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The Relationship Between Severity of Cerebral Palsy in Children and the Levels of Stress Experienced by their Parents.

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A research report submitted to the Faculty of Health Sciences of the University of the Witwatersrand in partial fulfilment of the degree of Master of Science, Physiotherapy.

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Abstract

Parenting is inherently stressful at times and several studies have shown that being a caregiver of a child who is disabled is even more stressful. A number of studies have tried to identify demographic and psychosocial variables which are predictive of parenting stress levels. It is obvious from these studies that parenting stress is complex as there is no general consensus as to what the factors are which exacerbate or mediate parenting stress in caregivers of children who are disabled.

The aim of this study was therefore to assess the parenting stress levels of caregivers of children who are disabled and to try to establish whether the level of the child's disability influenced parenting stress levels. Further objectives were to ascertain whether various psychosocial and demographic variables were predictive of parenting stress levels.

In order to meet these objectives the Parenting Stress Index/Short Form was sent to caregivers of children with cerebral palsy who were attending Frances Voorweg School in Johannesburg. Caregivers also completed a demographic questionnaire. The severity of disability of the children was classified using the Gross Motor Function Classification System.

Thirty-five parenting stress questionnaires were returned to the researcher. Means and frequencies were used to summarise the demographic data. T-tests were performed to establish whether there was any significant difference between the parenting stress levels of caregivers of children who were more functionally disabled and those whose children were less disabled. Pearson's correlations were used to determine whether there was any correlation between demographic variables and parenting stress levels.

The parents of the children in the sample showed clinically significant, and in many cases, pathological levels of parenting stress. This stress was however, not in anyway influenced by the severity of their children's disabilities. The only variable that correlated strongly to the level of parenting stress was found to be the income level of the family (r=0.8).

The results of this study confirm that parenting stress is complex and that it is not a simple matter to predict the parenting stress levels of caregivers of disabled children. Therapists should evaluate the needs of each family individually and follow a family centred approach when managing children with cerebral palsy.

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Declaration

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

Signed this day in Johannesburg

Signature

Date

List of Abbreviations

ADL: Activities of daily living

CP: Cerebral Palsy

DC: Difficult Child

GMFCS: Gross Motor Function Classification System

PCDI: Parent Child Dysfunctional Interaction

PD: Parent Distress

PSI/SF: Parenting Stress Index/Short Form

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Chapter One

1. INTRODUCTION

Ongoing medical advances have resulted in the increased survival of very premature and “small for gestational age” babies, with a concomitant increase in the population of babies with cerebral palsy (Palisano et al. 1997).

The stresses and hardships faced by families with a disabled child are well documented (Hirose and Ueda, 1990; Jones-Jessop and Stein, 1991; Lambrenos et al, 1996; Law et al, 1998; Mc Conachie et al, 2000; Mc Cubbin, 1989; Mobarak et al, 2000; O’Neill et al, 2001; Ong et al, 1998; Viscardis 1998). These families are required to deal with an alteration in the family dynamic which requires a modification of their activities with the increased burden of caring for a child who cannot adequately care for itself. There is also considerable stress associated with their concern for their child’s future potential and prognosis. Added to this is the financial burden and the time constraints placed on them by the need for specialised equipment and compliance with medical regimens. The burden of child disability on the family, therefore, needs to be examined in an effort to identify and minimise the main causal factors.

Mc Conachie et al (2000) showed that certain interventions resulted inadvertently in an added emotional cost for the parents, for example when attempting to participate in distant services etc. They suggested that service providers need therefore, to consider both the potential negative and the positive effects of their intervention in order to minimise the stress experienced by the parents.

It is widely recognised that for any therapeutic intervention to be of benefit, there needs to be carry-over into the child’s everyday life. Tasks incorporated into a child’s daily activities provide excellent practise opportunities to find solutions to

functional motor challenges. This requires parental involvement and compliance with the intervention (Rosenbaum et al, 1998). Law et al (1998) found that " a child's motivation, family support and frequency of practise of a task " were the most frequent factors enabling performance. Research undertaken by O'Neill et al (2001) suggests that the success of any intervention relies on a positive, supportive relationship between members of the intervention team and the caregivers and therefore, that services that include the whole family may be more successful in effecting change in a cerebral palsy child's functional development. Viscardis (2001) agrees and states that: " treating a child without considering them within a family, risks the treatment becoming inflexible and inappropriate ". She conducted a study amongst parents of children with cerebral palsy and found that they wanted, and were more likely to comply with a system that was responsive to the families' needs. Identifying and acknowledging these needs increased the parents' confidence and made them more able to cope in their role as caregivers. Empowered parents were also better able to teach their disabled children to advocate for themselves and to take control of their own lives.

In response to these needs, there has been a move away from the traditional role of the therapist as the expert who sets the goals in therapy and more towards an approach that acknowledges the role of the family in the child's life. This family-centred approach encompasses a philosophy of care in which the pivotal role of the parent is respected in the lives of children with special needs, and in which the family's strengths, needs and hopes determine the service plan. The parents and the professional are seen as equal partners both committed to developing optimal quality health care (Rosenbaum et al, 1998; Jones-Jessop and Stein, 1991). Viscardis (2001) sees it as involving education, support and self-help approaches in addition to the usual direct services and as requiring that the service provider supports and encourages the parents thereby enhancing their competence as caregivers.

Therapists treating children with cerebral palsy need to acknowledge that there may be times when the parents may have different priorities to themselves. A therapist will never succeed for example, in establishing compliance with a home exercise programme when the parents' main concern is where the next meal is coming from. To achieve success in such a situation and really make a difference in a family's ability to cope effectively with their disabled child requires a greater knowledge of possible family stressors and coping strategies, so that we can focus our energies in the appropriate direction and provide more appropriate, consumer-driven services.

Mc Cubbin (1989) and O' Neill et al (2001) found a direct relationship between the level of parenting stress experienced and an increased burden of care or severity of cerebral palsy. Hirose and Ueda (1989), Jones-Jessop and Stein (1991), Law et al (1998), Mc Conachie et al (2000), Mc Cubbin (1989) and Ong et al (1998) have suggested that factors other than severity such as financial incompetence within the family or lack of a second parent with whom to share the emotional burden, play a greater role in determining the level of stress experienced by the parents.

Aim

This study aims to establish whether parenting stress levels of caregivers of children with cerebral palsy are influenced by the severity of the child's disability.

Study Objectives

The object of this study is to determine which factors are most predictive of stress in mothers of children with cerebral palsy attending Frances Vorwerg Cerebral Palsy School. Interventions aimed specifically at minimising those stressors may then be developed.

Chapter Two

2. Literature Review

In this chapter literature relating to parenting stress and childhood disability is discussed. The Parenting Stress Index /Short Form is described in more detail.

Articles were sourced for this review using Pubmed, CINAHL, PSYCHInfo, Pedro and Cochrane Collaboration searches. A hand search was also conducted in the Health Sciences Library of the University of the Witwatersrand. Key words used in searches included; childhood disability, cerebral palsy, parenting stress.

2.1 Parenting Stress

The concept of stress is an abstract one. There is no single agreed upon definition of stress in the literature. Pearson and Chan (1993) define stress as arising out of the relationship between the individual and his environment. They see it as a " product of the subjectively defined demands of a situation and the capacity of an individual or a group to respond to these demands" (Pearson et al).

Expanding upon this definition by making use of Abidin's construct, parenting stress results from an interaction between the child's and the parents' characteristics with stress being generated in the parent when their capacity to fulfil their parenting role is exceeded by the demands made on them by their child (Pearson and Chan,1993; Abidin et al,1992). Stated more simply, a parent experiences stress when they perceive their child's behaviour and needs as superseding the resources they have available to cope with these.

Deater-Deckard and Scarr (1996) and Ostberg and Hagekull (2001) showed that both major life events (such as serious illness, socio-economic concerns) and daily care-taking demands (such as feeding, sleeping and behavioural problems)

resulted in increased parenting stress. Many other child, family and parent-related variables (child temperament; caregiver's age, education level and marital status; family income and the presence of social support) have been postulated through the years as influencing the degree of parenting stress experienced and have been studied in a variety of study populations as possible predictors of parenting stress (Mobarak et al 2000; Ong et al 1998; Mc Cubbin 1989; Hirose and Ueda 1990; Sloper and Turner 1993; Deater-Deckard and Scarr 1996; Button et al 2000; Failla and Jones 1991; Ford-Gilboe 2000; Manuel et al 2003; Thyen et al 1999).

Whatever the causes, parenting stress is seen as a factor influencing parenting behaviour with greater parenting stress being linked in the literature to problems in parent and family functioning and poor parent-child interactions. (Ostberg and Hagekull 2000) It stands to reason that parents with higher levels of stress will be less able to nurture their children. These parents are likely to be less warm and responsive towards their children and to be more inconsistent and negative in their dealings with them. Such parenting may adversely affect the development of a child's self esteem and place them at risk for emotional, behavioural and developmental problems. (Schor et al; 2003)

2.2 Parenting Stress and Caring for a Child with Cerebral Palsy

There is no doubt that parenting a child (even one in perfect health) is a uniquely challenging experience that presents with certain inherent stresses. To date, a number of studies have supported the notion that the stresses associated with parenting a child with a handicap such as cerebral palsy, are even greater. (Pearson and Chan 1993; Brehaut et al 2004; O'Neill et al 2001; Mobarak et al 2000; Ong et al 1998; Mc Cubbin 1989; Cadman et al 1991; Esdaile and Greenwood 2003; Failla and Jones 1991; Dyson 1991; Thyen et al 1999)

Certain unique challenges face families who rear a disabled child. Failla et al (1991) divides these into three different categories. There are acute stressors which occur periodically as incidents related to the child's disability e.g. at the time of diagnosis or when the child is recommended to undergo a specific medical or surgical procedure. Secondly, there are stressors usually linked to certain developmental milestones occurring throughout the child's life when there is a discrepancy between normative expectations and actual events e.g. when the child starts or leaves school. These she labels transitional stressors. Lastly, there are the chronic stressors, which are ongoing and must be faced on a daily basis.

There is the increased burden of caring for a child with a disability. This tends to bring about an alteration in the family dynamic and often limits their choice of recreational activities as a family thereby influencing their sociability. The costs involved with sourcing medication, specialized equipment, housing modification and medical care for the child may also place a financial strain on the family. Adding to their financial vulnerability is the fact that the parent may be forced to limit his/her work hours to accommodate caring for the child and keeping medical appointments. Thyen et al (1999) points out that, as a result of limited access to specialized day-care centres, two-parent families are in fact often limited to a single income at a time when their expenses have escalated. Parents also spend time worrying over the child's prognosis and future potential. Added to this is their concern that their child be accepted by a hostile society that attaches stigmas to any form of disability (Mc Cubbin 1989; Failla and Jones 1991).

Thus it becomes evident, that such parents are exposed to a multitude of stressors over a long period of time. This must inevitably place them under a great deal of strain and put them at risk for developing maladaptive, dysfunctional coping patterns that could ultimately result in a negative outcome for the child. Cadman et al (1991), found contradictory evidence to suggest that many such families were able to rise above the challenges they were facing without

becoming dysfunctional. How these families manage to triumph has been of great interest to clinicians and researchers alike and a number of different factors have been postulated as offering a mediating influence on the degree of parenting stress experienced.

2.3 Stressors and Stress-Mediators

2.3.1 Severity of disability

Research to date on the relationship between the severity of a child's disability and the parenting stress experienced has shown conflicting results with some studies failing to find any association.

Button et al (2001) conducted a study amongst 64 Caucasian and African-American families raising children with cerebral palsy. They aimed to determine the relationship between maternal parenting stress and level of impairment in the child. Amongst their sample, mothers of children with greater degrees of impairment reported significantly higher parenting stress. They therefore, proposed that level of impairment was a statistically significant predictor of maternal stress levels amongst families caring for a child with cerebral palsy.

Ong et al (1998) suggested that maternal stress levels were related to increased care-giving demands rather than to the severity of the disability itself. His Malaysian sample did however include a predominance of quadriplegics (who by definition have full body involvement and tend towards greater disability) and it could therefore be argued to have lacked sufficient variance to establish any real relationship between severity and parenting stress levels. Children with severe disability also tend to be less independent with activities of daily living and are more likely to exhibit associated problems such as feeding difficulties, communication problems and seizure disorders than those children with less severe involvement. They would generally therefore, demand more care from the

parent. Extrapolating from this we see that Ong et al (1998) did in fact establish an indirect relationship between child severity and parental stress.

Sloper and Turner (1993) reported statistically significant differences between mother's and father's perceptions of stress. They found that fathers were less affected by the child's characteristics than were mothers. More severe disability in the child was associated with greater levels of parenting stress in mothers only. They postulated that this was because in the majority of cases, it was the mothers who acted as the main caregivers and it was therefore, the mothers who were required to deal with the greater day-to-day difficulties occasioned by the more severely disabled children. Esdaile et al (2003) continued this work on gender differences in the experience of parenting stress and its relationship to severity of the child's disability. Their results concur with those of Sloper et al (1993) and suggest that although parenting a child with a disability is associated with increased stress in both sexes, it is the mothers as primary caregivers who are most effected by the more severely disabled child.

Ostberg and Hagekull (2000) also showed a direct relationship between increased care-taking hassles or caregiver workload and parenting stress. They defined care-taking hassles as comprising things such as difficulties with feeding, irregular sleeping patterns and caring for a child with an infection. Their study was done on 1500 parents of *normal* Swedish children but it does suggest a link between parenting stress level and burden of care that is likely to be greater when parenting a disabled child.

Mobarak et al (2000) conducted a study of stress amongst mothers of cerebral palsied children in Bangladesh. They found that behavioural problems were the strongest predictors of maternal stress and stated that they had found no relationship between severity of the child's disability and their parent's stress level. A careful study of the outcome measure used to gauge behaviour shows that the behavioural scales that were often reported as problematic were those

resulting from a lack of independence in activities of daily living (ADL) such as sleep disturbance and issues with continence. It could be argued therefore, that the more disabled child who is likely to have the greatest functional impairment and to be the least independent with regard to ADL would present with a greater number of " behavioural problems" as described by the authors. It follows that, the parents of these children be expected to be more stressed, than their counterparts. However, Mobarak et al (2000) reported no such relationship between severity and parental stress.

Manuel et al (2003) studied a large population of American cerebral palsy children and their parents over a period of five years. They found, that the mothers of the less severe, higher functioning children experienced more distress than the mothers of more severe children when they perceived a lack of social support. They pointed out that the parents of higher functioning children with cerebral palsy may in fact share a heavier psychological burden than expected. They postulated that it was because these more mildly affected children tended to look more unaffected and to function at levels closer to their same age, healthy peers, their parents tended to harbour higher, more unrealistic expectations of them. Despite these interesting findings, when perceptions of social support were controlled for, they were unable to find any direct relationship between either disability severity or child's functional status and level of parenting stress. It should be pointed out however that the disability severity and the child's functional status were both taken from parent reports alone and were not backed up with clinical data. The sample also lacked a midrange level of functional ability and this may have limited the significant results for the sample. The ages of the children in the sample were also widely varied (one year to 17 years). Since parents caring for children at very different ages are faced with a completely different set of challenges and stresses, this could also have affected the results.

2.3.2 Primary caregiver's education level

Parent education level has also been reported in the literature to have an effect on their experience of stress when dealing with their children. Here too, the evidence has been contradictory. This could be explained by examining the weaknesses in the study methods used as well as the variation of sample populations.

Pearson and Chan (1993) undertook a randomised controlled trial amongst a large population of Chinese families each having a child with a mental handicap. They found a definite correlation between parent education level and parenting stress with the less educated mothers experiencing heightened parenting stress. It was presumed by the authors that a poorer education failed to equip these mothers with the coping skills required to deal with the added difficulties imposed on them by their child's handicap. Their study revealed further that parents with low education levels also tended towards low income and suggested that together, these two factors may have a multiplier effect on the degree of parenting stress experienced.

Ong et al (1998) also found the level of maternal education to be inversely related to the parenting stress experienced. They were more specific showing that lower education level was associated with an elevated parent domain subscale on Abidin's PSI proving that the lack of education was in some ways contributing to these parents' vulnerability when dealing with their child's handicap. They also confirmed the relationship between low education and low income. They noted that these mothers experienced less access to job opportunities outside the home and that this limited their financial resources. Their poor education, the authors postulated, also left them less equipped to access a variety of socio-educational and medical resources all of which might have alleviated the strain of caring for their handicapped children. They pointed out the particular relevance of this relationship to mothers living in developing

countries such as their own (Malaysia) where information on disability is often lacking because medical, educational and social services for the disabled are not provided for by legislation.

Ostberg and Hagekull (2000) attempted to develop a multidimensional model of predictors of parenting stress using a sample of Swedish mothers of normal children. They failed to confirm their hypothesis that a lower maternal education level would be directly connected with the experience of greater parenting stress. They did however, find that the older mothers experienced more stress and that they also tended to be less educated than the younger mothers providing evidence for an indirect link between a poorer maternal education-level and increased parenting stress.

Mobarak et al (2000) sought to determine predictors of parenting stress amongst his sample of mothers of cerebral palsied children in Bangladesh. In contradiction to the studies mentioned above, their study failed to show any relationship between maternal education-level and parenting stress. They stated that 38% of their sample had received no formal education at all and that it had been impossible for the researches to get written consent from their subjects who had a low level of literacy. The authors make no further distinction between the various education levels found amongst their sample other than to say that they had either some education, or none at all. This begs the question of how educated the educated amongst their sample really were and if there was sufficient variance amongst their sample to enable them to really make any reliable statements concerning the effects of education on the experience of parenting stress. One could argue a place for the examination of whether a higher level of formal education (tertiary) amongst these women, would better equip them to face the challenges of dealing with their disabled children.

Deater-Deckard and Scarr (1996) examined a large sample of Caucasian and African–Americans and found that greater parenting stress amongst their sample

was weakly associated with poorer education levels. The authors state that their sample parents were all highly educated having a mean of 16 years of formal education. They also allude to an inverse relationship between socio-economic status and parenting stress. It therefore, remains unsure if the increased stress exhibited by some parents was in fact a result of differences in income rather than being reflective of any real differences in education level. Once again the lack of variance in their sample makes it questionable that the study was capable of adequately recognising statistically significant relationships between these variables.

Whilst the literature does seem to provide evidence for an inverse relationship between parent education level and parenting stress, the question of the degree of education required by the parent to offer a protective effect, warrants further investigation.

2.3.3 Family income and employment status

As previously discussed, families caring for a child with a disability such as cerebral palsy, face an added financial burden. In an effort to motivate for altered government policies which pay more attention to social welfare issues and to develop more appropriate medical services for the disabled, researchers have undertaken extensive studies which look at the effects of lack of employment and low household income on parenting stress levels and child outcomes.

The Task Force on the Family was created in America in 2003. It was made up of six paediatricians who were required to make an in-depth study of child care in American families and then, on the basis of their findings, to formulate recommendations for paediatric practice, public policy, professional education and research (Schor et al, 2003).

They found that lack of employment and poverty were the most dominant social factors associated with poor parent and child outcomes. Poverty limited

opportunity and was associated with increased parenting stress. Poor American families were faced with huge financial barriers to appropriate health care. These families were also more likely to reside at greater distances from health care service centres, to have less access to efficient transportation and less latitude within their jobs to attend to their child's health care needs often being forced to seek after hour services which were more expensive. Limited access to appropriate day-care as well as a lack of employee benefits such as health insurance, sick leave and flexi-hours, often forced mothers of disabled children to quit their jobs placing further strain on the families financially. As a result of poverty, these families were faced with the stressful task of deciding which essential needs could be met on their limited budgets. Such stresses had taken a toll on these parents and had negatively impacted their child-rearing behaviours with consequent poor child outcomes (Schor et al, 2003).

Mobarak et al (2000) found that household income and land ownership amongst his sample of mothers in Bangladesh, were negatively correlated with parenting stress. Deater-Deckard and Scarr (1996) confirmed this association amongst their sample despite the fact that they all occupied the upper socio-economic bracket and were therefore, considered less likely to be predictive of a relationship between low income and stress.

Thyen et al (1999) conducted a randomised controlled trial looking at the effects of parenting a disabled child on maternal employment. They found much lower rates of employment amongst mothers of children with a chronic condition especially in the lower income households. These families had difficulties recruiting regular day-care for their children since not all centres were prepared to accept children with disabilities and so the mothers were often forced to forgo employment opportunities in favour of caring for their child. Thus families who were already faced with escalating expenses, as a result of their need to access specialised health care for their disabled child, were often faced with the added stress of losing income. Their study also suggested that in addition to the

negative financial impact on the family, her decision to quit employment had a deleterious effect on the mother's mental health and on her ability to care for her child. Employment amongst their sample mothers was associated with less depression, independent of their socio-economic status and child condition. They suggested that under stressful circumstances at home, the work environment was providing these women with a break from their domestic routine responsibilities and in this way equipped them to cope with caring for their disabled child (Thyen et al; 1999).

Sloper and Turner (1993) and Pearson and Chan (1993) concur that a lack of resources such as finances and transport, put parents at a greater risk for experiencing pathological levels of stress. They also agreed with Thyen et al (1999) that a mother's employment outside the home afforded her a degree of protection against parenting stress. Pearson and Chan (1993) suggested that working provides the mother with time away from the stresses associated with caring for her child and allows her to develop an identity separate from her mothering role, thereby improving her sense of self- esteem. It also serves to lessen the mother's social isolation and imposes a normal structure on her life into which the child can fit rather than allowing the child to become the unhealthy, predominant focus of her daily activities. This improved self image and experience of "normality" make her more able to cope with the difficulties of caring for her disabled child.

The Task Force on the Family (2003) found contradictory evidence to suggest that in certain cases, stress at work can in fact have adverse effects on the parent's health and undermine their esteem and emotional well-being and that these parents may in fact have children who develop less well. Many of the families studied, reported significant conflicts between their work and family obligations that resulted in increased stress. They felt that their jobs were consuming too much of their time and emotional energies leaving little over for the job of parenting. They pointed out that it was not just any employment that

offered stress relieving benefits for the mothers but that this work had to be gratifying in order to result in improved maternal self-image and more positive interactions in the home. The effects of maternal employment they saw as being dependent on multiple factors, including the mother's marital relationship and status, her access to assistance with child-care, her income and most importantly her satisfaction with her work (Schor et al, 2003).

The literature does seem therefore, to present us with proof of a negative relationship between household income and parenting stress amongst families caring for a child with a disability. The results of studies that failed to show any relationship, direct or indirect between income and parenting stress (Ostberg and Hagekull, 2000; Manuel et al, 2003) need to be regarded with some scepticism because of weaknesses in their sample selection. These studies were conducted, one amongst all very low earning and the other amongst all very high earning parents and, it can be argued that they were therefore ill equipped to recognise the effects of differences in earnings on parenting stress.

2.3.4 Carer's marital status and level of social support.

Researchers have, for many years, been interested in establishing whether any relationship exists between the degree of support enjoyed by a parent and the level of parenting stress they experience. In an attempt to begin answering this question, several researchers have undertaken studies comparing parenting stress levels amongst single and two-parent families (McKinney et al, 1987).

Early studies of two-parent families with handicapped children have found that spousal support plays a key role in assisting a parent with the challenges he/she must face when rearing a child with a disability (Mc Kinney et al 1987). Mc Cubbin (1989), found that single mothers had greater difficulty engaging their children in activities and were less likely to be optimistic about their child's future and the family situation than were married mothers. She postulated that it was

their lack of a supportive partner with whom to share the burdens of the child's daily care, personal concerns and issues around the management of family life that made them less able to cope with the task at hand. It should be noted that her sample population was largely Caucasian. Her findings could, therefore, not be extended to include other cultural groupings where mothers may tend to rely more on extended social networks for support e.g. the child's grandparents.

Hirose and Ueda (1990) and Sloper and Turner (1993) also acknowledged the supportive contribution of the spouse. Importantly, they recognised the spouse as providing both practical as well as emotional support and saw these as being an important resource which could be used by the parent to develop successful coping strategies to help them deal with the added stresses of raising a disabled child. They suggested that it was not just the presence of a spouse but rather the quality of the marital relationship that would be the greatest predictor of successful and less stressful parenting.

Deater-Deckard and Scarr (1996) took this further in their quest to explore the potential moderating effects of marital satisfaction on parenting stress amongst mothers and fathers. They also found the marital relationship to be the primary source of support amongst the parents in their sample and suggested that the more egalitarian division of the child-care chores in modern society has a beneficial stress relieving effect on parents. It should be noted however that although this may be so for contemporary fathers, their research never took into consideration any ethnic differences in attitudes towards parenting roles and as such cannot be generalised to the population at large. Regardless of this, they did go further to describe a more significant and direct relationship between the parents' perception of the degree of their spouses emotional support and decreased parenting stress. Amongst their sample parents, they found that marital dissatisfaction was not only strongly associated with increased parenting stress for both parents but that it also had a negative impact on the types of discipline employed and on the child outcomes. Their study subjects were

parents of normal children. These parents might experience qualitatively different stresses and coping strategies than those parents raising children with a disability and their findings can, therefore be less reliably generalised.

Ostberg and Hagekull (2000) also described the buffering effect of spousal support on parenting stress. They agreed that it was the quality of the spousal relationship itself, rather than simply the presence of a spouse that would determine the effect on the level of parenting stress experienced. Button et al (2001) stated that it was the mothers who took on the bulk of child-care activities and all the stresses involved in caring for a disabled child and saw them as being dependent on their significant other for both emotional support and practical assistance. Whilst the majority of their sample mothers reported a greater need for practical assistance than emotional support, the mothers of the more severely impaired children were interestingly, found to be *more* stressed by their spouses' involvement in child-care tasks. Such mothers experienced their partner's practical involvement in caring for their severely impaired child as stressful because it disrupted their already established care-giving routines. These families actually reported functioning better when the spouse was less involved with the direct care giving. Button et al (2001) regarded these contradictory findings as undermining their theory that partner support mediated the level of parenting stress experienced. This study looked exclusively at the effect of the spouse's practical support without ever really examining the potentially beneficial effects of having an interested party with whom to share the emotional burden of raising a disabled child. Their sample fathers were also, by definition, all very involved fathers and thus showed insufficient variance to actually pick up any significant relationship between spousal support and parenting stress.

In 1993, the American Association of Pediatrics (AAP) employed a group of specialists to undertake a study of American family life. This 'Task Force on the Family' reported increased parenting stress and poorer child outcomes in single parent families and concluded that "parenting is difficult and is easier shared"

(Schor et al, 2003). They found that happily married American men and women were physically and emotionally healthier and better equipped to cope with stress. Married parents enjoyed the help, support, encouragement and love of another committed parent and as such were better able to share the pressures of raising a disabled child. The results, in most cases, were better nurtured and adapted children. They also pointed out that being part of a couple increased the number of people and social institutions with which an individual had contact and as such they enjoyed greater social support. They, therefore, came to the conclusion that raising children was likely to be easier and more successful when done in a shared partnership but qualified this by noting that this would only be so if the parents developed complementary roles and there was a mutual agreement on division of responsibilities.

Ford-Gilboe (2000) studied the existing literature that seemed to suggest that two-parent families coped better with raising a child and with difficult life events than did single parent families. It seemed that a parent's knowledge of a significant other on whom to rely for the emotional and tangible support needed to manage health problems, made it easier for them to handle these difficult life events. Yet, despite all the evidence to the contrary, the study noted that there were still some very well adapted and functional single-parent families. She undertook a study that looked at 142 single and two-parent Canadian families. She was interested in identifying their strengths and in studying how these had assisted them to deal with stressful life events. With her interviews, she discovered fewer differences between single and two-parent families than she had first expected. Both identified emotional closeness and cohesion within the family as their greatest strength. Although the two-parent families did report a greater sense of security afforded them by having another parent with whom to share the physical and emotional burden of life stresses, the increased hardships faced by the single-parent families had the effect of drawing the family members closer into a more cohesive family unit. The study concluded that it was the quality of a family's patterns of interaction and relationships that was the most

important determinant of their ability to cope with life stresses. She described a "hardy family" as being one in which all the family members work together as a team and towards a shared goal with the confidence that they could overcome the problem together. Such cohesion within the family, she found allowed the families to maintain a sense of control over events and assisted in helping them to maintain a positive mental outlook, thus avoiding depression. Ford-Gilboe (2000) suggests that it is this emotional closeness that engenders a sense of security in the parent and allows them to persevere in the face of obstacles and life challenges. Her study put a crack in the traditional mould of the perfect two-parent family but because it was conducted amongst mostly Caucasian Canadian families, her results might not be indicative of the family situations within a multi-cultural society such as exists in South Africa where family values, beliefs, roles and relationships differ amongst different groupings.

Manuel et al (2003) conducted a study amongst 270 parents of children with Cerebral Palsy in North Carolina. They were interested in determining whether the child's functional status and disability severity could predict the mothers at risk for depressive symptoms. They found that parents of low functioning children, who perceived high levels of social support, were less depressed than those who reported lower levels of social support. They concluded that perceived social support moderated the relationship between the child's functional status and maternal depressive symptoms and therefore spoke of the protective effects of social support. Since their sample mothers were all married, social support referred to the mothers' access to individuals other than the spouse e.g. extended family, friends, health care professionals and to resources such as health and day-care facilities that she could use to assist her to overcome the difficulties arising from raising a disabled child.

2.3.5 Conclusion

An examination of the literature available does seem to suggest that the key to helping a parent cope with the added stress of raising a disabled child is that they

have support and do not feel isolated in their efforts. Researchers differ on the form of support needed but it seems obvious that the greater the mother's access to both practical assistance or resources as well as emotional support, the greater will be her readiness to cope with the stresses at hand and the more likely she is to raise a well adjusted and successfully integrated child.

2.4 Outcome Measures

Various tools are available to measure parenting stress levels and to assess the level of severity of disability in childhood. The two chosen for use in this study, namely The Parenting Stress Index/ Short Form and the Gross Motor Function Classification System will be described in detail.

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

The PSI was created by Abidin in 1985, as a screening and diagnostic assessment tool, designed to yield a measure of the relative magnitude of stress in the parent-child system. It is a 120 item, Likert type parent self-report questionnaire that recognises a wide range of potential influences on parenting practises. It comprises 54 parent-focused items, 47 child-focused items and also includes 19 items dealing with general life stressors.

The Parent Domain is divided into seven subscales namely depression, attachment, role restriction, sense of competence, social isolation, relationship with spouse and parental health. The Child Domain is made up of six subscales namely adaptability, acceptability, demandingness, mood, distractibility/hyperactivity and reinforces parent. Together these 13 subscales represent Abidin's conceptualisation of parenting stress (Abidin, 1995).

This model is a comprehensive one with proven reliability and validity but has been regarded by researchers and clinicians alike as too time-consuming to

administer and use for screening purposes (Reitman et al, 2002; Pearson and Chan, 1993).

2.4.1.1 Development of the PSI-SF from the PSI

To address the need for a psychometrically sound but briefer measure of parenting stress, Abidin developed the 36 item PSI-SF as a direct derivative of the full length PSI (Abidin R, 1995).

Castaldi et al (1990) undertook a series of replicated factor analyses of the full length PSI that suggested that the short form would capture the primary components of the parent-child system if it focused on three factors namely the parent, the child and their interactions. Item responses on the full length PSI were then subjected to a principal components factor analysis with varimax rotation and only items loaded 0.40 on a given factor were retained. The 12 items with the highest loading on each of the three factors were kept thus making up the 36 item, three factor PSI-SF. The three factors were labelled as the three subscales of the PSI-SF:

a) Parental Distress (PD). This was derived from the Parent Domain scales of the full length PSI and determines the stress a parent is experiencing in his/her role as parent as a function of personal factors directly related to parenting. It includes a variety of component stressors such as impaired sense of parenting competence, stresses caused by restrictions placed on other life roles, conflicts with the child's other parent, lack of social support and presence of depression.
b) Parent Child Dysfunctional Interaction (PCDI). This contains items from the acceptability, reinforces parent and attachment subscales of the PSI and indicates the extent to which the parent feels alienated from the child and gives an idea of the strength of the parent-child bond.
c) Difficult Child (DC). This contains items from the Child Domain of the full length PSI and focuses on some of the basic behavioural characteristics

of the child that makes them either difficult or easy to manage. These may include child temperament as well as learned patterns of defiant, non-compliant and demanding behaviours (Abidin, 1995; Yeh et al, 2001, Reitman et al 2002).

Adding the results of each subscale together then provides the researcher with the resultant total parenting stress score (PSI-SF total).

2.4.1.2 Scoring and Interpreting the PSI-SF.

The PSI-SF is most frequently used as a preliminary screening device for the early identification of parent-child systems, which are under stress and therefore at risk for the development of dysfunctional parenting behaviours or behaviour problems in the child involved.

As previously stated the PSI-SF consists of three subscales, PD, PCDI and DC. Within each subscale are 12 items or statements, which the subject is required to rate from 1(strongly disagree) to 5 (strongly agree). Adding the item scores for each subscale therefore results in a figure, which ranges between 12 and 60. By further adding the results of each subscale score, the researcher is provided with the resultant total parenting stress score (PSI-SF Total), which can range from 36 to 180.

The total stress score is an indication of the overall level of parenting stress an individual experiences in his/her role as a parent and doesn't take into account any other additional life stressors. High scores on the subscales and hence the PSI-SF Total score indicate greater levels of stress. Parents who obtain a raw score of 90 or above (at or above the 90^{th} percentile) are experiencing clinically significant levels of stress and it is recommended that they be referred for closer diagnostic studies and or professional assistance.

Closer scrutiny of the subscale scores, which make up the total score gives insight into the probable causes for the high stress levels and helps to direct the interventions appropriately. When the PD scale is most elevated, therapeutic services designed to improve the parents self esteem and level of adjustment should be the main focus. High scores on the PCDI subscale suggest that the parent-child bond is threatened or has never been established and that there is a risk of child abuse. Urgent referral is required. Parents who produce high scores on the DC subscale usually always require professional assistance. They are experiencing difficulty coping with their child either because his/her behaviour is bad or because he/she has certain physical attributes which make him/her difficult to care for, for example a physical disability. It is also possible for the parents to earn a total score within the normal range and yet have a single subscale score that falls within the danger zone. These parents may also benefit from help. (Abidin, 1995; Lloyd and Abidin, 1992)

An extremely low total stress score may also be related to dysfunction in the parent-child dyad. The PSI-SF includes a Defensive Responding scale, which assesses the extent to which the questionnaire is approached by the parent with a strong bias to portray him/herself in a favourable light thereby minimising any indication of stress in the parent-child relationship. A score of less than 10 on the defensive responding scale alerts the researcher to one of three possibilities. Either the parent is not being honest but is trying to portray the image of a highly competent parent who is free of the stresses normally associated with parenting or the parent isn't invested in the role of parenting and therefore doesn't experience the usual stresses associated with caring for the child. The third possibility is that the parent is in fact a very competent individual who is able to handle the responsibility of parenting well and who maintains good working relationships with his/her spouse and others. The Defensive Responding scale doesn't actually indicate which of these three possibilities is the correct one but rather it is designed to alert the researcher and when examined in relation to

other information about the parent it becomes possible to gauge the situation accurately.

2.4.1.3 Reliability and Validity:

The final descriptive statistics and normative ranges for the 36 items were produced, by combining the initial and the replicative samples used by Abidin to establish the reliability and validity of his research tool. He found (1995) that the total stress scores on the PSI correlated 0.94 with the PSI-SF totals, the PSI Parent Domain correlated 0.92 with the parental distress subscale on the PSI-SF and the PSI Child Domain 0.87 with the Difficult child subscale on the PSI-SF. Using items drawn from both the Parent Domain and the Child Domain of the PSI, a scale unique to the PSI-SF, PCDI yielded a 0.73 correlation with the Child Domain and a 0.50 correlation with the Parent Domain. He also reported adequate test-retest reliability and internal consistency reliability when his PSI-SF was tested on a sample of 800 subjects attending a group paediatric practise in Virginia.

Roggman et al (1994) reported an internal consistency of the PSI-SF and it's subscales comparable to the full scale when used in a head start, primarily Caucasian population. Reitman et al (2002) replicated this earlier research on scale consistency and factor structure of the PSI-SF in a sample of primarily low income, African-American mothers. They found that it retained it's desirable psychometric qualities i.e. high internal consistency and factor structure, even when subjected to tests in a population quite different from the standardisation sample and stated therefore, that clinicians and researchers working in low socio-economic status, non-Caucasian populations, could use the PSI-SF confidently.

Yeh et al (2001) recognising that the PSI-SF was developed for use amongst Caucasian and African-American populations in Europe and the USA, went on to

develop their own Chinese version of this PSI-SF, which could be used amongst Taiwanese parents of children with cancer. This Chinese version maintained a level of reliability and validity similar to the full scale PSI and proved useful as an assessment tool to identify parents in need of assistance within their sample.

2.4.1.4 Conclusion

Thus it appears as if the PSI-SF which derives directly from the original, full scale PSI also shares its validity and reliability and can be used by researchers and clinicians alike, on various population samples to identify stress within the parent-child dyad. (Abidin et al 1992; Roggman et al 1994; Yeh et al 2001; Reitman et al 2002)

2.4.2 Gross Motor Functional Classification System (GMFCS)

Most of the systems used to classify cerebral palsy such as those that classify on the basis of distribution of involvement, rely heavily on clinical judgement and are as such of questionable validity and reliability. Palisano et al (1997) recognised the need for the development of a generally accepted, standardized system of classification of severity of motor disability that could be used easily and reliably, in clinical and research settings.

They believed that an alternative approach that classified children with cerebral palsy on the basis of their abilities and limitations in gross motor function would improve communication between professionals and families and set out to develop the GMFCS.

2.4.2.1 Development of the GMFCS.

Palisano et al (1997) reviewed the existing classification systems and research on the development of children with cerebral palsy. They then examined the developmental records and videotapes of children with cerebral palsy who had been identified by therapists as having mild, moderate or severe involvement.

They also reviewed the data from 275 children on whom the Gross Motor Function Measure (GMFM) of Russell et al (1989) was administered twice over a period of 6 months and then entered into extensive discussions.

A study of the observations made on gross motor function collected by Russell et al (1989), during the development of their GMFM, showed that plots of GMFM total scores against age, produced curves that appeared statistically to differ depending on the degree of disability as described by the severity level ascribed to the child by their therapist. They therefore, deduced that a standardised and reliable classification system could be created that would have wide applicability.

By examining individual scores for items that represented common motor milestones in each of the five dimensions of the GMFM i.e. lying and rolling, sitting, crawling and kneeling, standing and walking and running and jumping, the authors proposed a five level classification system which they felt would represent clinically meaningful distinctions in motor function.

The GMFCS was thus produced as being suitable for use in children between the ages of two and 12 years. It allowed children to be classified into one of five levels based on self-initiated movement with an emphasis on their function in sitting (truncal control) and walking. Levels were differentiated based on functional limitations, the need for assistive technology including mobility devices (such as crutches, walkers or canes) and wheeled mobility and to a much lesser extent quality of movement.

To make the classification system quick and easy to use, brief descriptions were provided for each level as well as a summary of the distinction between each pair of levels. This meant that a child could be classified on the basis of observed or reported motor function without the researcher or clinician having to undertake a lengthy standardized assessment. The descriptions were broad and not meant to

assess in detail individual children's development but rather to determine which of the five levels most clearly resembled the child's gross motor function.

The title of each level was stated as representing the highest level of mobility that the child could be expected to achieve between the ages of six and 12 years. Palisano et al (1997) recognised that the classification of motor function is dependent on age especially during infancy and early childhood and as such provided separate descriptions for children in several age bands, for each level. These were intended to serve as guidelines rather than as norms.

They also stated that emphasis during classification should be on the child's ***normal*** function within the home, school and community environments and should not be based on his/her best capacity (Palisano et al, 1997).

2.4.2.2 Reliability and Validity.

Content validity was established using modified nominal processes and Delphi survey methods on 28 physiotherapists and occupational therapists from three treatment centres in Ontario as well as on professionals recognised as leaders in the field of developmental disability and the treatment of cerebral palsy from North America, Europe and Australia. The international group of experts were unanimous in their agreement that a need existed for a classification system for children with cerebral palsy based on the construct of disability and functional limitation. They indicated that such a classification system would help professionals to present information on a child's current functional abilities and assist families and professionals in planning for a child's needs, including the recommended use of assistive technology and other specialist interventions. Consensus agreement concerning descriptions of the levels and the distinctions between them as well as the age group of children to whom the system could be applied was reached after the second round of the Delphi survey (Palisano et al, 1997).

Inter-rater reliability was examined by comparing the ratings of children from five different treatment centres in Ontario, by two different therapists and then by calculating Kappa statistics as a measure of chance-corrected agreement. For children two years to 12 years the Kappa was 0.75 establishing moderate support for the overall reliability of the classification system (Palisano et al, 1997).

Certain of the therapists expressed concerns with applying the classification system and these were addressed in the "Introduction and User Instructions" guide that is distributed together with the GMFCS. The authors also recommend that professionals who work together classify the gross motor function of several children from their caseloads independently and then discuss the results before using the classification system in their clinical practice (Palisano et al, 1997).

2.4.2.3 Conclusion

Thus the GMFCS was established as a valid and reliable means of classifying the severity of children with motor disabilities. It has widespread implications because it has provided health professionals with a consistency in terminology previously lacking in the field and which assists in the dissemination of treatment outcome research.

Chapter Three

3. METHODS

In this chapter, the methodology used in this research report will be presented. Demographic information will be presented first, followed by information on the outcome measures and scoring system used.

3.1 Location

This study was conducted at Frances Vorwerg School for Learning and Physically Disabled Children. The school is situated in the south of Johannesburg and caters to a learner population of 330 children, 41% of these children are learning disabled while the remaining 59% percent have been classified by medical professionals as having a variety of physical disabilities, the commonest of these being the 102 cases of cerebral palsy. The school is one of only very few in Gauteng that caters to children with special needs and draws learners from a very wide range of socio-economic backgrounds. The learner population is also multi-cultural and multi-racial making it a good sample of the general South African population.

3.2 Ethical Clearance

Prior to commencement of this study, ethical clearance was applied for and obtained unconditionally from the Committee for Research on Human Subjects of the University of the Witwatersrand (Clearance Number:M03-05-69). (See Appendix A). A numerical code was used to preserve confidentiality and the parents were not required to write their names on the questionnaires.

3.3 Sample Selection

All parents of cerebral palsied children who were attending Frances Vorwerg School and were between the ages of six and 12 years were identified. They were given the information sheet and their participation in the study was requested. Those agreeing to take part in the study were required to sign consent.

3.4 Inclusion and Exclusion Criteria

3.4.1 Inclusion criteria

All subjects were parents and their children who were:

- Between the ages of six and 12 years.
- Diagnosed as having cerebral palsy by a paediatric neurologist.
- Attending Frances Vorwerg School.

3.4.2 Exclusion criteria

Children and their parents were excluded from the study if:

- The child was no longer domicile with at least one of his/her biological parents.
- The questionnaires were returned incomplete or if they were incorrectly filled out.

3.5 The Study Population

A total of 88 children and their parents were identified as fulfilling the inclusion criteria. Of these 35 (40%) signed consent and returned correctly completed questionnaires. It was not necessary to exclude any subjects from the study.

The children and their parents came from Soweto, Lenasia or one of several suburbs of southern or eastern Gauteng and as previously stated, were drawn from widely varying socio-economic groupings and educational backgrounds. The sample was also a multi-racial and multi-cultural one and as such beliefs about child rearing may have varied amongst the different groups represented. Sixteen (46%) of the families making up the sample were white and 15 (43%) were black with coloured and Indian families each representing a further 5 % respectively. Eighteen of the children were males while the remaining 17 were females.

The questionnaires were completed by the children's' primary caregivers these being their mothers, in the greater majority of cases. In only one family, the father fulfilled this function and thus completed the questionnaires, whilst in a further family the child's grandmother was responsible for the child rearing.

Frances Vorwerg School employs a multi-disciplinary team of professionals. This team includes fulltime physiotherapists, occupational and speech therapists, a nursing sister and psychologists. A consulting paediatric neurologist also visits the school fortnightly. All the children forming part of the sample were receiving at least one of the therapies at the time of the study and their families had received some form of support by the team either in the form of a home-visit and or a home programme of exercises and advice concerning the child's activities of daily living.

3.6 Pilot Study

The PSI-SF was developed for use amongst Caucasian and African-American populations in Europe and the USA. It has also been showed to offer good reliability when used on a variety of Chinese subjects (Yeh et al, 2001) and on the cross- cultural sample of Solis and Abidin (1991).

Reitman et al in 2002 felt that concerns existed concerning the applicability of the PSI-SF to lower socio-economic status and minority populations such as single mothers. By undertaking a study of the literature he noted that multiple factors (e.g. economic stress, poverty, depression) seemed to have an affect on a mother's perceptions of parenting and her child's behavioural problems. He felt therefore, that socio-economic differences in study populations would threaten the psychometric integrity of the PSI-SF. He undertook a study in which he made use of Abidin's PSI-SF in a sample of primarily low income, African-American mothers and found it retained it's high internal consistency and factor structure even when subjected to tests in a population quite different to Abidin's standardization sample.

It becomes evident nevertheless that we need to exercise caution when applying the PSI-SF to our South African population that is unique in it's multi-cultural, multi-lingual and multi-racial makeup. In an attempt to establish whether the PSI-SF and demographic questionnaires were indeed understandable and suitable for use in this research sample, they were piloted on a sample of six children and their parents. These children were all drawn from the same population as the research sample i.e. they were all between the ages of six and 12 years and were all attending Frances Vorwerg School. They differed from the research sample only in terms of their disabilities being classified as having a number of physical disabilities other than cerebral palsy. The parents were informed of the study and were required to sign consent if they agreed to participate. They were then handed a written package comprising the PSI-SF and a demographic

questionnaire and were asked to return the completed questionnaires in a sealed envelope to the physiotherapy department. A request was made that the parents include a written indication of any difficulties they may have had whilst interpreting and completing the questionnaires. All six of the questionnaires were returned within two weeks and had been correctly completed. None of the parents indicated having experienced difficulties with interpreting and completing the questionnaires. Since the pilot sample was highly representative of the research sample, this was interpreted by the researcher as an indication that questionnaires were suitable for use without any modifications, amongst this research population.

3.7 Outcome Measures and the Study Procedure

An examination of learner statistics and records allowed the identification of 88 children attending the school that met the study criteria. A numerical code was assigned to each of these children.

A parent of each child was then approached by one of the members of the therapeutic team and verbally informed about the study. They were at the same time supplied with a written package labelled with the corresponding number. The package included an information sheet describing the details of the study, a demographic questionnaire and a Parenting Stress Index- Short Form. The parents were asked to take these home to study and told that should they then agree to form part of the study, they would be required to sign their consent and to return the completed package in the sealed envelope supplied, to the physiotherapy department. The coding system was used to ensure that only the researcher would have access to the data thus preserving the parents' confidentiality. Written reminders were sent to the parents after two weeks and again to those who hadn't responded after two months.

The written package was provided in English only. The first language spoken by the parents making up the sample was very varied and included Afrikaans, English, Zulu, Sotho and Pedi. English is, however the medium of education used at the school and all parents taking part in the study were deemed to have an adequate comprehension of the written and spoken English language. They were also informed that should they experience any difficulty in interpreting the content of the questionnaires, they could seek clarification from the researcher who had employed the assistance of the African support staff to act as interpreters. This was in fact only necessary in a single case.

3.7.1 The Gross Motor Function Classification System (GMFCS)

The children whose parents had consented to take part in the research were then classified for severity, into 1 of the 5 levels of the Gross Motor Functional Classification Scale (GMFCS). (See Appendix B) The classification was developed by Palisano et al in 1997 as a standardized and validated means for classifying the severity of a motor disability and has been widely used for research purposes since then. Since it could be quickly administered and did not require full-scale assessments of each child, its use within a busy provincial setting like the school with its limited resources, could be justified. Classification was based on each child's self- initiated movement during function within the school environment and under normal circumstances. The distinction between levels was based on the children's functional limitations, their need for assistive technology and mobility devices and lastly, to a much lesser extent on their quality of movement. As suggested by Palisano et al (1997) who developed the measure, the classification was undertaken by the researcher and two of her expert colleagues (all who were familiar with the children and their disabilities) independently and the results were then discussed to ensure correct interpretation of the guidelines provided with the GMFCS and to further establish inter-rater reliability (Palisano et al, 1997).

3.7.2 The Parenting Stress Index – Short Form (PSI-SF)

The completed Parenting Stress Index- Short Form questionnaires were then scored and analysed as suggested in the manual (Abidin et al, 1995). (See Appendix C) A Defensive Responding score was calculated by summing the scores on items 1, 2, 3, 7 ,8, 9 and11. This was designed by Abidin et al in 1995 and was intended to assist the researcher when assessing the extent to which each parent when completing the index, was biased to present the most favourable impression of him/herself and to minimise stresses present in their relationship with their child. As suggested by Abidin et al, 1995 in the manual, scores of 10 or less on this scale alerted the researcher to regard the results gleaned from the index with some scepticism. Scores were calculated for each of the subscales of the index (PD, PCDI, DC) respectively, by summing the values scored for each of their 12 items. By adding these three subscale scores, a total parenting stress value (PSI-SF Total) could then be calculated for each respondent. Abidin et al (1995) suggested that scores above the 90^{th} percentile i.e. raw scores of above 90 for the PSI-SF Total, could be regarded as indicative of clinically significant stress within the parent-child dyad and as requiring professional intervention. All parents in the sample population who scored 90 or above were therefore, referred to one of the two psychologists at the school for more detailed analyses of the dynamics of their relationship with their child and for assistance in coping with their stress.

3.7.3 The Demographic Questionnaire

The demographic questionnaire (See Appendix D) was designed to give the researcher details regarding the sample families' makeup for example number of siblings, socio-economic status, educational levels of parent, as well as the

degree of support, both tangible and emotional experienced by each different caregiver whilst fulfilling their child-rearing task.

3.7.4 Statistical Analysis

Means and frequencies were used to summarise the demographic data. “t-tests” were used to ascertain whether any categorical variables were related to parenting stress. Pearson’s correlations were done to ascertain whether there was any correlation between demographic variables and levels of parenting stress.

Chapter Four

4. Results

In this chapter the results of this study are presented. The demographic information of the children and their caregiver are presented followed by the data on the relationship between parenting stress and the variables measured.

4.1 Subjects

Thirty-five children between the ages of six and twelve years (mean age of eight years and six months) and their primary caregivers participated in this study. All of the children had a diagnosis of cerebral palsy and were attending Frances Vorwerg School in Johannesburg. All children had some degree of associated learning disability. The majority of the children were day scholars with only 3 (8.6%) staying in the school hostel during the week and going home over weekends and school holidays.

The sample was a multi-racial, multi-cultural one. Sixteen (46%) of the families were Caucasian and 15 (43%) were black with coloured and Indian families each representing a further 5% respectively. Eighteen of the children were male and 17 female.

The sample included a mixture of all the different types of cerebral palsy. The children's diagnoses and mean ages are presented in table 4.1 below.

Table 4.1 Children's characteristics

Diagnosis	Number of Children	Mean Age
Quadriplegic	4	8 years 2 months
Diplegic	8	9 years
Hemiplegic	11	8 years 8 months
Dystonic/Athetoid/Ataxic	8	9 years
Mixed	4	7 years 6 months

The questionnaires were completed by the children's primary caregivers these being their mothers in the greatest majority of cases. There were two exceptions, one in which the father fulfilled this role and a second family in which the maternal grandmother acted as the child's main carer. The demographic information extracted from the carer's questionnaires is summarised in table 4.2.

Table 4.2 Demographic information on caregivers.

	Frequency	Percent
Marital status		
Married	26	74.3
Single/divorced	9	25.7
Educational level		
None	1	2.9
Primary	1	2.9
Junior high	7	20.0
Matriculation	20	57.1
Tertiary	6	17.1
Income		
< R1000	7	20.0
R1000- R2500	12	34.3
R2500-R5000	7	20.0
>R5000	9	25.7
Number of children		
1	6	17.1
2	14	40.0
3	8	22.9
4	4	11.4
5	2	5.7
6	1	2.9
Employed		
Yes	11	31.4
No	24	68.6

4.2 Severity of Disability and Parenting Stress

All the children in this study were assessed and the severity of their disability was determined using the GMFCS. A summary of the GMFCS classification of the children and the mean PSI total scores is presented in table 4.3.

Table 4.3 GMFCS Classification

GMFCS Level	Frequency	Percentage	PSI-Total
I	17	48.6	110.5 ±22.7
II	4	11.4	68.5 ±20.2
III	8	22.9	81.5 ±17.6
IV	3	8.6	108.0 ±5.7
V	3	8.6	47.5 ±26.4

Most of the children in the study (48.6%) were classified according to the GMFCS as being the less severe level 1's whilst only a small number of children fitted into the more severe levels 4 and 5 i.e. 8.6% respectively. This fact can be attributed to the schools admission criteria. The school caters to children with physical or learning disabilities who have been tested as having normal Intelligence Quotients (IQ's). Children with the more severe cerebral palsy, by definition, have more extensive cerebral damage. This damage causes greater degrees of physical involvement whilst also commonly affecting their cognitive functioning and hence their IQ levels and makes them less eligible for admission to the school. Thus most of the study population are the ambulant and less severe cerebral palsied with only six children with more severe disability being classified as meeting the study criteria.

The primary caregiver of each child completed the Parenting Stress Index/ Short form. Table 4.4 provides a summary of the means and standard deviations for the total parenting stress score and the subscale scores.

Table 4.4 Mean PSI/SF scores.

	Mean	Standard deviation
Total stress	85.1	± 22.8
Parental dysfunction	30.3	± 10.8
Parent child dysfunctional interaction	24.4	± 7.8
Difficult child	30.3	± 8.6

Table 4.4 shows that the primary caregivers who took part in this study exhibited high levels of total parenting stress. Their mean total parenting stress score was 85.1. This falls on the 85th centile according to the norms established by Palisano et al in 1997. Fifteen of the 35 caregivers taking part in the study (42.8%) achieved total parenting stress scores of greater than 90 and could thus be regarded as exhibiting clinically significant and pathological levels of stress. (Palisano et al, 1997) These parents were referred to the schools clinical psychologists for evaluation and assistance with managing their stress. The mean PCDI scale scores of the PSI-SF were also noted to be slightly lower than those of the other two scales.

Due to the small sample size the data for children with GMFCS classifications of I and II were combined (Group 1) and data for children with GMFCS classifications of III, IV and V were combined (Group 2), these two groups were then compared with respect to their parenting stress scores. Table 4.5 shows the total stress scores for Group 1 and Group 2.

Table 4.5 Total PSI/SF score for Group 1 and Group 2

	Mean	Standard deviation
Group 1 (n=21)	86.2	± 23.6
Group 2 (n=14)	83.4	± 22.2

The two groups had very similar parenting stress total scores and there was no significant difference between them (p=0.73). The severity of disability of the child therefore did not have a significant impact on parenting stress levels of the caregivers in this sample

Further analysis was conducted to determine whether any of the demographic variables had a significant impact on parenting stress levels and whether any trends could be noted. These results are presented in section 4.3.

4.3 Demographic Variables and Parenting Stress

Table 4.6 Demographic variables and parenting stress

	Mean PSI/SF Total	Standard deviation	p value
Marital status			
Married	84.2	± 21.6	p= 0.7
Single/ divorced	87.7	± 27.2	
Child in hostel			
Yes	93.3	± 17.2	p= 0.5
No	84.3	± 23.3	
Employed			
Yes	80.4	± 28.7	p= 0.4
No	87.3	± 19.9	

None of the categorical variables illustrated above had a significant effect on parenting stress.

The relationship between parenting stress and the continuous variables measured, namely education level of the caregiver, number of children in the household and the monthly income of the family were investigated using Pearson's correlations. The results are shown in table 4.7.

Table 4.7 Factors influencing parenting stress

	Mean PSI/SF total	Standard deviation	r value
Education level of caregiver			
None	85	-	
Primary	78	-	
Junior high	89.9	±19.0	r=0.04
Senior high	81.7	± 26.8	
Tertiary	92.2	±14.7	
Number of children			
1	80.8	± 21.9	
2	94.9	± 24.0	
3	79.0	± 9.8	r=0.06
4	63.0	± 27.4	
5	98.0	± 28.3	
6	85.0	-	
Income			
<R1000	97.0	± 16.1	
R1000- R2500	81.0	± 26.6	r=0.8
R2500-R50000	89.4	± 18.4	
>R5000	77.9	± 23.7	

There was no correlation between the number of children in the household and parenting stress (r= 0.06), nor between the educational level of the caregiver and parenting stress (r= 0.04). There was however a strong correlation between the monthly income of the family and the parenting stress level of the caregiver (r=0.8). The higher the level of income the lower the parenting stress levels were.

4.4 Conclusion

The results of the study showed that amongst the primary caregivers of children with cerebral palsy attending Frances Vorwerg School, the parenting stress levels as measured by Palisano et al's PSI-SF (1997) were high. The severity of the child's disability that was assessed using the GMFCS had no influence over the degree of parenting stress experienced. Neither was the carer's degree of parenting stress influenced in any way by their marital status, education level or the number of children in their household. Total family income was in fact the only demographic variable found to correlate strongly with the degree of parenting stress experienced there being an inverse relationship between parenting stress experienced and family income amongst this study population.

The implications of these findings as well as the limitations of this study will be discussed in chapter five.

Chapter five

5. Discussion

This chapter will focus on a discussion of the results obtained in this study. These results will be compared to those recorded in previous studies. The implications and limitations of this study will be highlighted and some clinical and research recommendations will be made.

5.1 Sample Profile

a. Race, Culture and Socio-economic Status:

The study was conducted amongst a sample of 35 parents and their disabled children attending Frances Vorwerg School in Southern Gauteng. The sample included all the racial and cultural groups and was fairly representative of the broader, urban South African population. The group belonged largely to the lower and middle working class groups.

b. Age and Sex:

Many of the studies cited in the literature review used samples with very wide age ranges. Manuel et al (2003) for example used subjects whose disabled children ranged between the ages of one and 17 years. The challenges faced by parents raising children at different ages can be very different and unique and it is thus arguably very difficult and unreliable to compare parenting stress amongst parents of children whose ages are vastly varied. This is even more apparent in parents raising children with disabilities. As Failla and Jones (1991) point out, there are periods of increased parenting stress associated with different phases of the child's life. The child's diagnosis as cerebral palsied which usually takes place at about one year of age is a particularly stressful time for the parents. As too are those times associated with various developmental milestones in the child's life such as when he/she reaches school going or school leaving age. Also worth noting is that in the absence of major feeding difficulties, the burden of

caring for a baby or toddler with cerebral palsy is in fact very similar to caring for a child of a similar age with no disability since both are completely dependent on the parent for all needs and as such there is less of a discrepancy between normative expectations and actual events. It was therefore decided to exclude the younger child from this study and to include only children between the ages of six and 12 years.

The mean age of the children in the two groups of this study were also very similar with the mean age for Group 1 being eight years four months and that for Group 2 being eight years and eight months. They would therefore, be expected to be experiencing similar stressful life events making it easier to compare the levels of parenting stress experienced by their primary carers. The two groups were also well matched for sex with 50% of Group 1 being male compared to the 44% of males in Group 2.

Some researchers have suggested a difference in the quality of stress experienced by fathers and mothers. Only a single father in the study sample was found to be acting as the child's primary caregiver. The mothers of the remaining 34 children were acting as their primary carers and as such had completed the PSI-SF and demographic questionnaires. The mean age of the carers in the two different groups was 31 years for both groups.

c. Severity Classification Using the GMFCS:

The children were first classified according to the GMFCS into one of five levels. The sample size of this study is however small (35) and in order to detect any statistically significant relationships between variables, it became necessary to reduce these levels further into two groups according to the degree of assistance required by the children when mobilising. All children classified as level one or two of Palisano et al's (1997) GMFCS are by definition unassisted, functional walkers and are by ages six to 12 years, largely independent with basic activities of daily living. These children were grouped together as Group 1. Palisano et al's

(1997) levels three, four or five comprise the more severely restricted children who are unable to mobilise without some form of assistive device and who are as a result much less independent with activities of daily living. These children were grouped together as Group 2.

5.2 Parenting Stress Levels and Carers of Children with Cerebral Palsy:

As expected, parenting stress levels amongst the primary caregivers of the cerebral palsy children studied were found to be generally high. The mean PSI-Total (85.1) fell on the 85th percentile while 42.6% of the study sample were identified as experiencing pathological levels of parenting stress with total scores of greater than 90. These results duplicate those of a small pilot study undertaken by Haniff et al in 2005 on a very similar study population. They compared the parenting stress levels amongst a group of parents whose children attended a Johannesburg crèche for able-bodied children to those of children with physical disabilities attending Hope School in Johannesburg. They found that the parents of children attending The Hope School achieved significantly higher total parenting stress scores (mean of 81 and falling on the 85th percentile) than did those whose children attended the creche (mean of 69.4 and falling on the 50th percentile). The findings of both of these studies therefore suggest that a similar situation exist in this South African urban setting to that cited in the literature and supports the notion that parenting a child with a disability is a uniquely stressful and challenging experience. As such, these parents are at a potentially very real risk for developing maladaptive, dysfunctional coping patterns to assist them in dealing with their disabled children certain of which have been shown in the literature to result in negative outcomes for their children (Ostberg et al, 2000; Schor et al, 2003).

More careful analysis of the PSI-SF subscale scores amongst the caregivers in the study sample however, showed that although the mean total parenting stress

was high, the scores for the PCDI subscale were proportionately lower (mean of 24.4) than those achieved on the other two subscales i.e. PD and DC (means of 30.3 respectively). This suggests that the parents' relationships with their children were well enough established so as to contribute to a lesser extent to their increased total parenting stress scores. The higher PD and DC subscale scores are more likely attributable to certain inherent traits in the parents themselves or characteristics of the children i.e. physical or behavioural, which make it more difficult for these parents to cope with the added stresses of caring for their disabled children.

5.2.1 The Relationship between Severity of The Child's Disability and the Degree of Parenting Stress Experienced.

The study findings duplicate the results of the Manuel et al study (2003) but in a South African urban setting. The severity of the children's disabilities was not found to be reliably predictive of the levels of parenting stress amongst their carers. As in the 2003 study there was a suggestion that the parents with children in the most severe level 5 category were in fact experiencing lower levels of stress (mean PSI-SF Total of 66) than those with less severely disabled children belonging to level one of the GMFCS (mean PSI-SF Total of 90.5). It is tempting to attribute this, as do Manuel et al (2003), to the fact that the least affected children, being closer in function to their able bodied peers, are more likely to evoke unrealistic expectations amongst their carers and to inadvertently cause stress when failing to meet these. It is important to note, however that the study only included three level five children and that when the PSI-SF totals for these three carers were added to those of the carers of children in the next most severe level four category (n=6) the mean PSI-SF Total for these two levels was 85.3 which is very comparable to those achieved by the parents with children in the least severe level 1 grouping.

A study of the PSI-SF Totals for the grouped levels (refer to Table 4.5) shows no statistical differences between the scores achieved by Group 1 as compared to those of Group 2. The severity of disability of the child did not seem to have a significant impact on parenting stress levels of the caregivers in the sample.

The comparatively small numbers of level IV and V children in the study sample should however be mentioned (n=6). It is interesting to note that 14 of the 37 parents i.e. 37.8% who were asked to take part in the study but failed to sign consent had children who could be classified as belonging to level V.One could speculate as to their reluctance to participate in the study. Could it not have been a function of extremely high parenting stress levels leaving them insufficient time and energy to even contemplate taking part in a study that required them to complete forms?

The small numbers of level IV and V children in the sample made it necessary for statistical purposes to include children from GMFCS levels III to those in levels IV and V to form Group 2. These children although they all do require assistance to mobilise either on foot or in a motorised device nevertheless, represent quite a broad spectrum of disability severities. Whilst the children in levels IV and V are almost or completely dependent on their carers for ADL, those in level III have a greater degree of independence with tasks though they may require some assistance with the more difficult ones. The inclusion of the level III children into Group 2 it could be argued might have “watered down” the groups severity making it difficult to pick up any significant differences in parenting stress levels between the two groups. This lack of variance in severity amongst the two groups in the study sample might very well have attributed to the studies failure to support the findings of other researchers in the field (Button et al 2001, Sloper and Turner 1993, Esdaile and Greenwood 2003) who all suggested a direct relationship between severity of childhood disability and parenting stress levels.

5.3 The Influence of the Parent's Education Level, Marital Status, and the Number of Children in the Household on Parenting Stress Levels.

The study failed to find any statistically significant relationship between any of a variety of variables (marital and employment status, education level) and parenting stress. Neither did it seem to be at all influenced by the number of children in the household.

5.3.1 Carer's Marital Status versus Parenting Stress

Contrary to the findings of Mc Cubbin et al (1989), Ostberg and Hagekull (2000), Schor et al (2003) and Ford-Gilboe (2000) whose results all seemed to suggest that parenting was easier and less stressful when shared with a supportive spouse, the single and the married carer's in this study sample were found to exhibit equally high parenting stress levels (refer to Table 4.6). It follows therefore that these carers' parenting stress levels seemed to be unaffected by their marital status.

The literature suggests that the key to helping a parent cope with the task at hand, is having a significant other to support them so that they feel less isolated in their efforts. It should be noted that this study looked solely at whether the parents were married or single. At no stage was any attempt made to qualify the status of the marital relationship in the married parents. Hirose et al (1990), was the first to acknowledge that it was not just the presence of a spouse with whom to share the burdens of the child's care, but the quality of the marital relationship that was the greatest predictor of successful and less stressful parenting. Deater-Deckard and Scarr (1996), took this even further by suggesting that it was in fact, the parent's perception of the degree of spousal support enjoyed that was directly related to the level of parenting stress they were experiencing. The "Task Force on the Family" reiterated that the presence of a spouse could only be expected to reduce the load of parenting if both parties enjoyed a mutually agreed upon division of responsibilities (Schor et al, 2003). Deater-Deckard and

Scarr (1996), went even further to suggest that marital dissatisfaction actually could increase the stress of parenting a child with a disability thereby influencing the types of discipline employed and negatively impacting on the child outcomes.

This study's failure to find any direct relationship between parents' marital status and the level of parenting stress they experienced may be attributable to one or more of three factors. Firstly, certain of the parents' marriages could have been strained such that the partner's presence was perceived as less of a support with the tasks of parenting. This study's failure to look at the primary carers' perceptions of their spousal relationship might very well have missed this and have skewed the results.

Secondly, the multi-cultural status of the sample might well have resulted in very different attitudes to the role of parenting amongst certain of the spouses than previously found in studies undertaken in first world, single culture populations. Deater-Deckard and Scarr (1996) points to the more egalitarian division of child care chores in modern societies, as offering the primary carer with practical support and as such having a "stress relieving" effect on the parenting task. In this more third world study sample, however beliefs surrounding parenting roles might not always allow for an equal division of labour with child caring tasks. In a more patriarchal household where child-care is regarded as being a woman's role, being married is unlikely to lead to increased practical assistance for the mother. In such situations the mother's first choice of support, both practical and emotional might very well be her extended family e.g. the child's grandparents, rather than her spouse.

Thirdly, as suggested by Ford-Gilboe et al (2000), the single parent families in this study might very well have been particularly "hardy" ones with well developed extended social support structures to enable them to cope independently with the added burdens of caring for their disabled children.

5.3.2 Carer's Education Level versus Parenting Stress

No statistically significant relationship could be found amongst the sample studied between the degree to which a parent is educated and their level of parenting stress. Contrary to the work of Pearson and Chan (1993), Ong et al (1998) and Deater-Deckard and Scarr (1996) which seems to suggest that less educated mother's experience heightened stress because of their resultant limited ability to access certain socio-economic and medical resources, this study found no differences in the degree of parenting stress experienced by the least and the most educated of the carers.

More careful study of the sample shows that the greatest majority of the study sample (77.1%) had some secondary education. There were very few parents however, at the extremes of the education scale. Five point eight percent had received either no or little (primary) education whilst only 17.1% had received some form of tertiary training. It could be argued that as in Mobarak et al's (2000) Bangladesh sample which also failed to prove any correlation between parenting stress and education level, this sample lacked sufficient variance in education levels to pick up any significant relationship between the two variables. Just how much education is required to provide the parents with adequate coping skills to have a beneficially stress reducing effect is yet to be studied. It is distinctly possible that the large majority of the sample parents studied, although not highly educated, did have sufficient training to allow them to access assistance and by doing so to lighten their loads.

5.3.3 Carer's Employment Status versus Parenting Stress

Contrary to the findings of Schor et al (2003), Thyen et al (1999), Sloper and Turner (1993), Pearson and Chan (1993), the findings of this study failed to confirm any relationship between the parents' employment status and their level of parenting stress.

Only one of the single mothers in the sample reported being unemployed and relying on a disability grant as the family's only form of income. All but two of the other unemployed carers had a spouse with an income on whom they could rely. As a result, the household incomes for this group of parents were very similar to those of the single working parents. If as suggested by the above researchers, there is indeed a causative relationship between unemployment, increased financial burden and increased parenting stress, then this might very well explain the lack of correlation between employment status and parenting stress amongst the sample studied.

Thyen et al (1999), Sloper and Turner (1993) and Pearson and Chan (1993) suggest that employment offers the parents benefits other than the more obvious financial ones. They suggest a positive psychological and stress-reducing benefit for the mother from having a different and more normal focus to distract her from the constant concerns of caring for her disabled child. This was not confirmed by the results of is study. No effort was however made to determine the carer's degree of satisfaction in the workplace. Parents who perceive their jobs not gratifying and demanding that they spend too much time away from their families it has been suggested, might in fact be even more stressed than those parents who find themselves unemployed (Schor et al, 2003). The study might have failed to pick up any correlation between these two variables because it never looked more qualitatively at the parent's degree of satisfaction in the workplace.

5.3.4 Protection of Higher Income Against Parenting Stress

Household income was the only one of all the demographical variables studied to show a strong and statistically significant relationship to the carer's level of parenting stress. These findings concur with those of other researchers in the field (Schor et al, 2003; Mobarak et al, 2000; Deater-Deckard and Scarr, 1996) and suggest that poverty is the dominant factor affecting the degree of parenting stress experienced by a carer. The sample included parents from very varied

socio-economic backgrounds although the majority of parents were low to mid income earners. Parenting stress was definitely less in the households with the higher incomes. These higher earners generally had their own transport and experienced less financial barriers to accessing the appropriate health care for their children.

Caring for a child with a disability is expensive. Disabled children have bigger needs for specialised schooling, equipment and medical care. It stands to reason then that for those higher earning parents, accessing such care will be more easily and successfully accomplished. Parents whose financial resources are limited are more likely to have to face the stressful challenge of deciding which of the families needs must take priority.

5.4 Implications of the Study Findings for Clinical Practice

Parental participation in and compliance with home programmes is vital to ensure carry-over into the home environment thereby making therapy successful. Whilst parental participation in therapy programmes is accepted as having beneficial effects on child-related outcomes, therapists need to consider the effects of such participation on the parents themselves.

Saloojee (2005), points out that parental involvement in therapy programmes can impose an additional stress factor on parents who are already stressed by the demands of caring for their disabled children and as such may in fact have negative consequences for these parents. The family may experience the therapy itself as stressful because it forces them to focus on the child with the disability to the exclusion of their other problems. It may also have financial implications on the family. Parents who are without adequate income for transport may very likely have difficulty accessing therapy services. It may also be very difficult for them to raise the funds required for orthotics and other necessary specialised equipment. Their need to prioritise the families basic

needs over their disabled child's medical needs must surely be enormously stressful for any parent and also associated with feelings of guilt. Such guilt can very easily and unwittingly be nurtured by over enthusiastic but well-meaning therapists. These concerns become even more relevant when considering the results of the present study. These suggest that, in parents whose disabled children are attending Frances Vorwerg School, household income is likely the only reliable predictor of the level of parenting stress they are likely to experience.

Rather than simply adding one more demand to the load of an already overburdened parent, the therapist needs to work on developing ways of enhancing the quality of the interaction between parent and child whilst remaining constantly aware of the constraints offered by their financial situation. For therapy to succeed in South Africa, it is clearly necessary for the therapist to adopt a stronger family-centred approach that takes into account the cultural diversity in parenting styles and other environmental and economic factors.

Therapy in poorer families can only be appropriate if therapists understand the broader context in which it takes place and make an effort to address the underlying issues of real concern to the caregivers. Treatment goals need to be developed in a non-judgemental and collaborative fashion whilst always remembering that the parent's priorities may very well differ vastly from those of the therapist. Compliance with and success of therapy is limited to a greater extent by what the families are able to cope with than by the child's actual potential to achieve under ideal circumstances. The therapist who bases his/her treatment plan purely on theoretical possibilities sets him/herself up for failure

This study highlights the importance of planning cost effective treatments for therapists working amongst poorer communities. Making more home visits instead of requiring parents to travel to centre-based services may reduce transport costs whilst also allowing the therapist to observe the child in his/her

natural setting. Teaching parents how to make their own simplified equipment from scrap e.g. corner seats and standing frames from paper mache is also more cost effective. Therapists may also reduce the need for expensive equipment during their therapy by educating parents about the importance of positioning their child correctly for ADL's, by teaching them basic stretching techniques and handling skills and by keeping the treatments as simple as possible.

The study results also show that contrary to expectations, the level of parenting stress experienced by the sample carer's is not influenced to any significant degree by the severity of the child's disability but is instead more dependant on economics. A therapist working with this population of children would therefore be misusing her resources if she focused more time and attention on assisting the parents of only the most severe children. Most importantly, the research highlights the uniqueness and complexity of each family's situation and the importance therefore, of developing specialised therapy programmes for each child considering their differing needs within the context of their family.

5.5 Limitations of this study and suggestions for future research.

The results of this study are of value because they highlight poverty as a major factor increasing parenting stress levels amongst the carer's of disabled children attending Frances Vorwerg School. By so doing, therapists working in similar settings are alerted to the importance of altering the focus of their therapy to accommodate for each specific families economic situation and needs. In poorer families, therapy needs to be cost effective in order to produce the desired results whilst at the same time keeping the parenting stress experienced to a minimum.

a) Limitations

- the relatively small sample size, which makes the results less easily generalised and specific only to the study population. The size of the

sample also made accurate and meaningful statistical analyses difficult. It proved necessary to combine the five levels of the GMFCS into two different groupings. Insufficient numbers of the more severely disabled children (GMFCS level four and five) necessitated the addition of the more moderate (Level three) children to Group two to make two similarly sized groupings. As a result the two groups appear less dissimilar in severity on paper than they actually are. This sample thus displays an insufficient degree of variance between the two groupings, which might have influenced the findings.

- The fact that it is purely quantitative and fails to look more deeply or qualitatively into certain of the parents demographics e.g. satisfaction with marital relationships and degree of gratification derived by the parent from being employed.

b) Recommendations for future research.

*Qualitative studies that look more closely at the family dynamics of disabled children may yield interesting results. Such studies may provide more useful information for therapists who strive towards following a more family-centred approach.

*The South African situation with its multi-cultural population is a unique one. Larger scale studies with bigger sample sizes are needed amongst this population. Such studies will allow South African therapists to identify significant relationships between study variables more reliably. It might also be interesting to examine whether any variables act as modifiers thereby reducing the levels of parenting stress experienced.

Chapter Six

6. Conclusions

The study was undertaken to determine the presence of any relationship between the severity of a child's disability and the level of parenting stress experienced by the primary carer. It was further aimed at identifying additional demographic stressors which need to be taken into account by therapists when attempting to develop more effective and appropriate treatment strategies.

The results of the study allow the following conclusions to be drawn:

1. The parenting stress levels (measured using the PSI-SF) amongst parents with cerebral palsied children who attend Frances Vorwerg School are generally very high.
2. The level of parenting stress experienced by the primary carers of these children is in no statistically significant way influenced by the severity of the children's disabilities (as determined by the GMFCS).
3. Household income is the only one of a group of demographic variables that could be strongly linked to the level of parenting stress in the carer with the most stressed parents being those with the lowest incomes.

It is unclear how some single and two-parent families of children with disabilities manage to maintain healthy levels of parenting stress despite the increased demands placed on them whilst in others, parenting stress levels increase to pathological levels. Certain families seem to display an intrinsic "hardiness" which helps them to manage their stress more successfully than others. There is thus a need for therapists working in this field to undertake a careful assessment of each family's different merits and adjust their treatment accordingly. This will be most successfully accomplished by adopting a family-centred approach to therapy.

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Appendix A

Ethical clearance

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

COMMITTEE FOR RESEARCH ON HUMAN SUBJECTS (MEDICAL)
Ref: R14/49 Pugin

CLEARANCE CERTIFICATE **PROTOCOL NUMBER** M03-05-69

PROJECT The Relationship Between Functional Abilities of Cerebral Palsy Children and the Levels of Stress Experienced by their Parents

INVESTIGATORS Miss AJ Pugin

DEPARTMENT School of Therapeutic Sci, Wits Medical School

DATE CONSIDERED 03-05-30

DECISION OF THE COMMITTEE Approved unconditionally

Unless otherwise specified the ethical clearance is valid for 5 years but may be renewed upon application
This ethical clearance will expire on 1 January 2008.

DATE 03-07-08 CHAIRMAN 25/7/03
.....(Professor P E Cleaton-Jones)

* Guidelines for written "informed consent" attached where applicable.

c c Supervisor: J Potterton
Dept of School of Therapeutic Sci, Wits Medical School
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DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10001, 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 form. I/we agree to inform the Committee once the study is completed.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B

Gross Motor Function Classification System

Gross Motor Function Classification System

Level I
Walks without restrictions; limitations in more advanced gross motor skills.

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

From age 2 to 4th birthday: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

From age 4 to 6th birthday: Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

From age 6 to 12th birthday: Children walk indoors and outdoors, and climb stairs without limitations. Children perform gross motor skills including running and jumping but speed, balance, and coordination are reduced.

Level II
Walks without assistive devices; limitations walking outdoors and in the community.

Before 2nd birthday: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

From age 2 to 4th birthday: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

From age 4 to 6th birthday: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

From age 6 to 12th birthday: Children walk indoors and outdoors, and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines, and walking in crowds or confined spaces. Children have at best only minimal ability to perform gross motor skills such as running and jumping.

Level III
Walks with assistive mobility devices; limitations walking outdoors and in the community.

Before 2nd birthday: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

From age 2 to 4th birthday: Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using an assistive mobility device and adult assistance for steering and turning.

From age 4 to 6th birthday: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with an assistive mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.

From age 6 to 12th birthday: Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Depending on upper limb function, children propel a wheelchair manually or are transported when travelling for long distances or outdoors on uneven terrain.

Level IV
Self-mobility with limitations; children are transported or use power mobility outdoors and in the community.

Before 2nd birthday: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

From age 2 to 4th birthday: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

From age 4 to 6th birthday: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.

From age 6 to 12th birthday: Children may maintain levels of function achieved before age 6 or rely more on wheeled mobility at home, school, and in the community. Children may achieve self-mobility using a power wheelchair.

Level V
Self-mobility is severely limited even with the use of assistive technology.

Before 2nd birthday: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

From age 2 to 12th birthday: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.

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

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

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

DISTINCTIONS BETWEEN LEVELS IV AND V
Children in Level V lack independence even in basic antigravity postural control. Self mobility is achieved only if the child can learn how to operate an electrically powered wheelchair.

Appendix C

Parenting Stress Index/Short Form

Name_____ Gender ____ Date of birth _____ Ethnic group _____ Marital status_____

Child's name_____ Child's gender_____ Child's date of birth _____ Today's date_____

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

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

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

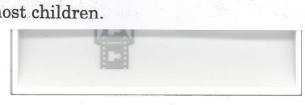
22.	I feel that I am: 1. not very good at being a parent 2. a person who has some trouble being a parent 3. an average parent 4. a better than average parent 5. a very good parent	1	2	3	4	5
23.	I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
24.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

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

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

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

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



Appendix D

APPENDIX 2

DEMOGRAPHIC QUESTIONNAIRE

Please circle the appropriate response where applicable.

1) Sex Female Male

2) Age: _____ years

3) Marital status? Single Married Divorced Live in Partner

4) Highest education level achieved by:
yourself _____
your partner/spouse_____

5) Are you employed? Yes No
Is your partner employed? Yes No

6) If your answer is yes do you work part-time or full-time.
If your partner works does he/she do so part-time or full-time.

7) What is your occupation? _____
What is your partner's occupation? _____

8) What is the approximate household income for the month? _____

9) Do you have any other children? Yes No If your answer is yes, please provide their ages.

_____
_____
_____
_____
_____
_____

10) Does your child who has cerebral palsy suffer from any other medical conditions for example asthma or epilepsy? Yes No
If your answer is yes, please specify. _____

11) Is your child on any chronic medication? Yes No
If your answer is yes, please specify. _____

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

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

14) How far from the school do you live? _____

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

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

17) Do you employ someone to help care for your disabled child's needs on a regular basis? Yes No