9.00 (5.00)	9.40 (5.65)	9.00 (0-19)	10.00 (0-18)	0.77	0.92	0.93
Caregiver Assistance Social Function score	11.44 (4.60)	11.26 (4.44)	11.00 (4-22)	11.00 (4-22)	0.84	0.92	0.92

4.4.1.1. Caregiver Assistance Self Care domain scores

Table 4.14-The correlation and internal consistency for the Caregiver /Self care domain scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Caregiver Assistance/ Self Care score	13.60 (6.39)	13.80 (6.56)	13.50 (0-24)	16.00 (0-23)	0.85	0.90	0.90

The median was slightly higher on therapists than on caregivers' scores. Lower quartiles were the same and upper quartiles were similar (Table 4.14) indicating caregivers scored the children as needing similar amount of caregiver assistance in the self-care domain. There was good correlation between caregivers' and therapists scores with a Spearman's correlation coefficient of 0.85. The linear relationship between caregivers and therapists' scores is shown on Figure 4.7 and it appears that the scores of therapists can be used to predict scores of

caregivers. The coefficient of determination (R2) was 0.82 indicating a good fit at p(F) ≤ 0.0001 which means that whether the PEDI is done by the caregivers or therapists the results can be used for treatment planning in rehabilitation.

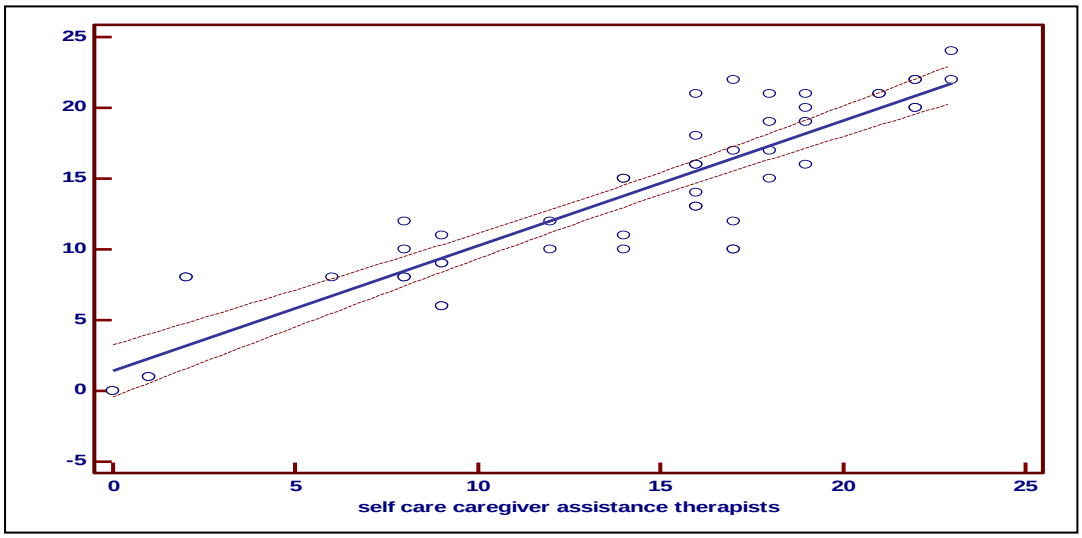


Figure 4.7 Linear relationship between parent/caregiver and therapists – self-care caregiver assistance scores

4.4.1.2. Caregiver Assistance Mobility domain scores

Table 4.15-The correlation and internal consistency for the Caregiver /mobility domain scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Caregiver Assistance/ Mobility score	9.00 (5.00)	9.40 (5.65)	9.00 (0-19)	10.00 (0-18)	0.77	0.92	0.93

Medians, lower quartiles and upper quartiles were all similar on caregivers and therapists scores indicating that caregivers scored the children as needing similar amount of caregiver assistance in the mobility domain (Table 4.15). A Spearman's rho of 0.77 was achieved indicating good correlation. The linear relationship between caregivers' and therapists' scores is shown on Figure 4.8

and it appears that the scores of therapists can be used to predict scores of caregivers. The coefficient of determination (R2) was 0.63 indicating a moderate fit at p(F) ≤ 0.0001

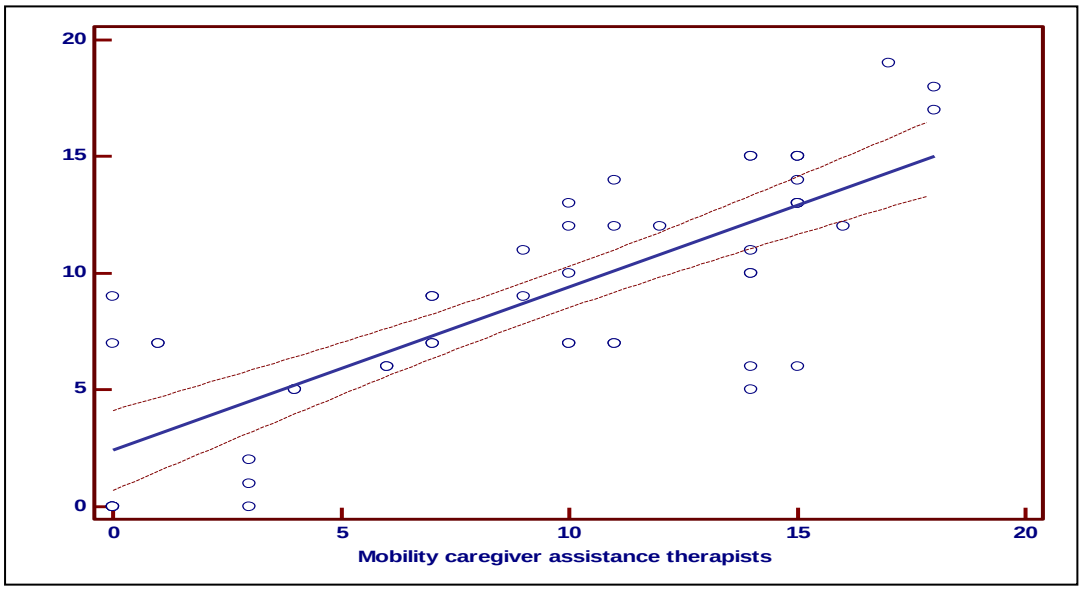


Figure 4.8 Linear relationship between parent/caregiver and therapists – mobility caregiver assistance scores

4.4.1.3. Caregiver Assistance Social Function domain

Table 4.16-The correlation and internal consistency for the Caregiver /Social Function domain scores by caregivers and therapists n=50

Variable	Mean (SD)		Median (Lower Quartile and Upper Quartile		rho	Cronbach's alpha	
	Caregivers	Therapists	Caregivers	Therapists		Caregivers	Therapists
Caregiver Assistance Social Function score	11.44 (4.60)	11.26 (4.44)	11.00 (4-22)	11.00 (4-22)	0.84	0.92	0.92

The medians, lower quartiles and upper quartiles were all the same for caregivers and therapists (Table 4.16) indicating that caregivers rated children the same as therapists for this domain. There was good correlation between caregivers' and therapists' scores with a Spearman's rho of 0.84. The Linear relationship between caregivers' and therapists scores is shown on Figure 4.9 and it appears

that the scores of therapists can be used to predict scores of caregivers. The coefficient of determination (R2) was 0.76 indicating a good fit at p(F) ≤ 0.0001

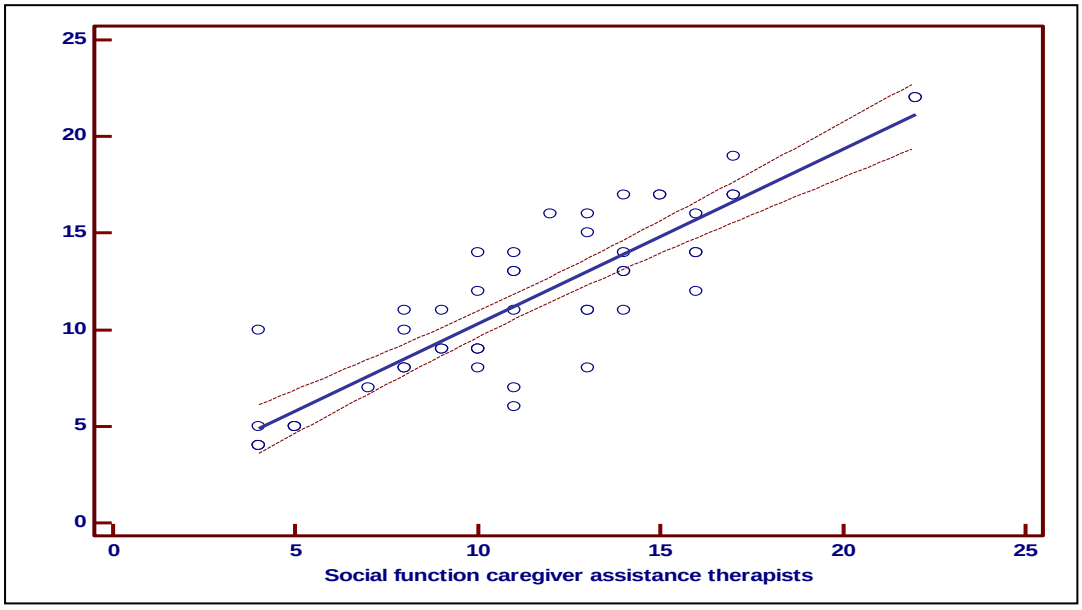


Figure 4.9 Linear relationship between parent/caregiver and therapists – social function caregiver assistance scores

4.5. The Paediatric Evaluation of Disability Index scores for different Gross Motor Function Classification System and Manual Ability Classification System levels

4.5.1 Gross Motor Function Classification System levels

Recap of the GMFCS levels considered in this study.

Table 4.17- Gross Motor Function Classification System levels for children 4-6 years of age

Between 4th and 6th Birthday	
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 an assistive mobility device on level surfaces and climb stairs with assistance from an adult -Children frequently are transported when travelling 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 power wheelchair
Level V .	-Physical impairments restrict voluntary control of movement and the ability to maintain anti gravity 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 -Children have no means of independent mobility and are transported or children achieve self-mobility using a powered wheelchair with extensive adaptations

When the scores on the PEDI for the different GMFCS levels were compared for the caregivers and the therapists there was no significant difference between them (Table 4.18). Scores for the three domains per GMFCS level are presented separately in subsections 4.5.1.1 to 4.5.1.3.

Table 4.18- The Paediatric Evaluation of Disability Index scores for children at different Gross Motor Function Classification System levels

Variable	Mean (SD)		Median (Lower and upper quartile)		p value
GMFCS Level III (n=19)	**Caregivers**	**Therapists**	**Caregivers**	**Therapists**	
Functional Skills/ Self Care Score	35.82 (7.53)	32.47 (9.62)	33.00 (32-40)	31.00 (26-36)	0.99
Functional Skills/ Mobility score	18.82 (2.98)	18.06 (3.09)	19.00 (17-21)	18.00 (16-21)	
Functional Skills/ Social Function score	35.94 (9.76)	35.18 (9.65)	39.00 (31-43)	38.00 (28-43)	
Variable	**Mean (SD)**		**Median (Lower and upper quartile)**		
GMFCS Level IV (n=7)	**Caregivers**	**Therapists**	**Caregivers**	**Therapists**	
Functional Skills/ Self Care Score	19.43 (7.53)	21.57 (8.89)	22.00 (11-25)	23.00 (18-29)	0.61
Functional Skills/ Mobility score	11.57 (2.98)	11.00 (5.69)	10.00 (9-12)	9.00 (8-18)	
Functional Skills/ Social Function score	19.43 (9.76)	21.57 (12.79)	14.00 (12-23)	21.00 (14-30)	
Variable	**Mean (SD)**		**Median (Lower and upper quartile)**		
GMFCS Level V (n=24)	**Caregivers**	**Therapists**	**Caregivers**	**Therapists**	
Functional Skills/ Self Care Score	18.75 (14.25)	17.21 (14.89)	15.00 (10.50-21.50)	12.50 (5.50-25.50)	0.93
Functional Skills/ Mobility score	6.13 (3.98)	6.13 (3.88)	5.50 (3.50-8.50)	5.00 (3-9.50)	
Functional Skills/ Social Function score	23.50 (15.87)	24.75 (15.25)	21.00 (7.50-37.50)	21.00 (12.50-36.50)	

4.5.1.1. Functional Skills Self Care domain scores

Table 4.19- Functional Skills/Self Care domain scores for children at different Gross Motor Function Classification System levels

GMFCS Level	Mean (SD)		Median (Lower and upper quartile)	
	Caregivers	Therapists	Caregivers	Therapists
GMFCS Level III (n=19)	35.82 (7.53)	32.47 (9.62)	33.00 (32-40)	31.00 (26-36)
GMFCS Level IV (n=7)	19.43 (7.53)	21.57 (8.89)	22.00 (11-25)	23.00 (18-29)
GMFCS Level V (n=24)	18.75 (14.25)	17.21 (14.89)	15.00 (10.50-21.50)	12.50 (5.50-25.50)

Medians and lower and upper quartiles for the elf care domain on caregivers' and therapists' scores were in descending order from GMFCS level III through to V (Table 4.19).

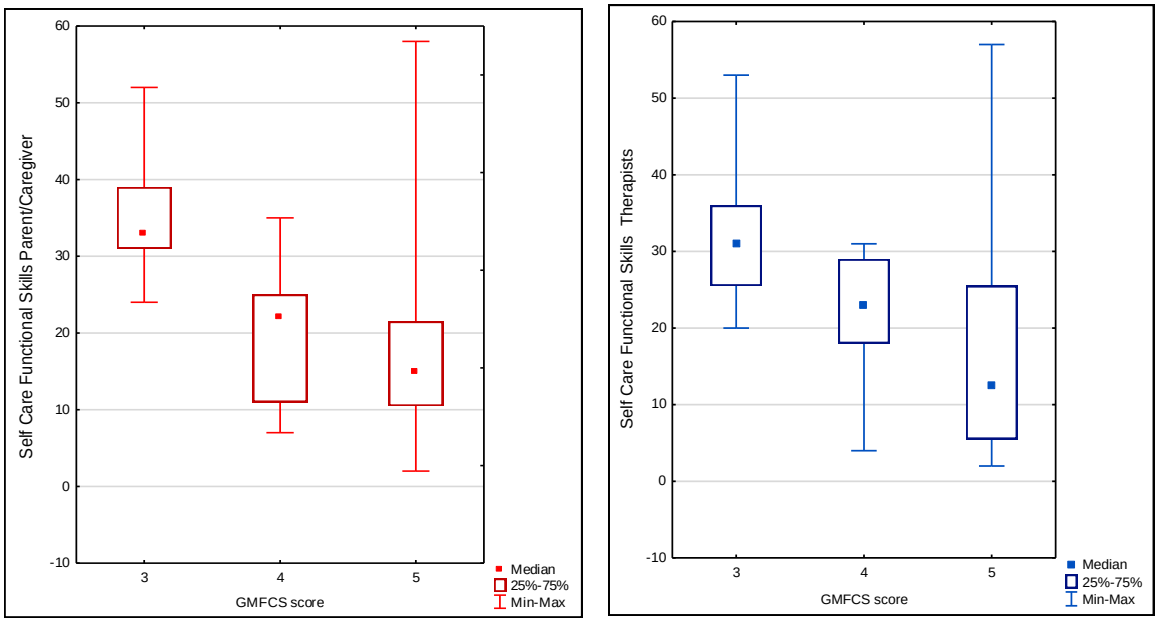


Figure4.10-Self-care scores for different levels of Gross Motor Function Classification System by caregivers and therapists

The variation in the scores for the caregivers and therapists were similar. It can be seen for GMFCS level III for functional skills self care that the parent score is

always slightly higher than the therapists score while for GMFCS level IV the therapists scored the children higher on the functional skills self-care (Figure 4.10). The scores between the levels differed significantly at (p=0.05).

4.5.1.2. Functional Skills Mobility domain scores

Table 4.20- Functional Skills/Mobility domain scores for children at different Gross Motor Function Classification System levels

GMFCS Level	Mean (SD)		Median (Lower and upper quartile)	
	Caregivers	Therapists	Caregivers	Therapists
GMFCS Level III (n=19)	18.82 (2.98)	18.06 (3.09)	19.00 (17-21)	18.00 (16-21)
GMFCS Level IV (n=7)	11.57 (2.98)	11.00 (5.69)	10.00 (9-12)	9.00 (8-18)
GMFCS Level V (n=24)	6.13 (3.98)	6.13 (3.88)	5.50 (3.50-8.50)	5.00 (3-9.50)

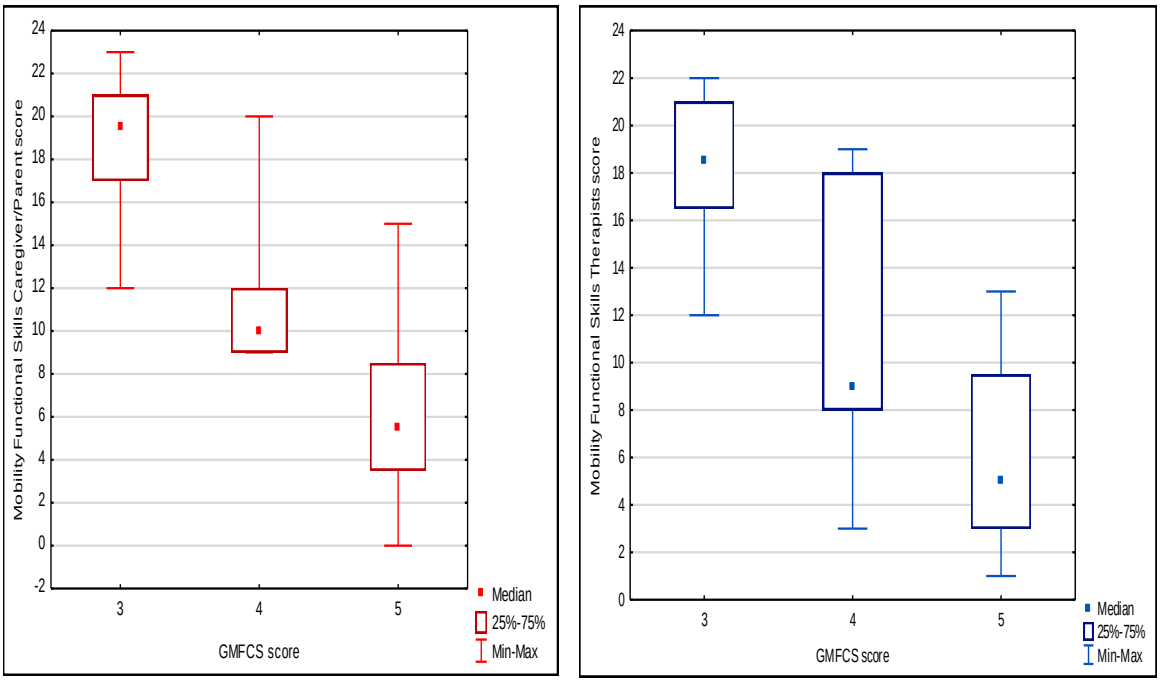


Figure 4.11 Mobility Functional Skills scores for different levels of Gross Motor Function Classification System by therapists and caregivers

Medians and lower and upper quartiles for the mobility domain were generally in descending order from GMFCS level III through to V on scores from both and

therapists (Table 4.20). The therapists' median scores on the PEDI for the children were lower than the caregivers' for all GMFCS levels. The scores between the three GMFCS levels differed significantly at (p=0.05) (Figure 4.11).

4.5.1.3. Functional Skills Social function domain scores

Table 4.21- Functional Skills/Social Function domain scores for children at different Gross Motor Function Classification System levels

Variable	Mean (SD)		Median (Lower and upper quartile)	
	Caregivers	Therapists	Caregivers	Therapists
GMFCS Level III (n=19)	35.94 (9.76)	35.18 (9.65)	39.00 (31-43)	38.00 (28-43)
GMFCS Level IV (n=7)	19.43 (9.76)	21.57 (12.79)	14.00 (12-23)	21.00(14-30)
GMFCS Level V (n=24)	23.50 (15.87)	24.75 (15.25)	21.00 (7.50-37.50)	21.00 (12.50-36.50)

Median on caregivers' scores on social function was highest for GMFCS level III and lowest for level IV (Table 4.21). Unlike a similar pattern of scores in the other domains, therapists had higher scores for children on GMFCS level IV and the same score as caregivers for children on GMFCS level V (Figure 4.12)

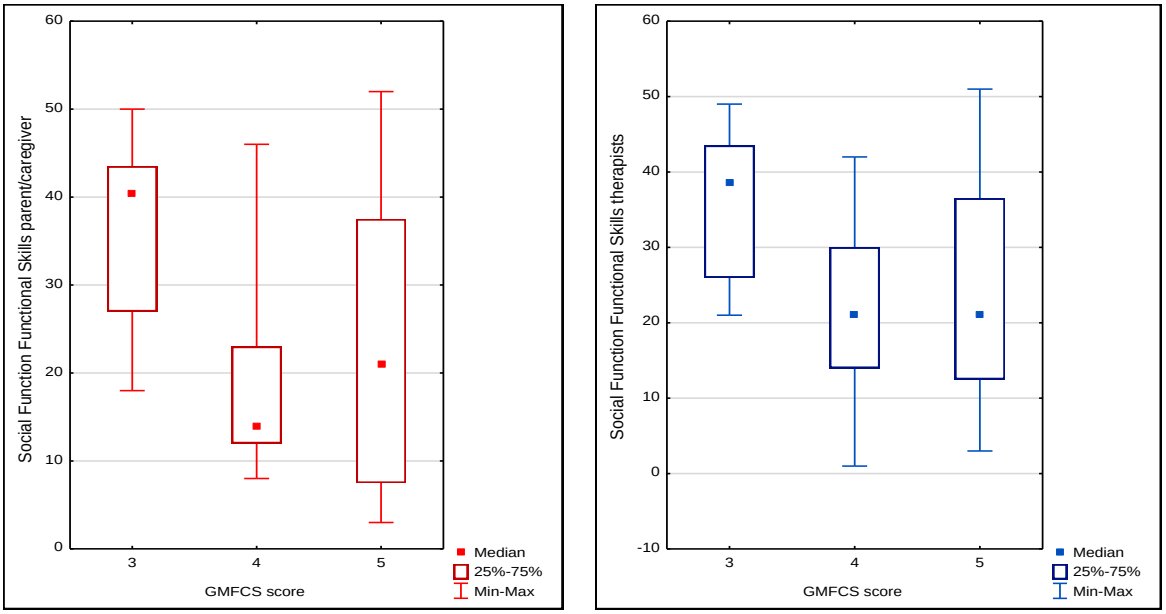


Figure 4.12 Social Function scores for different levels of Gross Motor Function Classification System by Caregivers and Therapists

4.5.2 Manual Ability Classification System levels

When the scores on the PEDI for the different MACS levels were compared for the caregivers and the therapists there was no significant difference between them (Table 4.22a and b). Results for each domain are presented separately in subsections 4.5.2.1 to 4.5.2.3.

Table 4.22aThe Paediatric Evaluation of Disability Index scores for children at different Manual Ability Classification System levels I, II and III

Variable	Scores				p value
MACS Level I (n=1)	**Caregivers**		**Therapists**		
Functional Skills/ Self Care Score	42.00		31.00		**0.84**
Functional Skills/ Mobility score	18.00		16.00		
Functional Skills/ Social Function score	31.00		28.00		
	Mean (SD)		**Median (Lower and upper quartile)**		
MACS Level II (n=16)	**Caregivers**	**Therapists**	**Caregivers**	**Therapists**	
Functional Skills/ Self Care Score	38.31 (4.77)	36.94 (11.63)	35.50 (31.00-46.50)	33.50 (29.50-47.50)	0.99
Functional Skills/ Mobility score	18.12 (2.72)	17.63 (3.84)	19.50 (17-21)	18.50 (16.50-20.50)	
Functional Skills/ Social Function score	38.75 (12.75)	38.69 (9.03)	42.50 (36-44)	40.50 (33.50-45)	
Variable	**Mean (SD)**		**Median (Lower and upper quartile)**		
MACS Level III (n=17)	**Caregivers**	**Therapists**	**Caregivers**	**Therapists**	
Functional Skills/ Self Care Score	21.94 (4.77)	23.35 (4.90)	22.00 (15-32)	23.00 (20-28)	0.99
Functional Skills/ Mobility score	11.24 (2.72)	11.12 (3.62)	10.00 (9-15)	11.00 (9-13)	
Functional Skills/ Social Function score	24.59 (12.75)	27.35 (11.79)	22.00 (14-35)	24.00 (18-34)	

There was only one participant at MACS level I hence scores for this level were excluded from further analysis. There were only four participants at MACS level IV. Although this level was included in analysis, the small number of participants might have had a bearing on the results.

Table 4.22bThe Paediatric Evaluation of Disability Index scores for children at different Manual Ability Classification System levels IV and V

Variable	**Mean (SD)**		**Median (Lower and upper quartile)**		
MACS Level IV (n=4)	**Caregivers**	**Therapists**	**Caregivers**	**Therapists**	
Functional Skills/ Self Care Score	16.75 (8.18)	11.75 (6.55)	16.50 (11.5-22.00)	11.50 (7.50-16.00)	0.80
Functional Skills/ Mobility score	10.25 (7.80)	9.00 (8.29)	8.00 (4.50-16.00)	6.00 (3.50-14.50)	
Functional Skills/ Social Function score	23.00 (10.90)	21.50 (14.71)	26.00 (15-31)	25.50 (11-32)	
Variable	**Mean (SD)**		**Median (Lower and upper quartile)**		
MACS Level V (n=12)	**Caregivers**	**Therapists**	**Caregivers**	**Therapists**	
Functional Skills/ Self Care Score	10.00 (4.77)	6.67 (3.28)	10.50 (6.00-14.50)	5.50 (5.00-7.50)	0.50
Functional Skills/ Mobility score	3.83 (2.72)	3.17 (1.59)	3.50 (2.00-6.50)	3.00 (2.50-3.50)	
Functional Skills/ Social Function score	15.42 (12.75)	14.92 (10.98)	11.50 (6.50-20.00)	13.00 (7.50-16.00)	

4.5.2.1. Functional Skills Self Care domain scores

In the self care domain the therapists' scores for all levels of MACS were lower than those of the caregivers except for MACS level III (Table 4.23 and Figure 4.13).

Table 4.23- Functional Skills/Self Care scores for children at different Manual Ability Classification System levels

MACS Level	Scores			
	Mean (SD)		Median (Lower and upper quartile)	
	Caregivers	Therapists	Caregivers	Therapists
MACS Level II (n=16)	38.31 (4.77)	36.94 (11.63)	35.50 (31.00-46.50)	33.50 (29.50-47.50)
MACS Level III (n=17)	21.94 (4.77)	23.35 (4.90)	22.00 (15-32)	23.00 (20-28)
MACS Level IV (n=4)	16.75 (8.18)	11.75 (6.55)	16.50 (11.5-22.00)	11.50 (7.50-16.00)
MACS Level V (n=12)	10.00 (4.77)	6.67 (3.28)	10.50 (6.00-14.50)	5.50 (5.00-7.50)

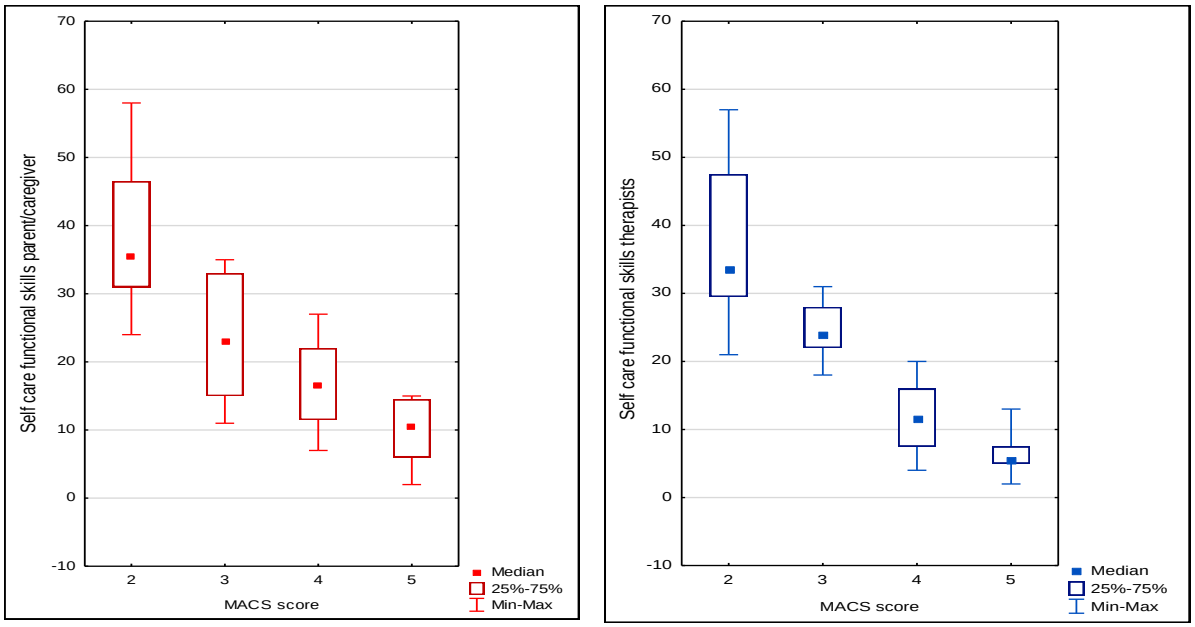


Figure 4.13 Self care Functional Skills scores for different levels of Manual Ability Classification System according to Caregivers and Therapists

4.5.2.2. Functional Skills Mobility domain scores

Medians and lower quartiles on both caregivers' and therapists' scores were largest at MACS level II and decreased in order through levels III and IV to reach smallest at level V (Table 4.24 and Figure 4.14).

However, upper quartiles were ranked in descending order as follows: level II, level IV, level III, and level V. The same descending order was observed on scores for both caregivers and therapists.

Table 4.24- Mobility Domain scores for children at different Manual Ability Classification System levels

MACS Level	Scores			
	Mean (SD)		Median (Lower and upper quartile)	
	Caregivers	Therapists	Caregivers	Therapists
MACS Level II (n=16)	18.12 (2.72)	17.63 (3.84)	19.50 (17-21)	18.50 (16.50-20.50)
MACS Level III (n=17)	11.24 (2.72)	11.12 (3.62)	10.00 (9-15)	11.00 (9-13)
MACS Level IV (n=4)	10.25 (7.80)	9.00 (8.29)	8.00 (4.50-16.00)	6.00 (3.50-14.50)
MACS Level V (n=12)	3.83 (2.72)	3.17 (1.59)	3.50 (2.00-6.50)	3.00 (2.50-3.50)

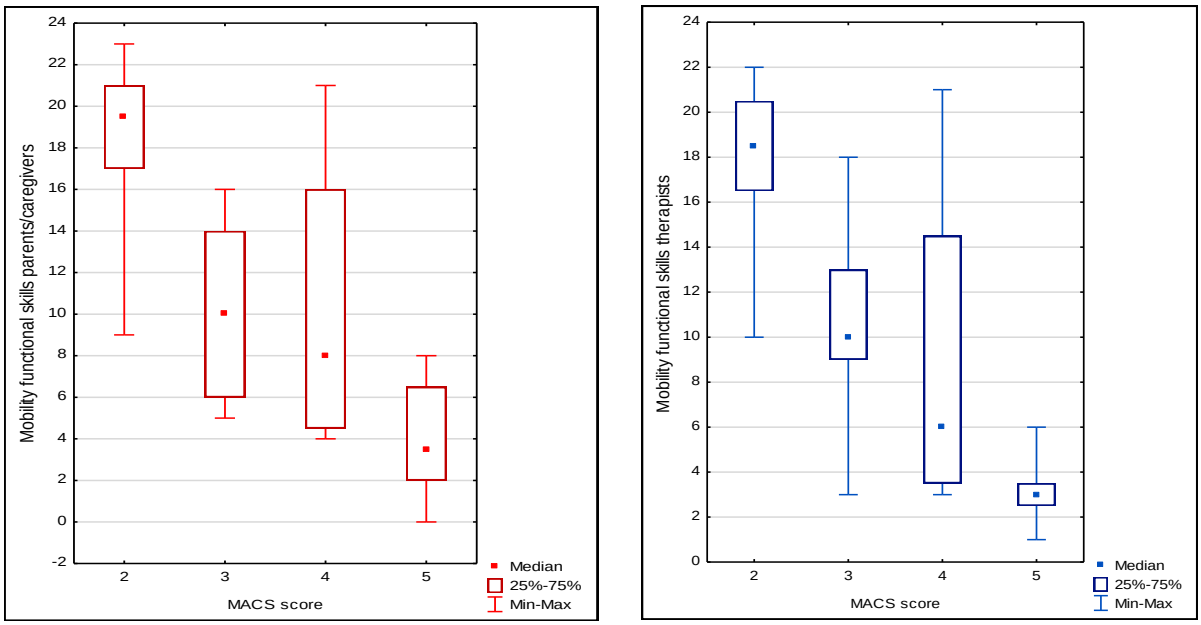


Figure 4.14 Mobility Functional Skills scores for different levels of Manual Ability Classification System according to Caregivers and Therapists

4.5.2.3. Functional Skills Social function domain

Table 4.25- Social Function Domain scores for children at different Manual Ability Classification System levels

Variable	Scores			
	Mean (SD)		Median (Lower and upper quartile)	
	Caregivers	Therapists	Caregivers	Therapists
MACS Level II (n=16)	38.75 (12.75)	38.69 (9.03)	42.50 (36-44)	40.50 (33.50-45)
MACS Level III (n=17)	24.59 (12.75)	27.35 (11.79)	22.00 (14-35)	24.00 (18-34)
MACS Level IV (n=4)	23.00 (10.90)	21.50 (14.71)	26.00 (15-31)	25.50 (11-32)
MACS Level V (n=12)	15.42 (12.75)	14.92 (10.98)	11.50 (6.50-20.00)	13.00 (7.50-16.00)

Medians on both caregivers' scores on social function were highest at MACS level II, followed by IV and III respectively and smallest at level V.

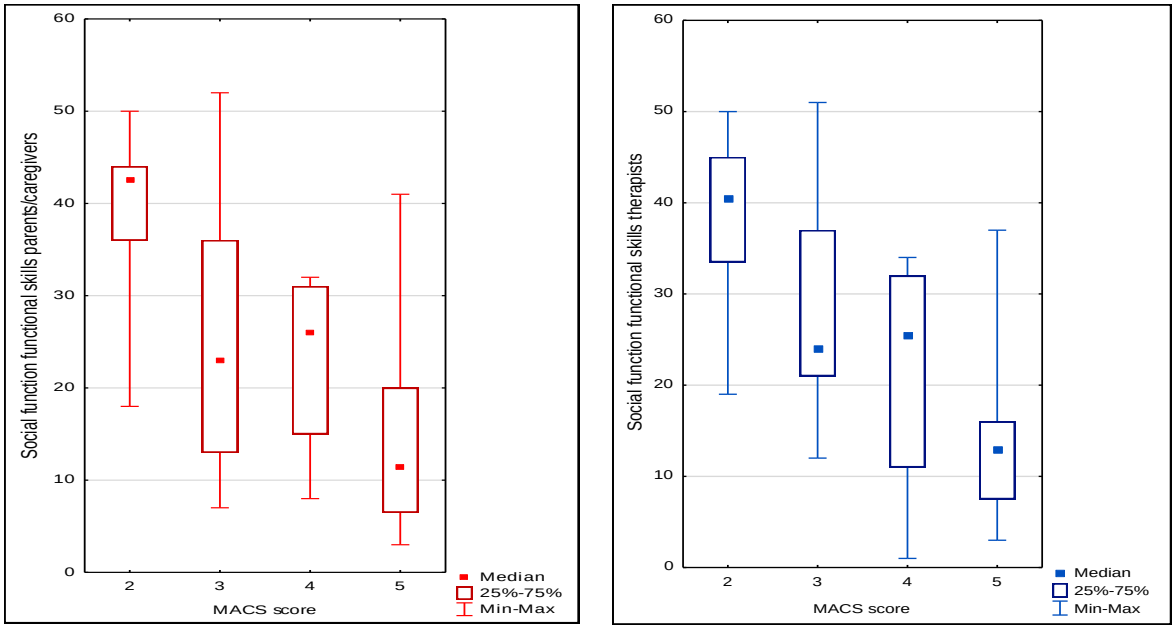


Figure 4.15 Social Function Functional Skills scores for different levels of Manual Ability Classification System according to Caregivers and Therapists

The therapists' scores for all levels of MACS were lower than those of the caregivers except for MACS level III. These were generally in descending order from MACS level II through to V (Table 4.25 and Figure 4.15).

4.6 Relationship between level of disability and perceived level of occupational performance

4.6.1 Relationship between the Paediatric Evaluation of Disability Index score for different Gross Motor Function Classification System levels

The results clearly indicated a decrease in functional skills on the PEDI as the GMFCS level of the children showed more severe deficits (Figure 4.7, 4.8 and 4.9). There was a negative moderate correlation between the PEDI scores and the GMFCS levels for self care functional skills. The correlation was negative as the higher functional skills are expected in children with the lowest GMFCS score.

Between mobility functional skills and the GMFCS levels there was a negative strong correlation but a negative weak correlation for social function PEDI scores and the GMFCS levels (Table 4.26).

Table 4.26- The correlation between the Paediatric Evaluation of Disability Index functional skills scores and Gross Motor Function Classification System levels (n=50)

Variables	**Caregivers**	**Therapists**
	rho	**rho**
Functional Skills/ Self Care Score	-0.58	-0.56
Functional Skills/ Mobility score	-0.84	-0.79
Functional Skills/ Social Function score	-0.37	-0.34

Between self-care and mobility functional skills and the MACS levels there was a negative strong correlation but a negative weak correlation for social function PEDI scores and the MACS levels (Table 4.27).

Table 4.27- The correlation between the Paediatric Evaluation of Disability Index functional skills scores and Manual Ability Classification System levels (n=50)

Variables	Caregivers	Therapists
	rho	rho
Functional Skills/ Self Care Score	-0.80	-0.78
Functional Skills/ Mobility score	-0.69	-0.68
Functional Skills/ Social Function score	-0.35	-0.34

4.7 Summary

There were small differences in PEDI functional skills and PEDI caregiver assistance scores by and therapists. The correlations for scores between the caregivers and therapists for both functional skills and caregiver assistance were strong to excellent as was the internal consistency for both groups.

When the scores on the PEDI for the different GMFCS and MACS levels were compared for the caregivers and the therapists there were no significant differences between them.

A marked decrease in functional skills on the PEDI was noted as the GMFCS level of the children showed more severe deficits. There was a negative moderate correlation between the PEDI scores and the GMFCS levels for self care functional skills. Between mobility functional skills and the GMFCS levels there was a negative strong correlation but a negative weak correlation for social function PEDI scores and the GMFCS levels.

Between self-care and mobility functional skills and the MACS levels there was a negative strong correlation but a negative weak correlation for social function PEDI scores and the MACS levels.

Internal consistence was excellent for all functional skills domains and caregiver assistance for both therapists and caregivers.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter presents a discussion of the findings firstly in relation to demographics and the treatment context. The evaluation of the occupational performance and the assistance needed by children with CP rated on the PEDI by caregivers and rehabilitation professions is then discussed. Finally, the association between PEDI scores for children with CP and their levels on the GMFCS as well as levels on the MACS is also discussed.

5.2. Demographics

The sample had equal number of male and female children participants. This happened by chance and was not a requirement in terms of selection and should not affect the results although it made the sample balanced in terms of gender.

Most of the children with CP (46%) were in the age range 4 years to 4 years 5 months. A similar number of children made up the other four age groups with an increase of six month intervals until the age of 6 years to 6 years 6 months. This was a reflection of the fact that the research settings were hospital and clinic outpatient services to which younger children are brought for rehabilitative therapy. Age range of 4 years to 4 years 5 months was the minimum age range set for inclusion for this study. It is normally expected that at age four and above children are less dependent on the caregiver for function hence caregivers can report more clearly on children's performance than they would for younger children. Age range of 4 to 6 years 6 months was chosen. This ensured applicability of all instruments that the researcher was going to use namely the GMFCS, MACS and PEDI. Children older than 6 years 6 months do not attend these clinics for rehabilitation as they usually go to preschool/school settings where they also receive occupational therapy and physiotherapy sessions.

Although children are expected to be in preschool at around 4 years if they do not suffer from any disabilities, children with CP usually start school when they are

older and are often behind in the expected performance levels in functional skills because of their motor and associated difficulties (James *et al*., 2014). This was found to be true of the children in this study with a large number of children aged 4 years to 4 years 5 months still attending the clinics and not yet going to preschool.

The most frequent diagnoses in this study were spastic quadriplegia, dystonia and athetosis with children with these three forms of CP making up 62% of the sample. These forms of CP are considered to affect functional skills more than the others and children with these diagnoses were more likely not to have started pre school and will still be staying at home and coming for outpatient therapy. Children with other forms of CP (diplegia, hemiparesis, hypotonic) are more likely to have better functional skills and therefore will have started preschool or school. For example, the children with hypotonic CP often get stronger as they grow older, and those with hemiparetic and diplegic CP compensate with their unaffected limbs to achieve considerable functional skills (Accardo & Hoon, 2008). For the same reason the children attending the hospital outpatient were most likely to have a GFMCS score of V with poor functional skills although the hand function of the children varied from a MACS score of II to V almost equally across the group and hand function may not have limited functional skills in this group as much as gross motor function.

The majority (60%) of the care givers that filled in the PEDI of the children with CP were mothers. This was a reflection of the social contexts in which the research study was carried out. Mothers are expected to look after their children more than fathers are and some mothers who are working would take a day off from work to bring their children for therapy. A few mothers who were not able to get time off work would send the child to therapy with the maid who looked after the child at home. A few of the children were orphaned and were being cared for by relatives like grandmothers and aunts. All the caregivers attending therapy with the child were the primary caregivers who had knowledge of the child's functional skills.

5.3 Treatment Context

Three treatment contexts were selected for the study. These are the main treatment contexts found in Zimbabwe and the researcher wanted to have a representative sample but socioeconomic status was not considered as a variable in this study. The first was a hospital based outpatient setting in a public hospital, the second was private outpatient rehabilitation centre and the third was an outreach point where therapists go to attend to the children at a community centre.

5.4. Relationship in evaluation of functional skills and caregiver assistance between therapists and caregivers.

The first objective of this study was to determine and establish the correlation of the caregivers' and therapists' scores when evaluating self care, mobility and social domains and the assistance needed using the PEDI for children attending therapy at CP clinics.

When the therapists treating the child and their parent/caregiver rated the children in all three domains of the PEDI (self-care, mobility and social function) there were few differences in the way the therapists and caregivers rated the children. The correlation for all three scores was excellent. Linear relationships between caregiver and therapists scores implied that the scores of therapists can be used to predict scores of caregivers. Coefficients of determination indicated good fit for regression models for all domains on Functional Skills and Caregiver assistance except the caregiver mobility domain which had moderate fit. These results implied that whether the PEDI is done by the caregivers or therapists the results can be used for treatment planning in rehabilitation.

For functional skills: self-care and mobility mean and median scores were higher than those of the therapists by a small amount so the caregivers scored the children as a more independent in self care and mobility than did the therapists.

The small difference in score may have been caused by the fact that therapists have a limited time with the children to adequately observe functional

performance compared to caregivers. Therapists may miss some newly emerged behaviour which caregivers are able to observe at home (Diamond & Squires, 1993). Behaviour of children in new/unfamiliar environment may also have contributed to the slight differences. Children may use different forms of mobility in different contexts and over different terrains, which cannot always be observed in the clinic (Tieman *et al.*, 2004). Some mothers may deny that their children are not able to even do the simplest tasks by themselves hence they may exaggerate the child's capabilities to some extent.

These findings for functional skills agree with those reported by Vargus-Adams *et al*. (2011) and by Elad *et al*. (2013) in their studies with mothers having slightly higher scores on the PEDI for self-care and mobility. These studies were carried out in Brazil and Israel respectively and indicate the PEDI provides similar results for this aspect irrespective of cultural differences and environmental resources in different counties.

Neither of these studies evaluated the social domain but therapists in this study scored the children as more independent in the social domain than did the caregivers, with a five point difference in the median score. It was apparent in the PEDI interviews that caregivers feel that therapy should be about children's mobility and self-care and to a lesser extent social function capabilities. Caregivers however see their children in social situations which cannot be observed in the clinic and may have observed behaviour with other children and adults which affect the ratings they gave.

Diamond & Squires (1993) point out that it is not necessary that professionals and caregivers agree completely in terms of the child's occupational performance. In terms of evaluation it has been shown that on average positive correlation between caregivers' and professionals' scores is found on 75%-95% of the items from standardised tests. The differences in the items may reflect skills the child is just beginning to develop seen either by the caregivers or therapists in settings that differ (Diamond & Squires, 1993; Squires *et al*., 1990).

On the caregiver assistance scale, there were very small differences in the scores between caregivers and therapists. Their scores were very similar for all three domains although the therapists in this case had higher median scores of 1 to 2 points for both self care and mobility.

These results were also reflected in the study in Israel by Elad *et al*. (2013) but with the biggest discrepancies of 59% and 72% negative correlation, respectively found in the caregiver assistance in the self-care and mobility domain scores of PEDI. Mothers rated their children lower as they perceived their children needing more assistance in performing everyday self care activities and in moving around than did the therapists. The differences seen in the amount of discrepancy between caregivers and therapists in this study and the Israeli study may be because of the age range for participating children which was 6 to12 years in that study as compared to 4 to 6 years 6 months in the current study. The perceived need and provision of caregiver assistance by mothers in the Israeli study was attributed to parental psychological and emotional mechanisms, where mothers saw their children as vulnerable and needing protection. This meant that older children who are expected to require less assistance were still provided assistance for some activities where for example overprotective caregivers did not allow older children to be independent in activities like bathing alone (Elad *et al*., 2013).

The null hypothesis that there is no relationship in evaluation of functional skills self care, mobility and social function domains and caregiver assistance using the PEDI for children for CP children between therapists and of children attending CP clinics in Harare is therefore rejected. On the caregiver assistance scale, there were very small differences in the scores between caregivers and therapists.

5.5 Relationship between level of disability and perceived level of occupational performance

Caregivers base their rankings on direct everyday observations in various environments whereas therapists rely on one observation at one point in time and

cannot observe all activities. Therapists may also base their judgement on the severity of the condition they observe. Therefore it was important to determine the relationship between the scores on the PEDI given by caregivers and therapists according to the GMFCS and MACS levels which reflect the severity of the child's CP. This formed objectives two and three of the study which considered the relationship between level of disability measured by the levels on both the GMFCS and MACS and perceived level of occupational performance measured by the PEDI.

5.5.1. The Paediatric Evaluation of Disability Index scores and the Gross Motor Function Classification System levels

The PEDI scores and GMFCS level were linked to ascertain if there was any relationship between the scores and the levels. GMFCS functional classification has been recommended as a good indicator of mobility function for children with CP. The higher the GMFCS level the lower the Functional Skills Mobility Skills domain scores on the PEDI (Chagas *et al*., 2008). However, majority of the studies done so far regarding this relationship have been done in developed countries and none have been done in the context of the current research.

The results indicate that the functional skills: self-care and mobility scores were in a descending order from level GMFCS level III through to V. Self-care and mobility depend a lot on gross and fine motor skills which are directly affected in CP. The results clearly indicated a decrease in functional skills self-care and mobility on the PEDI as the GMFCS level of the children decreases indicating more severe deficits. This supports the findings of Ketelaar *et al*. (2014) who concluded that development in self care is faster in children with lower GMFCS levels, indicating an association with their better gross motor function (Ketelaar *et al*., 2014)

This was confirmed by the negative moderate correlation between the PEDI scores and the GMFCS levels for self care functional skills. The correlation is negative as the higher functional skills are expected in children with the lowest GMFCS score. When the scores of the and therapists for the functional skills self care were compared for the various GMFCS levels it was found that there was

some variation although no significant difference. The variation was greatest in the caregivers' scores which were higher than the therapists' scores except for level IV where the scores were the same. Elad *et al*. (2013) found similar variation in their study with mothers scoring children on GMFCS III, IV and V slightly higher than the therapist (Elad *et al*., 2013)

For the mobility functional skills and the GMFCS levels and PEDI scores there was a negative strong correlation indicating that the mobility domain is more closely associated with the gross motor function of the child with CP in this study. Previous research has also shown a moderate association between the severity of CP as measured on the GMFM-66 and the mobility domain of an occupational performance assessment for children with disability measured by the PEDI Functional Skills Scale (Han *et al*., 2011). Brandäo *et al*. (2012) also established a relationship between GMFCS levels and mobility skills while Ketelaar *et al*. (2014) also found that for mobility, differences in the rate of development are most likely between GMFCS level I-III and GMFCS level IV and V (Ketelaar *et al*., 2014). This was supported by the findings in this study in which the scores for children with GMFCSIII were double those of children with GMFCS level IV for both caregivers and therapists.

The caregivers also scored the children's mobility as higher than the therapists for all GFMCS levels. There was far more variation in the therapists scores which may have been influenced by their knowledge or the child's other deficits such as tone, sensation and weakness which influenced their judgement. There was no significant difference between the caregivers' and therapists' scores for this domain on the PEDI however. Again Elad *et al*. (2013) found similar results but with far less variation in the therapists scores, especially for GMFCS level III. This may be because the therapists assessing the children in the Israeli study by Elad *et al*. (2013) did not know the children previous to the assessment and were not influenced by other knowledge about the child.

For functional skill social domain the highest score was at GMFCS level III and the lowest at level IV. The lack of congruence between the GMFCS scores and social function reflects the fact that social function is less affected by motor

dysfunction than self-care and mobility. This was reflected in the negative weak correlation for social function PEDI scores and the GMFCS levels. The therapists again scored the children higher for social function at all the GMFCS levels particularly level IV although there was no significant difference in the scores between the and the therapists. In these results greater variation was seen in the caregivers' scores. These findings do raise the concern that therapists rarely see the child in their social context and may be unaware of concerns in this area. Occupational therapists in particular should be concerned with social function and may not be setting realistic goals for the child in relation to this as they may underestimate the child's dysfunction.

The lower correlation found between functioning in self-care on the PEDI and the GMFCS levels when compared to that found between mobility function on the PEDI and the GMFCS levels may be due to the children with dipelgia and hemiplegia whose self care is not as affected by gross motor deficits as they have better hand function. Therefore the PEDI scores were correlated with the MACS scores as well.

5.5.2. The Paediatric Evaluation of Disability Index scores and the Manual Ability Classification System levels

The PEDI scores and MACS levels were also linked to ascertain if there was any relationship between the scores and the levels. MACS functional classification has been recommended as a good indicator of manual function of children with CP (Chagas *et al*., 2008). Studies have been carried out to identify and compare the information made available by the classification system to that by functional tests to ascertain if they show any relationship which can be utilised in intervention planning but no previous studies have been done in the context of the current research.

When the results for the MACS level were analysed only one child presented at MACS level I, and this child was excluded from analysis. The PEDI scores were highest at MACS level II and got smaller in descending order to reach lowest at MACS level V for self-care and mobility. This finding supports the findings of Öhrvall *et al*. (2010) who investigated the acquisition of self-care and mobility skills using PEDI in children with CP in relation to their manual ability MACS

scores. Children at MACS levels I or II were found to score higher than those at levels III to V on the self-care as well as the mobility domain of the PEDI. Their research also indicates that self-care ability increases as children at MACS levels I or II get older and they are likely to achieve independence in self-care although at a later age than children who did not have CP. Children at higher MACS levels showed minor progress relative to their age and remained dependent, needing assistance from caregivers (Öhrvall *et al*., 2010).

The same order was not observed for social function which had a lower score for children with MACS level III than those with MACS level IV, but this level only had four participants which may have influenced the results.

There was a negative strong correlation between self-care functional skills scores on the PEDI and the MACS levels in this study which was higher than that found between the mobility functional skills scores on the PEDI and the MACS levels. This finding confirms that of Brandäo *et al*. (2012) who found an association between hand function skills and functional performance in children with CP whereas mobility had a stronger relationship to the GMFCS. The association was further established by Kwon *et al*. (2013). Their study revealed that the severity levels of CP and Bimanual Fine Motor Function levels had a moderate relationship with the self-care domain of the PEDI Functional Skills Scale. Kwon *et al*. (2013) however, attribute the outcome to the large number of individuals in their study group with quadriparesis and gross motor function levels IV and V, which resulted in lower scores in all areas of the PEDI (Kwon *et al*., 2013).

When the scores of the caregivers and therapists for the functional skills self care and mobility were compared for the various GMFCS levels it was found that these had no significant difference. Again there was variation between the caregivers' and therapists' scores and the caregivers' scores were higher than therapists' scores. The exception was for MACS level III self care functional skills scores where the therapists' scores were higher. This variation has not been reported elsewhere and may be due to the small number of children in this study, particularly MACS level IV.

There was a moderate negative weak correlation between the social function scores and the MACS levels in the study. These findings reflect the hand function required to lay and do household chores which are part of the social domain on the PEDI and mobility function like crossing the road. Other aspects measured in the social domain are not reliant on hand function and mobility however.

The null hypothesis that there is no relationship between level of disability and perceived level of occupational performance measured by the PEDI and the levels on both the GMFCS and MACS is therefore rejected.

It is clear that ratings that caregivers and therapists give on the PEDI for the limitations in self care, mobility and social function according to the severity level of the child with CP is realistic and that the combined setting of goals for each child according to their GMFSCS and MACS level , is possible.

5.6. Implications of the findings

Findings of this study help to affirm that collaboration between caregivers and therapists in Family Centred Functional Therapy can be used for the rehabilitation of children with CP in this context. Since caregivers in the study population rated their children similar to therapists, goal setting and intervention planning is made easier when working from similar perceptions of strength/weaknesses of children with CP.

Therapists as well as need to be educated on the importance of social function and probably social participation of their children with CP so that they do not only focus on movement dysfunction and its effect on mobility and self-care but rather on all aspects of quality of life.

The GMFCS and MACS classifications can be used to predict mobility function and self care skills function respectively and be utilised for intervention planning for children with CP in the current research context. This is important especially in the public sector rehabilitation units where the re is usually overwhelming patient to therapist ratio and there may not be enough time to administer the PEDI and similar tests which are time consuming.

5.7. Internal consistency of the Paediatric Evaluation of Disability Index when used with caregivers and therapists at cerebral palsy clinics in Harare.

Internal consistency for both caregivers and therapists was excellent for all domains on Functional Skills and Caregiver Assistance categories of the PEDI. All Cronbach's Alpha values were 0.89 and above for both caregivers and therapists for all domains (Tables 4.9 and 4.13). This is similar to a study in Israel by Elad *et al*. (2013) where high alpha scores were found for the reliability of the PEDI for self care and mobility when used by mothers' and rehabilitation professionals' with older children with CP(Elad *et al*., 2012).These findings confirm the reliability for this aspect as reported by Haley *et al*. (1992) in the report psychometric properties of the PEDI when it was developed (Haley *et al*., 1992).This indicates that this assessment has internal consistency when used by and therapists in the Zimbabwean context.

5.8. Limitations of the study

This study was cross sectional. It would be helpful to carry out a longitudinal study to ascertain if caregivers and therapists would rate children with CP similarly as the children age and when they are older, especially for caregiver assistance.

The current research evaluated the changes in functional performance at higher levels of GMFCS levels III to V and no children at lower levels were included as they do not present with functional problems, they usually delay in achieveing the skills.

Although the researcher tried to select representative centres for sampling, school based facilities were not considered mainly because some of the children stay in boarding where family caregivers are no longer the carers for the children. It would be helpful to include school settings for sampling in order to get the view of teachers comparing their scores to caregivers' and therapists' because teachers are important in the multidisciplinary team that works with children living with CP.

5.9 Summary

The sample had equal number of male and female children participants who were drawn from three typical settings for child rehabilitation in Harare. This helped make the sample representative. Most of the participating children were in the age range 4 years to 4 years 5 months reflecting the fact that the research settings were hospital and clinic outpatient services to which younger children are brought for rehabilitative therapy. Children older than 6 years 6 months do not usually attend these clinics for rehabilitation as they go to preschool/school settings where they also receive occupational therapy and physiotherapy sessions.

The most frequent diagnoses in this study were spastic quadriplegia, dystonia and athetosis. These forms of CP are considered to affect functional skills more and children with these diagnoses were more likely not to have started pre school and will still staying at home and coming for outpatient therapy. The majority of the caregivers that filled in the PEDI of the children with CP were mothers. This was a reflection of the social contexts in which the research study was carried out. Mothers are expected to look after their children more than fathers.

The correlation of scores for self-care, mobility and social function between therapists and caregivers was excellent with significant linear regression. On the caregiver assistance scale, there were very small differences in the scores between caregivers and therapists.

The results indicated a decrease in functional skills self-care and mobility on the PEDI as both the GMFCS and MACS level of the children decreased indicating more severe deficits but the lack of congruence between the GMFCS scores and social function reflects the fact that social function is less affected by motor dysfunction than self-care and mobility. In these results greater variation was seen in the caregivers' scores and this raises the concern that therapists rarely see the child in their social context and may be unaware of concerns in this area.

Internal consistence for both caregivers and therapists was excellent for all domains on Functional Skills and Caregiver Assistance categories of the PEDI.

CHAPTER 6: CONCLUSION

It was the researchers opinion that there appears to be a lack of insight among of children with CP attending outpatient clinics in Harare about how much their children can do for themselves and also that therapists may be unaware of the exact circumstances in a child's home environment that impact on their occupational performance. This could lead to misalignment of goals for intervention yet well aligned goals are important for FCFT. The study therefore aimed to compare the evaluation of the occupational performance and assistance needed to carry out self care, mobility and social function activities of children with CP by caregivers to that of therapists using the PEDI. The association between occupational performance of the children and the different GMFCS and MACS levels were confirmed as well the reliability of using the PEDI for caregivers and therapists in Harare.

The Spearman's correlation coefficients and logistic regression were used to test for correlation between the caregivers' and the therapists' PEDI scores. The association between the severity of the CP on the GMFCS and the MACS was correlated with the domain scores and assistance scores on the PEDI using Spearman's correlation coefficients and logistic regression also.

6.1. Relationship in evaluation of functional skills and caregiver assistance between therapists and caregivers.

Small differences were recorded in PEDI functional skills and PEDI caregiver assistance scores by caregivers and therapists but the differences were not statistically significant. The correlations for scores between the caregivers and therapists for both functional skills and caregiver assistance were strong to excellent.

It was concluded that caregivers and therapists in Harare score CP children the same in functional skills self care, mobility and social function domains and caregiver assistance on the PEDI.

6.2. Relationship between level of disability and perceived level of occupational performance

A marked decrease in functional skills on the PEDI was noted as the GMFCS level of the children showed more severe deficits. There was a negative moderate correlation between the PEDI scores and the GMFCS levels for self care functional skills and a negative strong correlation between mobility functional skills and the GMFCS levels but a negative weak correlation for social function PEDI scores and the GMFCS levels.

The results clearly indicated a decrease in functional skills self-care and mobility on the PEDI as the GMFCS level of the children decreased indicating more severe deficits.

There was a negative strong correlation between self-care functional skills and the MACS levels and also between mobility functional skills and the MACS levels but a negative weak correlation for social function PEDI scores and the MACS levels. These findings reflect the hand function required to lay and do household chores and mobility to get around which are part of the social domain on the PEDI. Other aspects measured in the social domain are not reliant on hand function however.

It was concluded that level of occupational performance measured by PEDI decreased as the level of disability increased on both the GMFCS and MACS.

6.3. Internal consistency of the Paediatric Evaluation of Disability Index when used with caregivers and therapists at cerebral palsy clinics in Harare.

Internal consistency for both and therapists was excellent for all domains on Functional Skills and Caregiver Assistance categories of the PEDI and it was concluded that that the PEDI has internal consistency when used by and therapists in the Zimbabwean context.

6.4. Recommendations for future research

Randomised Control Trial studies will be helpful. PEDI evaluations for the children after particular interventions to find out efficacy of the approaches for children in this context are recommended.

It is also recommended to include teachers in future studies to compare teachers', family's and therapists' opinions of disabled children's occupational performance because teachers work with disabled children in schools

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APPENDICES

APPENDIX ADEMOGRAPHIC QUESTIONNAIRE

To be kept separate

Code _____

Child's name _____

Parent/Caregivers name _____

Therapists treating child _____

DEMOGRAPHIC QUESTIONNAIRE

Code _____

1. Age _____

2. Gender _____

3. Attends Physiotherapy as an outpatient Yes ☐ No☐

   If yes -How often _____

4. Attends Occupational therapy as an outpatient Yes ☐ No☐

   If yes -How often _____

5. Attends other therapy as an outpatient

   Specify what and how often _____

6. Primary caregiver

   Mother ☐ Father ☐ Grandmother ☐

   Other – Specify _____

7. Person responsible for achieving therapy goals at home

   Mother ☐ Father ☐ Grandmother ☐

   Other – Specify _____

APPENDIX BGROSS MOTOR FUNCTION CLASSIFICATION SYSTEM FOR CEREBRAL PALSY

Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi (1997)

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System for cerebral palsy is based on self-initiated movement with particular emphasis on sitting (truncal control) and walking. When defining a 5 level Classification System, our primary criterion was that the distinctions in motor function between levels must be clinically meaningful. Distinctions between levels of motor function are based on functional limitations, the need for assistive technology, including mobility devices (such as walkers, crutches, and canes) and wheeled mobility, and to much lesser extent quality of movement. Level I includes children with neuromotor impairments Whose functional limitations are less than what is typically associated with cerebral palsy, and children who have traditionally been diagnosed as having “minimal brain dysfunction” or “cerebral palsy of minimal severity”. The distinctions between Levels I and II therefore are not as pronounced as the distinctions between the other Levels, particularly for infants less than 2 years of age.

The focus is on determining which level best represents the child’s present abilities and limitations in motor function. Emphasis is on the child’s usual performance in home, school, and community settings. It is therefore important to classify on ordinary performance (not best capacity), and not to include judgments about prognosis. Remember the purpose is to classify a child’s present gross motor function, not to judge quality of movement or potential for improvement. The descriptions of the 5 levels are broad and are not intended to describe all aspects of the function of individual children. For example, an infant with hemiplegia who is unable to crawl on hands and knees, but otherwise fits the description of Level I, would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children with cerebral palsy are equally distributed among the 5 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 current gross motor function. The title for each level represents the highest level of mobility that a child is expected to achieve between 6-12 years of age. We recognize that classification of motor function is dependent on age, especially during infancy and early childhood. For each level, therefore, separate descriptions are provided for children in several age bands. The functional abilities and limitations for each age interval are intended to serve as guidelines, are not comprehensive, and are not norms. Children below age 2 should be considered at their corrected age if they were premature. An effort has been made to emphasize children’s function rather than their limitations. Thus as a general principle, the gross motor function of children who are able to perform the functions described in any

particular level will probably be classified at or above that level; in contrast the gross motor functions of children who cannot perform the functions of a particular level will likely be classified below that level.

DISTINCTIONS BETWEEN LEVELS

Distinctions between Levels I and II

Compared with children in Level I, children in Level II have limitations in the ease of performing movement transitions; walking outdoorsand in the community; the need for assistive mobility devices when beginning to walk; quality of movement; and the ability to perform grossmotor skills such as running and jumping.

Distinctions between Levels II and III

Differences are seen in the degree of achievement of functional mobility. Children in Level III need assistive mobility devices and frequentlyorthoses to walk, while children in Level II do not require assistive mobility devices after age 4.

Distinctions between Level III and IV

Differences in sitting ability and mobility exist, even allowing for extensive use of assistive technology. Children in Level III sitindependently, have independent floor mobility, and walk with assistive mobility devices. Children in Level IV function in sitting (usuallysupported) but independent mobility is very limited. Children in Level IV are more likely to be transported or use power mobility.

Distinctions between Levels IV and V

Children in Level V lack independence even in basic antigravity postural control. Self-mobility is achieved only if the child can learn how tooperate an electrically powered wheelchair.

GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM FOR CEREBRAL PALSY ASSESSMENT

Code _____

Age _____

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 any assistive 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 an assistive mobility device on level surfaces and climb stairs with assistance from an adult	
	Children frequently are transported when travelling 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 power 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	
	Children have no means of independent mobility and are transported or children achieve self-mobility using a powered wheelchair with extensive adaptations	

Between 6th and 12th Birthday		
Level I	Children walk indoors and outdoors, and climb stairs without limitations.	
.	Children perform gross motor skills including running and jumping but speed, balance, and coordination are reduced	
Level II	Children walk indoors and outdoors, and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines, and walking in crowds or confined spaces.	
	Children have at best only minimal ability to perform gross motor skills such as running and jumping.	
Level III.	Children walk indoors or outdoors on a level surface with an assistive mobility device	
	Children may climb stairs holding onto a railing.	
.	Depending on upper limb function, children propel a wheelchair manually or are transported when travelling for long distances or outdoors on uneven terrain	
Level IV	Children may maintain levels of function achieved before age 6 or rely more on wheeled mobility at home, school, and in the community.	
	Children may achieve self-mobility using a power 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	
	Children have no means of independent mobility and are transported or. children achieve self-mobility using a power wheelchair with extensive adaptations	

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Reference: Dev Med Child Neurol 1997; 39:214-223
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APPENDIX C MANUAL ABILITY CLASSIFICATION SYSTEM FOR CHILDREN WITH CEREBRAL PALSY 4-18 YEARS

Information for users

The Manual Ability Classification System (MACS) describes how children with cerebral palsy (CP) use their hands to handle objects in daily activities. MACS describes five levels. The levels are based on the children's self-initiated ability to handle objects and their need for assistance or adaptation p to perform manual activities in everyday life. The MACS brochure also describes differences between adjacent levels to make it easier to determine which level best corresponds with the child's ability to handle objects.

The objects referred to are those that are relevant and age-appropriate for the children, used when they perform tasks such as eating, dressing, playing, drawing or writing. It is objects that are within the children's personal space that is referred to, as oppose to objects that are beyond their reach. Objects used in advanced activities that require special skills, such as playing an instrument are not included in this considerations.

When establishing a child's MACS level, choose the level that best describes the child's overall usual performance, in the home, school or community setting. The child's motivation and cognitive ability also affect the ability to handle objects and accordingly influence the MACS level. In order to obtain knowledge about how a child handles various everyday objects it is necessary to ask someone who knows the child well.

MACS is intended to classify what the children usually do not their best possible performance in a specific test situation. MACS is a functional description that can be used in a way that is complement to the diagnosis of cerebral palsy and its subtypes. MACS assesses the children's overall ability to handle everyday objects, not the function of each hand separately. MACS does not take into account differences in function between the two hands; rather, it addresses how the children handle age-appropriate objects. MACS does not intend to explain the underlying reasons for impaired manual abilities.

MACS can be used for children aged 4–18 years, but certain concepts must be placed in relation to the child's age. Naturally there is a difference in which objects a four-year old should be able to handle compared with a teenager. The same applies to independence –a young child needs more help and supervision than an older child. MACS spans the entire spectrum of functional limitations found among children with cerebral palsy and covers all sub-diagnoses. Certain sub-diagnoses can be found at all MACS levels, such as bilateral CP, while others are found at fewer levels, such as unilateral CP. Level I includes children with minor limitations, while children with severe functional limitations will usually be found at levels IV and V. If typically developed children were to be classified according to MACS, however, a level "0" would be needed.

Moreover, each level includes children with relatively varied function. is unlikely that MACS is sensitive to changes after an intervention; in all probability, MACS levels are stable over time.

The five levels in MACS form an ordinal scale, which means that the levels are 'ordered' but differences between levels are not necessarily equal, nor are children with cerebral palsy equally distributed across the five levels

MACS classifies how children with cerebral palsy use their hands to handle objects in daily activities.

MACS describes how children usually use their hands to handle objects in the home, school, and community settings (what they do), rather than what is known to be their best capacity.
In order to obtain knowledge about how a child handles various everyday objects, it is necessary to ask someone who knows the child well, rather than through a specific test.
The objects the child handles should be considered from an age related perspective.
MACS classify a child s overall ability to handle objects, not each hand separately.

What do you need to know to use MACS?
The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing unfamiliar situations.
In which situation is the child independent and to what extent do they need support and adaptation?

Distinctions between Levels I and II
Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

Distinctions between Levels II and III
Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

Distinctions between Levels III and IV
Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

Distinctions between Levels IV and V
Children in Level IV perform part of an activity; however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a button or occasionally hold undemanding objects.

MANUAL ABILITY CLASSIFICATION SYSTEM FOR CHILDREN WITH LEVELS

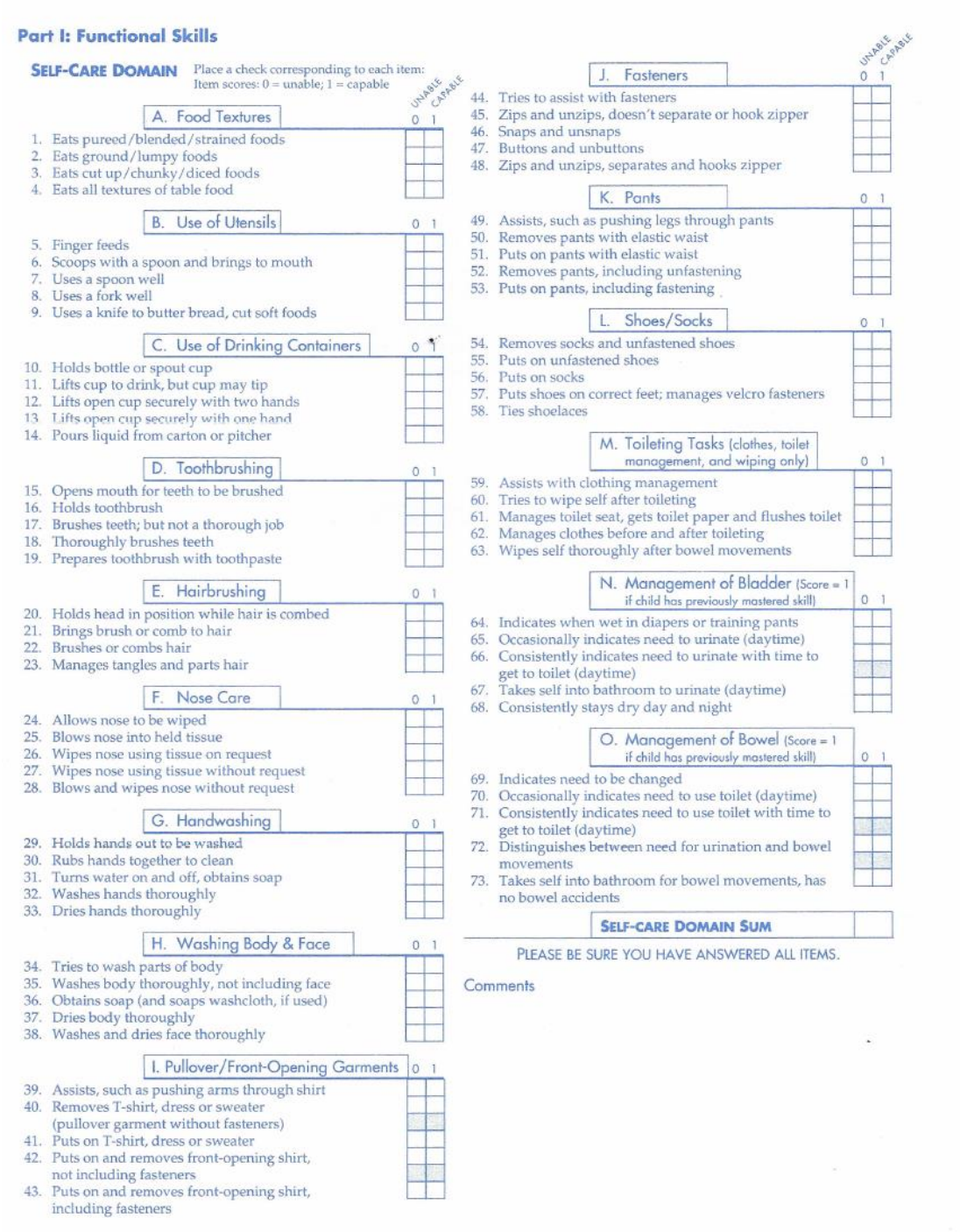
Code _____

Age _____

Level I.	**Handles objects easily and successfully.**	
.	At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities	
Level II.	**Handles most objects but with somewhat reduced quality and/or speed of achievement.**	
	Certain activities may be avoided or be achieved with some difficulty alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.	
Level III.	**Handles objects with difficulty; needs help to prepare and/or modify activities.**	
	The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.	
Level IV.	**Handles a limited selection of easily managed objects in adapted situations.**	
	Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.	
Level V.	**Does not handle objects and has severely limited ability to perform even simple actions.**	
	Requires total assistance.	

Reference: Eliasson AC, Krumlinde Sundholm L, Rösblad B, Beckung E, Arner M, ÖhrvallAM , Rosenbaum P. The ManualAbility Classification System (MACS) for children with cerebral palsy: scale development and evidence of validityand reliability. Developmental Medicine and Child Neurology 2006 48:549-554

APPENDIX DPEDIATRIC EVALUATION OF DISABILITY INVENTORY.



Part I: Functional Skills

SELF-CARE DOMAIN Place a check corresponding to each item:
Item scores: 0 = unable; 1 = capable

A. Food Textures

		UNABLE 0	CAPABLE 1
1.	Eats pureed/blended/strained foods		
2.	Eats ground/lumpy foods		
3.	Eats cut up/chunky/diced foods		
4.	Eats all textures of table food		

B. Use of Utensils

		0	1
5.	Finger feeds		
6.	Scoops with a spoon and brings to mouth		
7.	Uses a spoon well		
8.	Uses a fork well		
9.	Uses a knife to butter bread, cut soft foods		

C. Use of Drinking Containers

		0	1
10.	Holds bottle or spout cup		
11.	Lifts cup to drink, but cup may tip		
12.	Lifts open cup securely with two hands		
13.	Lifts open cup securely with one hand		
14.	Pours liquid from carton or pitcher		

D. Toothbrushing

		0	1
15.	Opens mouth for teeth to be brushed		
16.	Holds toothbrush		
17.	Brushes teeth; but not a thorough job		
18.	Thoroughly brushes teeth		
19.	Prepares toothbrush with toothpaste		

E. Hairbrushing

		0	1
20.	Holds head in position while hair is combed		
21.	Brings brush or comb to hair		
22.	Brushes or combs hair		
23.	Manages tangles and parts hair		

F. Nose Care

		0	1
24.	Allows nose to be wiped		
25.	Blows nose into held tissue		
26.	Wipes nose using tissue on request		
27.	Wipes nose using tissue without request		
28.	Blows and wipes nose without request		

G. Handwashing

		0	1
29.	Holds hands out to be washed		
30.	Rubs hands together to clean		
31.	Turns water on and off, obtains soap		
32.	Washes hands thoroughly		
33.	Dries hands thoroughly		

H. Washing Body & Face

		0	1
34.	Tries to wash parts of body		
35.	Washes body thoroughly, not including face		
36.	Obtains soap (and soaps washcloth, if used)		
37.	Dries body thoroughly		
38.	Washes and dries face thoroughly		

I. Pullover/Front-Opening Garments

		0	1
39.	Assists, such as pushing arms through shirt		
40.	Removes T-shirt, dress or sweater (pullover garment without fasteners)		
41.	Puts on T-shirt, dress or sweater		
42.	Puts on and removes front-opening shirt, not including fasteners		
43.	Puts on and removes front-opening shirt, including fasteners		

J. Fasteners

		0	1
44.	Tries to assist with fasteners		
45.	Zips and unzips, doesn't separate or hook zipper		
46.	Snaps and unsnaps		
47.	Buttons and unbuttons		
48.	Zips and unzips, separates and hooks zipper		

K. Pants

		0	1
49.	Assists, such as pushing legs through pants		
50.	Removes pants with elastic waist		
51.	Puts on pants with elastic waist		
52.	Removes pants, including unfastening		
53.	Puts on pants, including fastening		

L. Shoes/Socks

		0	1
54.	Removes socks and unfastened shoes		
55.	Puts on unfastened shoes		
56.	Puts on socks		
57.	Puts shoes on correct feet; manages velcro fasteners		
58.	Ties shoelaces		

M. Toileting Tasks (clothes, toilet management, and wiping only)

		0	1
59.	Assists with clothing management		
60.	Tries to wipe self after toileting		
61.	Manages toilet seat, gets toilet paper and flushes toilet		
62.	Manages clothes before and after toileting		
63.	Wipes self thoroughly after bowel movements		

N. Management of Bladder (Score = 1 if child has previously mastered skill)

		0	1
64.	Indicates when wet in diapers or training pants		
65.	Occasionally indicates need to urinate (daytime)		
66.	Consistently indicates need to urinate with time to get to toilet (daytime)		
67.	Takes self into bathroom to urinate (daytime)		
68.	Consistently stays dry day and night		

O. Management of Bowel (Score = 1 if child has previously mastered skill)

		0	1
69.	Indicates need to be changed		
70.	Occasionally indicates need to use toilet (daytime)		
71.	Consistently indicates need to use toilet with time to get to toilet (daytime)		
72.	Distinguishes between need for urination and bowel movements		
73.	Takes self into bathroom for bowel movements, has no bowel accidents		

SELF-CARE DOMAIN SUM

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

Comments

MOBILITY DOMAIN

Place a check corresponding to each item: Item scores: 0 = unable; 1 = capable

A. Toilet Transfers

	UNABLE 0	CAPABLE 1
1. Sits if supported by equipment or caregiver		
2. Sits unsupported on toilet or potty chair		
3. Gets on and off low toilet or potty		
4. Gets on and off adult-sized toilet		
5. Gets on and off toilet, not needing own arms		

B. Chair/Wheelchair Transfers

	0	1
6. Sits if supported by equipment or caregiver		
7. Sits unsupported on chair or bench		
8. Gets on and off low chair or furniture		
9. Gets in and out of adult-sized chair/wheelchair		
10. Gets in and out of chair, not needing own arms		

C. Car Transfers

	0	1
11. Moves in car; scoots on seat or gets in and out of car seat		
12. Gets in and out of car with little assistance or instruction		
13. Gets in and out of car with no assistance or instruction		
14. Manages seat belt or chair restraint		
15. Gets in and out of car and opens and closes car door		

D. Bed Mobility/Transfers

	0	1
16. Raises to sitting position in bed or crib		
17. Comes to sit at edge of bed; lies down from sitting at edge of bed		
18. Gets in and out of own bed		
19. Gets in and out of own bed, not needing own arms		

E. Tub Transfers

	0	1
20. Sits if supported by equipment or caregiver in a tub or sink		
21. Sits unsupported and moves in tub		
22. Climbs or scoots in and out of tub		
23. Sits down and stands up from inside tub		
24. Steps/transfers into and out of an adult-sized tub		

F. Indoor Locomotion Methods (Score = 1 if mastered)

	0	1
25. Rolls, scoots, crawls, or creeps on floor		
26. Walks, but holds onto furniture, walls, caregivers or uses devices for support		
27. Walks without support		

G. Indoor Locomotion: Distance/Speed (Score = 1 if mastered)

	0	1
28. Moves within a room but with difficulty (falls; slow for age)		
29. Moves within a room with no difficulty		
30. Moves between rooms but with difficulty (falls; slow for age)		
31. Moves between rooms with no difficulty		
32. Moves indoors 50 feet; opens and closes inside and outside doors		

H. Indoor Locomotion: Pulls/Carries Objects

	0	1
33. Changes physical location purposefully		
34. Moves objects along floor		
35. Carries objects small enough to be held in one hand		
36. Carries objects large enough to require two hands		
37. Carries fragile or spillable objects		

I. Outdoor Locomotion: Methods

	UNABLE 0	CAPABLE 1
38. Walks, but holds onto objects, caregiver, or devices for support		
39. Walks without support		

J. Outdoor Locomotion: Distance/Speed (Score = 1 if mastered)

	0	1
40. Moves 10-50 feet (1-5 car lengths)		
41. Moves 50-100 feet (5-10 car lengths)		
42. Moves 100-150 feet (35-50 yards)		
43. Moves 150 feet and longer, but with difficulty (stumbles; slow for age)		
44. Moves 150 feet and longer with no difficulty		

K. Outdoor Locomotion: Surfaces

	0	1
45. Level surfaces (smooth sidewalks, driveways)		
46. Slightly uneven surfaces (cracked pavement)		
47. Rough, uneven surfaces (lawns, gravel driveway)		
48. Up and down incline or ramps		
49. Up and down curbs		

L. Upstairs (Score = 1 if child has previously mastered skill)

	0	1
50. Scoots or crawls up partial flight (1-11 steps)		
51. Scoots or crawls up full flight (12-15 steps)		
52. Walks up partial flight		
53. Walks up full flight, but with difficulty (slow for age)		
54. Walks up entire flight with no difficulty		

M. Downstairs (Score = 1 if child has previously mastered skill)

	0	1
55. Scoots or crawls down partial flight (1-11 steps)		
56. Scoots or crawls down full flight (12-15 steps)		
57. Walks down partial flight		
58. Walks down full flight, but with difficulty (slow for age)		
59. Walks down full flight with no difficulty		

MOBILITY DOMAIN SUM

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

SOCIAL FUNCTION DOMAIN

Place a check corresponding to each item: Item scores: 0 = unable; 1 = capable

A. Comprehension Word Meanings

	0	1
1. Orients to sound		
2. Responds to "no"; recognizes own name or that of familiar people		
3. Understands 10 words		
4. Understands when you talk about relationships among people and/or things that are visible		
5. Understands when you talk about time and sequence of events		

B. Comprehension of Sentence Complexity

	0	1
6. Understands short sentences about familiar objects and people		
7. Understands 1-step commands with words that describe people or things		
8. Understands directions that describe where something is		
9. Understands 2-step commands, using if/then, before/after, first/second, etc.		
10. Understands two sentences that are about the same subject but have a different form		

UNABLE CAPABLE

C. Functional Use of Communication

		0	1
11.	Names things		
12.	Uses specific words or gestures to direct or request action by another person		
13.	Seeks information by asking questions		
14.	Describes an object or action		
15.	Tells about own feelings or thoughts		

D. Complexity of Expressive Communication

		0	1
16.	Uses gestures with clear meaning		
17.	Uses single word with meaning		
18.	Uses two words together with meaning		
19.	Uses 4-5 word sentences		
20.	Connects two or more thoughts to tell a simple story		

E. Problem-resolution

		0	1
21.	Tries to show you the problem or communicate what is needed to help the problem		
22.	If upset because of a problem, child must be helped immediately or behavior deteriorates		
23.	If upset because of a problem, child can seek help and wait if it is delayed a short time		
24.	In ordinary situations, child can describe the problem and his/her feelings with some detail (usually does not act out)		
25.	Faced with an ordinary problem, child can join adult in working out a solution		

F. Social Interactive Play (Adults)

		0	1
26.	Shows awareness and interest in others		
27.	Initiates a familiar play routine		
28.	Takes turn in simple play when cued for turn		
29.	Attempts to imitate adult's previous action during a play activity		
30.	During play child may suggest new or different steps, or respond to adult suggestion with another idea		

G. Peer Interactions: (Child of similar age)

		0	1
31.	Notices presence of other children, may vocalize and gesture toward peers		
32.	Interacts with other children in simple and brief episodes		
33.	Tries to work out simple plans for a play activity with another child		
34.	Plans and carries out cooperative activity with other children; play is sustained and complex		
35.	Plays activities or games that have rules		

H. Play with Objects

		0	1
36.	Manipulates toys, objects or body with intent		
37.	Uses real or substituted objects in simple pretend sequences		
38.	Puts together materials to make something		
39.	Makes up extended pretend play routines involving things the child knows about		
40.	Makes up elaborate pretend sequences from imagination		

Comments

UNABLE CAPABLE

I. Self-Information

		0	1
41.	Can state first name		
42.	Can state first and last name		
43.	Provides names and descriptive information about family members		
44.	Can state full home address; if in hospital, name of hospital and room number		
45.	Can direct an adult to help child return home or back to the hospital room		

J. Time Orientation

		0	1
46.	Has a general awareness of time of mealtimes and routines during the day		
47.	Has some awareness of sequence of familiar events in a week		
48.	Has very simple time concepts		
49.	Associates a specific time with actions/events		
50.	Regularly checks clock or asks for the time in order to keep track of schedule		

K. Household Chores

		0	1
51.	Beginning to help care for own belongings if given constant direction and guidance		
52.	Beginning to help with simple household chores if given constant direction and guidance		
53.	Occasionally initiates simple routines to care for own belongings; may require physical help or reminders to complete		
54.	Occasionally initiates simple household chores; may require physical help or reminders to complete		
55.	Consistently initiates and carries out at least one household task involving several steps and decisions; may require physical help		

L. Self-Protection

		0	1
56.	Shows appropriate caution around stairs		
57.	Shows appropriate caution around hot or sharp objects		
58.	When crossing the street with an adult present, child does not need prompting about safety rules		
59.	Knows not to accept rides, food or money from strangers		
60.	Crosses busy street safely without an adult		

M. Community Function

		0	1
61.	Child may play safely at home without being watched constantly		
62.	Goes about familiar environment outside of home with only periodic monitoring for safety		
63.	Follows guidelines/expectations of school and community setting		
64.	Explores and functions in familiar community settings without supervision		
65.	Makes transaction in neighborhood store without assistance		

SOCIAL FUNCTION DOMAIN SUM

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

APPENDIX E HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE

Occupational Therapy

R14/49 Mrs Beniginer Chigonda

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140830

NAME: (Principal Investigator)	Mrs Beniginer Chigonda
DEPARTMENT:	Occupational Therapy The Premier Rehabilitation Center and Harare Central Hospital Children's Rehabilation Unit , Zimbabwe
PROJECT TITLE:	Parents'/Caregivers' and Rehabilitationn Professionals' Perpectives of Occupational Perfomance of Children with Celebral Palsy: A Comparative Study
DATE CONSIDERED:	29/08/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Denise Franzsen
APPROVED BY:	Professor Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	10/11/2014

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

THERAPEUTIC Sciences

APPENDIX F PERMISSION LETTER TO INSTITUTIONS

RE: REQUEST FOR PERMISSION TO CARRY OUT RESEARCH AT YOUR INSTITUTION

Manager,

……..Hospital, Service, Clinic

Dear Sir /Madam

Re: **Parents'/caregivers' and rehabilitation professionals perspectives of occupational performance of children with cerebral palsy: A comparative study.**

My name is BeniginerChigonda, a student undertaking a study for partial fulfilment of a Master of Science in Occupational Therapy degree at the University Of Witwatersrand Faculty Of Health Sciences. I am investigating if there are any differences between the evaluation of occupational performance of children with cerebral palsy by parents and evaluation by rehabilitation workers using the Paediatric Evaluation of Disability Inventory (PEDI).Iwould be most grateful if you would allow me to carry out the study at your clinic/hospital. Data collection is expected to run for six months commencing January 2015.

Previous research has indicated that parents tend to underrate their children's performance compared to health professionals hence parents tend to give more assistance to their children than is necessary. I do not know if this is true in Zimbabwe so I will be grateful if you will allow me to carry out the study at your institution to examine this.

The researcher will use the Gross Motor Function Classification System(GMFCS) and the Manual Ability Classification System to determine children's level of disability and level of hand use in handling objects respectively. The researcher will then interview and score their responses on the PEDI evaluation form.

The treating occupational/physiotherapist will assess the same children and fill out the PEDI evaluation form. The researcher will then compare PEDI scores done by the therapists to those done by the researcher interviewing the .

Therapists may benefit by gaining insight into how parents view their children's performance and the knowledge can be used in goal setting together with the parents. Parents may benefit by having increased parental awareness of developmental patterns, greater insight into levels of assistance they give to their children, increased knowledge of what they should work on with their children and increased confidence to introduce new skills, improved ability to fully participate in goal setting within school and/or therapy settings, ability to facilitate their children's independence in activities they had previously been doing for them and enhancing children's quality of life by allowing them to experience the feeling of being useful in their own care.

If you have any questions please feel free to contact me at 00263-4-251526/6 or cellphone number 00263-712-876720 or bchigonda@gmail.com. Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at 011 7171234 or anisa.keshav@wits.ac.za for reporting of complaints / problems

Regards,

BeniginerChigonda

Telephone: 621100-19
Fax: 621157

ZIMBABWE

Reference: HCHEC 061014/62

HARARE CENTRAL HOSPITAL
P. O. Box ST 14

SOUTHERTON

Harare

08 October 2014

Mrs Beniginer Chigonda
Box 1431 Avondale
HARARE

Dear Beniginer,

REF: PARENTS'/CAREGIVERS' AND REHABILITATION PROFESSIONALS' PERCEPTIVES OCCUPATIONAL PERFOMANCE OF CHILDREN WITH CEREBRAL PALSY: A COMPARATIVE STUDY

I am glad to advice you that your application to conduct a study entitled: **Parents'/Caregivers' And Rehabilitation Professionals' Perceptives Occupational Performance Of Children With Cerebral Palsy: A Comparative Study,** has been approved by the Harare Hospital Ethics committee.

This approval is premised on the submitted protocol. Should you decide to vary your protocol in any material way please submit these for further approval.

You are advised to avail the results of your study whether positive or negative to the hospital through the committee for our information.

Yours sincerely,

HARARE CENTRAL HOSPITAL
DEPARTMENT OF MEDICINE
08 OCT 2014
P.O. BOX ST 14, SOUTHERTON
HARARE

DR. C. Pasi

Chairman Harare Central Hospital Ethics Committee

The treating occupational/physiotherapist will assess the same children and fill out the PEDI evaluation form. The researcher will then compare PEDI scores done by the therapists to those done by the researcher interviewing the parents/caregivers.

Therapists may benefit by gaining insight into how parents view their children's performance and the knowledge can be used in goal setting together with the parents. Parents may benefit by having increased parental awareness of developmental patterns, greater insight into levels of assistance they give to their children, increased knowledge of what they should work on with their children and increased confidence to introduce new skills, improved ability to fully participate in goal setting within school and/or therapy settings, ability to facilitate their children's independence in activities they had previously been doing for them and enhancing children's quality of life by allowing them to experience the feeling of being useful in their own care.

If you have any questions please feel free to contact me at 00263-4-251526/6 or cell phone number 00263-712-876720 or bchigonda@gmail.com. Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at +2711 7171234 or anisa.keshav@wits.ac.za for reporting of complaints / problems.

Thank you.

Regards.

Beniginer Chigonda

Cc- Rehabilitation General Manager- Ms. G. Mudzengi

Approved/~~Not approved~~

Name.....

Signature.....

Date 28/10/14

APPENDIX G INFORMATION SHEET AND CONSENT FORM FOR PARENTS/LEGAL GUARDIAN

PARENTS'/CAREGIVERS' AND REHABILITATION PROFESSIONALS' PERSPECTIVES OF OCCUPATIONAL PERFORMANCE OF CHILDREN WITH CEREBRAL PALSY: A COMPARATIVE STUDY.

Good Day,

My name is Beniginer Chigonda, a student undertaking a study for partial fulfilment of a Master of Science in Occupational Therapy degree at the University Of Witwatersrand Faculty Of Health Sciences. I am investigating if there are any differences between the evaluation of occupational performance of children with cerebral palsy by parents and evaluation by rehabilitation health workers using the Paediatric Evaluation of Disability Inventory (PEDI).Iwould be most grateful if you and your child would consider participating in this research.

In Israel, previous research has indicated that parents tend to differ in their evaluation of their children's performance compared to rehabilitation professionals hence parents tend to give more assistance to their children than is necessary. I do not know if this is true in Zimbabwe so I will be grateful if you and your child will participatein a study to examine this.

I am asking permission to view your child's medical records to confirm their diagnosis. I will use the Gross Motor Function Classification System (GMFCS) and the Manual Ability Classification System to determine your child's level of disability and level of hand use in handling objects respectively.

Iam then asking that I be able to interviewyou and score your responses on the PEDI evaluation form about what your child can do for themselves in terms of self. This will take approximately 30 minutes.

The treating occupational/physiotherapist will also be asked to complete the PEDI evaluation form on your child. This can be done while I am interviewing you or at a later date if we both agree and will take approximately 30 minutes.

You may benefit by having increased parental awareness of developmental patterns and greater insight into levels of assistance you give your children, and how to facilitate their children's independence in activities.

The study is completely voluntary and not taking part in it, or withdrawing from it, carries no penalty of any sort.

Confidentiality will be maintained by the use of a code instead of names on all evaluation forms. Only I will have a list of names and codes to enable the code to be linked to a particular child. This list will be kept by me locked in an office.

If you have any queries, more information may be obtained from myself at telephone number 00263-4-251526/6 or cellphone number 00263-712-876720 or email bchigonda@psmi.co.zw

Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at 011 7171234 or anisa.keshav@wits.ac.za for reporting of complaints / problems

If you are happy participate and to allow your child to take part in the study, please read and sign the attached consent form.

Thank you.

Beniginer Chigonda

Consent form

I agree to participate and allow my child to participate in the study **Parents'/caregivers' and rehabilitation professionals' perspectives of occupational performance of children with cerebral palsy: A comparative study.**

Parent:

Name _____

Signature _____

Date_____

Consent form

I give consent for you to view my child's medical records for the study. **Parents'/caregivers' and rehabilitation professionals' perspectives of occupational performance of children with cerebral palsy: A comparative study.**

Parent:

Name _____

Signature _____

Date_____

Verbal Assent Form -Child

Hello,

I am Beniginer and I would like you to help your therapist – (Name) - see how you can move and use your hands. Would you like to come and do these things with her so we can see how well you do?

Witness _____

Witness signature _____

Date _____

APPENDIX H INFORMATION SHEET AND CONSENT FORM FOR THERAPISTS

Parents'/caregivers' and rehabilitation professionals' perspectives of occupational performance of children with cerebral palsy: A comparative study.

Good Day,

My name is Beniginer Chigonda, a student undertaking a study for partial fulfilment of a Master of Science in Occupational Therapy degree at the University of Witwatersrand, Faculty of Health Sciences. I am investigating if there are any differences between the evaluation of occupational performance of children with cerebral palsy by parents and evaluation by rehabilitation health workers using the Paediatric Evaluation of Disability Inventory (PEDI).Iwould be most grateful if you would consider participating in this research.

In Israel, previous research has indicated that parents tend to underrate their children's performance compared to health professionals hence parents tend to give more assistance to their children than is necessary. I do not know if this is true in Zimbabwe so I will be grateful if you will participate in a study to examine this.

I will use the Gross Motor Function Classification System(GMFCS) and the Manual Ability Classification System to determine children's level of disability and level of hand use in handling objects respectively. I will then interview and score their responses on the PEDI evaluation form.

I am requesting that you as the treating occupational/physiotherapist complete the PEDI assessment on the same children I will then compare PEDI scores done by the therapists to those done by the researcher interviewing the .

You may benefit by gaining insight into how parents view their children's performance and the knowledge can be used in goal setting together with the parents. The study is completely voluntary and not taking part in it, or withdrawing from it, carries no penalty of any sort.

Confidentiality will be maintained by the use of a code instead of names on all evaluation forms and your name will not be used. Only I will have a list of names and codes to enable the code to be linked to a particular child. This list will be kept by me in locked in an office.

If you have any queries, more information may be obtained from the researcher at telephone number 00263-4-251526/6 or cell phone number 00263-712-876720 or email bchigonda@psmi.co.zw. Should there be any ethical queries about the research please feel free to contact the Human Research Ethics Committee (HREC) Chairman Prof P Cleaton-Jones at 011 7171234 or anisa.keshav@wits.ac.za for reporting of complaints / problems

If you are happy participate in the study, please read and sign the attached consent form.

Thank you.

Beniginer Chigonda

Consent form

I agree to participate in the research by assessing children and completing PEDI forms for the study: **Parents'/caregivers' and rehabilitation professionals' perspectives of occupational performance of children with cerebral palsy: A comparative study.**

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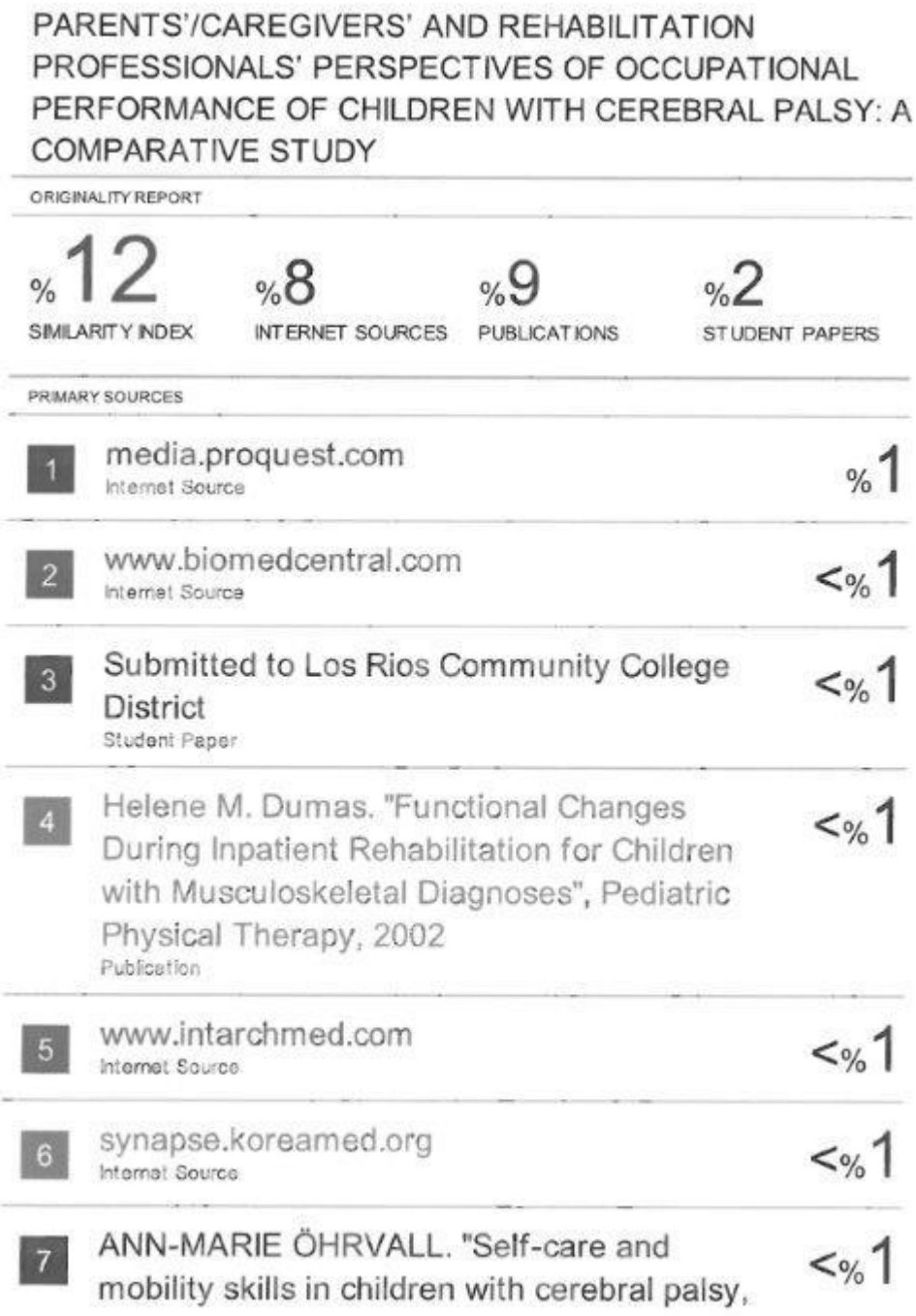
Therapist:

Name _____

Signature _____

Date_____

APPENDIX I



PARENTS'/CAREGIVERS' AND REHABILITATION PROFESSIONALS' PERSPECTIVES OF OCCUPATIONAL PERFORMANCE OF CHILDREN WITH CEREBRAL PALSY: A COMPARATIVE STUDY

ORIGINALITY REPORT

%12	%8	%9	%2
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	media.proquest.com Internet Source	%1
2	www.biomedcentral.com Internet Source	<%1
3	Submitted to Los Rios Community College District Student Paper	<%1
4	Helene M. Dumas. "Functional Changes During Inpatient Rehabilitation for Children with Musculoskeletal Diagnoses", Pediatric Physical Therapy, 2002 Publication	<%1
5	www.intarchmed.com Internet Source	<%1
6	synapse.koreamed.org Internet Source	<%1
7	ANN-MARIE ÖHRVALL. "Self-care and mobility skills in children with cerebral palsy,	<%1

APPENDIX JDATA ANALYSIS

Descriptive statistics – frequencies for demographic data

Category	Frequency table: Sex (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
1	25	25	50.00000	50.0000	50.00000	50.0000
2	25	50	50.00000	100.0000	50.00000	100.0000
Missing	0	50	0.00000		0.00000	100.0000
Category	Frequency table: Age (Data – Beniginer Chigonda) NOTE: This variable contains some non-integer values. Those values were ignored.					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
4	7	7	14.00000	14.00000	14.00000	14.00000
5	1	8	2.00000	16.00000	2.00000	16.00000
6	3	0	0.00000	0.00000	0.00000	0.00000
Missing	0	0	0.00000		0.00000	0.00000
Category	Frequency table: Diagnosis (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
1	10	10	20.00000	20.0000	20.00000	20.0000
2	11	21	22.00000	42.0000	22.00000	42.0000
3	10	31	20.00000	62.0000	20.00000	62.0000
4	6	37	12.00000	74.0000	12.00000	74.0000
5	5	42	10.00000	84.0000	10.00000	84.0000
6	8	50	16.00000	100.0000	16.00000	100.0000
Missing	0	50	0.00000		0.00000	100.0000

Category	Frequency table: Place child is treated (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
1	15	15	30.00000	30.0000	30.00000	30.0000
2	23	38	46.00000	76.0000	46.00000	76.0000
3	12	50	24.00000	100.0000	24.00000	100.0000
Missing	0	50	0.00000		0.00000	100.0000

Category	Frequency table: Treating therapist (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
1	15	15	30.00000	30.0000	30.00000	30.0000
2	9	24	18.00000	48.0000	18.00000	48.0000
3	14	38	28.00000	76.0000	28.00000	76.0000
4	12	50	24.00000	100.0000	24.00000	100.0000
Missing	0	50	0.00000		0.00000	100.0000

Category	Frequency table: Respondent (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
1	30	30	60.00000	60.0000	60.00000	60.0000
2	11	41	22.00000	82.0000	22.00000	82.0000
3	4	45	8.00000	90.0000	8.00000	90.0000
4	3	48	6.00000	96.0000	6.00000	96.0000

Category	Frequency table: Respondent (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
5	2	50	4.00000	100.0000	4.00000	100.0000
Missing	0	50	0.00000		0.00000	100.0000

Category	Frequency table: GMFCS score (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
2	2	2	4.00000	4.0000	4.00000	4.0000
3	17	19	34.00000	38.0000	34.00000	38.0000
4	7	26	14.00000	52.0000	14.00000	52.0000
5	24	50	48.00000	100.0000	48.00000	100.0000
Missing	0	50	0.00000		0.00000	100.0000
Category	Frequency table: MACS score (Data – Beniginer Chigonda)					
	Count	Cumulative Count	Percent of Valid	Cumul % of Valid	% of all Cases	Cumulative % of All
1	1	1	2.00000	2.0000	2.00000	2.0000
2	16	17	32.00000	34.0000	32.00000	34.0000
3	17	34	34.00000	68.0000	34.00000	68.0000
4	4	38	8.00000	76.0000	8.00000	76.0000
5	12	50	24.00000	100.0000	24.00000	100.0000
Missing	0	50	0.00000		0.00000	100.0000

Descriptive data for the PEDI

Variable	Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	50	24.30000	23.50000	14.00000	33.00000	14.07596
M/FS C score	50	11.72000	11.00000	6.00000	18.00000	6.87213
SF/FS C score	50	26.92000	23.00000	14.00000	42.00000	14.65918
SC/CA score	50	13.60000	13.50000	9.00000	20.00000	6.38877
M/CA score	50	9.00000	9.00000	6.00000	13.00000	4.99796
SF/CA score	50	11.44000	11.00000	8.00000	14.00000	4.59885
SC/FS T score	50	22.92000	23.00000	12.00000	31.00000	13.95450
M/FS T score	50	11.22000	10.50000	4.00000	17.00000	6.61257
SF/FS T score	50	27.54000	28.00000	16.00000	39.00000	13.90230

PEDI scores according to GMFCS levels – again report on medians and lower and upper quartiles (will look for significance when you have done the tables)

Variable	**GMFCS score=5**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	24	18.75000	15.00000	10.50000	21.50000	14.25010
M/FS C score	24	6.12500	5.50000	3.50000	8.50000	3.98162
SF/FS C score	24	23.50000	21.00000	7.50000	37.50000	15.86903
SC/CA score	24	10.91667	10.00000	7.00000	16.50000	7.05825
M/CA score	24	5.75000	7.00000	1.50000	8.00000	3.97000
SF/CA score	24	9.83333	9.50000	5.00000	13.00000	5.09618
SC/FS T score	24	17.20833	12.50000	5.50000	25.50000	14.88501
M/FS T score	24	6.12500	5.00000	3.00000	9.50000	3.88209
SF/FS T score	24	24.75000	21.00000	12.50000	36.50000	15.25223
Variable	**GMFCS score=3**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	17	35.82353	33.00000	32.00000	40.00000	7.526912
M/FS C score	17	18.82353	19.00000	17.00000	21.00000	2.984026
SF/FS C score	17	35.94118	39.00000	31.00000	43.00000	9.756220
SC/CA score	17	17.47059	18.00000	15.00000	21.00000	4.214820
M/CA score	17	13.11765	14.00000	12.00000	15.00000	3.722942
SF/CA score	17	14.23529	15.00000	13.00000	17.00000	3.307745
SC/FS T score	17	32.47059	31.00000	26.00000	36.00000	9.624952

Variable	**GMFCS score=5**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
M/FS T score	17	18.05882	18.00000	16.00000	21.00000	3.091735
SF/FS T score	17	35.17647	38.00000	28.00000	43.00000	9.645176

Variable	**GMFCS score=4** Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	7	19.42857	22.00000	11.00000	25.00000	9.65845
M/FS C score	7	11.57143	10.00000	9.00000	12.00000	3.86683
SF/FS C score	7	19.42857	14.00000	12.00000	23.00000	12.75222
SC/CA score	7	14.28571	15.00000	9.00000	16.00000	4.46148
M/CA score	7	8.71429	9.00000	5.00000	11.00000	2.75162
SF/CA score	7	10.57143	10.00000	8.00000	11.00000	3.10146
SC/FS T score	7	21.57143	23.00000	18.00000	29.00000	8.88552
M/FS T score	7	11.00000	9.00000	8.00000	18.00000	5.68624
SF/FS T score	7	21.57143	21.00000	14.00000	30.00000	12.79137
Variable	**GMFCS score=2** Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	2	10.00000	10.00000	10.00000	10.00000	0.000000
M/FS C score	2	19.00000	19.00000	18.00000	20.00000	1.414214
SF/FS C score	2	17.50000	17.50000	16.00000	19.00000	2.121320
SC/CA score	2	10.50000	10.50000	10.00000	11.00000	0.707107
M/CA score	2	14.00000	14.00000	13.00000	15.00000	1.414214
SF/CA score	2	10.00000	10.00000	9.00000	11.00000	1.414214
SC/FS T score	2	15.00000	15.00000	12.00000	18.00000	4.242641
M/FS T score	2	15.00000	15.00000	14.00000	16.00000	1.414214
SF/FS T score	2	17.00000	17.00000	17.00000	17.00000	0.000000

PEDI scores according to MACS levels – again report on medians and lower and upper quartiles (will look for significance when you have done the tables)

Variable	**MACS score=5**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	12	10.00000	10.50000	6.000000	14.50000	4.76731
M/FS C score	12	3.83333	3.50000	2.000000	6.50000	2.72475
SF/FS C score	12	15.41667	11.50000	6.500000	20.00000	12.74547
SC/CA score	12	5.66667	7.00000	1.000000	8.00000	4.14144
M/CA score	12	3.16667	1.50000	0.000000	7.00000	3.43335
SF/CA score	12	7.00000	5.00000	4.500000	10.50000	3.30289
SC/FS T score	12	6.66667	5.50000	5.000000	7.50000	3.28449
M/FS T score	12	3.16667	3.00000	2.500000	3.50000	1.58592
SF/FS T score	12	14.91667	13.00000	7.500000	16.00000	10.98311
Variable	**MACS score=3**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	17	21.94118	22.00000	15.00000	32.00000	9.13421
M/FS C score	17	11.23529	10.00000	9.00000	15.00000	4.53499
SF/FS C score	17	24.58824	22.00000	14.00000	35.00000	14.14240
SC/CA score	17	14.47059	13.00000	10.00000	20.00000	4.87491

Variable	**MACS score=5**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
M/CA score	17	9.00000	9.00000	7.00000	12.00000	3.18198
SF/CA score	17	10.41176	9.00000	9.00000	12.00000	2.87356
SC/FS T score	17	23.35294	23.00000	20.00000	28.00000	4.89823
M/FS T score	17	11.11765	11.00000	9.00000	13.00000	3.62081
SF/FS T score	17	27.35294	24.00000	18.00000	34.00000	11.78951

Variable	**MACS score=2**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	16	38.31250	35.50000	31.00000	46.50000	10.61897
M/FS C score	16	18.12500	19.50000	17.00000	21.00000	4.20912
SF/FS C score	16	38.75000	42.50000	36.00000	44.00000	8.90318
SC/CA score	16	18.93750	19.50000	16.50000	21.00000	3.17214
M/CA score	16	12.75000	13.00000	11.00000	15.00000	3.10913
SF/CA score	16	15.62500	16.00000	14.00000	17.00000	3.96443
SC/FS T score	16	36.93750	33.50000	29.50000	47.50000	11.63024
M/FS T score	16	17.62500	18.50000	16.50000	20.50000	3.84491
SF/FS T score	16	38.68750	40.50000	33.50000	45.00000	9.03120
Variable	**MACS score=4**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	4	16.75000	16.50000	11.50000	22.00000	8.18026
M/FS C score	4	10.25000	8.00000	4.50000	16.00000	7.80491
SF/FS C score	4	23.00000	26.00000	15.00000	31.00000	10.89342
SC/CA score	4	12.25000	11.00000	9.50000	15.00000	4.03113
M/CA score	4	10.00000	7.50000	6.00000	14.00000	6.16441
SF/CA score	4	12.00000	12.00000	10.50000	13.50000	1.82574
SC/FS T score	4	11.75000	11.50000	7.50000	16.00000	6.55108
M/FS T score	4	9.00000	6.00000	3.50000	14.50000	8.28654
SF/FS T score	4	21.50000	25.50000	11.00000	32.00000	14.70827

Variable	**MACS score=1**Descriptive Statistics (Data – Beniginer Chigonda)					
	Valid N	Mean	Median	Lower Quartile	Upper Quartile	Std.Dev.
SC/FS C score	1	42.00000	42.00000	42.00000	42.00000	
M/FS C score	1	18.00000	18.00000	18.00000	18.00000	
SF/FS C score	1	31.00000	31.00000	31.00000	31.00000	
SC/CA score	1	14.00000	14.00000	14.00000	14.00000	
M/CA score	1	15.00000	15.00000	15.00000	15.00000	
SF/CA score	1	13.00000	13.00000	13.00000	13.00000	
SC/FS T score	1	31.00000	31.00000	31.00000	31.00000	
M/FS T score	1	16.00000	16.00000	16.00000	16.00000	
SF/FS T score	1	28.00000	28.00000	28.00000	28.00000	

Regression analysis
Functional Skills
Self care v

Dependent Y	Self_care_Scores Self care Scores

Independent X	SC_FS_T_score SC/FS T score

Sample size	50
Coefficient of determination R^2	0.8522
Residual standard deviation	5.4670

Regression Equation

y = 2.9569 + 0.9312 x

Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	2.9569	1.4978	-0.05450 to 5.9684	1.9742	0.0541
Slope	0.9312	0.05597	0.8187 to 1.0437	16.6383	<0.0001

Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	8273.8867	8273.8867
Residual	48	1434.6133	29.8878

F-ratio	276.8318
Significance level	P<0.0001

Mobility

Dependent Y	Mobility_score Mobility score
Independent X	M_FS_T_score M/FS T score

Sample size	50
Coefficient of determination R^2	0.8585
Residual standard deviation	2.6123

Regression Equation

y = 0.9163 + 0.9629 x

Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	0.9163	0.7331	-0.5577 to 2.3903	1.2499	0.2174
Slope	0.9629	0.05644	0.8494 to 1.0764	17.0620	<0.0001

Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	1986.5298	1986.5298
Residual	48	327.5502	6.8240

F-ratio	291.1109
Significance level	P<0.0001

Social Function

Dependent Y	Social_Function_score Social Function score
Independent X	SF_FS_T_score SF/FS T score

Sample size	50
Coefficient of determination R^2	0.8446
Residual standard deviation	5.8393

Regression Equation

y = 0.2328 + 0.9690 x					
Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	0.2328	1.8474	-3.4816 to 3.9472	0.1260	0.9002
Slope	0.9690	0.06000	0.8484 to 1.0897	16.1495	<0.0001

Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	8892.9811	8892.9811
Residual	48	1636.6989	34.0979

F-ratio	260.8073
Significance level	P<0.0001

Caregiver Assistance

Self care

Dependent Y	SC_CA_C_score SC/CA C score
Independent X	SC_CA_T_score SC/CA T score

Sample size	50
Coefficient of determination R^2	0.8198
Residual standard deviation	2.7401

Regression Equation

y = 1.4351 + 0.8815 x					
Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	1.4351	0.9098	-0.3943 to 3.2644	1.5773	0.1213
Slope	0.8815	0.05965	0.7616 to 1.0015	14.7779	<0.0001

Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	1639.6209	1639.6209
Residual	48	360.3791	7.5079

F-ratio	218.3861
Significance level	P<0.0001

Mobility

Dependent Y	M_CA_C_score M/CA C score
Independent X	M_CA_T_score M/CA T score

Sample size	50
Coefficient of determination R^2	0.6267
Residual standard deviation	3.0854

Regression Equation

y = 2.4212 + 0.6999 x					
Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	2.4212	0.8530	0.7062 to 4.1362	2.8386	0.0066
Slope	0.6999	0.07797	0.5431 to 0.8566	8.9765	<0.0001

Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	767.0600	767.0600
Residual	48	456.9400	9.5196

F-ratio	80.5771
Significance level	P<0.0001

Social Function

Dependent Y	SF_CA_C_score SF/CA C score
Independent X	SF_CA_T_score SF/CA T score

Sample size	50
Coefficient of determination R^2	0.7623
Residual standard deviation	2.2656

Regression Equation

y = 1.2662 + 0.9035 x					
Parameter	Coefficient	Std. Error	95% CI	t	P
Intercept	1.2662	0.8805	-0.5041 to 3.0365	1.4381	0.1569
Slope	0.9035	0.07283	0.7571 to 1.0500	12.4056	<0.0001

Analysis of Variance

Source	DF	Sum of Squares	Mean Square
Regression	1	789.9439	789.9439
Residual	48	246.3761	5.1328

F-ratio	153.9001
Significance level	P<0.0001