The relationship between gross motor function and psychological well-being in adults with cerebral palsy.

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Declaration

A research project submitted in partial fulfilment of the requirements for the degree of MA by coursework and Research Report in the field of Psychology in the Faculty of Humanities, University of the Witwatersrand, Johannesburg, January 2008.

I declare that this research report is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university, January 2008.

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Abstract

Motor deficits are debilitating in that they affect everyday function in human beings (Zillmer & Spiers, 2001). Cerebral Palsy (CP) is one particular disorder that is primary characterised by motor deficits, more specifically gross motor function deficits. As a result, people with CP are restricted in their everyday function and lack independence and self-sufficiency. With other factors such as stigmatisation and prejudice, social participation becomes limited which leads to isolation and loneliness, which may further lead to psychological disorders such as depression, anxiety, low self esteem and poor quality of life. These assumptions are based on the application of the mental health model, and one could assume the poorer the level of functioning the more likely a person's psychological well-being will suffer. Thus, the study attempted to investigate these assumptions by exploring the relationship between levels of gross motor function and psychological well-being.

A sample of 43 participants based in a care centre in Johannesburg completed a demographic questionnaire, the Major Depression Inventory (MDI), The Becks Anxiety Inventory (BAI), The Rosenburg Self Esteem Scale (RSE) and the Comprehensive Quality of Life Scale (COMQOL – A5). In addition, through observation, the level of gross motor function was determined by utilising the Gross Motor Function Classification System (GMFCS). The data that was gathered and was statistically manipulated to explore three main questions.

Before the relationship between gross motor function and psychological well-being could be explored it was necessary to examine the suitability of the use of psychological measure on an adult with CP sample. Results indicated that the MDI ($r = 0.78$), BAI ($r = 0.76$). RSE (0.77), and COMQOL ($r = 0.99$) had high internal constancy reliability.

The relationship between demographical variables, namely, age, gender, years of residency, experience of motor deterioration and presence of epilepsy, were tested against the level of gross motor function. No significant results were found apart from motor

deterioration. More participants with a higher level of gross motor function experienced motor deterioration (77%) than those with a lower level of gross motor function (44%).

Lastly, the relationship between psychological variables and gross motor function was investigated as well as difference between the levels. Correlations revealed very weak positive relationships, with the exception of depression having a very weak negative relationship. All relationship were non significant. Although slight differences were seen between levels, they were non significant. 7% of participants were diagnosed with depressive disorders, and 47% with anxiety disorders. Problems with certain questions pertaining to the BAI raised concerns over the suitability of its use in CP adult samples.

The study concluded that psychological measures, excluding the BAI, were suitable for use on a sample of adults with CP. It also highlighted that the level of motor functioning is not related to or determines psychological well-being in adults with CP.

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Chapter 1: Introduction

A recent debate concerning the definition and classification of cerebral palsy (CP) raised awareness of issues such as cognition, behaviour and sensory aspects of CP (Morris, 2007). CP is a complex disorder characterised by motor deficits. Motor deficits can be debilitating as it is basic human action (e.g. walking, running and climbing stairs). Motor functioning is also a higher order function in human beings and therefore forms part of a much broader order in the brain (Zillmer & Spiers, 2001).

Motor deficits in a person leads to an inability to do or complete certain actions, for example, eating. This inability to do certain tasks results in a person having to rely on another and thus self-sufficiency and independence are lacking. Also a person with motor deficits may be limited in their social participation (Refer to 2.9). Motor deficits are also not limited to tasks such as walking and feeding, but also affect other basic functions such as speech. With poor motor function, a person with CP may experience difficulty in verbal communication and further, creates difficulties in personal relationships such as understanding or expression. Consequently, individuals with CP may suffer psychiatric or behavioural problems inclusive of mood and anxiety disorders (Beckung & Hagberg, 2002). This results in further problems such as behavioural and psychological problems which are discussed in greater detailed in 2.9 and 2.10.

Both CP and psychological disorders are products from dysfunction in brain, although psychological disorders are not entirely organic. Impaired fine and gross motor function which may result in difficulties in everyday day functioning and lead to secondary problems such as learning difficulties or problems of social interaction often further complicated through concomitant deficits in perception, mental retardation and or epilepsy (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2007; Morris, 2007; Bobath, 1980; Ross & Deverell, 2004). Because CP and its aetiology is complex (Refer to 2.3) and there are behavioural components of CP (Beckung & Hagberg, 2002) it is likely that there may be degree of comorbidity. However, research which investigates this specific relationship is limited.

Present consensus suggests that when investigating motor aspects of CP, researchers must also lend cognisance to the behavioural and performance aspects that accompany the disorder (Rosenbaum, et al., 2007). In addition, it has also been noted that different disorders appear at different life periods and may become more significant to people at different time periods. Research therefore needs to be conducted on perceptions, psychological well-being and coping over the life span. In investigating the relationship between motor functioning and psychological well-being one can begin to assess the psychological needs of individuals with CP.

The field of CP has generated a lot of research, mainly of a medical and rehabilitative nature. Much of the research is focused on children and very little focuses on adult populations, especially older adult populations (Strauss, Ojdana, Shavelle & Rosenbloom, 2004). This is of significance as, according to Strauss, et al. (2004) adults with CP tend to acquire medical conditions, not commonly seen in children with CP. Many adults experience joint stiffness, muscle contractures, and degenerative osteoarthritis and these musculoskeletal difficulties advance with age (Strauss, et al., 2004 and Rosenbaum, et al., 2007). Many patients also suffer from pain, especially cervical pain (Strauss, et al., 2004). Strauss (2004) also notes that with age, everyday abilities such as walking, speech and self-feeding, decline. Little however is known about how these physical limitations and decline in functioning affects the psychological well-being in individuals with cerebral palsy. In this regard, as physical functioning, as well as motor functioning are very broad areas of research, this research will limit its focus to a large extent to gross motor function and a few indicators of psychological well-being.

At the outset it was considered important to review the literature pertinent to the current debate on definition and classification of CP and consider the implications thereof in determining the parameters for the present research. This is followed by a discussion of gross motor function and deterioration and how this affects individuals with CP, in terms of their psychological well-being. There is very little literature which focuses on psychological well-being or psychological aspects of individuals with CP, especially in

terms of the relationship between different levels of gross motor function and how this affects psychological well-being.

Motivated by the lack of research in the area, the present research assesses the relationship between gross motor function and psychological well-being in adults with CP by investigating the different levels of gross motor function according to the Gross Motor Function Classification System (GMFCS) and their relationship to aspects of psychological well-being, such as, depression (Major Depression Inventory), anxiety (Beck's Anxiety Inventory), self-esteem (Rosenburg Self Esteem Scale) and quality of life (Quality of Life Measure – 88). This was investigated using a correlational, group differences design, where the independent variable was gross motor function and dependent variables were psychological well-being and demographic variables.

Before correlational analyses were conducted, each psychological measure was tested for reliability and internal validity with a CP sample. Differences in levels of functioning in terms of age, gender, years in care centre and the experience of motor deterioration were also investigated.

The participants in this research were residents of a care centre situated in Johannesburg, South Africa. The care centre is a non-profit organisation which receives little to no government funding. Residents live at the care centre on a full time basis. Residents with greater functionality live in communal houses on the property, where full time staff are available. Residents who are unable to function independently or have less functionality stay in more hospital like conditions known as 'the haven'. Full time staff are always available. Residents are also given the opportunity to work in the factory where they perform manual tasks. Residents who have less functionality are also able to work in the factory. Levels of gross motor functioning of employed residents ranged between Level1 and Level5. The vast majority of participants were employed at the factory.

In South Africa there are no statistics available on prevalence or incidence of CP or the on psychological aspects of CP, especially among adult populations. The results and

discussion of this research therefore intended to provide information and knowledge about psychological well-being and its relationship with gross motor function in adults with CP.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents a review of the literature relevant to gross motor function and psychological well-being in adults with CP. The chapter will begin by discussing CP in terms of its definition, types and classification and its implications for researching gross motor function and psychological well-being. The discussion will then move on to discuss motor deterioration in adults with CP and its inconclusive research findings. It will be demonstrated, that although findings are inconclusive, a concern has been raised about psychological well-being and coping of individuals with CP and how this relates to gross motor functioning.

2.2 Defining Cerebral Palsy

The term Cerebral Palsy (CP) has been discussed and debated in terms of its definition and classification for more than 150 years (Dammann & Kuban, 2007; Morris 2007). The history of CP can be traced back to the 1830s, when Heine, a German orthopaedic surgeon, first distinguished CP from flaccid paralysis. In 1943, an English orthopaedic surgeon, William Little, recognised that spasticity and paralysis was caused by damage to the brain which occurred during infancy and more profoundly in preterm birth and perinatal asphyxia (Morris, 2007). This was the first etiological reference to CP, which was then integrated into its definition. CP then became know as ‘Little’s Disease’.

Bax’s (1964) definition of CP as "a disorder of movement and posture due to a defect or lesion of the immature brain" (cited in Rosenbaum, et al., 2007, pg. 8) is often used when referring to CP. Bax did add that people should be excluded from this diagnosis if their disorder was short in duration, due to a progressive disorder, or due completely to a mental deficiency. Unfortunately, these comments are very frequently excluded from literature (Rosenbaum, et al., 2007). Early definitions placed entire focus on motor

function and stressed early brain damage as opposed to late-acquired damage and, for the most, excluded important, possibly disabling aspects of CP, such as, cognitive, behavioural, and sensory aspects and these are often just as disabling (Morris, 2007). This could account for the limited perspective of CP, which describes CP only in terms of a motor disorder. Therefore a lack of investigation into psychological aspects of cerebral palsy occurred in earlier years.

In 2004, a multidisciplinary, international workshop was held in Bethesda (USA), in order to discuss the reconsideration of the definition and classification of CP. After consensus, a document (The Definition and Classification of Cerebral Palsy: April 2006) was released with the agreed upon definition and classification. According to Morris (2007, p.6), the current agreed upon definition is: "Cerebral Palsy (CP) describes a group of permanent disorders of development 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 CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems."

The word 'Cerebral' is defined as 'related to the cerebrum' and 'Palsy' refers to an abbreviation of paralysis. Paralysis refers to the impairment in motor function (Dammann & Kuban, 2007, p.17). Even though the word 'palsy' is no longer used in medical jargon, the term CP has established itself in literature and is used universally by clinicians, therapists, epidemiologists, researchers, policy makers, healthcare funding organizations and lay people. The term was retained in order to relate to future, past and current research or published literature (Rosenbaum, et al., 2007).

The term CP describes an identifiable group of people with neurodevelopmental disabilities. Thus, it is assumed CP is a heterogeneous etiological condition and has different types and levels of severity. People with CP are classified according to types which aids in differentiating, however overlapping does occur (Dammann & Kuban, 2007). For example a person may both have spastic and hemiplegic CP. The term CP is

used to bring these types together, instead of using the term ‘cerebral palsies’ (Rosenbaum, et al., 2007). It is important for CP definition to have inclusive and exclusive criteria as this aids in minimising or eliminating the crossing of treatment (Hirtz, 2007).

The CP definition is more recently moving away from being conceptualised as a syndrome, to being viewed as a disease (Bax, Flodmark & Tydeman, 2007). Because of this transition, individuals previously diagnosed CP now have a different diagnosis e.g. Girls who were misdiagnosed with CP because of motor disorganization are now identified as suffering from Rett’s syndrome, which is caused by an inherited gene problem with the X chromosomes. This example emphasises an issue with the definition, where it describes a disorder based on motor characteristics and does not indicate how an impairment can occur, as a wide range of aetiologies can render CP a disorder (Dammann & Kuban, 2007).

2.3 Aetiology of CP and its role in definition

The term CP also describes a disorder which occurs very early in development and therefore excludes disorders where lesions in the brain are acquired after basic motor development is relatively well established (Sanger, Russman & Ferreiro, 2007). The age limit for CP diagnosis is however a contentious issues. In order to discuss this issue we need to understand what can cause brain lesions which lead specifically to CP.

Lesions in the brain can occur either prenatally, perinatally or postnatally. The lesion, or lesions, can cause different levels of disability (Ross and Deverell, 2004). However, the causes of lesions to the brain are hard to specify. Some causes can occur prenatally. These causes include, intrauterine exposure to radiation, bacterial and viral infections such as rubella and HIV, ingestion of teratogenic drugs (e.g. anti-depressants, antibiotics and cocaine), foetal alcohol syndrome and chromosomal abnormalities, congenital malformation, maternal seizures, maternal bleeding, environmental toxins, intrauterine growth restrictions, infections, nutritional deficits, multiple births, prematurity, low birth

weight, abnormalities of blood flow to the brain, and malformations of the brain structure (Griffin, Fitch, & Griffin, 2002; Ross & Deverell, 2004; Bax, et el., 2007). Perinatally, causes include, premature detachment of the placenta, complications during delivery such as prematurity, asphyxia (reduced oxygen to the brain) and hyperbilirubinaemia and toxoplasmosis, breech presentation, short or long deliveries, delayed onset of breathing, maternal fever during labour, chorioamnionitis, sepsis, kenicterus, electrolyte disturbances, central nervous system infection, hypoxic-ischemic encephalopathy with results in cerebral haemorrhage, seizures, brain swelling, hypotonia, and electroencephalogram abnormalities (Griffin, et al., 2002; Ross & Deverell, 2004; Bax, et el., 2007). Postnatally, causes include head injuries, seizures, viral and bacterial infections such as meningitis and deprivation of oxygen due to accidents or choking (Griffin, et al., 2002; Ross & Deverell, 2004; Bax, et. el., 2007).

Although there is a dominant line of thought that the diagnosis of CP can be established before the 18th month age (Griffin, et al., 2002), there problems with this are that twofold. Firstly, CP can result from injury during the first 2 years of life (Cans, 2000), and secondly, the absence or presence of CP is determined by the age of 2 (Hirtz, 2007). However, Rosenbaum et al. (2007) content that even though a diagnosis can be made within the first 2 to 3 years of life, there is no official upper age limit. Inherent in these contentions are confusions and a lack of consensus on what the upper age limit is for diagnosis. In response to these issues, Sanger et al. (2007) suggest that one should rather focus on pathology and treatment, whereas Dammann and Kuban (2007) suggest the exclusion of post-natally acquired motor disability.

Sanger, et al. (2007) suggest that a useful definition for neurologists is one which includes pathology and response to treatment. They recommend that a definition should include similar pathophysiology and exclude other disorders because treatments differ according to when a lesion occurred i.e. treatment is different for a child who acquired a lesion prenatally than a child with a postnatal embolic stroke. Dammann and Kuban (2007), suggest that post-natally acquired motor disability should be considered a non-CP disorder and CP should rather be specified according to the cause and outcome, e.g. HIV,

meningitis or traumatic brain injury that leads to quadriplegia, hemiplegia, etc. Dammann and Kuban (2007) recognise that it may be difficult to establish which cases of CP occurred prenatally, perinatally and, postnatally, but recommend that by separating the disorder etiologically, this will stimulate research in prevention and help clinicians. They also recommended that with support of neuro-imaging we can better establish aetiology. Although this may be true, a result of disagreement and lack of heterogeneous classification and diagnosis of CP may or has affected research. The lack of clearly defined and operationilised variables, or blurred classification lines, may or have resulted in issues of validity in research.

As mentioned, Dammann and Kuban (2007) have criticised the new definition for being overly inclusive because it includes postnatal etiological diagnosis. However, the April 2006 Consensus offers a definition of CP which excludes any motor disorders that may arise solely from spinal cord, peripheral nerve, muscular or mechanical damage (Rosenbaum, et al. 2007). This definition is far more exclusive because previous literature merely describes CP as arising from "various insults to different areas within the developing nervous system" (Koman, et al., 2007; p.1619). The new definition excludes spinal and muscular injuries and therefore assumes injury that causes CP results in the brain. Therefore in assessing an individual it is important to note the primary inflicted area, yet, as previously mentioned this may be very challenging. Lezak, Howieson, and Loring (2004), conversely argue that motor disorders cannot necessarily be linked with particular anatomic areas. They argue that a cortical lesion may reflect a specific disability of motor coordination or may reflect perseveration or inability to sustain a motor pattern and may also be a symptom of subcortical rather than a cortical pathology. As a result they recommend diagnosis to be made through observation of defective movements.

From another perspective some argue that CP is not an etiological diagnosis. Love (2007) argues that CP is a descriptive term and even though the term describes motor impairment, one should not assume that only motor impairment describes CP, nor assume that motor impairment has the greatest impact on function. The April 2006 Workshop

(Rosenbaum, et al., 2007) also recognised that CP is not an etiological diagnosis but a clinical descriptive term, however criticised the focus on motor function in the definition. It was agreed at the workshop that the way forward was to maintain an emphasis on the motor aspect of CP but also to recognise and incorporate the accompanying behavioural and performance aspects of the disorder. In this regard, Koman, et al., (2007) recognised that different manifestations of neurodevelopmental disorders appear at different life periods and may become more significant to that person at different time periods as well. This motivates the need for research directed at perceptions, psychological well-being and coping during the life span of people with CP. In first determining if there is relationship between gross motor functioning and psychological well-being we can build on the literature and aid in assessing the psychological needs of people with CP.

Importantly, certain aetiologies identified as the causation of CP have also been associated with psychological disorders. For example, in foetal alcohol syndrome (FAS), children show deficits in attention and memory and symptoms of inattention, impulsivity, hyperactivity, poor organisation, communication deficits and behavioural problems are common (Zillmer & Spiers, 2001). Teenagers and adults with FAS struggle with basic interpersonal interaction with peers as a result of cognitive deficits and show high prevalence of antisocial behaviours and substance abuse. Hypoxia and abnormalities in brain structure also demonstrate significant difficulties in concentration, short term memory, learning and judgement (Zillmer & Spiers, 2001). Therefore, when psychologically assessing a person with CP one should be aware that both aetiologies and CP may play a role in psychological deficits and rather not immediately assume these to be the result of 'living with CP'.

2.4 Contentious issues with motor impairment

Another contentious issue with the definition of CP is that if a person is not primarily affected by 'movement and posture' they are excluded from diagnosis of CP. This implies that individuals who are not limited in their execution of tasks or actions would

not be classified as CP (Rosenbaum, et.al., 2007). For example a person with CP may be able to walk and run very well (and may compete in Special Olympics) in comparison to other people with CP, however, very small indications of slowness and deficits in motor coordination may not be clearly observable. Aetiologies are also described as 'non-progressive' which means that CP occurs from a single event or discrete series of events that do not remain active and these are associated with later developments of pathology or additional manifestations. Motor dysfunctions caused by progressive disorders are therefore not considered for diagnosis (Rosenbaum, et al., 2007). The current definition also does not describe what syndromes should specifically be excluded (Morris, 2007). More importantly, the definition does not specify or mention lower limits of severity of motor impairment. Again, the lack of a clear definition raises issues of validity of research.

It is also argued that the definition of CP reflects clinical presentations and creates a misleading impression of the causes of CP and assumes the same cause. Alberman and Mutch (2007, p.32) argue that the revised definition should rather include the concept of CP being non-progressive and occurring during brain development, but that it 'largely depends on the type and precise timing of the initiating cause'. They stress that finding causes of CP will allow for better preventative interventions to be created. Koman, Smith and Shilt (2007) suggest there are issues with CP being conceptualised as non-progressive. They argue that musculoskeletal problems may develop over the life span (either in childhood or later life) and are related to age, physical growth, muscle spasticity and other factors. According to Rosenbaum et al. (2007) and Koman et al. (2007), CP can be described as evolving over time through factors such as development, learning, activities, therapies, ageing and other influences and therefore contradicts the notion that CP is 'non-progressive'. Even though CP is defined as non-progressive it is also often changing in syndromes (Griffin, et al., 2002). Criticisms of the April 2006 consensus definition are that 'non-progressive' is unclear. For example, one may assume a person has a level of motor function that may not improve or worse with age.

Further contentious issues involve severity of motor impairment. Koman, et al. (2004) describe how severity of motor impairment can range from subtle impairment to involvement of the entire body. The epidemiologist perspective agrees with the idea of creating a definition that minimises misclassification. They argue this by saying that a definition which diagnoses individuals without CP as CP, can result in a bias in research or clinical trials in which there will be little or no treatment effect (O'Shea, 2007). There is a need for more specific information on severity of, for example, hypertonia and hyper-relexia. O'Shea (2007) further describes how many research projects or clinical trials have excluded 'mild CP' or 'non-disabling CP' because of the ambiguity of the definition. Even though these issues have been identified, little has been offered in terms of suggestions, alternatives or solutions.

According to Flodmark (2007), neuro-radiology allows one to define different types of brain pathology including postnatal malformations. Neuro-radiology has shown that the formation of certain lesions in the brain is determined by the maturation of the brain and neuro-radiology can locate a specific lesion and relate it to a specific time period during which the lesion occurred. In effect, different types of brain injury occur at different stages in brain development. This opinion is similar to that of Rosenbaum et al. (2007) and Koman et al. (2007) regarding the issues with defining CP. Flodmark (2007) also suggests that different types of brain injury occur at different developmental stages, rather than type of insult. By way of illustration, abnormalities seen in cleavage (splitting of cells) causes holoprosencephaly and this occurs in the 4^{th} to 6^{th} week of gestation, an abnormality in the cortical organization can cause polymicrogyria and occur around the 20^{th} week of gestation. He does however recognise that the duration and severity of the insult are important factors in determining the pattern of pathology.

Neuro-imaging is a luxury in developing countries and, as mentioned previously, there are no statistics available on prevalence or incidence on CP (in South Africa) and many South Africans lack access to health care and basic necessities such as water and electricity (Ross & Deverell, 2004). In South Africa we also face discrimination and stigmatization of people with physical disabilities. The White Paper (1997) addressed this

topic by trying to obtain human rights for people with disabilities. The white paper recognised that people with disabilities are marginalised and discriminated against. Currently, South Africa's primary concerns are crime, poverty, inequality and service delivery. In the health sector, the primary concern involves access, availability and affordability of health care with much focus on HIV/AIDS (Freund, 2006). Neuro-imaging is expensive and is not on the South African agenda in terms of access and affordability.

Other forms of assessments have been criticised for not providing functional information when it comes to assessing patients with CP (Hirtz, 2007). According to Hirtz (2007, p.23) CP is determined if two or more of the following are found: 1) a delay in motor milestones; a motor quotient of 70 or less; 2) abnormalities of tone, deep tendon reflexes, co-ordination and movement; and 3) aberration in primitive reflexes, positive support reflex, tonic labyrinthine relax, and/or posture reactions. Individuals with CP have compromised maturation of the central nervous system which manifests as abnormal fine (precise motor movement) and gross (foundation for developing movement such as fine motor movement) motor function and impairment of co-ordination. This leads to difficulties in walking, feeding, swallowing, coordinated eye movement, articulation of speech and secondary problems with behaviour (such as inattention and learning difficulties) and social interaction (Rosenbaum, et al., 2007; Morris, 2007; Bobath, 1980; Ross and Deverell, 2004). Other disorders which arise from cerebral lesions include disorders of perception, mental retardation and or epilepsy and may suffer from psychiatric or behavioural problems such as autism, ADHD, sleep disturbances, mood disorders and anxiety disorders (Beckung & Hagberg, 2002). These disorders have received little to no attention in the field of CP, especially with regard to it relationship with gross motor functioning.

Behavioural effects of brain lesions vary with the nature, extent, location and duration of brain lesion, age, sex, physical condition, psychosocial background and status of individuals (Lezak, Howieson, & Loring, 2004). As argued previously, the type of brain lesion (i.e. aetiology) can also affect or determine behavioural deficits in individuals. The

question however remains, to what extent do cerebral lesions (organicity) affect behaviour of an individual with CP?

2.5 Cerebral lesions, gross motor function and behavioural deficits.

The control of movement is largely associated with the anterior brain region (Kolb & Wishaw, 2003). Movement also takes on different forms which include reflex action, automatic repetitive actions (e.g. walking), semi voluntary actions (e.g. yawning), and voluntary actions (Zillmer & Spiers, 2001). Behaviour, on the other hand can be described as encompassing 3 functions, namely: (1) cognition (the information handling of behaviour), (2) emotionality (feelings and motivation), (3) executive functions (how behaviour is expressed), (Lezak et al., 2004, pg. 18). Regardless of the size or location of brain lesion, it usually affects all 3 systems of behaviour. These two seemingly different systems have shown apparent associations in research.

In a research conducted by Abernethy, Cooke and Foulder-Hughes (2004), caudate and hippocampal volumes, intelligence, and motor impairment was investigated in children who were born preterm. Their research found a significant association between minor motor impairment and total brain volume, which was more common in children with thinning posterior corpus callosum. Although the control of motor movement is largely associated with the anterior region of the brain, the posterior is linked to visual processing, and thus motor processing in the posterior region is related to reaction to visual stimulus (Eliassen, Bayes, Gazzaniga, 2000). More importantly, it is suggested that in preterm children there is delay in neurologic maturation and other factors and, as many as 40% of children show learning difficulties which are also associated with minor motor impairments and problems with visuo-spaital perception. In the past the basal ganglia and cerebellum were initially thought to be the motor control centre in the brain. However, it has been seen that the basal ganglia and cerebellum influences on cognition, psychiatric disorders and an active role in processing abstract learned information (Lezak, et al., 2007). With regards to CP, we see many associated disorders, including behavioural

disorders, however we are unacquainted with relationship between gross motor function and psychological well-being, i.e. are there differences in psychological wellbeing between different levels of gross motor function?

2.6 Types of Cerebral Palsy

Sigmund Freud advocated that CP should be classified according to clinical presentations. Freud argued that lesions in the brain do not specifically relate to the type of pathology presented because factors such as repair process will alter clinical presentations. He argued that it is impossible to separate congenital causes from acquired causes and the quest to associate clinical syndromes with neuropathology was futile (Bax, et al., 2007). Today, advances in CP can be mainly attributed to the development in neuro-imaging whereby information can now be obtained about the pathophysiology (Bax, et al., 2007). However, as previously stated this is a luxury in countries such as South Africa.

Traditionally the terms 'spastic diplegia', 'spastic quadriplegia', 'hemiplegia', and 'dystonic', have been used to describe different presentations of CP. The term ‘Spastic diplegia’ refers to a child with gross motor problems, particularly in the lower limbs and usually involves partial fine motor function in the upper limbs (Bax, et al., 2007). This presentation is mainly associated with immature damage in white brain matter, including periventricular leukomalacia (ischemic brain injury in premature infants) and periventricular haemorrhage (burst blood vessel causing brain injury in premature infants). Although with some degree of overlap, damage to white matter located chiefly in the posterior cerebrum and less extensively seen in anterior, middle and posterior cerebrum. The underlying causes of the white matter damage have not been established but research is progressing with the help of neuro-imaging (Bax, et al., 2007). Immature white matter damage is also associated with other disorders and is commonly seen as an underlying cause for visual disability. The dorsal and ventral streams in the brain are associated with visual perception and semantic association. At the same time the dorsal stream is involved in motor function and the ventral with perception. It is predicted that

in future it is likely that many children diagnosed with diplegia CP will show comorbid higher visual deficits (Bax, et al., 2007).

The second type of CP is known as spastic quadriplegia and it is argued that spastic quadriplegia shows significant clinical differences from spastic diplegia. In general, those with spastic quadriplegia have more severe motor impairment (Bax, et al., 2007). The third type of CP is known as hemiplegia.

In hemiplegia problems are unilaterally restricted to one side of the body. According to Bax, et al. (2007) hemiplegia has been observed to be a consequence of stroke and asymmetrical periventricular leukomalacia. Patients usually have difficulty with their leg on the affected side of their body, which may sometimes develop shorter than their other leg. Regular physiotherapy can prevent exacerbation of deficit due to shortening of muscles through lesser/restricted or no activity. In hemiplegia, one arm is also affected, yet still have the use of another arm/hand. Despite the fact that motor function may be less impaired than in spastic types, visual and psychiatric and behavioural problems are still significant. Goodman and Yude (2000), (as cited in Bax, et al, 2007) found that hemiplegic children do demonstrate an increased tendency for anxiety, depressive and conduct disorders. In addition, they describe the classroom behaviour of hemiplegic children as fidgety and restless encompassing poor concentration and high levels of distractibility. Goodman and Yude believe it is important to understand the causes of these behavioural problems and attribute it to brain rather than social or environmental causes. This study created an awareness of psychological well-being in children with hemiplegia but more knowledge is needed to be gained in other types of CP and the psychological aspects of CP in adults.

Athetoid or dystonic CP is less common and the lesion usually occurs in the basal ganglia, which means movement is disorganised and motor function is severely disabled. Some patients have trouble with speech and cognitive function. This type of CP is usually caused by rhesus incompatibility. With medical advances this should rarely occur (Bax, et al., 2007).

What is interesting to note is that hemiplegia and dystonic types of CP appear to be more association with cognitive and behaviour disorders than more 'severe' or disabling types such as diplegia and quadriplegia. Testing for difference however can become difficult as overlapping of types does occur. Moving away from an emphasis on motor aspects, there are many associated conditions within CP groups as which affect a large population, i.e. visual, cognitive dysfunctions and epilepsy. Bax, et al. (2007) note that epilepsy occurs between 28%-50% of people with CP, depending on which type. They also note that communication problems occurred in 58% of their study and visual problems were noted in 48%. Dorsal and ventral systems in the brain are not only used for motor function but for perceptual function as well. Damage in the anterior and midbrain have also been associated with learning difficulties. Psychiatric or behavioural problems have also been noted with topographical damage, mostly seen in children with hemiplegia (Bax, et al., 2007).

Another form of description and assessment of CP is the classification system.

2.3 Classification of Cerebral Palsy

A classification system for CP has many uses. Mainly it helps describe CP by providing information on different levels of severity. It allows professionals to assess the level of care and treatment needs. It allows for a direct comparison of different types of CP. Most importantly for the current research, it allows one to evaluate gross motor function in an individual and allows for comparison. Aging has been recognised as an important factor for classification and the possibility of changing classifications over time is noted as an important consideration. A limitation of classification is the difficulty in placing some individuals within one category as categories are not mutually exclusive. Also, there is an issue with the term 'spastic diplegia' in that it is imprecise and therefore not reliable and is recommended to be discontinued (Rosenbaum, et al., 2007).

Early classifications were divided into hemiplegic, diplegic and paraplegic, and as far as possible etiological information was given. It was advocated that classification should include reference to the pathology of CP (Morris, 2007).

Below is a table explaining the classification of CP (adapted from Rosenbaum, et al., 2007).

Table 1: Classification of Cerebral Palsy

Components	Sub-components	What is being assessed	Examples	Classification
1. Motor Abnormalities	A. Nature and typology of the motor disorder	Tonal abnormalities	Hypertonia, hypotonia	1. Spastic 2. Dyskinetic – dystonia or choreoathetois 3. Ataxic *Usually classified according to dominant type. May classify as mixed by practitioner must provide justified information.*
		Diagnosed movement disorders	Spasticity, ataxia, dystonia, and/or athetosis	
	B. Functional motor abilities	The extent to which individual is limited in motor functioning	Walking, speech, and/or self feeding	Classified according to lower and upper body extremities. GMFCS and BFMF used.
2. Accompanying impairments		Presence or absence of later developing musculoskeletal problems		
		Accompanying non-motor neurodevelopmental disorders	Seizures, attentional, behavioural, and/or cognitive	
		Sensory problems	Visual, communication and/ or hearing impairments	
3. Anatomical and neuro-imaging findings	A Anatomical distribution	Parts of body affected by motor impairment	Trunk, limbs, bulbar region etc.	
	B. Neuro-Imaging findings	Neuroanatomic findings on CT scans or MRI	Ventricular enlargement, white matter loss, and/or brain anomaly	
4. Causation and timing		Whether there is a clear identifiable cause	Meningitis, head injury etc.	
		When brain malformation occurred, and/or presumed time frame, if known	First trimester of pregnancy etc.	

The first component of the table is motor impairment which is divided into two areas, namely, the nature and typology of the motor disorder, and the functional motor abilities. The nature and typology of motor disorder describes the type of abnormal muscle tone or

involuntary movement disorder a person may experience and is divided into are three types of groupings: spastic, dyskinetic or ataxic, with dyskinesia. Dyskinesia is further differentiated into dystonia and choreoathetosis. People are usually grouped according to a predominant type of motor impairment they experience. For issues of overlapping (more than one dominant type) room is made for a mixed type. However, if the need arises to describe a person as mixed it must be further substantiated.

The second component of motor impairment is the functional motor abilities. This is separated into upper and lower bodily extremities and use objective functional scales in order to assess activity limitation and the extent to which motor disorders affect a person's ability to participate in activities. One of these scales is the Gross Motor Classification System (GMFCS). The GMFCS offered consensus at a time when the definition and classification of CP underwent many alterations and contentions. The GMFCS offered a system that was valid, standardised and reliable in the evaluation of children with CP (Morris, 2007). This instrument will be used in order to asses the level of gross motor function each participant is at. Psychometric properties of this instrument will be discussed in more detail in the methods chapter.

The second component of the classification system is the aspect of accompanying impairments. This is where impairments that affect daily living are recorded and include impairments that are not motor in nature, but which limit a person even further, e.g. blindness. These impairments are usually from the same or similar pathophysiologic process as motor disorder. For this reason, Rosenbaum et al., (2007) recommends that people with CP have their IQ, hearing and vision assessed and noted whether epilepsy is present or not. This type of information (except for IQ) is made available through the use of the Comprehensive Quality of Life Scale. This scale will also be used in order to include these issues and act as a measure of quality of life. Again, this instrument will be discussed in more detail in the methods chapter.

The third component is the anatomical and neuro-imaging findings which are divided into anatomic distribution and neuro-imaging findings. The anatomic distribution requires that

all body regions are described individually with regards to impairment of movement and posture, i.e. trunk, each limb, and oropharyx. It has been recommended that terms of diplegia and quadriplegia are no longer used as they have created imprecise terms in clinical practice. Rosenbaum et al. (2007) recommend that if these terms are used then one must clearly describe and characterise what they mean.

The final component of the table addresses cause and timing. It is recommended that even though in many cases a cause cannot be found it should still be investigated. As of yet a categorization by cause cannot be achieved and therefore it is recommended that timing of brain lesion be noted if there is reasonable and firm evidence which indicates so, e.g. a traumatic birth causing an ischemic stroke would indicate perinatal timing. However one cannot make an assumption that if adverse events are present that they are the cause (Rosenbaum, et. el., 2007).

A new classification system for CP was offered in the April 2006 consensus paper. Dummann and Kuban (2007) criticises this classification system for oversimplifying different CP forms and making it difficult for researching different CP populations. They criticise the dropping of the term ‘spastic diplegia’ and ‘quadriplegia’ by arguing that topographic description of CP helps professionals such as neurologists to localise lesions in the brain by knowing the gradation, severity and symmetry of the topography. However, the GMFCS also relies on topographic description in describing people in terms of their level of gross motor function. The limitation of describing people in terms of diplegia and quadriplegia is that, as mentioned earlier, there are comorbid conditions which aids in determining the prognosis of individuals (Palisano, Rosenbaum, Walter, Russell, Wood & Galuppi, 1997). Dammann and Kuban (2007) further argue that tone or movement should be described by a single dominant type because spasticity and dystonia can co-occur and require different treatment and each type informs about lesion localization.

Love (2007) argues that there is a need for a multidimensional or multilayered classification and descriptive system. Traditional classification systems described CP

according to motor impairments, e.g. Spastic diplegia is characterised by hypertonia and spasticity located in the lower extremities. There is a need to better define and refine characteristics used in the description of motor impairments and especially there is a need for reliability of these descriptions. Love (2007) suggests that even though there are measures available to describe CP in patients, motor impairment description needs to remain separate. The Australian Cerebral Palsy Register in 2002 proposed a flow chart which requires one to consider each type of motor impairment and rank their predominance, with provision for equality. This chart allows patients to be grouped according to a primary type of impairment and describes features and combinations of clinical impressions.

Love (2007) also argues that a definition of CP should not arise out of causal/aetiological factors. O'Shea (2007) argues that one risks creating groups or subgroups that are too heterogeneous in nature when looking at causal factors. He argues that the heterogeneous nature of the three subgroups, quadriplegia, diplegia and hemiplegia may not be only due to random variability but may be attributed to the differences in aetiologies that lead to specific subtypes of CP. To create more homogeneous groups we need to consider combining subgroups. These opinions further highlight the contestations in the field and the need for reconciliation in definition and classification.

With these issues in mind, this research intends to investigate gross motor function in terms of the GMFCS. However, an important issue to further discuss is that of CP and the argument that it is 'non-progressive'. The following section will attempt to address the issue of motor deterioration.

2.8 Motor Deterioration

Ando and Ueda (2000) conducted a longitudinal study in order to examine the problem of functional deterioration of adults with CP. The participants of this study were taken from community workshops throughout Japan. The study was longitudinal in nature. Ando and Ueda (2000) classified levels of CP according to the degree of independence a participant

had in two activities of daily living: eating meals and locomotor activities. These were divided into 4 levels. The first classification was, 'Without any device'. This involved participants who could accomplish the activities without assistance, and without the use of self-help devices such as braces or wheelchairs, e.g. a participant who can walk or run without a device. The second classification, 'With device or minimal assistance', which involved participants who used self help devices or minimal assistance to accomplish both activities. For example a participant who uses braces to walk. The third classification is, 'With some assistance', involved participants who required partial assistance with one or both tasks. For example a participant requires some one to help them eat. And lastly, the fourth classification, 'Completely dependent', involved participants who needed assistance in accomplishing both activities, e.g. participants who cannot feed themselves or walk and are dependent on someone for constant assistance. Limitations of these classifications include: the lack of definition of the term 'locomotor activities', as well as the ambiguity between the second and third classifications, i.e. 'Minimal assistance' was not distinguishable from 'Some assistance'.

Even though this research was limited, it did provide information with regards to motor deterioration. Ando and Ueda (2000) used physicians from participating organizations that specialised in rehabilitation medicine, to examine and assess their sample for motor deterioration. This collaborative information strengthened their argument. Their results also supported the understanding that both baseline ability levels and advancing age contribute to motor deterioration within the group. The study found that motor deterioration was significant in factors such as age and degree of disability. They found that functional deterioration can occur in adults with CP, within a working population. They found deterioration to be more frequent in adults with involuntary movement in the neck region. Ando and Ueda (2000) noted that intrinsic factors to CP are mostly responsible for functional deterioration, but environmental factors can play a role as well. However Ando and Ueda (2000) concluded that there was no significant relationship found between the home environment and functional deterioration. They explained this by stating that in the home environment allows one to change posture more easily as compared to the work environment. Unfortunately the study did not provide a control

group or a comparison to the general population and because of the nature of the study causal conclusions could not be made.

Strauss, et al. (2004) further contributed to the understanding of functional decline in a study focusing on 3 specific discrete age groups, namely 20, 40 and 60. Although the research design was cross sectional as opposed to longitudinal, they did not provide an age range. Nevertheless they included an older population, which is so frequently omitted from the research which normally focus on younger adult populations. In the study they employed their own functional classification system which was not standardised yet was more comprehensive and less ambiguous in comparison to Ando and Ueda's developed instrument. However Strauss et al. (2004) did not provide reliability or validity scores for their instrument. Their study aimed to look at functional deterioration and mortality over time. Their results showed that functional ability declines with age, with rapid decline in people aged over 60 years, regardless of their previous functional status. Walking greatly declined after 60 years of age where as functions such as feeding and speech showed less decline. Strauss et al. (2004) discuss how gross motor function declines with age. Other studies, such as Bottos, Feliciangeli and Sciuto's (2001) study looking at functional status of adults with cerebral palsy and implications for treatment of children, and Murphy, Molnar, and Lankasky's (1995) study which looked at medical and functional status of adults with cerebral palsy, confirm Strauss et al. notion of functional decline with age. Strauss, et al. (2004) also attributed motor deterioration mostly to musculoskeletal problems. This study also compared their results to the general population (in the United Kingdom), and successfully highlighted the highly significant difference in motor decline experienced by people with CP.

Although Strauss, et al. (2004) drew attention to the lack of knowledge identified by Andersson and Mattson (2001) with regards to motor deterioration experienced by people with CP. It remains apparent that knowledge of the developmental process in adults with CP is limited in comparison to the knowledge base in the developmental process children with CP. Although similarities may be seen between children and adults, they are

however at different stages of social development and face different critical conflicts (Erikson, 1987).

One reason for this is because there are many health facilities to care for children with CP. When a child with CP becomes an adult they lose contact with health services and as a result their health status is affected (Andersson & Mattsson, 2001). Andersson and Mattsson (2001) also found that with age, motor function decreases. However, little is known about how adults cope with this change. In attempting to understand this we can begin by first assessing whether different levels of gross motor functioning affect psychological well-being in adults with CP. Before investigating the relationship between these two concepts, we first need to conceptualise psychological well-being.

2.9 Psychological Well-being and adults with CP

Mental health and mental illness are much debated concepts in the field of psychology. The concept of well-being has been theorized by many but remains a complex and controversial issue (Ryan & Deci, 2001). Some arguments focus on causality i.e. genetic aetiologies, while others focus on a person's current reality and how social factors play a role in mental illness (Lamb & Zusman, 1982). Priebe and Finzen (2002) argue that mental illness is determined by one's context. According to Perlmutter (1982) we need to view mental health and mental illness on a continuum as mental health services need to deal not only with diagnosable illness but also help people with interpersonal problems that cause them stress.

Mental health is defined in different ways with the definitions ranging from mental health being conceptualised merely as an absence of mental illness to the more comprehensive but somewhat abstract idealisations of mental health as incorporating autonomy, integration, growth and self actualization, positive attitudes towards the self, perception of reality and environmental mastery (Mann, 1979). The importance of the definition lies in the idea that how one defines well-being may influence practices in government,

therapy, clinician practice, etc. (Ryan & Deci, 2001) as is elaborated on below with specific reference to hedonism and eudemonism.

There are two philosophies used to describe well-being. The first being hedonism, which defines well-being according to pleasure and happiness. The second view is eudemonism, which views well-being as being more than happiness and believes that the actualization of human potential is what defines well-being (Ryan & Deci, 2001). Both views ask different questions about development and social process and in a way they prescribe different ways of living.

In hedonism, happiness is subjective and well-being suggests pleasant rather than unpleasant experiences. The goal, in this view, is to obtain maximum happiness (Ryan & Deci, 2001).There are three components in the assessment of this type of well-being: life satisfaction, presence of positive mood and absence of negative mood. These three components create 'subjective well-being' (Ryan & Deci, 2001).

Many philosophers, including Aristotle, criticised hedonism for assuming human beings to be followers of desires. The eudemonic perspective views well-being as something that is not necessarily reached through obtaining desires. It assumes that even though a pleasurable feeling can be found when obtaining desires, it may not be good for a person. It assumes that well-being is reached when a person is their true self and their living activities are congruent with their values in a holistic way. A human being needs to flourish and grow and realize their potential (Ryan & Deci, 2001).

Psychological well-being is distinct from subjective well-being in that it is multidimensional. According to Ryff & Keyes (1995), there are six components to psychological well-being: autonomy, personal growth, self-acceptance, life purpose, mastery, and positive relatedness. The Mental Health model is derived from this philosophy.

According to the Mental Health model, mental health refers to the development of competence or coping abilities and a sense of social relatedness. It also assumes that an increase in mental illness results from social class and social isolation (Mann, 1979).

The Mental Health Model "is an attempt to conceptualise a strategy for influencing human behaviour, largely within the setting of the community mental health centre" (Mann, 1979, p.79). The model associates mental illness with a person's social context and the relationship between people and their environment. Albee (cited in Lamb & Zusman, 1982) uses the following formula to describe mental illness:

$$\text{Mental Illness} = \frac{\text{Stress + Physical vulnerability}}{\text{Social skills + coping skills + self-esteem}}$$

Basically, this formula implies that mental illness can be defined in items of the stress and vulnerability of a person and the skills they have in order to overcome these stresses. According to Fryers, Melzer and Jenkins (2003) mental disorders are more likely to occur in socially disadvantaged groups and the factors that determine lack of ability to cope are factors such as education level, income and other material resources.

According to this model, adults with cerebral palsy are immediately placed at a disadvantage as they are 'socially disadvantaged'. They are also further disadvantaged and more at risk of mental illness because they face difficulty obtaining jobs (either through discrimination or inability) and may have less income. One may therefore assume that a CP adult is at high risk of mental illness. However, in review of literature to follow this is seemingly not the case. Literature will now be reviewed in terms of quality of life, depression, anxiety and self esteem which form the psychological well-being variables for this study.

2.10 Factors that determine psychological well-being in adults with CP

According to Kerr, McDowell and McDonough (2006) motor impairments are experienced differently by children with CP and vary with regards to the spectrum of the disorder. Kerr et al. (2006) suggest that it is difficult to quantify a child's experience of motor impairment and their involvement in life situations as experiences may vary as a factor of their functional levels and social backgrounds. Wiegerink, Roebroeck, Donkervoordt, Stam, Kettenis, (2006) identify may other factors which may affect social relationship, which are classified according to personal, functional and environmental factors. They are list below:

Personal

- General Psychological characteristics
- Self Efficacy
- Sexual self-esteem

Functional limitations

- Physical functioning

Environmental factors

- Family
- Peers
- Attitudes of others and social support
- Accessibility and transportation
- Performing social activities

Self efficacy (concept describing ability), (Sandstrom, 2007) is seen by Wiegerink et al. (2006) as one of the most important components for social competence.

A study which investigated the relationship between motor function and participation restriction was Kerr et al. (2006). Instruments that were utilized included the Gross Motor Function Measure (GMFM-88); a highly recognised scale which has undergone much

statistical review, and The Lifestyle Assessment Questionnaire – Cerebral Palsy (LAQ-CP). It was found that better physical function is correlated with better quality of life; however correlation was small with a 27% variance. Despite the lack of correlation with the overall score, it is interesting to note significance of the findings relative to certain specific dimensions thereof. It was also noted that physical independence was the strongest influence on participation restriction because it related to functional tasks such as washing, dressing and stair climbing. From Ryff and Keyes (1995) philosophy on wellbeing, this forms 2 of the 6 components of psychological wellbeing, namely autonomy and mastery. With 2 components of psychological well-being affected one would assume that psychological wellbeing is affected negatively with the lack of autonomy in performing tasks and the inability to master motor skills, specifically if one has spastic or dystonic type of CP. This assumption is based on the theory that physical function relates to a person's quality of life. According to the mental health model, physical vulnerability forms a component of mental illness in the mental health model. Therefore, one could argue that self esteem and social participation are linked to physical independence.

Kerr, et al. (2006) study appears to address the issue of whether physical vulnerability and social disadvantage do in fact affect a person's wellbeing. The study looked at two types of mobility, namely functional and social mobility. These types of mobility look at clinical and everyday function. What was found was that children appeared to require more assistance when outdoors and in the community settings, rather than at home. Kerr, et al. (2006) do not attempt to explain this, however it could be argued that outdoor and community settings are much larger environments with greater distances and unfamiliar surroundings and logically a child with CP would require more assistance. Also, a person with CP also benefits from being in a context, be it either home of care centre, that meets his/hers need requirements (Heller, Factor & Hahn, 1999). LePage, Noreau, Bernard and Fougeyrollas (1998) also confirm the notion that the severity of physical functions influences the degree of social participation in children with CP. They also add that the severity of cognitive function may also influences social participation. However, LePage

et al. (1998) fail to expand on what is meant by cognitive function and this is rather a broad term which may encompass many deficits.

Kerr et al. (2006) study also found a significant correlation between social integration and gross motor function, with better functioning being associated with improved social interaction. This follows the argument that with better mastery and autonomy and less physical vulnerability one may have better psychological well-being. It is also important to note that the results of this study only apply to children and the same has not been established for an adult population which is why further research is required. They also did look not address the difference between the home setting and an institutional setting in social and functional terms. For example, a person at home may receive a lot of family support but may, due to stigmatisation, not leave their home and thus experience little social interaction. Conversely, a person who is living at an care centre or care facility may or may not receive family support but may experience much social interaction with other peers and through social outings (This example by no means reflects fact).

Wiegerink et al. (2006) reviewed 76 papers which discussed social and sexual relationship among people with CP, physical disabilities and congenital disabilities. In comparison to able functioning children and adolescents, children or adolescents with CP are less exposed to peer culture. Adolescents and young adults were also significantly less active, spent less time on leisure activities and spent less time with their friends. Wiegerink et al. (2006) do not provide contextual information in terms of whether these individuals were living with their family or living in a care centre. It could be argued that individuals who live in an care centre may have more social exposure than those who live at home because they are in constant contact with peers. This however is a tentative hypothesis and requires further investigation. Further, the actual level of gross motor function may have affected their social exposure.

Children and adolescents with minor physical disabilities perceived themselves as less competent in their physical abilities, appearance and social life, in comparison to other children or adolescents with more severe physical disabilities (Miyahara & Piek, 2006).

Miyahara and Piek (2006) hypothesized that the differences between two discrete physical disabilities could possibly be because children and adolescents are subjected to more criticism and judgement by peers and significant others. They also hypothesize that those with major physical disabilities have developed skills for coping with their disabilities where as those who are less disabled have not. In essence, a child with CP grows up with social support and as a result develops self acceptance. A limitation of this view is that Miyahara and Piek (2006) discuss perceptions and disabilities as a whole and groups CP children and adolescents in one group and assumes they are all severely physically disabled. However, CP ranges in severity of physical disability as seen in the Gross Motor Classification System, which ranges from Level 1, where a child can walk or run with limitations in speed, to Level 5, where a child is confined to a wheelchair and is totally reliant on others for care.

Another limitation of this study and others like it is that it focuses on children and adolescents, and sometimes young adults. Yet little is known about older adults. This is especially important to investigate as older adults enter different developmental stages and other results in children's studies may not be applicable to an adult population.

Bleck (1987) investigated young adults with spastic CP and found that communication, self-care, and community participation were important for life satisfaction (cited in Bier, Prince, Tremont and Msall, 2005. Adulthood appears to be a significant time when people with CP have been diagnosed with major mental health problems. These include depression, bipolar disorder, schizophrenia and nervous breakdowns (Crawford, 1996). Although mental illness is present it is hard to determine whether there is a significant difference in comparison to the general population.

Motor deficits impact on social interaction and participation and as a result this impacts on a person's quality of life, as indicated by the mental health model. For example, an individual may require the use of a wheelchair and may suffer from uncontrollable muscle contractions. As a result the individual may be restricted in visiting certain social areas due to a lack of facilities such as a ramp for a wheel chair. Alternatively other

people may feel uncomfortable to approach an individual who does not have complete control of their movements. Consequences of this may be reduced self esteem which can also be a risk factor for anxiety and depression (Harter, 1987).

2.10.1 Depression in adults with CP

Depression among adults with disabilities has been compared with the general population in a study by McDermott, Moran Platt, Issac, Wood and Dasari (2005). The specific disabilities that were addressed were that of autism, cerebral palsy (with mental retardation), cerebral vascular accidents or strokes and traumatic brain injury. Although individuals with cerebral palsy (and mental retardation) had a significantly lower risk for depression than then general population the relevance of their findings are somewhat limited as an indicator for the present study in that their sample consist only of cerebral palsied adults with mental retardation. However, many individuals with CP may have average and above average intelligence (Ross & Deverell, 2004). Therefore these findings cannot be generalised. Excluding this limitation the study did provide information in terms of differences between adult onset disabilities and early acquired disabilities. What was found is that individuals who have adult onset disabilities have a significantly higher risk depression than those individuals with early acquired disabilities such as CP. In addition, those individuals with lifelong disabilities have a lower prevalence of depression compared to the general population. These points are in contradiction to Kerr at al. (2006) and Bleck (1987) notion that functional disability results in less social interaction and thus, according to the mental health model, results in a higher vulnerability to mental illness. However, reasons for the presence of depression in adult onset disability may be because severe psychosocial stressors or events have been shown to precipitate major depression in individuals (DSM-IV-TR). The difference in depression between adult onset and acquired disability is rather not the disability itself but rather significant change. Because a person with CP is born with it they may only be aware of their current level of functioning and have never really been experienced other levels of functioning, even though they are aware they exist. Therefore a person with previously normal functioning may experience loss and change as a result of onset disability. The same could be held for individuals with CP whose level of functioning

significantly decreases. Therefore with regards to the health belief model, if own were to assess a person from their own base function, rather than the norm, we may gain a more realistic and accurate representation of mental health in individuals with CP.

Because of other varying reports on depression in adults with disabilities, the 1997 Roundtable report of Aging and Cerebral Palsy suggested that emotional and psychological issues need to be addressed and further investigated. One particular variable of interest is that of gender. The DSM –IV-TR notes that depression in women is more prevalent than in men. Differences in gender have not been researched with regards to CP however the Roundtable report of aging and Cerebral Palsy noted than women with CP have experienced difficulty in coping with their menstrual cycle, i.e. in terms of hygiene and difficulty with self care. This is heightened by a type of depression know as pre-menstrual depression (not yet recognised by the DSM-IV-TR), which is due to an imbalance in hormones which occurs before and even during menstrual cycle (Musikanth, 1997). Another type of depression known as Involutional Melancholia can occur through hormonal disturbances due to menopause (Musikanth, 1997). Therefore further investigation is required in this regard.

Further, it is important to describe what is meant by depression in this study. This study utilised the *Major Depression Inventory (MDI)*, which will be described in greater detail in chapter 3. The MDI utilises both ICD-10 and DSM-IV-TR descriptions of depression and categorises depression into 3 categories, namely mild, moderate and severe. These categories describe types of depression such as atypical, dysthymic and major depression (Musikanth, 1997). A common comorbid disorder of depression is anxiety (Barlow & Durand, 2005), which is further discussed in terms of CP below.

2.10.2 Anxiety in Adults with CP

The Roundtable reported that because aging can cause anxiety, the disabled population may experience anxiety more significantly. Individuals with CP may experience more anxiety because with age, physical abilities decrease and this may cause major concerns and anxiety for people with CP. It is not only the individuals with CP who suffer from

anxiety and other psychological problems, it extends to their family and care-givers, where they can become 'disabled' (Evans, Darrah, Pain, Adkins & Kratochvil, 2001). Family members may also become overprotective of their disabled member which may result in an adult or adolescent with CP feeling restricted. Further, the older an individual with CP becomes, the more likely they are also to experience loneliness (Balandin, Berg & Waller, 2006). Another issue that may arise is that of the person's aging parents, who with age, may become limited in their ability to aid their adult child with CP. This may further heightened anxiety in a person with CP.

One particular study by Krakovsky, Huth, Lin and Levin (2007) investigated functional changes in children, adolescents, and young adults with cerebral palsy. One particular aspect of their study investigated anxiety and depression levels among their sample aged 11-39 years old. Their results indicated that 63% of their sample had experienced anxiety and 10% reported depression. This study used a questionnaire developed by the principle investigator, which was not provided as an attachment. Reliability and validity indicators of this questionnaire were also not provided. Therefore results of emotional functioning are questionable. The use of standardised and recognised psychological assessments would have supported the reliability of findings.

Other literature, as discussed earlier, indicates that as individuals with or without CP age, anxiety becomes more common. There are however no prevalence or incident rates available, or statistics which are compared to other variables in studies, especially in samples with older adults.

2.10.3 Loneliness in adults with CP

Balandin, et al., (2006) conducted a study in which they assessed loneliness (using the UCLA – University of California Los Angeles Loneliness Scale version 3), in 2 groups of older adults (defined as over 40) with CP. One group consisted of individuals who used natural speech to communicate, and the other group used augmentative and alternative communication (AAC). The researchers used speech as a variable of loneliness which is not only attributed to isolation but to the lack of meaningful communication as well

(Hopps, Pepin, Arseneau, Frechette & Begin, 2001). Loneliness in adults with CP has also been attribute to factors such as, the loss of a spouse, friends or partner, increase in symptoms of ill health, changes in financial income, problems with access to transport, changing living environments (e.g. moving to a nursing home) and not having children (Balandin, et al., 2006). Older adults with CP who use AAC are said to experience loneliness more as they are less likely to form relationships and be employed (Baladin & Morgan, 2001). However, there is no reported significant difference between individuals who used natural speech and those who used AAC. According to Balandin et al., (2006) older adults with CP are significantly lonelier than the general population; however, it should be noted that a limitation to their study is that their sample's experience of loneliness was higher that previously used sample in other research, therefore highlighting threats to validity.

However seemingly apparent loneliness appears to be in adults with CP we one cannot immediately assume they are lonelier than the general population. Evidence has not been provided to indicate a significant difference in loneliness between adults with CP and the general population.

One factor which Balandin et al. (2006) attributed to loneliness in adults with CP was the transition of living environments, for example, moving into a nursing home. The question of placing individuals with CP in a nursing home or care centre is one that is sensitive and contentious. Some people may perceive it unnecessary to place an individual with disability in a nursing home if they do not require 24 hour care or have health problems (Lakin, Hill & Anderson, 1991). Differences between home care and nursing care have not been established. Nevertheless, it has been indicated that adults with CP who move between nursing homes, instead of residing at one nursing home have benefited in terms of health and community function. Movers mobility limitations also improve, where as non movers show no significant changes (Heller, Factor & Hahn, 1999). Improvement in mobility limitation can been attributed to greater access to devices and equipment which may only be provided at certain centres which aid with specific needs. However findings in determining relevant changes in health are limited as Heller, et al. (1999) indicate their

sample was too small for analysis and they relied on a post hoc examination of changes in skin, anaemia, and urinary conditions. Therefore changes in health are inconclusive.

What was interesting to note however was that depression levels between the two groups did not change over the years. Heller et al. (1999) contradict their early claim of improved community function in movers, but stating further in discussion that there were no significant changes between either group over the years. Heller et al. (1999) however do suggest that the impact of moving should also be further investigated in order to assess perceived quality of life and satisfaction. This type of study cannot be performed in South Africa as care centre or nursing homes that focus on CP needs are extremely limited. Nevertheless one can investigate the amount of time one has spent in an care centre, nursing home or care centre and assess whether there are relationship with quality of life, depression, anxiety etc.

2.11 Rationale

People with CP are a vulnerable group that face much discrimination and marginalization (Crawford, 1996). People with CP are perceived as a vulnerable group because they may lack the ability to independently make decisions or consent. This 'inability' may be due to a person not understanding or retaining relevant information to make a decision. It may also mean that a person is unable to see foreseeable consequences of a decision or may not be able to make a decision (Campbell & Oliver, 1996). Many people however assume that a person with CP is mentally retarded. People with CP can present with mental retardation but many have average and above average intelligence (Ross & Deverell, 2004). Many times a person with CP (and their families) may feel alienated or isolated from society because of prejudice and this can lead to psychological problems such as depression (Crawford, 1996).

The field of CP has generated a lot of research, mainly in terms of medical and rehabilitation research. Much of the research is focused on children and very little focuses on adult populations, especially older adult populations (Strauss, Ojdana, Shavelle &

Rosenbloom, 2004). According to Strauss, et al. (2004) adults with CP tend to acquire medical conditions, not commonly seen in children with CP. Many adults experience joint stiffness, muscle contractures, and degenerative osteoarthritis and these musculoskeletal difficulties advance with age (Strauss, et al., 2004 and Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2007). Many patients also suffer from pain, especially cervical pain (Strauss, et al., 2004). Strauss (2004) also notes that with age, everyday abilities such as walking, speech and self-feeding, decline. Some literature suggests that this is a factor for social participation; however this is reliant on social context i.e. living in a care centre. The mental health model also assumes that with social isolation one becomes more prone to mental illness. One would assume thus the prevalence of mental illness is thus higher in persons with CP, however this has not been compared and therefore the assumption is challenged.

As discussed, there is the tendency for research investigating wellbeing to group CP and assume the same level of gross motor function. However, if one can stated level of functioning affects social participation, we can assume that the level of gross motor function may thus affect well-being.

Another contentious issue is that of living at care centres. There are advantages and disadvantages to residing in a home or care centre however the difference is unclear. Because of constraints, the study will not focus on institutionalism itself but rather view ‘years of residency’ as a possible extraneous variable.

This study will also investigate whether motor deterioration has been experienced and whether there is a significant difference between different levels of gross motor function and the experience of motor deterioration.

Research on CP from a psychological perspective is minimal. Much research focuses on developmental stages of children (Andersson & Mattsson, 2001). Even when discussing issues such as definition and classification, authors tended to focus on children or just describe CP as occurring in children.

Ross and Deverell (2004) describe how the loss of function/ ability in stroke patients or amputees can lead to psychological distress and disorders, such as anxiety or depression, can manifest themselves. Research indicates that those with a lesser functional ability are more likely to have a decreased quality of life. Kerr et al. (2006) also indicate that those with better gross motor function have better social integration. This research intends to investigate whether there is a relationship between different levels of gross motor function and quality of life and whether there are significant differences between each group in terms of quality of life.

Depression, Anxiety and Self Esteem will be investigated in the same manner. Research in these areas is minimal and inconclusive. Therefore by further investigating these concepts and how they relate to gross motor function it is intended to add knowledge to these areas.

2.12 Research Aims

This research primarily aimed at assessing the relationship between gross motor function in adults with Cerebral Palsy (CP) and psychological well-being. The research focused on an adult CP population and aimed at investigating different levels of gross motor functioning, according to the Gross Motor Function Classification System (GMFCS), and their correlates with psychological well-being. Psychological well-being was measured in terms of self esteem, quality of life, levels of anxiety, and depression.

Secondary aims of the research involved the investigation of differences in psychological well being among different gross motor functioning levels. Differences in age, gender, years at care centre and the experience of motor deterioration, among different levels of motor functioning were also investigated.

Reliability and internal consistency for psychological measures with a CP sample were investigated.

2.12 Research questions

1. Are the psychological instruments utilised reliable and have internal consistency with a CP sample?
2. Is there an association between age, gender, years at care centre and the experience of motor deterioration with different levels of gross motor functioning?

   Do depression, Anxiety, Self Esteem and Quality of Life scores correlate with gross motor functioning in adult with CP?

   Are there differences between levels of motor functioning in terms of psychological well being?
3. Is there an association between age, gender, years at care centre and the experience of motor deterioration with different levels of gross motor functioning?

   Do depression, Anxiety, Self Esteem and Quality of Life scores correlate with gross motor functioning in adult with CP?

   Are there differences between levels of motor functioning in terms of psychological well being?

Chapter 3: Methods

The purpose of this chapter is to describe what methods and procedures were used in order to implement this study. It will include a discussion on the research design, participants, measures used, methods of analysis and ethical considerations.

3.1 Research Design

A non-experimental, correlational and group differences design, which aimed at investigating variables which occurred naturally as opposed to manipulating them (Rosnow & Rosenthal, 1996). A group of 43 participants were used in order to view the relationship between gross motor functioning and psychological well-being. The independent variable was the level of gross motor functioning and dependent variables were demographic and psychological wellbeing variables. Demographics variables included age, gender, years of residency and the experience of motor deterioration. Psychological well-being variables included quality of life, depression, anxiety and self-esteem.

There was no random assignment of participants or manipulation of variables and the aim of the research was to investigate the relationship between variables (Coolican, 2004). A weakness of this study therefore, and that which is typical of non-experimental design, is the inability to establish causation.

The Comprehensive Quality of Life Inventory (5th edition), The Rosenburg Self Esteem Scale, The Major depression Inventory and The Beck's Anxiety Inventory were tested for reliability in the sample of adults with cerebral palsy.

3.2 Participants

The participants for this study were obtained through convenience sampling at a care centre for adults with CP. Choice of using adults with CP at a care centre was motivated by several reasons. Firstly, care centres for adults with CP are extremely minimal in South Africa. Further, because individuals with CP experience stigmatisation and thus isolation, finding and tracking a sample without the aid of an organisation would be very difficult. By investigating individuals and their length of stay at the care centre one can assess whether it is a variable that reflects a relationship with psychological well-being, at the same time excluding a potential cofounding variable in the investigation of the relationship between gross motor function and psychological well-being.

Residents at the care centre were full time residents. Permission from social worker and care centre management was firstly obtained (Appendix D). 56 adults were approached individually for participation. Each participant participated on a voluntary basis with written consent obtained after verbal and written explanation of the purpose of the study. 50 participants initially responded, only 48 participated. 5 more participants were excluded as 3 had different head injuries and 2 participants presented with extreme cognitive disabilities and were unable to understand questions and continuation in study would have been unethical. Many of the residents at the centre were ‘orphans’, as they had no family or were abandoned by their family. The centre was also a non-government organisation and therefore permission did not need to obtained through government departments.

Participant’s age ranged from 22 to 60 years, with a mean age of 45 and SD of 10. Participant’s years of residency ranged from 0 to 38 years, with a mean of 16 and SD of 13.5. 24 participants were male and 19 were female. Participants were grouped according to their level of gross motor function based on the 5 levels from the GMFCS. 23.26% of participants were level 1, 23.26% were level 2, 13.95% were level 3, 20.93% were level 4, and 18.6% were level 5. Because of the small sample size distributed over the 5 levels of gross motor function, it was decided for statistical purposes to divide the 5 levels into

2 categories. Level 1 and 2 were grouped into ‘those who functioned without devices’ and Level 3, 4 and 5 were grouped into ‘those who functioned with devices’. Devices included wheelchairs or walking aids, based on the GMFCS. Because levels of the GMFCS are distinct it becomes easy to differentiate (Palisano, Rosenbaum, Walter, Russell, Wood and Galuppi, 1997). 46.5% of participants were in the group “no devices”, and 53.5% of participants were in the group “with devices”. Devices included wheelchairs or walking aids, based on the GMFCS. 46.5% of participants were in the group “no devices”, and 53.5% of participants were in the group “with devices”.

3.3 Procedure

This studies proposal was accepted by a higher committee at the University of the Witwatersrand. The proposal was sent to an external ethics committee and was approved (Appendix E). As previously mentioned, permission was obtained from care centre management. Information letters (Appendix B) and consent forms (Appendix C) were then distributed individually to prospective participants and their parents/ guardian if needed. Each participant was approached in order to ensure the participant fully understood the information letter and consent form. Some participants were blind, could not read, or could not write and therefore needed to be spoken to individually. Participants who consented to research were then taken individually to a quiet, private room at the care centre, where they were asked to complete the questionnaire containing all the measures. Each participant was reinformed about consent, confidentiality and their right not to answer questions or told they could stop at anytime. Each participant was also informed that they may approach the on site social worker for counselling or other problems they encountered. For participants who were not comfortable speaking to the social worker, a toll-free number for The Depression and Anxiety Group of South Africa was provided. For the majority of participants the researcher had to fill in responses on the questionnaire. In 2 instances participants had to return the next day to continue the questionnaire as they had speech problems and struggled in responding and therefore answering questions were timely.

The set of questionnaires that was administered contained the Biographical questionnaire, The Major Depression Inventory, The Beck's Anxiety Inventory, The Rosenburg Self Esteem Scale and The Comprehensive Quality of Life Inventory. Each participant took between 30-45min on average to complete questionnaire.

Gross motor function was assessed separately where the researcher observed participants in their work setting and determined which level of gross motor functioning each participant should be categorised in. Questionnaires were coded in order to keep track of participants' responses. The data collection and observation period lasted 6 weeks.

3.4 Measures

Measures such as the Comprehensive Quality of Life Measure and Rosenberg Self Esteem Measure were used to identify social skills, coping skills and self esteem. Levels of stress were defined in terms of depression and anxiety levels and physical vulnerability was defined as the levels of gross motor function (as per the Mental Health model discussed earlier).

Psychological well-being encompasses many aspects. For purposes of this research certain aspects will be focused on, such as, quality of life, depression, anxiety and self esteem. These measures were viewed independently in order to assess whether any interaction occurred and to test for reliability (Rosenthal & Rosnow, 1991).

3.4.1 Demographic questionnaire

Participants were asked to complete a brief demographic questionnaire, which was utilised to capture information including age, gender, how many years they had been residing at the centre and whether they had experienced motor deterioration. This questionnaire was developed by the researcher. Questionnaire took approximately two minutes to complete.

3.4.2 Gross motor function measure

Gross Motor Function Classification System

As mentioned earlier, people with CP are classified according to the GMFCS. The GMFCS is based on self-initiated movement with emphasis on sitting and walking and is ordinal in nature. The GMFCS essentially classifies gross motor ability according to five levels. Distinctions between the five levels are clinically meaningful and based on functional limitations, the need for assistive technology, including mobility devices and quality on movement (which is not a main focus), (Palisano, et al., 1997).

In order to classify the severity of motor impairment in participants, the GMFCS will be used. This measure can be administered through observation or by asking participants a few questions. The GMFCS has good inter-rater reliability and content validity and is highly regarded classification system and is used as a standardised system to classify children with CP and used in research (Palisano, et al., 1997). Jahnsen, Aamodt, and Rosenbaum (2006) conducted a study in order to investigate the use of GMFCS in adult CP populations. Their study's results indicated interclass correlation coefficients of 0.93 and 0.95 (95% confidence level) and concluded that the GMFCS is a reliable instrument for describing gross motor function in adults with CP.

3.4.3 Psychological well-being measures

The Comprehensive Quality of Life Inventory (5th edition) (COMQOL –A5).

A measure which has shown validity in measuring anxiety, depression and subjective well-being is The Comprehensive Quality of Life Inventory (Cummins, 1997). According to the manual, quality of life is defined as "…both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Objective domains comprise culturally-

relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by their importance to the *individual*" (Cummins, 1997; p.6).

The COMGOL measures 7 domains, namely:

1. Material well-being
2. Health
3. Productivity
4. Intimacy
5. Safety
6. Place in community
7. Emotional well-being

These 7 domains are measured in 3 sections. Section 1 contains 21 items. Section 2 and 3 measure subjective quality of life. Section 2 investigates the 'importance' of the 7 domains. It is measured on a 5 point scale. Section 3 investigates 'satisfaction' across the 7 domains and is measured on a 7 point scale (Cummins, 1997).

Each domain produces an 'importance' score and 'satisfaction' score. These are then totalled. For purposes of this study 2 items were altered. The first item that was altered was one which asked where the participant lives and whether they own or rent. Because participants resided at the care centre participants and resided in hostels or the hospice (generally a room), they were given a score of 1. Another item asked participants to state their personal gross income before tax. This was altered to the average South African income. The vast majority of participants worked in the factory and received minimum wage and thus were given a low score, depending on the amount of hours they worked.

According to McAlinden and Oei (2006), the COMQOL has an overall Cronbach alpha of 0.85 and shows consistent concurrent, conducted a study in order to test the validation of the COMQOL and found this measure to show consistent concurrent, discriminant, predictive, and criterion-related validity. An overall Cronbach alpha of 0.85 was also determined (McAlinden & Oei, 2006).

The COMQOL has a specific test for those who have mental retardation, however it was decided to used the COMQOL – A5 as it was established that participants had below average to above average intelligence.

Major (ICD-10) Depression Inventory (MDI)

The MDI is widely used around the world and is based on ICD 10 and DSM-IVTR symptoms of depression. It is a self-report mood questionnaire which was developed by the World Health Organisation. This scale includes duration criteria, and intensity criteria which measure symptoms on a 6 point scale. This measurement has been established to be utilised for diagnostic purposes and research purposes (Rosenham, 1984). There are no reports of the MDI use in a CP population, however internal and external validity has been reported to be better than the Zung Self-rating scale in a sample of people with Parkinson's disease (Bech and Wermuth, 1998).

The Becks Anxiety Inventory (BAI)

The BAI was developed by Aaron T. Beck in order to serve as an instrument that would be reliable in discriminating between anxiety and depression. It is also know to be valid and reliable, easy to administer and used around the world (Hewitt & Norton, 1993).

The scale consists of 21 items that describe common symptoms of anxiety. Each item is scored on a 4 point scale and items are totalled in order to obtain a score (Hewitt & Noron, 1993).

To the knowledge of the researcher, the BAI has not been used in investigatation or research in adult CP populations. The BAI has however showed internal consistency (0.89) in investigation in older adults and is recommended for use in clinical and research settings in assessing anxiety (Morin, Landerville, Colecchi, McDonald, Stone, & Ling, 2004).

Rosenburg Self Esteem scale

This measure intends to measure self esteem. The higher the score, the higher the self esteem of a person. This measure has 10 items on a Likert Scale, with each item scored on a 4 point scale (Crandal, 1973).

In one study, where self esteem was investigated in Japanese Stroke Patients, the Cronbach coefficient alpha was found to be 0.77 (Junko, Kazunori, Katsuaki, Shigeko and Ayako, 2002). In another study, which measure psychological wellbeing in a sample of HIV-positive patients on antiretroviral treatment, found a Cronbach alpha of 0.86 for the Rosenburg Self Esteem scale (Radomsky & Salomon, 2002).

3.5 Methods of Analysis

Before analysis began on data collected it was important to establish the reliability of the psychological measures. Cronbach Coefficient alphas were calculated in order to establish reliability (Rosenthal & Rosnow, 1991). Reliability was tested in the MDI, BAI, RSE and COMQOL. It is important to investigate reliability for these measures as pervious psychometric information is not available.

Data to be utilised for analysis was cleaned and checked for inconsistencies by running frequency checks (Rosenthal & Rosnow, 1991). Incorrect inputs were corrected or made as missing depending on the ambiguity of data already inputted. SAS Enterprise Guide 3(9.1) was used to run analyzes.

The first analysis that was utilised was the Chi-squared Tests of Association. This type of analysis was used to establish the nature of the relationship between demographic variables, namely age, gender, years of residency (YOR), experience of motor deterioration (MD), and epilepsy and the level of gross motor function (Coolican, 2004).

Data was inputted into Microsoft Excel. Age and Years of residency were nomialised through categorisation, where age was categorised as 20-40 years, 40-50 years, and 50-60 years. Years of residency was categorised as 0-10 years, 10-30 years 30-40 years. Gross motor function was categorised into two groups, namely those who required device and those who did not. Chi-squared test of association was utilised in order to establish whether independent variables (age, gender and years of residency) were independent of each other or likely to impact on the study. Because these variables were categorised, certain information was lost.

Before further analysis could be conducted it was necessary to establish whether or not the data was suitable for parametric analysis. In order to perform parametric analyses we need to be able to reasonable assume random independent sampling, interval scale of measure for dependent variables, and normal distribution (Howell, 1997). Normality was established by assessing means and standard deviations, histograms, and in some instances the Kolmogorov-Smirnoff test of normality.

In order to answer the question pertaining to the relationship of psychological well-being and the level of gross motor function, Spearman's Correlation Coefficients were calculated (With the exception of BAI, where Pearson's Correlation Coefficient was used). This type of analysis indicated the direction and strength of the relationship between 2 variables. Fisher–z transformations was utilised to establish significance between relationships (Coolican, 2004).

In order to establish differences between the levels of gross motor function and psychological well-being, one sample t-test analysis was utilised to establish difference. T-tests provide difference between the sample means by an estimate of the standard error (Tredoux & Durrheim, 2002). Scatterthwaite or pooled variance was used depending on equality of variance and other criteria for parametric analysis.

3.6 Threats to validity

Certain factors affected the validity of the current study. One such factor was the sample size. Due to the small nature of the sample, certain statistical or types of analysis could not be utilised. In order to carry out analysis, certain variables had to be categorised which resulted in a loss of information.

A small sample also affected the generalisability of the results to other contexts and populations. This is further problematic with the use of a context specific sample (Rosenthal & Rosnow, 1996).

3.7 Ethical Considerations

This study was carried out on the premises of the centre for adults with CP, which was located in the greater Johannesburg area.

As mentioned before, this study was accepted by a higher committee and the external ethics committee.

Residents at the centre were given an information letter which stated the exact nature of the study and give contact details. Consent and confidentiality forms residents and their guardians will also be given. Each participant was informed that they could drop out of the study at any time and would not suffer any consequences if they did.

No participant directly benefited from this research.

In order to ensure confidentially, questionnaires that are filled out by participants did not contain any identifying information. Each completed questionnaire was placed in envelopes (each equal in appearance). A coding system was used to keep track of measures. All information will be destroyed once the research report is complete.

Results are given in a group form, not individually. A report was made available to the care centre. Summary reports were made available for any participant who wishes to have a copy.

Chapter 4: Results

In order to address the research questions, statistical analyses were carried out. Firstly, reliability was tested in instruments utilised. Statistical techniques, namely, chi-squared analysis, correlational analysis and t-tests (group differences) were utilised to answer questions 2 to 4.

4.1 Reliability of instruments

As noted earlier, there are no psychometric properties available on the use of the MDI, BAI, RSE and COMQOL in a population of CP adults therefore it was necessary to establish internal consistency reliability estimates using Cronbach Coefficient Alphas.

Table 2: Reliability of psychological tests

	Cronbach Coefficient Alpha	
	Raw Variables	Standardised Variables
MDI	0.778	.
BAI	0.755	.
RSE	0.769	.
COMQOL	0.999	0.999

Table 2. indicates that there was high level of internal consistency reliability for the MDI ($\alpha = 0.78$), BAI ($\alpha = 0.76$), RSE ($\alpha = 0.77$), and COMQOL ($\alpha = 0.99$).

4.2 Frequencies of demographic variables and independent variable

The sample size was 43 and because of effect size it was decided to categorize the demographic variables, namely, Age, Gender, YOR, MD and Epilepsy. As mentioned earlier the 5 levels of gross motor functioning were grouped into to 2 groups namely, 'Devices' and 'No Devices'. The frequencies for each group are summarized in the table below:

Table 3: Frequencies of demographic variables

AGE		YOR	No.	GENDER	No.	MD	No.	DEVICES	No.		No.
20-40 yrs		0-10 yrs	21	Male	24	MD	18	Dev	23		11
40-50 yrs		10-30 yrs	11	Female	19	No MD	25	No Dev	20		32
50-60 yrs		30-40 yrs	11								

4.3 Chi-squared analysis of demographic variables and motor functioning

In order to investigate the relationship between demographic variables, namely age, gender, YOR, MD, an epilepsy, with the independent variable, gross motor function, a series of Chi-squared Tests of Association (χ^2) were carried out (Coolican, 2004). Results are summarised on the table below.

Table 4: Chi-squared Tests of Association between demographic and independent variables

	Pearson's Chi-Square	Continuity Adjusted Chi-square	Phi Co-efficient
Age	2.324	-	0.233
Gender	3.051	2.071	0.267
YOR	3.048	-	0.266
MD	4.368	3.168	-0.319
Epilepsy	0.007	0.00	0.012

A χ^2 analysis of the difference between Devices and No Devices frequencies across Age was non significant, χ^2 (2, N=43) = 2.33, p = 0.31.

A χ^2 analysis of the difference between Devices and No Devices frequencies across Gender was non significant, χ^2 (1, N=43) = 3.05, p = 0.08.

A χ^2 analysis of the difference between Devices and No Devices frequencies across YOR was non significant, χ^2 (2, N=43) = 3.05, p = 0.22. This analysis was invalid as some levels of YOR were less than 5.

A χ^2 analysis of the difference between Devices and No Devices frequencies across Epilepsy was non significant, χ^2 (1, N=43) = 0.01, p = 0.94.

Results, as indicated in Table 4 show no significant relationships between demographic variables and gross motor function, which suggests that we can determine an influence of gross motor function of psychological well-being, independent of factors such as age, gender, YOR and Epilepsy. However, the experience of motor deterioration was significantly related to gross motor function.

A χ^2 analysis of the differences between Devices and No Devices frequencies across Motor Deterioration was significant, χ^2 (1, N=43) = 4.37, $p < .05$. 25% of participants who did not use devices to function (GMFCS levels 1 & 2) experienced no motor deterioration, whereas 57% of participants who used devices experienced no motor deterioration. 75% of participants who experienced motor deterioration did not use devices, whereas 44% of participants who did experience motor deterioration used devices. The effect size was medium where Cramer's V = 0.32. As a result, MD is likely to be an extraneous variable in this study (Rosnow & Rosenthal, 1996).

4.4 Normality of data

Certain assumptions need to be met in order to use parametric techniques of analysis. These assumptions include random independent sampling, at least interval scale of measure for dependent variables and homogeneity of variance and normally distribution (Coolican, 2004). It can be assumed that psychological measures are at least interval. In order to assess normality of distribution, histograms, analysis of means and standard deviations and Kolmogorov-Smirnov Tests of normality were used.

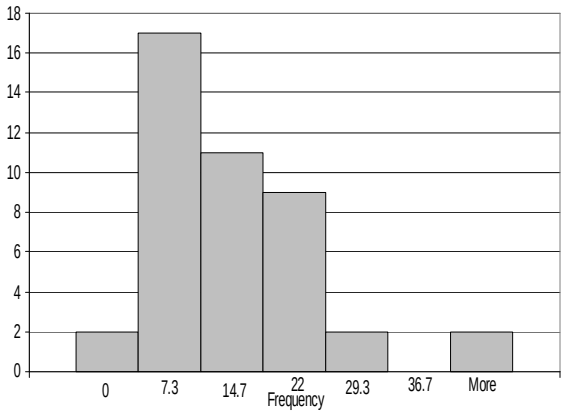

Figure 1: Histogram: MDI

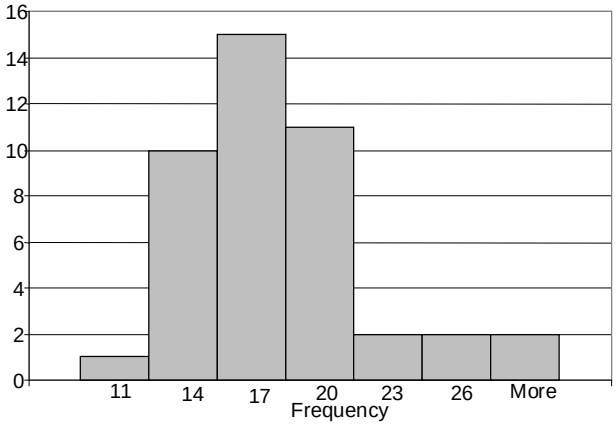

Figure 2: Histogram: BAI

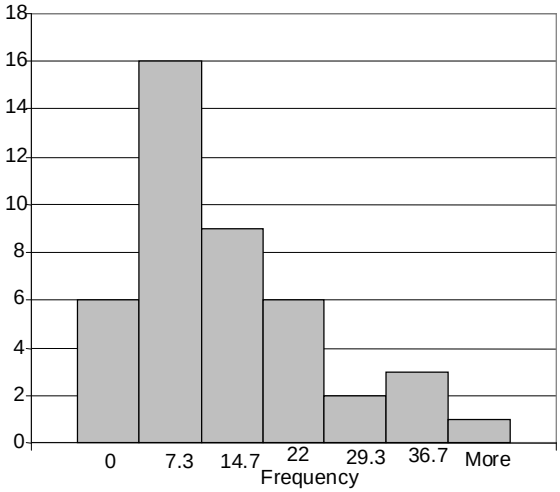

Figure 3: Histogram: RSE

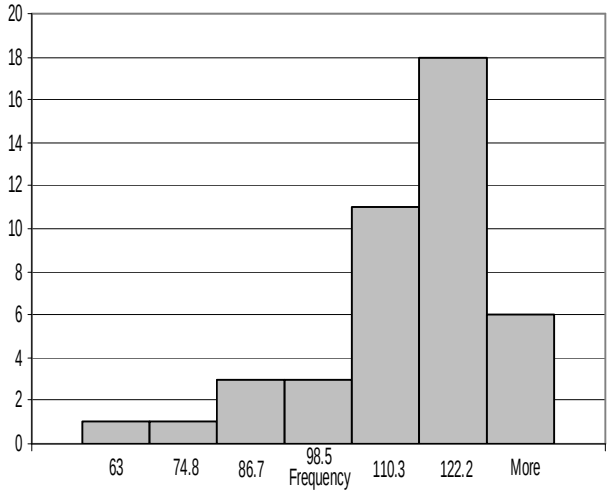

Figure 4: Histogram: COMQOL

On presentation of the histograms it appears that the MDI, BAI and the RSE are positively skewed, and the COMQOL is negatively skewed and therefore not normally distributed. This is confirmed on review of summary statistics in the tables below.

Table 5: Summary statistics for dependent variables

	MDI	BAI	RSE	COMQOL
Mean	10.63	10.6	17.3	108.51
Standard deviation	9.93	11.27	3.91	15.56
Median	8	7	17	113
Mode	1;5	0	14;16	113
Range	0-44	0-44	11-29	63-134

Summary statistics allow us to assess the average score differences in psychological well-being indicators as well as provide us with information regarding distribution and normality (Coolican, 2004). As indicated by the table and histogram it appears that MDI and BAI and significantly positively skewed whereas COMQOL only slightly negatively skewed. RSE on review on the table appears to be sufficiently normally distributed to allow for parametric analysis on the basis of an overall scores where the mean = 17.3 and the median = 17.

Kolmogorov-Smirnov Tests of normality were also carried out in order to further assess normality and are represented in the table below.

Table 6: Kolmogorov – Smirnov Tests of Normality for the tests

	Statistic D	p – Value
MDI	0.153	<0.010
BAI	0.173	<0.010
RSE	0.135	p = 0.046
COMQOL	0.211	<0.010

The results in the table indicate that only RSE is normally distributed (p = 0.135). On review of histograms and summary statistics it is decided that there is insufficient evidence to assumed normality with MDI, BAI and COMQOL, however there appears to be enough evidence to assume RSE is normally distributed.

4.5 Correlations of psychological well being and motor functioning

Before discussing relationships of variables, mean scores will be described in terms of what they represent according to their respective measure.

The mean Depression score was 10.63 (SD=9.93) which is in the very low range for this measure and indicates no depression or very mild depression. 7% of participants were diagnosed with depression, 2.3% with major depression and 4.6% with moderate depression. The mean Anxiety score was 10.6 (SD=11.27) which is in the very low range of anxiety, indicating mild anxiety. 14% of participants were diagnosed with severe anxiety, 12% with moderate anxiety and 21% with mild anxiety, based on BAI scores according to Beck and Steer (1993). The mean Self Esteem score was 17.3 (SD=3.91) which indicates moderate self esteem. The mean Quality of Life was 108.51 (SD=15.56). Within the COMQOL, the mean score for 'Importance' was 91.12 (SD=8.29) whereas the mean score for 'Satisfaction' was 82.7 (SD=13.73).

A correlational analysis was utilised to investigate the relationships between psychological wellbeing variables (Depression, Anxiety, Self Esteem and Quality of Life) and motor functioning (Devices/No Devices). Psychological wellbeing variables are interval in nature and motor functioning variable is ordinal in nature and therefore non parametric correlations will were used.

A Spearman's correlational analysis was used to investigate the relationship between psychological wellbeing variables and gross motor functioning. Gross motor functioning variable is ordinal in nature and therefore Spearman's is used instead of Pearson's (Coolican, 2004). Results are indicated in table below.

Table 7: Spearman Correlation Coefficients

	DEV/NO DEV
DEV/NO DEV	1.0000
MDI	-0.1149 p = 0.4631
BAI	0.1770 p =0.2561
RSE	0.0126 p = 0.9361 (Pearson's correlation coefficient)
COMQOL	0.0150 p = 0.9237

The Spearman and Pearson correlation coefficients between Depression scores, Anxiety scores, Self Esteem Scores and Quality of Life total scores, with Motor functioning were found to be non significant. The relationship also appears to be positive and very weak, with the exception of Depression having a negative relationship.

The Spearman correlation between Importance and Motor functioning was found to be non significant with r = -0.02, p = 0.88. The Spearman correlation between Satisfaction and Motor functioning was found to be non significant with r = 0.22, p = 0.14. The Spearman correlation was used to investigate the relationship between Importance and Satisfaction and was found to be significant with r = 0.80, $p < 0.0001$.

4.6 t-test analysis of differences between groups of gross motor functioning and psychological well being

In order to investigate the psychological wellbeing differences between the two groups, namely devices and no devices, a t-test analysis will be used. Depending on meeting criteria for equality of variance and normality, parametric and non parametric analysis was used.

Participants with devices had a mean depression score of 8.43 (SD=5.5) which was lower than participants with no devices who had a mean depression score of 13.15 (SD=13.06). The decrease was statistically non significant, t (24.8) = 1.5, p = 0.15, two tailed.
Depression scores did not have equality of variance and normality was not established; therefore non parametric t tests were used.

Parametric t-tests were utilised for the investigation of anxiety as well, although there was equality of variance (p= 0.064). The mean score of anxiety for participants with no devices was 10.15 (SD=13.61), which was slightly lower than the mean score of anxiety for participants with devices, which was 11 (SD=9). The decrease was statistically non significant, t (41) = -0.24, p = 0.81, two tailed.

Self Esteem scores were different in that the mean score for participants with no devices was 17.25 (SD=3.24), which was the same for the mean score of self esteem for participants with devices, which was 17.35 (SD = 4.5).

Results which were also statistically non significant was that of quality of life. The mean total score of quality of life for participants with no devices was 105.9 (SD = 21.06), which was slightly lower than the mean total score of quality of life for participants with devices, which was 110.78 (SD = 8.22). This decrease was statistically non significant, t (24) = -0.97, p = 0.34, two tailed. Non parametric analysis was used and there was no equality of variance.

When separating quality of life into satisfaction and importance it was found that the mean score for satisfaction for participants with no devices was 81 (SD= 18.31), which

was slightly lower than the mean score of satisfaction for participants with devices which was 84.17 (SD= 8.09). This decrease was statistically non significant, t (25.4) = -0.72, p = 0.46, two tailed. Non parametric analysis was used as there was no equality of variance. Similarly, the mean score for importance for participants with no devices was 88.95 (SD = 10.95), which was slightly lower than the mean score of importance for participants with devices, which was 93 (SD = 4.44). This decrease was statistically non significant, t (24.4) =-1.55, p = 0.13. Non parametric analysis was used as there was no equality of variance.

This chapter presented results of statistical analyses which were used to explore the research question. The next chapter will discuss these results in relation to their implications and relationship with literature in the field.

Chapter 5: Discussion

5.1 Discussion of results

The primary aim of the research was to assess the relationship between gross motor function in adults with CP and psychological well-being. Much has been generated in terms of medical and rehabilitative studies, however very little research has been undertaken in the investigation of psychological well-being in adults with CP. Adults with CP are prone to medical conditions, which may advance with age. Previous research has assumed that difficulties in fine and gross motor function leads to difficulties in normal functioning and thus leads to secondary problems of behaviour such as difficulties in learning and social interaction. These are further complicated through concomitant deficits in perception, mental retardation and or epilepsy (Rosenbaum, et al. 2007; Morris, 2007; Bobath, 1980; Ross and Deverell, 2004). It has been assumed that because a person may have difficulties in interaction such as communication, this may result in depression or anxiety, or other mood and psychiatric disorders (Beckung & Hagberg, 2002). Social participation has also been linked to level of motor functioning (Wiegerink, et al. 2006). A lack of social participation is thus assumed to create a sense of alienation and isolation and further become factors for depression, anxiety, self esteem and quality of life, whether this is the case, provides us with the main rationale for this study. Assessing whether different levels of gross motor functioning do in fact affect the

psychological well-being of adults with CP offers insight and implications to providers, health care professional and future interventions.

In attempting to answer this question, the study first assessed the reliability of psychological well-being instruments, namely the MDI (r=0.78), BAI (r=0.76), RSE (r=0.77) and COMQOL (r=0.99). These instruments were found to have high internal consistency reliability and thus suitable to be used on an adult with CP. Although the COMQOL scored very high for internal consistency reliability, this may suggest that the questionnaire asks too many equivalent questions (Rosnow & Rosenthal, 1998). By confirming reliability we can examine the relationship between demographic variables and gross motor function. This served to eliminate extraneous variables.

A series of chi-squared analyses was performed on demographic variables and gross motor function. It was found that age and gender did not relate to the level of gross motor function. However, the order to fully estimate whether age is a factor in the level of gross motor function, ones needs to perform a longitudinal study. Interestingly as well, the years of residency, as well as epilepsy did not relate to the level of gross motor function, yet a longitudinal study will again offer better insight as this is not the focus on the study.

One demographic variable which was related to the level of gross motor function is that of motor deterioration. Level 1 and 2 participants were combined to form a group that described adults with CP and did not use devices such as wheelchairs or walker to aid them in general gross motor functioning such as walking. Similarly, level 3, 4 and 5 were group into those who use devices. More participants with a better level of gross motor function were seen to experience motor deterioration (75%) compared to those with weaker levels of gross motor functioning (44%). Those people who function at level 1 and 2 are able to walk and run, but when compared to the average person, their ability and co-ordination is weaker (GMFCS). For this reason gross motor deterioration may be more significant for a more able bodied person in comparison to a person who uses a wheelchair. It be hypothesised that people who function at level 1 and 2 have better fine motor function and therefore the experience of motor deterioration may be more

significant for them. Although there were significant reports of motor deterioration, especially in more able bodied individuals, there were no differences in psychological well-being between the groups. This was unexpected given the theoretical understanding that as ones functioning lessens so does social participation and thus, according to the mental health model, makes one more prone to mental illness. This emphasises Ryan and Deci's (2001) criticism for hedonistic belief models such as those which psychology disorders are based on such as depression and anxiety. These disorders are based on the philosophy where there is an absence of positive mood and a presence of negative mood. However, as Ryan and Deci (2001) argue, a more multifaceted approach needs to be taken when investigating well being, and the presence.

As indicated by Wiegerink et al. (2006), psychological profile and physical functioning are 2 components of well-being, the third being environmental factors. These environmental factors may be the reason for general well-being seen in the CP sample. Participants from the study had access to facilities, performed in social activities organised by the centre and interacted with peers. These are environmental factors which affect well-being. A few environmental factors were present in the sample, in comparison to many personal and functional limitations. However, this suggests that well-being cannot be quantified in terms of meeting a number of factors or criteria. This critiques one school of thought in the hedonistic philosophy of happiness where it is believed that happiness can be quantified in terms of the intensity, duration and number of pleasure (Ryan & Deci, 2001).

In measuring psychological well-being, the MDI, DAI, RSE and COMQOL were used. Correlations and t-tests were used to investigate the relationship between psychological well-being and gross motor function and well as measure differences between the 2 groups of different functioning. In general, participants scored very low in depression (mean = 10.63) and low in anxiety (mean = 10.6). According to the Beck's Anxiety Inventory (Beck & Steer, 1993), low anxiety scores might possibly be unrealistic. It justifies this by saying that a person may be in denial or may "mask" their symptoms and could indicate that one is detached from themselves, others or their environment. It

should be noted that during data collection a few participants mentioned their dissatisfaction with their treatment by some of the staff at the centre. Others expressed their happiness with the staff and their dissatisfaction with the treatment from their family or lack of interest their family held towards them. A number of participants were also orphaned and had been residing in the care centre for up to 40 years.

Although overall there was a low an anxiety score, 47% of participants were diagnosed with mild to severe anxiety. According to a survey, based on the World Health Organization World Mental Health Survey, reports the lifetime prevalence of anxiety disorders to be 29% (Kessler, Berglund, Demler, Jin, Merikangas, Walters, 2005). In comparison, the studies participants had a much higher rate of diagnosed anxiety disorders. The Beck's Anxiety Inventory was found to be reliable and valid for the CP sample. It is important to note that difficulties arose with certain items, e.g. wobbliness in legs, numbness of tingling, hands trembling, shaky/unsteady. These items were often confused with symptoms of CP such as spasticity which highlights difficulty in distinguishing or separating between anxiety symptoms that are physical in nature, and motor impairment. This could also contribute for high rates of anxiety in participants. Reasons for heightened anxiety in participants may be due to feelings of restriction, as suggested by Balandin, et al. (2006). People in care centres may feel restricted to the 'outside' world, which could contribute to loneliness. With the additional factor of age, anxiety in adults with CP appears to be likely.

Depression score on the other hand were low, with only 7% of participants diagnosed with a depressive disorder. This in comparison with the DSM-IV-TR prevalence rate of depression (7% - 18%) is low average. Further, in the above mentioned survey, it was reported that the prevalence of mood disorders is 20.8%. In comparison, the participant's rate of depression is very low, although mood disorders include other diagnoses such as bipolar disorder. It is however interesting to note that in comparison to anxiety scores, depression is low which contradicts the general norm of both disorders comorbidity, which may suggest that the earlier comment on problematic questions in the BAI is valid. Thus, the BAI may not be a suitable questionnaire to use on CP sample.

And, although depression scores were low, self-esteem scores were moderate (mean = 17.3). Many participants appeared to be self accepting and confident with themselves and their abilities, whilst others felt they were useless or did not have much to be proud of. However, differences were non-significant. Miyahara and Piek (2006) assert that children and adolescents with minor physical disabilities perceived themselves as less competent than children or adolescents with more severe physical disabilities. This however was not replicated within the studies adult sample. Reasons for this may be explained by Erikson's theory. Children and adolescents resolve different developmental than adults. In childhood a difficult period for a chid with CP may be stage 3 of development, known as Initiative vs. Guilt, where children master locomotor and language skills. By mastering these skills, children expand their social participation and gain purpose (Sadock & Sadock, 2003). Children who do not resolve this stage are know to develop conversion disorder, inhibition, or phobias .In other who overcompensate, psychosomatic symptoms become an expression of their stress (Sadock & Sadock, 2003). For adults, specifically those aged between 21-40, the formation of intimate or close relationships, friendships and partnerships are important (Sadock & Sadock, 2003). In this sense it is important for adults with CP to form close relationships. By living in a care centre, it provides the opportunity to form these relationships and thus resolve the stage of Intimacy vs. Isolation.

A criticism of Miyahara and Piek (2006) is that they did not contextualise their study and provide information as to living arrangements in their sample. Therefore institutionalism appears to be a reappearing factor.

In terms of quality of life, participants scored highly in what they viewed as important and their satisfaction for material well-being, health, productivity, intimacy, safety, place in community and emotional well-being (COMQOL). Many participants view their health, safety, relationship with their family and friends, etc. as highly important and are generally satisfied. There was also a very strong positive significant relationship (r=0.8;

$p<0.0001$) between what participants viewed as importance and the satisfaction they have gained, and thus feel that certain needs have been met.

The sample for this study was obtained through a care centre. A care centre, which provides a workshop, which allows the opportunity for residents to make an income. The care centre also provides much in terms of stimulation, such as art classes, and art centre, sports etc. A few participants were involved in the Special Olympics, and were gold medallists. This may create an environment more conducive for mental health. It may be interesting, as stated earlier, to compare institutionalised people with CP with people who stay at home. It could be tentatively said that people with CP can benefit from being in a care centre or care centre as it has been established that the degree of disability in CP affects family satisfaction. Evans, Darah, Pain, Adkins and Kratochivil (2001) looked at how families cope with a family member with CP. Evans et. al. (2001) found that the degree of disability affected family satisfaction. Family relationships are affected and thus may negatively impact on the member with a disability.

The effects of epilepsy were also investigated to see if there were any significant differences. A significant difference was found in depression, where participants with epilepsy were more depressed than participants without epilepsy. Participants without epilepsy on average revealed no depression whereas participants with epilepsy revealed mild to moderate depression. Reports of whether or no epilepsy and depression are related are contentious. Nevertheless, Sadock and Sadock (2003) assert that other disorders such as schizophrenia are more often seen in people with epilepsy than mood disorders such as depression and mania and may be related to the specific are in the brain where epileptic foci affect i.e. the temporal lobe of non-dominant cerebral hemisphere. Although epilepsy was investigated as a factor that may influence well-being in adults with CP. It could be suggested that further research investigate sensory disabilities such as speech, visual and hearing impairments as an influence in the well-being.

5.2 Contribution to knowledge

The study has revealed findings which either confirm or deny previous research. It also attempted to investigate a previously unanswered area in CP, namely that of the relationship between gross motor function and psychological well-being, highlighting no significant relationship. The study also answered questions pertaining to the suitability of the MDI, BAI, RSE and COMQOL in a CP population. However so, there are flaws to the research which should be highlighted.

The sample for this study was also predominantly white, and since whites are a minority in South Africa, the sample is therefore not representative. The sample was also specialised and obtained through 1 care centre. The care centre provided many facilities and medical care to residence, however the care centre is a non-governmental organisation and therefore funds are limited. Not all residents have family members who pay for their stay, and their disability grant goes toward their care. Participants at the care centre were also residents who worked in the workshop and therefore received an income. Because of the specialised nature of the sample and its ungeneralisability, it raises questions about the authority of the findings (Rosnow & Rosenthal, 1996). Thus, one would question if a larger sample size would produce similar results.

It is also worth noting, that as a result of the small sample size, certain variables had to be nominalised and as a result led to the loss of information. With a larger sample size the statistical power could also have been improved (Coolican, 2004).

Although there are limitations to the study, it did however make positive contributions. Theoretically, because no relationship was found between psychological wellbeing and different levels of motor functioning it challenges the notion that a less functional person is more likely to have low social interaction and participation and as a result suffer emotionally or behaviourally. An explanation that could be offered is that people with CP are born with the condition and do not really know a different level of functioning although they are exposed to it by viewing other people functioning. Difference in attitude are seen in people with average gross motor function who, for example suffer a

stroke or are injured as a result of an accident. These injuries may lead to changes or loss in their level of functioning and as a result be more prone to psychological problems.

Literature has assumed that disabilities or disabilities in motor functioning, affects the psychological wellbeing of people. It is also assumed that the worse the level of functioning the more prone a person with CP may be to psychological distress. However the findings of this study suggest this is not the case and highlights resources people with CP have in coping with their disability.

5.3 Directions for future research

However inconclusive results from this study are, it has provided a basis for further research in the area. One are in need of further research is based on an earlier point on motor lose that is experienced by stroke or motor vehicle accident victims. This lose may also be experienced in people with CP who experience motor deterioration over long periods of time. A more comprehensive longitudinal study is needed to investigate the degree of gross motor deterioration and a possible decrease in psychological well-being.

An earlier noted limitation of an unrepresentative sample also highlighted areas of future investigation into cultural differences toward the treatment and care of people with CP. It would also be interesting to investigate the impact of CP on individuals and their families in rural or traditional communities and investigate cultural differences in stigmatisation and prejudice. The appropriateness of treatment or lack of care centre available to individuals with CP is also a serious issue which needs attention in South Africa.

Earlier, it was also noted that some participants felt they were treated well or poorly by staff at the care centre. It is therefore suggested that further qualitative investigation is undertaken in order to access fully any grievances that people with CP may have if they live in a care centre. It would also be interesting to compare this group with people who live at home.

5.4 Conclusion

Early discussion in the contested nature on definition and classification of cerebral palsy highlights the uncertain nature of CP. As a result, findings and conclusions of research are problematic as there is a need for union and especially a need for universally available and used instruments of measure. This study offers an initial exploration in to the area of gross motor function and psychological well-being. Although results are tentative and inconclusive, they are however interesting, thought provoking and challenging. Further research which utilises representative and larger sample in necessary in order to establish definite conclusions.

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Appendix A: Information letters

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School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg, South Africa
Tel: (011) 717-4524/5 Fax: (011) 717-4556
Email: johnstonc@umthombo.wits.ac.za

Dear Resident

My name is Monica Timmins, and I am conducting research for the purposes of obtaining a Masters degree at the University of the Witwatersrand. My area of focus is that of well-being in adults with Cerebral Palsy. I aim to explore the relationship of physical movement with psychological well-being. I would like to invite you to participate in this study.

Participation in this research will entail completing questionnaires. The questionnaires will take approximately an hour to complete. Participation is voluntary, and you will not be advantaged or disadvantaged in any way for choosing to complete or not complete the questionnaires. While questions are asked about your personal circumstances, no identifying information, such as your name or I.D. number, is asked for. Your completed questionnaires will not be seen by any person at Forest Farm at any time, and will only be processed by myself. Your answers to the questionnaires will be compared to all other answers obtained from other participants. This means that feedback that will be given to Forest Farm and will be in the form of group responses and not individual perceptions.

If you choose to participate in the study you can inform Jean or myself. You will then be given questionnaires and asked to complete as carefully and honestly as possible. Once you have answered the questions, place the questionnaires in the envelope provided. I will collect the questionnaires directly after answering. This will ensure that no one will have access to the completed questionnaires, and will ensure your confidentiality. Because there will be no identifying information on questionnaires, no one will be able to identify you. I will also keep names and information confidential and no one will be referred to by name in the research report or discussion of results. If you wish to participate in the study please sign attached consent form.

You may chose to stop your participation in the study at any time, without any disadvantage to you. You may also chose not to answer any question you do not want to answer. Should you feel you would like counselling as a result of the research please inform myself or Jean.
My cell phone number is 082 334 4481.

I will also provide a summary report of the study which you will be able to obtain from Jean.

Kind Regards

Monica Timmins

School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg, South Africa
Tel: (011) 717-4524/5 Fax: (011) 717-4556
Email: johnstonc@umthombo.wits.ac.za

Dear Parent/Guardian

My name is Monica Timmins, and I am conducting research for the purposes of obtaining a Masters degree at the University of the Witwatersrand. My area of focus is that of well-being in adults with Cerebral Palsy. I aim to explore the relationship of physical movement with psychological well-being. I would like to invite your son/daughter to participate in this study.

Participation in this research will entail completing questionnaires. The questionnaires will take approximately an hour to complete. Participation is voluntary, and your son/daughter will not be advantaged or disadvantaged in any way for choosing to complete or not complete the questionnaires. While questions are asked about personal circumstances, no identifying information, such as a name or I.D. number, is asked for. Completed questionnaires will not be seen by any person at Forest Farm at any time, and will only be processed by myself. Your answers to the questionnaires will be compared to all other answers obtained from other participants. This means that feedback that will be given to Forest Farm and will be in the form of group responses and not individual perceptions.

If you choose to allow your son/daughter to participate in the study you can inform Jean or myself. Because there will be no identifying information on questionnaires, no one will be able to identify your son/daughter. I will also keep names and information confidential and no one will be referred to by name in the research report or discussion of results. If you wish to allow your son/daughter to participate in the study please sign attached consent form.

Participation in the study may be stopped at any time, without any disadvantage to your son/daughter. Your son/daughter may also chose not to answer any question they do not want to answer. If you would like any other information my cell phone number is 082 334 4481.

I will also provide a summary report of the study which you will be able to obtain from Jean.

Kind Regards

Monica Timmins

Appendix B: Consent Forms

Subject Consent form

I _____ consent to participating in Monica Timmins's study on motor functioning in adults with Cerebral Palsy. I understand that:

- Participation in this study is voluntary.
- That I may refuse to answer any questions I would prefer not to.
- I may withdraw from the study at any time.
- No information that may identify me will be included in the research report, and my responses will remain confidential.

Signed _____

Date _____

Parent consent form

I _____ consent to allowing my son/daughter _____ to participate in Monica Timmins's study on motor functioning in adults with Cerebral Palsy. I understand that:

- Participation in this study is voluntary.
- That my son/daughter may refuse to answer any questions I would prefer not to.
- My son/daughter may withdraw from the study at any time.
- No information that may identify my son/daughter will be included in the research report, and responses will remain confidential.

Signed _____

Date _____

Appendix C: Demographic questionnaire

Demographic questionnaire **Code:**

Please do not provide your name on questionnaire

How old are you?

Are you male or female?

How long have you been at Forest Farm?

Have you experienced any motor deterioration? YES _____ NO_____

Appendix D: Ethical clearance letter

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Timmins

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER H070609**
PROJECT	The effects of motor function on psychological well-being in adults with cerebral palsy.
INVESTIGATORS	Miss MC Timmins
DEPARTMENT	School of Human and Community Development/Psychology
DATE CONSIDERED	07.06.15
DECISION OF THE COMMITTEE*	Approved unconditionally
NOTE:	

This ethical clearance is valid for 2 years and may be renewed upon application

DATE 07.06.29 **CHAIRPERSON** .....
(Professor M Vorster)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr K Greenop
School of Human and Community Development

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

This ethical clearance will expire on 1 February 2009

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix E: Faculty Permission Letter

Faculty of Humanities - Postgraduate

Private Bag 3, Wits 2050, South Africa • **Tel:** +27 11 717 4003/7 • **Fax:** +27 11 717 4037 • **E-mail:** Maropeng.maake@wits.ac.z
• **E-mail:** lushy.konar@wits.ac.za

Student Number: 0201095F

MS M TIMMINS
P O BOX 73184
FAIRLAND
2030

26 July 2007

Dear Ms Timmins

FULL CANDIDATURE FOR THE DEGREE OF MASTER OF ARTS BY COURSEWORK AND RESEARCH REPORT

I am pleased to be able to advise you that the readers of the Graduate Studies Committee have approved your proposal entitled "The effects of gross motor functioning on psychological well being in adults with cerebral palsy." and you have now been admitted to full candidature. I confirm that Dr K Greenop have been appointed your supervisor in the Department of Psychology.

The research report is normally submitted to the Faculty Office by 15 February, if you have started the beginning of the year, and for mid-year the deadline is 15 August. All students are required to RE-REGISTER at the beginning of each year.

You are required to submit 2 bound copies and 2 unbound copies (loose pages) of your research report to the Faculty Office. The 2 bound copies go to the examiners and are retained by them and the 2 unbound copies are eventually sent to Archives and to the Library.

Please note that should you miss the deadline of 15 February or 15 August you will be required to submit an application for extension of time and register for the research report extension. Any candidate who misses the deadline of 15 February will be charged fees for the research report extension.

I should be glad if you keep us informed of any changes of address during the year.

Yours sincerely

Maropeng Maake (Mr)
Postgraduate Division
Faculty of Humanities
Private Bag X3
Wits, 2050
Tel: +27 11 717 4008
Fax:+27 11 717 4037

Note to all MA and PhD candidates who intend graduating shortly: All ETD requirements are to be met at least 4 weeks prior to graduation

Appendix D: Permission Letter

FOREST FARM & FOREST HAVEN CENTRES

CEREBRAL PALSY RESIDENTIAL CENTRE

Authorised under the NONPROFIT ORGANISATION REGISTRATION ACT 71 OF 1997
Registration Number NPO 017-813
Affiliated to the National Association for Person with Cerebral Palsy

P O Box 68519, Bryanston, 2021 William Nicol Drive, Bryanston
Tel (011) **789-3008/3065** **Fax (011) 886-6015**

15th May 2007

Department of Psychology
University of Witwatersrand
Johannesburg

Dear Sirs

Monica Timmins – Masters in Research Psychology at the University of Witwatersrand

We hereby give permission for the above-named to conduct research at Forest Farm Centre as well as having access to interviewing our residents. We feel that her research on "the effects of motor deterioration on the psychological wellbeing in adults with cerebral palsy" will be a most worthwhile and fascinating topic.

If possible, we would appreciate a copy of Monica's thesis. We trust that her research will be carried out in a courteous, professional manner; maintaining the dignity and confidentiality of our residents.

Please advise should you require further information. We wish Monica well in her endeavours.

Kind regards

Jean Esterhuysen

Jean Esterhuysen
Social Worker