STRESS & COPING

IN PARENTS OF CHILDREN WITH CEREBRAL PALSY

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ABSTRACT

Parental adaptation was investigated in fifty-nine families with a child with cerebral palsy. Fifty-nine mothers and twenty-five fathers completed self-administered questionnaires and were interviewed in their own homes. Associations between descriptor variables (child characteristics, life events, parental resources and coping strategies) and outcome measures of stress were investigated. Twenty-five dyads of mothers and fathers were compared. Results indicated high levels of stress in both parents, particularly mothers. The overall ability of the child, in particular socialisation and communication skills, was related to stress in both mothers and fathers. Parental life events, unmet service need, neuroticism and the use of wishful thinking were related to stress in both mothers and fathers. Child behaviour problems were related to stress in mothers. In both parents the use of practical coping strategies and seeking support was related to improved outcome.

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CHAPTER ONE: INTRODUCTION

1. OVERVIEW

This study aimed to investigate parental adaptation in families with a child with cerebral palsy. This chapter will initially discuss research concerning parenting children with disabilities, and the approaches that have hitherto been undertaken. It will then review a model of stress and coping. The research relating to this model will subsequently be discussed, including research findings on outcomes, stressors, coping resources and coping strategies. The chapter will finally focus on cerebral palsy and the rationale for the present study.

2. PARENTING CHILDREN WITH DISABILITIES

Although a disabled child can have a huge impact on the whole family (Cooke & Lawton, 1985), this project will look specifically at the impact on parents. Many studies examining parents of children with disabilities have shown that they are more likely to suffer from stress, anxiety and depression than other parents (Philp & Duckworth, 1982). Mothers in particular have been found to experience more psychological distress than mothers of healthy children (Byrne & Cunningham, 1985). The main burden of care for the disabled child has been shown to fall on the mother (Carey, 1982).

However, there is a wide variation in the adaptation of mothers to their disabled children. Research in learning disabilities has shown that a number of families have made a successful adaptation to the learning disabled child (e.g. Donovan, 1988).

Traditionally research has focused on the stressors associated with caring for a disabled child and the detrimental impact that these have on parents' well being (Chetwynd, 1985). Research studies assumed a pathological approach, suggesting that having a child with a disability inevitably results in stress for the parents (Byrne, Cunningham & Sloper, 1988). Recent research has begun to move away from describing these stressors, instead focussing on how parents cope with a disabled child. This work has important implications for informing interventions aimed at preventing or reducing stress experienced by parents, and thereby facilitating child adaptation and development. The aim of research has therefore been to identify child and family factors related to successful adaptation, as well as risk factors for poor adaptation.

Much of the earlier research in this area was carried out atheoretically. Models of stress and models of the family have recently been used to guide research, e.g. family systems models (Kazak, 1986) and the ABCX model of family stress and adaptation (McCubbin, 1988). However, these models have proven to be somewhat limited. They do not account for the role of intrapersonal factors or factors external to the family, and outcomes are described on the family level rather than the individual level. Since research has shown that there is considerable variability in response to the same 'stressful' situation, it indicates that adaptation is not simply a function of the disabled child. Thus, viewing the family as a dynamic transactional system has been of increasing importance (Sameroff, Seifer & Zax, 1982). Models of stress that can account for these differences in parental adaptation have therefore been identified.

3. MODEL OF STRESS AND COPING

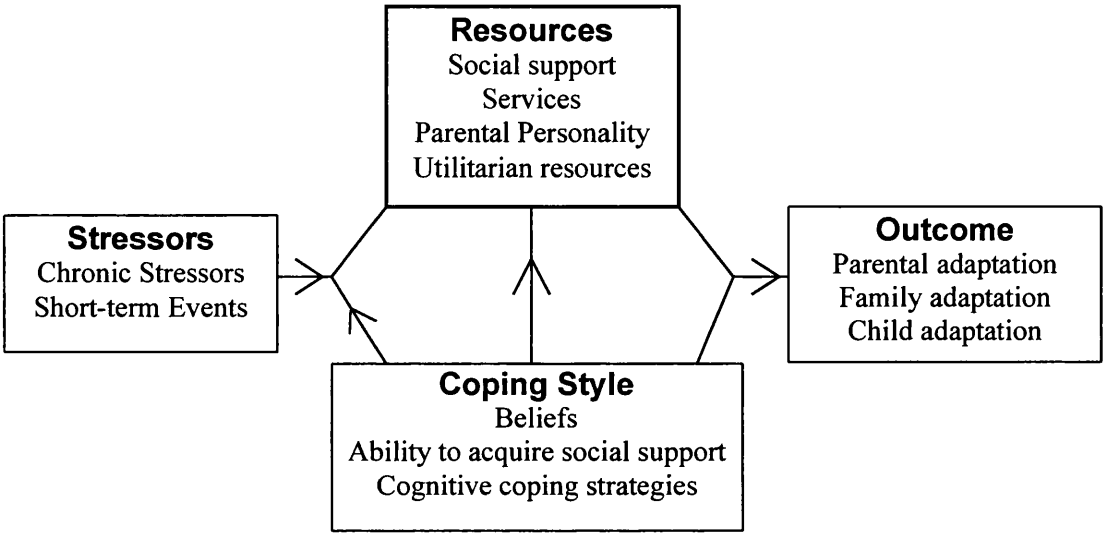
The cognitive theory of stress and coping (Lazarus & Folkman 1984) is a transactional theory in which a dynamic relationship exists between the person and the environment. In the theory stress is defined as " a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p.19).

The process of appraisal is perceived as critical in the decision of whether a particular person-environment interaction is stressful. Appraisal is defined as "the cognitive process through which an event is evaluated with respect to what is at stake (primary appraisal) and what coping resources and options are available (secondary appraisal)" (Lazarus & Folkman, 1984b, p.223). Thus in primary appraisal the individual evaluates the encounter. For example, whether he / she may be harmed or benefit from it. A range of personality characteristics influences this. In the secondary appraisal coping options are evaluated. Thus appraisal is mediated by situational, personal and internal factors.

Lazarus & Folkman (1984) describe coping as the cognitive or behavioural effort to master, reduce or tolerate the demands arising from a stressful transaction. "... the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person" (p.283). It describes coping as a process; an ongoing complex interaction between an individual and the environment. Coping is a mobilisation of effort that includes cognitive and behavioural efforts to manage demands. The theory takes a realistic view of stress, recognising that not all problems can be mastered, and thus coping is viewed in terms of management.

McConachie (1994) outlines a model of stress and coping drawn from a summary of research studies in childhood disability. This is based on the model from Lazarus & Folkman (1984).

Proposed Model (McConachie, 1994)



3.1 Outcome

The process model is concerned with the individual level, rather than the family system, and thus outcomes are measured on this level. The majority of studies have focused on outcome in terms of the parent rather than the child. Measures of physical and mental health have been used e.g. the Malaise Inventory (Rutter, Tizard & Whitmore, 1970), which are taken as indicators of adaptation to the demands of caring for and bringing up a disabled child. A positive outcome is regarded as the absence of psychopathology.

3.2 Stressors

The model maintains that nothing can be identified as a specific cause of stress. For every individual, an event will have different meanings and effects; thus it is the individual's appraisal of the event which is important. Stressors have been described as risk factors for adaptation that are mediated by socio-ecological factors, intrapersonal factors and coping (Wallander, Varni, Babani, DeHaan, Thompson Wilcox and Banis, 1989). Stressors have been divided into chronic and short-term stressors.

3.2.1 Chronic stressors appear to vary between disability groups. For families of children with severe learning difficulties the child's behaviour problems and functional skills seem to be predictive of poor outcome (Frey, Greenberg & Fewell, 1989; Sloper, Knussen, Turner & Cunningham, 1991). Frey et al. (1989) also reported that low child communication skills were related to negative outcome in both parents. In families of children with physical disability the severity of disability and communication problems have been found to be predictive of poor outcome, particularly in mothers (Sloper & Turner, 1993). However, other studies have failed to corroborate this (Wallander, Pitt & Mellins, 1990). Differences in results may be due to differences in sampling.

3.2.2 Short-term events have been specified as two types: stages in the life cycle and life events. Life events have only recently been a subject for research in this area. However, they have been shown to be significant stressors for both mothers and fathers with children with learning difficulties and physical disabilities (Sloper et al., 1991, Sloper & Turner, 1993). Wallander, Pitt & Mellins (1990) argue that mothers of children with disabilities experience more major life events, such as hospitalisation of the child, and daily hassles than mothers of healthy children. Wikler (1981) suggests that there is increased stress at certain transition points in the life cycle, such as the child going to school or nursery. However, longitudinal research is needed to investigate this suggestion.

3. 3 Coping Resources

These have been shown to be a vital part of the coping process, consistently accounting for the variance in psychosomatic complaints and psychological distress (Mechanic, 1978). The absence of a particular coping resource means that the associated coping strategy cannot be used, thus coping resources are sources of the coping strategies that an individual uses.

According to the model coping resources mediate vulnerability to the effects of stress; thus the less the resources, the more vulnerable the individual is. However, the use of coping resources can have positive and negative effects. Thus, coping resources have been described as both resistance and risk factors in relation to vulnerability to stress (Sloper & Knussen, 1991). There is an increased risk of vulnerability to stress if an individual does not have access to a particular resource.

Coping resources can also impact upon the appraisal process. Knussen & Sloper (1992) propose that coping resources are likely to change over time and different situations.

Coping resources include physical resources such as health, energy, stamina; utilitarian resources: finance, employment, housing; social resources: social networks and support; and psychological resources: personality, belief systems and problem solving skills.

3.3.1 Intrapersonal Coping Resources

3.3.1.i. Personality Variables

Research has shown that personality variables are important in the coping process and that these affect the availability of other coping resources (Sloper et al., 1991). Personality includes neuroticism, extraversion, and locus of control.

Neuroticism has been found to be related to greater distress and poorer outcome in parents (Bolger, 1990). Research from longitudinal studies suggests that this leads to increased vulnerability and reactivity to stressful events (Bolger & Schilling, 1991). High levels of neuroticism were related to an increase in the use of the use of wishful thinking and self-blame coping strategies. In parents of children with Down's Syndrome neuroticism scores significantly predicted mothers' and fathers' perceived satisfaction with life and their mental and physical health (Sloper et al., 1991).

Extraversion has received a limited amount of research, but has been found to be positively associated with maternal adaptation, (Sloper & Turner, 1993) and acceptance of a physically disabled child (Judson & Burden, 1980). McCrae & Costa (1986) suggest that extraversion is related to the use of adaptive coping strategies.

An important aspect of personality is belief about locus of control, which impact upon all aspects of an individual's functioning. An internal locus of control denotes the belief that the individual him / herself is in control of his / her life, whereas external locus of control beliefs describe individuals who believe they have no control over their lives. General psychological research has shown that locus of control beliefs act as moderators in the stress-adjustment relationship. Petrosky & Birikimer (1991), amongst others, have found that locus of control beliefs affect the use of coping strategies. Locus of control beliefs have been found to be predictive of mother's perceptions of disability-related stressors. Frey et al. (1989) found that mothers with internal locus of control beliefs perceived fewer difficulties with the disabled child than those with external beliefs.

3.3.1.ii. Parenting Skills

These include the behaviours and competencies that enable parents to manage their children. Quine & Pahl (1989) found increased rates of behavioural and sleeping problems in children with disabilities. An increased sense of competence has been associated with levels of parental stress (Pisterman, Firestone, McGrath, Goodman, Webster, Magory & Goffin, 1992). Competency in dealing with behaviour problems reduces behavioural difficulties as well as enhancing parents' sense of competence (Quine & Wade, 1991).

3.3.1.iii. Health

This has been found to be a major resource for parents of children with disabilities (Brown & Hepple, 1989). In research, it has often been conceptualised as an outcome rather than a coping resource. Meltzer, Smyth & Robus (1989) found 37% of mothers reported that having a disabled child had been detrimental to both their physical and mental health. Quine & Pahl (1986) found that parents of disabled children had poorer mental and physical health.

3.3.1.iv. Coping experiences

The history of individual experiences may affect the appraisal of an event, and in addition, the coping strategies used. Koch-Hattem (1987) found that parents' reactions to the diagnosis were moderated by previous experiences of a disabling condition. In mothers of children with disabilities perceptions of coping efficacy in parents, which is affected by prior coping experiences, was positively associated with low psychological distress (Frey et al., 1989).

3.3.2. Socio-ecological Coping Resources

These are present in an individual's environment or social context and include: social support, support services, practical resources, employment, marital status and economic circumstances. They can function as risk and resistance factors to an individual's adjustment.

3.3.2.i. Social Support

Social support is often viewed as a mediating or buffering factor in the coping process. Philp & Duckworth (1982) found that parents often become isolated in the community when caring for a disabled child. Social isolation has been shown to be at its greatest level in single-parent families or when the marital relationship is strained (Spain, 1973). In caring for a disabled child, research has shown that lack of social support can be one of the most stressful factors (Quine & Pahl, 1985). There may be a number of disability-related constraints that may lead to social isolation. For example, Meltzer, Smyth & Robus (1989) found that parents can feel restricted by the disabled child's antisocial behaviour.

Social support has been examined in terms of three levels (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983). Intimate relationships form the first level of support. This includes the marital relationship and close family. The second level includes friendships. In the third level there is neighbourhood or community support. This includes formal and institutional support. There are a number of functions of social support, including emotional support, practical support and the receiving of information (Barrera & Ainlay, 1983).

Social support networks have also been conceptualised, in relation to families with disabled children (Kazak & Marvin, 1984), in terms of network size, density and boundary density. Network size is the number of people offering different types of support. It is proposed that the larger the network, the greater the likelihood of successful adaptation. Network density refers to how interrelated the social network is. It is the number of people who know each other, disregarding the link with the focal person. In parents of children with spina bifida, Kazak & Wilcox (1984) have found that high-density networks are related to stress. Boundary density is the number of network members that both parents know and use. High boundary density, the extent of the network overlap, has been linked to marital stability (Kazak & Wilcox).

Social support has been found to be highly predictive of parental outcome in many studies (McConachie, 1994). In mothers of children with autism, an association was found between available social support and parental and family stress (Bristol, 1979).

Greater social support has been associated with more positive maternal behaviour and attitudes towards the disabled child (Crnic et al., 1983). Thus parents who are not coping well may have poor social support. If these parents are feeling stressed they are then unlikely to be able to use social support. Pahl & Quine (1985) found that some families with a learning disabled child were so overwhelmed with stress that they were not able to seek or use social support.

A number of factors mediate the efficacy of social support. The quality and availability of the support is important. There are individual differences in the ability to seek and use support. Kirkham, Schilling, Norelius & Schinke (1986) found that socially skilled parents can extend their support network more easily than parents with poor social skills. Successful adaptation to the birth of a disabled child has been linked to parents' support skills in seeking and using social support (Trute & Hauch, 1988).

In a number of studies spousal support or the existence of a confiding relationship has been shown to be highly predictive of parental adaptation (Brown, Bhrolchain & Harris, 1975; Trute, 1995). The majority of studies have examined fathers supporting mothers, reflecting the fact that mother's are mostly responsible for the child's care (Carey, 1982). In a review of families of children with disabilities Sloper & Knussen (1991) found that in both mothers and fathers spouse support was related to positive outcome. Spouse support has been inferred by measuring the quality of the marital relationship. It has been shown to be predictive of coping behaviour by increasing mothers' feelings of being able to cope with the needs of the child (Friedrich, 1979).

The importance of the extended family in providing practical support, and in particular child minding, has been shown (Beresford & Lawton, 1993). Factors relating to disability can affect this support. For example, in families of children with learning difficulties, the severity of behaviour problems was related to the size of the parents' formal and informal support networks (McGrath & Grant, 1993).

The burden placed on informal support networks can be relieved by formal agencies. Formal sources of family support are needed because not all families have the same resources at the onset of a crisis (Cooley, 1994). There may be a fluctuating need for external support within a family. Dunst, Trivette & Deal (1988) suggest that the success of external support relies on whether it encourages families to build upon strengths, and whether the support offered coincides with the needs of the family. Professionals have been found to overestimate the negative impact of the disabled child on the family. They were also shown to underestimate parents' ability to use teaching and behavioural management techniques (Blackard & Barsh, 1982).

The evaluation of support services for families with a disabled child has been limited. Families may receive a variety of services from health, social and educational systems. This variety leads to difficulties in evaluating formal services (Beresford, 1994).

3.3.2.ii. Support Services

Support services can also be conceived as a coping resource. Formal support is used differently to informal support, in that it is frequently limited to times of crisis once other forms of support have been tried first (Unger & Powell, 1980).

The research on the effect of professional services in predicting parental adaptation is conflicting. Professional support has been found to be a very important factor (Kazak, 1986). Davis & Rushton (1991) found that a counselling and advocacy intervention increased parents' satisfaction with their relationships with their child and other family members.

However, some studies have shown that services may be perceived as a source of stress, with the lack of a co-ordinated input and unmet needs (Harris & McHale, 1989). These conflicting results may reflect the differences in measures regarding use of services. Some studies have used crude measures such as the total number of contacts with different services. Sloper & Turner (1991b) used a measure of the perceived adequacy of service response to parental need (Quine & Pahl, 1989). They found that levels of unmet need were more strongly related to maternal adaptation than the total number of needs, whether or not the needs were met. Thus, the service response can have a protective effect on maternal adaptation.

Research suggests the need for a 'link' person who would act rather like a key worker negotiating the most appropriate mix and timing of services for an individual family (Sloper & Turner, 1992). The provision of such a service has been recommended in a number of official reports (Warnock Report, DES, 1978), although it appears that these recommendations are not being carried out (Sloper et al., 1991).

3.3.2.iii. Maternal Employment

Mothers of disabled children differ from other mothers in that they are often not able to return to work after early childhood. A study of employment in mothers of disabled children found 33% to be employed compared to 48% in mothers of healthy children. This difference appears to increase as the child grows older. In mothers whose children were over the age of 11, 45% with disabled children were working, compared to 86% of mothers of normal children (Baldwin, 1981).

In mothers of disabled children maternal employment has been found to be predictive of well being (Hirst, 1984). The benefits of this may be more therapeutic than financial. Pahl & Quine (1987) found that the reason for wanting to work in unemployed mothers was to increase social contact and to have a break from the burden of caring for the disabled child.

Knussen & Sloper (1992) suggest however, that in certain situations employment may add to stress, for example, when attending hospital appointments or when the child is ill. They recommend that in examining employment further investigation is needed into the type of work, the mother's desire to work and the extent of support given by the husband.

3.3.2.v. Marital Status

It appears that marital status *per se* may be an important coping resource (Lawton, 1992). The reasons for this are unclear. For single parents there may be financial difficulties (McCubbin, 1989) as well as having to carry the burden of care alone (Wikler, Haack & Intagliata 1984). A lack of social support may also lead to increases in stress levels (Quine & Pahl, 1985). There are, however, conflicting results from research by McCubbin (1989) who found that single parents were more adaptable to the demands and changes of having a disabled child with cerebral palsy.

3.3.2.vi. Socio-economic circumstances

Researchers have shown that there is often an economic impact of having a child with a disability (e.g. Baldwin, 1981). This can involve direct costs, such as special diets, childcare and extra clothing; and indirect costs, such as lost work time and interference with career advancement.

Having a disabled child often requires house modifications such as ramps, widened doorways and lifts. Locks for cupboards and bars for windows may also be required (Klein, 1977). However, in a nation-wide survey, the largest expense for families with disabled children was for babysitting. This relates to the continued dependence of disabled children (Harbaugh, 1984).

Parents of children with disabilities often have to spend more time with the child because of their special needs. This in turn can impact upon career advancement or whether a parent has a job at all (Morris, 1987).

In families with a disabled child deprivation has been associated with high levels of stress (Sloper & Turner, 1993). In mothers of children with disabilities family income has been found to be positively associated with 'social functioning', such as participating in social and leisure activities (Wallander et al., 1989). Longitudinal studies appear to suggest that in some families with children with disabilities symptoms of distress are chronic and persistent, and likely to be associated with financial hardship (Quine & Pahl, 1989; Sloper, Cunningham, Knussen & Turner, 1988). Families of children with severe physical disability who do not own cars have also reported major lifestyle constraints (Sloper & Turner, 1991b).

3.4 Coping Strategies / Style

There are two major functions of coping: addressing the problem which is causing the distress (problem-focused coping) and regulating emotion (emotion-focused coping) (Folkman, Lazarus, Gruen & DeLongis, 1986).

Emotion is defined as complex, organised psychophysiological reactions consisting of cognitive appraisals, action impulses and patterned somatic reactions (Lazarus, Kanner & Folkman, 1980). They are described as operating together as a unit. Action impulses emphasise the fact that the action of emotion can be inhibited. The patterned somatic reaction describes the physiological response, which reflects the type of emotion.

Lazarus (1993) proposes that a key appraisal component in emotion is motivational. In order for an emotion to exist there must be an active goal in each encounter. There is no emotion without a goal. Emotions result from how events are evaluated in terms of their significance for our well being. If our goals are thwarted a negative emotion results, whereas a positive emotion results from achieving or making progress towards our goals.

Lazarus (1991) proposes that 15 or more different emotions can be identified; 9 of which are negative: anger, fright, anxiety, guilt, shame, sadness, envy, jealousy and disgust; and 4 of which are positive: happiness, pride, relief and love. He suggests that there are 3 further emotions that can be ambiguous: hope, compassion and gratitude. Each emotion has its own special scenario and is a result of the appraisal of the personal significance of an encounter.

Recently, Lazarus (1993) has proposed that emotion is a more important aspect of coping than hitherto envisaged. He suggests that the concept of emotion includes that of stress and that appraisal and coping theory applies to both. It is proposed that the emotions have more scope and depth than stress.

Coping is viewed as a mediator of emotions. Folkman & Lazarus (1990) propose three ways in which coping affects emotion: firstly, that cognitive activity impacts upon the use of attention; secondly, that cognitive activity influences the subjective meaning of the encounter for well-being; and finally, that actions alter the terms of the person-environment relationship.

There has been little research into the mediating effects of coping on emotion despite the fact that clinical interventions are often based on the premise that changing deficiencies in coping skills can improve people's emotional lives and psychological well being.

Folkman & Lazarus (1991) describe one research study, which suggests that in stressful encounters coping is a significant mediator of the emotional response. They found that problem-solving and positive reappraisal were positively associated with pleased / happy emotions and confident / secure emotions. Confrontive coping and distancing were negatively associated with the same emotions. However, more research is needed in this area.

Lazarus (1993) suggests that coping shapes emotion in the same way it shapes psychological stress. It involves problem focused coping, i.e. attempts to change the person-environment realities behind negative emotions; and emotion-focused coping which tries to change what is attended to or how it is appraised. Studies have shown that coping usually involves both functions. In middle aged men 98% of stressful encounters involved both forms of coping (Folkman & Lazarus, 1980).

Folkman & Lazarus (1991) propose that even in the most simple of encounters there are multiple implications for well being, which is why there may be more than one emotion for any encounter. They suggest that in order to understand the emotion process, emotions must be linked to the cognitive appraisal that influences them.

Following a number of research studies using the revised Ways of Coping Questionnaire, Folkman & Lazarus (1990) conclude that coping is a multidimensional process. Eight different kinds of coping were identified. Two of these were problem-focused: confrontive and interpersonal coping, and problem solving. They focus on altering the troubled person-environment relationship. Six kinds of emotion-focused coping were identified which include: distancing, escape-avoidance, accepting responsibility or blame, seeking social support, positive reappraisal and controlling the expression of feelings. These emotion focused coping strategies are directed at managing distress rather than changing the troubled person-environment relationship.

Folkman & Lazarus (1991) highlight the fact that coping effectiveness relies on the choice of coping strategy fitting the possibilities for coping in an encounter. This depends upon whether an outcome is within a person's control. It is proposed that coping strategies, which have a poor fit with the actual conditions, will adversely affect the emotional response.

Beresford (1994) suggests that different coping strategies are required for controllable and uncontrollable stressors. For managing controllable stress problem-focused coping strategies are generally appropriate; whereas emotion-focused coping may be more appropriate for uncontrollable stress. Thus it is suggested that the nature of the stresssor affects the type of coping strategy.

The model of stress and coping does not predict styles of coping or consistency in these styles (Knussen & Sloper, 1992). However, these authors suggest that if the stressor remains the same then strategies may be stable over time. Hatton, Knussen, Sloper & Turner (1992) found that parents who were using wishful thinking and practical coping strategies were using these strategies three years later.

Whether or not an attempt to manage a stressor is successful or not, it is defined as coping according to the process model of stress and coping (Folkman, 1984). Traditional definitions of coping included only successful attempts. Thus, coping is independent of the outcome. Coping strategies that are useful at one point of a stressful encounter may not be helpful at another stage.

In caring for a disabled child parents are coping with a great variety of stressors in a number of different situations. Coping strategies are used in a variety of combinations; individually, consecutively etc. Thus coping strategies may impact upon each other and outcomes may therefore be confounded.

The process model of stress and coping has been used only recently in parents with a disabled child and the research is limited.

The relationship between emotion-focused coping and problem-focused coping with parental well being was examined in parents of children with Duchenne Muscular Dystrophy (Thompson, Zeman, Fanurik & Sirotkin, 1992). High use of emotion-focused coping was related to poor adjustment, as was a higher ratio of emotion-focused compared to problem-focused coping strategies. In mothers of physically disabled children Miller, Gordon, Daniele & Diller (1992) found similar results; emotion-focused coping strategies were positively associated with distress, whereas problem-focused strategies were associated with lower distress.

In mothers of children with severe learning difficulties Quine & Pahl (1991) found that coping through catharsis was associated with poor outcome. However, this contradicts other research that found families who expressed emotions showed better adaptation (Beavers, Hampson, Hulgus & Beavers, 1986). This may reflect differences in measures used. Quine & Pahl (1991) also found that perceived coping skills were positively associated with adjustment and parental well being.

In parents of children with physical or learning disabilities Frey et al. (1989) found that both mothers and fathers were less stressed and experienced less parenting stress if they used problem-focused coping strategies. In mothers less psychological distress was associated with seeking social support. High psychological distress in both mothers and fathers was associated with avoidance coping and wishful thinking.

Sloper et al. (1991) looked at mothers and fathers of children with Down's syndrome, and found that practical coping significantly predicted mothers' perceived satisfaction with life. Poor mental and physical health was significantly predicted by the use of wishful thinking. For fathers satisfaction with life was negatively associated with passive acceptance.

In parents of children with severe physical disabilities Sloper & Turner (1993) found wishful thinking to be a maladaptive coping strategy with respect to satisfaction with life, acceptance of, and adaptation to, the child. Mothers who sought social support at the time of diagnosis were found to be more satisfied with their lives. For fathers no coping strategies were related to adjustment.

4. THE IMPACT OF CEREBRAL PALSY

4.1 Definition

Cerebral palsy is a permanent, non-progressive disability of movement arising from damage or dysfunction of the immature brain. Motor impairment affects muscular power, tone and posture (Barabas & Taft, 1986). There is often associated sensory, language, and visuospatial disabilities, and sometimes epilepsy. The brain damage can be widespread, in which case there may also be learning difficulties. Cerebral palsy can be differentiated into different types depending on the parts of the body affected by the paralysis. Hemiplegia involves one side of the body; quadriplegia involves all four limbs; and diplegia encompasses the lower limbs. A major difficulty is often postural, involving balance (ataxic cerebral palsy) or involuntary athetoid or choreoathetoid movements (dyskinesia).

4.2 Prevalence

The overall prevalence rate is between 1.5 and 3 per 1000 (Rutter et al., 1970). Boys are slightly more affected than girls.

4.3 Aetiology

The probable cause depends upon the type of cerebral palsy. Approximately two-thirds of cases involve perinatal causes such as prematurity, birth injury and neonatal jaundice. Genetic causes account for one-fifth of cases and the remainder is accounted by miscellaneous factors such as postnatal trauma and infections (Graham, 1986).

4.4 Clinical Description

There is a wide variation in the nature and severity of the condition (Graham, 1986). A child who is only mildly affected may have only a slight incoordination and weakness in a limb. However, a child who is severely affected may be quadriplegic, blind, and have severe or profound learning difficulties.

Graham (1986) describes a typical childhood history. There is often a difficult birth followed by intensive care treatment where the child appears to make a good recovery. Sometimes there are early swallowing difficulties. Often in the first year of life the child is found to be unusually stiff or floppy. There are delays in motor milestones and articulation disorders are common. If a diagnosis has not been made at birth, a clinical examination and the child's history are often used to make a diagnosis. Children with cerebral palsy often have a wide scatter of skills, and although there is a wide variation, in general verbal skills are more highly developed than non-verbal skills.

In the Isle of Wight Survey (Rutter, Graham & Yule 1970b) 40% of children with cerebral palsy were found to have significant emotional or behavioural problems. This is much higher than the rate of psychiatric disorder in the general population (6-7%). Graham (1986) suggests a number of reasons that may account for this including the direct effect of brain damage and dysfunction; rejection by peers and siblings; poor self-concept and low self-esteem; problems in parental attitude; difficulties with family relationships and educational failure.

4.5 General Intelligence

About 50% of children with cerebral palsy have IQs below 70 (Rutter et al., 1970b). However, children with cerebral palsy can have normal or superior intelligence. In considering intelligence it is important to consider the type of cerebral palsy. Children with diplegia and quadriplegia are more likely to have learning difficulties than children with hemiplegia. Children with choreoathetosis have the least affected intelligence.

In general, the greater the physical disability the greater the learning difficulties. However, there are exceptions to this. For example some children with gross physical disabilities, particularly of the dyskinesic type, have very high intelligence.

5. RATIONALE FOR PRESENT STUDY

The majority of studies examining factors related to successful adaptation, and risk factors for poor adaptation, in families of children with disabilities have focused on families of children with learning difficulties (Byrne & Cunningham, 1985). There has been limited research in this area regarding physical disability. It is largely unclear whether the findings from research in learning disabilities will generalise to physical disability and more specifically cerebral palsy. The impact that a child with learning disabilities has upon family life may be different to a child with a major motor disorder, such as cerebral palsy, which may also be comorbid with learning disabilities. Moreover, a child that has a major motor disorder in addition to learning disabilities may produce further demands. The number and type of service contacts and medical / paramedical needs are likely to be different.

Research into physical disabilities has generally involved a range of disorders including spina bifida, degenerative disorders and other disorders, as well as cerebral palsy. Different disorders may have particular effects in, for example, the nature of the stressors and the impact that this has on parental outcome. This study aims to look at cerebral palsy alone.

It is important to acknowledge that this study will not be using a control group. There may be advantages in using a control group such as parents of children with physical or learning disabilities. This would show the specific differences between these groups and the parents of children with cerebral palsy. However, the main thrust of this research will be in identifying within-group factors related to successful adaptation, as well as risk factors for poor adaptation, in families of children with cerebral palsy. This work has important implications for informing interventions aimed at reducing stress in these families. Due to time and resource limitations it will not be possible to collect statistically valid samples from both a control group and the target group. The decision has therefore been taken to concentrate efforts in collecting data for a valid within-group study.

It seems that very few studies have sought to examine the specific experiences of families having a child with cerebral palsy and how the particular stressors, coping strategies and resources interact. There has been limited research into coping strategies in general, as this is a relatively new area of study. This study plans to examine the use of coping strategies in parents.

Research studies that have looked at stress as an outcome measure of the coping process have typically used relatively short measures of stress, such as the Malaise Inventory (Rutter et al., 1970). By using a longer and more specific measure of parenting stress (the Parenting Stress Index, Abidin, 1985) in addition to the Malaise Inventory, a more accurate picture of parenting including specific details concerning the source of the stress will be obtained.

Studies of this type that have examined families of children with physical disabilities have used differing and often relatively short measures of the child's ability. This study will use a comprehensive measure of the child's ability; a standardised clinical tool, The Vineland Adaptive Behaviour Scales (Doll, 1965). In addition to assessing overall functioning this scale provides details on communication, daily living skills, socialisation, motor skills and maladaptive behaviour. Thus this study will include a detailed assessment of child stressors.

The vast majority of studies of family functioning have used only mothers' responses. Although the main burden of care of the child has been shown to fall on the mother (Romans-Clarkson et al., 1986) the importance of the father in family functioning has also been shown (Pedersen, 1980). Furthermore, recent research has found that there may be important differences between mothers and fathers (Sloper et al., 1991; Trute, 1995).

It has been suggested that mothers and fathers may differ because of their role differentiation within the family (Gunz & Gubrium, 1972). Thus the mother may take an expressive role regarding the internal affairs of the family, and the father may have a more instrumental role concerning the external affairs of the family. Hence the father may be more involved with finances and future planning, and the mother's concerns may be more to do with the emotional strain of caring for a child with a disability and the impact that this has on family relationships. Therefore, this study will examine both mothers and fathers.

More research is needed to examine which factors in fathers are related to different outcomes. The characteristics of the marital relationship have been suggested to have an important impact on the father's adaptation (Gallagher, Cross & Scharfman, 1981). Child characteristics such as the severity of the disability and the visibility of the handicap has been shown to be related to paternal stress levels (Meyer, 1985).

The marital relationship has also been found to play an important part in supporting the mother's role and sense of competence in parenting ability (Pedersen, 1980). Marital relationships with a high degree of role segregation have been linked to depressive symptoms in the post-partum period (Oakley, 1979). Thus fathers play an important role in family functioning, however, more research is needed in examining factors related to adaptation.

Studies have generally involved examining families with younger children, which may differ substantially from families with older children. The stresses on parents may augment as the child increases in age. For example, concerns about the child's future or increasing financial burdens. On the other hand the stresses may decrease with the increase in age of the child with disability. This study will examine parents of children from a range of ages, from two to twelve years. (A lower limit of two years was chosen to allow adequate time for a diagnosis to have been made and to give parents some time to assimilate this.)

The results of the present study will provide a better insight into the nature and types of stressors, coping strategies and resources in families with a child with cerebral palsy. This information will enable clinicians and services to think more effectively about the impact of cerebral palsy in relation to parental and family functioning. Clinicians and researchers will be able to develop specific and more appropriate support for families with a child with cerebral palsy.

6. HYPOTHESES

1. Outcomes

1. Parents of children with cerebral palsy will show higher levels of stress than the normal population on the Malaise Inventory and the Parenting Stress Index outcome measures.

2. Stressors

2.1. Greater overall severity of disability will be associated with poor parental outcome, i.e. higher levels of stress.

2.2. Lower levels of communication skills, functional skills, motor skills and socialisation skills will be associated with poor parental outcome, i.e. higher levels of stress.

2.3. Behavioural problems will be associated with poor parental outcome, i.e. higher levels of stress.

2.4. Greater strain from life events will be associated with poor parental outcome, i.e. higher levels of stress.

3. Coping Resources

3.1 Personality

3.1.i. Higher levels of extraversion will be associated with good maternal outcome, i.e. lower levels of stress.

3.1.ii. Higher levels of neuroticism will be associated with poor parental outcome, i.e. higher levels of stress.

3.2 Social Support

Higher levels of satisfaction with and availability of social support will be associated with good parental outcome, i.e. lower levels of stress.

3.3 Support Services

3.3.i. Lower levels of unmet service need will be associated with good parental outcome, i.e. lower levels of stress.

3.3.ii. Descriptive analysis will examine the presence of a family 'link' person who negotiates the most appropriate mix and timing of services.

3.4 Maternal employment

3.4.i. Maternal employment will be associated with good maternal outcome, i.e. lower levels of stress.

3.4.ii.a) Descriptive analysis will examine the type of work, which mothers undertake.

3.4.ii b) It will also examine whether mothers who do not work, would like to work, and whether their partner would support them in this.

3.5 Socio-economic Circumstances

3.5 Higher levels of deprivation, as measured employment status will be related to poor parental outcome, i.e. higher levels of stress.

4. Coping Strategies / Style

4.1. Greater use of practical and problem-focused coping will be associated with good parental outcome, i.e. lower levels of stress.

4.2 Greater seeking of professional / informal support will be associated with good parental outcome, i.e. lower levels of stress.

4.3 Greater use of wishful thinking will be related to poor parental outcome, i.e. higher levels of stress.

5. Mother and Father Dyads

5.1 Exploratory analysis will examine any differences between mother and father dyads.

CHAPTER TWO: METHOD

1. OVERVIEW

Sixty-one families with a child with cerebral palsy, participated in the study. Parents completed self-administered questionnaires, which were measures of potential stressors, coping resources, coping strategies and stress. Parents were visited in their own homes. They were interviewed regarding the child's abilities and behaviour and if required were helped to complete the questionnaires.

2. PARTICIPANTS

Participants were recruited from three healthcare trusts: Chelsea & Westminster Healthcare NHS Trust; Kingston and District Community NHS Trust; and Richmond, Twickenham and Roehampton Healthcare NHS Trust.

Inclusion criteria for the study were:

1. The child with cerebral palsy was in the age range of 2 - 12 years

2. At least one parent was fluent in English

Hospital databases, card index files, and individual medical files were used to obtain details concerning the diagnosis, date of birth, child's name, address and telephone number. Telephone numbers were unavailable in some cases and in these instances, directory enquiries were contacted. Families were only contacted if they satisfied the inclusion criteria and an address and telephone number were also available.

Letters were sent to 108 families, which explained the nature of the research study. Of the 108 families contacted by letter, 42 were from the Kingston and District Community NHS Trust, 38 were from Chelsea & Westminster Healthcare NHS Trust, and 28 were from Richmond, Twickenham and Roehampton Healthcare NHS Trust. The letter was followed up with a telephone call to ask if families would be willing to participate in the study.

From the 108 families who were contacted by letter, 61 families (56%) participated in the study. With respect to the remaining 47 families who did not participate: 10 families (9%) contacted did not want to participate; 7 (6.5%) had moved; 5 (4.5%) phone numbers were incorrect or had changed; 6 (5.5%) families were telephoned, but were never successfully contacted. One family (0.9%) was not in the country, one (0.9%) family contacted did not speak fluent English and in another family (0.9%) the diagnosis was not cerebral palsy. A further 13 (12%) families initially agreed to participate, but 11 later cancelled. A further 2 (2%) were not in for the arranged appointment and were subsequently unavailable to contact.

Regarding the 61 families who participated, 26 (43%) were from the Kingston and District Community Healthcare NHS Trust; 19 (31%) were from Chelsea & Westminster Healthcare NHS Trust and 16 (26%) were from Richmond, Twickenham and Roehampton Healthcare NHS Trust.

Of the 61 families which participated: 34 (56%) involved mothers only completing the questionnaires; 25 (41%) involved both mothers and fathers completing questionnaires, and 2 (3%) included fathers only participating.

The fathers only who participated were not used in the analysis of the study. These two fathers were the main carers for the child, and were arguably taking on different parenting roles to the other fathers in the study. Thus the analysis subsequently focused on 59 families to which the remainder of this section shall refer.

The age of mothers responding was between the ranges 21-25 and 51-55 years, with a mean in the 31-35 years age range. For fathers ages ranged from 21-25 to 56-60 years, with a mean in the 31-35 years age range. Regarding ethnicity, 48 families (81.3%) were Caucasian, describing their ethnicity as British, European or American, and 11 families (18.6%) were from ethnic minorities, describing their ethnicity as Black (African / Caribbean) or Indian.

The Vineland Adaptive Behaviour Scales (Survey Form) were administered by the researcher to 49 mothers only (83%) and 10 mothers and fathers together (16.9%).

With respect to family composition: 47 (79.7%) families comprised of 2 parents which were married or living together, and 12 (20.3%) families had single mothers (including divorced or separated).

Regarding parental status, for mothers, 57 (96.6%) were natural mothers of the child with cerebral palsy, 1 (1.7%) was a foster mother of the child and 1 (1.7%) was an adoptive mother of the child. Regarding the 47 fathers in families, 45 (95.7%) were natural fathers, 1 (2.1%) was a foster father and 1 (2.1%) was an adoptive father.

With respect to the children with cerebral palsy, their ages ranged from 2 to 11 years of age. The mean age was 6.4 years (S.D. = 2.8). Regarding gender, 34 (57.6%) children were male, and 25 (42.4%) were female. The length of time since receiving the diagnosis of cerebral palsy ranged from 6 months to 11.7 years, with a mean of 6 years (S.D. = 2.9 years).

3. ETHICAL APPROVAL

Ethical approval was obtained from the Riverside Research Ethics Committee and Kingston and Richmond Local Research Ethics Committee. Copies of letters of acceptance can be found in the appendix.

4. PROCEDURE

Each potential family was contacted by letter, which briefly explained the purpose and nature of the research study. Families were given some time to think about whether they wished to participate in the study.

The letter was then followed up by a telephone call to explain the study in further detail, to answer any questions and to ask if families would be willing to participate in the study. If parents agreed to participate an appointment was made for the researcher to visit the family at home.

Prior to the visit, parents were sent the questionnaires and a consent form with the option of completing them independently if they were able to do so before the visit. Participants who were unable to complete the questionnaires were assured that they would be given the opportunity to complete these at the time of the visit.

At the visit participants were initially reminded of the purpose and nature of the study. Participants were also reminded that all information gained would remain confidential. At this stage parents were asked to complete a consent form if they had not already done so.

The researcher then administered the Vineland Adaptive Behaviour Scales (Survey Form) to one or both parents (if both were present).

Following this any uncompleted questionnaires were then administered. Participants were subsequently debriefed and thanked for their participation.

Copies of the initial letter sent to parents, the letter confirming the time of the home visit (sent with the questionnaires), the information sheet, and consent form, can be found in the appendix.

5. MEASURES:

5.1 Outcome Measures:

Two outcome measures were used:

5.1.i. The Parenting Stress Index (PSI) (Abidin, 1983)

This is a 101-item questionnaire, which is based on a model of the determinants of dysfunctional parenting. The model posits that the total stress a parent experiences is a function of certain salient child characteristics, parental characteristics and situational variables which are directly related to the role of being a parent. The questionnaire consists of child and parent subscales.

The child subscale consists of the characteristics of children that are seen as stressors associated with parenting. There are four temperament-related subscales that include adaptability, demandingness, mood and hyperactivity/ distractibility. There are two further subscales related to 'parents expectations of' their child (acceptability) and 'feelings of being rewarded' by their child (child reinforcing the parent).

The parent subscale consists of the characteristics within parents and situational characteristics that are seen as stressors associated with parenting. Characteristics within parents include depression, sense of competence in the parenting role and parental attachment. There are four situational variables, which comprise: relationship with the spouse, social isolation, parental health and restrictions of role (impact of parenthood on the parent's personal freedom and other life roles).

The PSI has been used in previous research as an outcome measure and has good reliability and validity for the child domain, parent domain and the total stress score (Hauenstein, Scarr & Abidin, 1986). The respondent is required to rate the degree to which they agree or disagree with statements, on a 5 point Likert scale ranging from 'strongly agree' to 'strongly disagree'. An example of a statement from this questionnaire is: "*Being a parent is harder than I thought it would be.*"

5.1.ii. The Malaise Inventory (Rutter, Tizard & Whitmore, 1970)

This is a 24-item checklist of psychosomatic symptoms associated with emotional distress. It has been used in studies of families with disabled children. This measure correlates moderately well with other measures of stress and has good test-retest reliability (e.g. Quine & Pahl, 1985). The respondent is required to answer 'yes' or 'no' to each question. A sample question from this questionnaire is: " *Do you feel tired most of the time*?"

5.2 Potential Stressors:

5.2.i: The Vineland Adaptive Behaviour Scales (Survey form) (Sparrow, Balla, & Chicchetti, 1984).

This scale was used to measure personal and social sufficiency in the child with cerebral palsy. The scale measures adaptive behaviour in four areas / domains: communication, daily living skills, socialisation and motor skills. Each domain consists of subdomains. The Communication domain consists of receptive, expressive and written subdomains. Daily living skills domain includes personal, domestic and community subdomains. The Socialisation domain consists of interpersonal relationships, play and leisure time, and coping skills subdomains. Motor skills includes gross and fine motor skills subdomains. The scale also includes a maladaptive behaviour subscale. However, this can only be administered to children of 5 years of age and older.

The survey form contains 297 items, which provide a general assessment of adaptive behaviour. The user conducts a semi-structured interview with a respondent who is familiar with the individual's behaviour, usually a parent. The interview involves the use of a number of general questions in a given area, followed by appropriate probes. The respondent can respond to open-ended questions and describe activities in his / her own words. S/he may also answer 'yes / no / sometimes' to more specific probes.

The interviewer is required to give a score of 2, 1 or 0 to each item following strict guidelines from the manual. A high score on adaptive behaviour items reflects more advanced development. Basal and ceiling rules are applied to each domain, which restricts administration and scoring to the items that are appropriate for the individual's level of functioning.

The child's chronological age is computed in years, months and days and the results of the semi-structured interview are analysed using norm-referenced information for the child's age. A global ability score, called the Adaptive Behaviour Composite is computed from the total scores for the four domains. There are standard scores for the domains and the Adaptive Behaviour Composite: mean = 100, standard deviation = 15.

A sample item from the communication domain of this questionnaire is: '*Speaks in full sentences*'. However, the interviewer may say something more open-ended, such as: " *Tell me about .....'s (child's name) speech and language*".

Part 1 of the Maladaptive behaviour domain was used, which describes minor maladaptive behaviours with norm-referenced data for the chronological age of the child. This part of the domain consists of 27 descriptions of behaviour. All items are administered; there are no basal or ceiling rules. The behaviour in each item is described and the respondent is asked to say whether the child usually, sometimes or never engages in the activity. The items are scored 2,1 or 0, and a high score reflects more negative behaviours. When compared with the norm-referenced data the child is assigned to a maladaptive behaviour level either: non-significant, intermediate or significant. An example of an item is: *'Has poor concentration and attention.'*

These scales are a widely used clinical tool, with good standards of validity and reliability (Sparrow et al., 1984).

5.2.ii. Life Events

The occurrence of life events in the last year was measured using a 42-item checklist. This assesses the occurrence of life events and individual perceptions of the strain of these life events on a 10 point Likert scale (Cheang & Cooper, 1984). If an event has occurred to the respondent within the previous year, s/he is required to tick a box and then rate how stressful s/he found that event. This scale has good reliability and validity (Cheang and Cooper, 1984), and has been used in previous research (Sloper & Turner, 1993). A sample item from this checklist of life events is: '*Marital problem*'

5.2.iii. Further Child Variables:

These included: gender, age, and length of time since diagnosis

5.3 Resources:

5.3.i. Eysenck Personality Inventory (Eysenck & Eysenck, 1964)

The Eysenck Personality Inventory (EPI) is a 57-item questionnaire, which is used to measure two major dimensions of personality: extraversion and neuroticism. The Eysenck Personality Questionnaire (EPQ), (Eysenck & Eysenck, 1975) is similar to the EPI, although it includes an additional personality trait: psychoticism. However, the EPI was chosen because it has been used in similar research investigating parenting children with disabilities (Sloper et al., 1991; Sloper & Turner 1993) and would therefore make a useful tool for comparison.

The EPI consists of a list of questions about the way the individual behaves, which requires the respondent to tick a 'yes / no' response. The test-retest reliability and validity are reported to be good (Eysenck & Eysenck, 1963a; 1964). A sample question from this questionnaire is: "*Do you often worry about things that you should not have done or said*?"

5.3.ii. The Social Support Questionnaire (shortened version) (Sarason, Levine, Basham and Sarason, 1983)

The Social Support Questionnaire was used to measure the availability of, and satisfaction with, social support. This is a 6-item scale where the respondent is required to give a two-part answer to each question. The individual has to list the people whom they could turn to in specified sets of circumstances (availability). The respondent can list up to 9 people for each item. The respondent then rates how satisfied they are with the available support (satisfaction) for each item on a 6 point Likert scale, ranging from 'not at all satisfied' to 'very satisfied'. The questionnaire has been shown to have good test-retest reliability and good criterion validity (Sarason et al., 1983). An example of a question is: "*Who accepts you totally, including both your worst and best points*?"

5.3.iii. Perceived Needs Scale (Quine & Pahl, 1989)

The Perceived Needs Scale, is a 22 item checklist of problems encountered by families of children with disability. Sloper & Turner (1993) used this scale with the addition of one item – help with transport problems, which made a total of 23 items. The 23-item scale was used in this study. Parents were asked to tick one of 5 options for each item (getting enough help; getting help but would like more; not getting help but need it; not getting help but do not want it; no problem). The Perceived Needs Scale has been used in previous research and has good reliability and validity (Quine & Pahl, 1989). An example of an item from this scale is: '*Information about services for your child*'.

5.3.iv. Demographic Variables:

These were employment status (employed / unemployed); marital / relationship status; age of parent; parental status (natural, step, foster, adoptive) and maternal occupational skills classified into Professional, Managerial and technical, Skilled, Partly skilled and Unskilled (Office of Population Censuses & Surveys, 1995).

5.4 Coping Strategies / Style

5.4.i. The Ways of Coping (revised) Questionnaire (Folkman & Lazarus, 1985) adapted by Knussen, et al., (1992)

This was used to measure the ways in which parents coped with problems concerning their child with disabilities. The adapted version of this questionnaire has been shown to have adequate qualities of internal reliability and validity (Knussen et al., 1992). This adapted measure contained 63 items, which respondents had to rate on a four-point Likert scale, from 'not used' to 'used a great deal'. The results were analysed using subscales proposed by Knussen et al. (1992) using a relative scoring technique (Vitaliano, Russo, Carr, Maiuro & Becker 1987). The subscales used in the analysis were practical coping, wishful thinking and seeking professional / informal support. An example of an item from this questionnaire is: '*I talk to someone to find out more about the situation.*'

CHAPTER THREE: RESULTS

OVERVIEW

The results are presented below in 3 sections; the first examining responses from 59 mothers only, the second examining the responses from 25 fathers, and the third looking at the differences between the 25 mother and father dyads.

The sections will follow the model of stress and coping, looking firstly at outcomes and then at how these are related to stressors, coping resources and coping styles. Some demographic data will also be initially examined to check for the possible impact that these may have. Analysis will include descriptive statistics, statistical data analysis and where applicable, some qualitative information.

SECTION ONE: MOTHERS ONLY

1. Outcomes

Two outcome measures were used: the Malaise Inventory and the Parenting Stress Index. The Parenting Stress Index (PSI) provides 3 scores: a child domain subscale score, a parenting domain subscale score, which together combine to yield a total stress score. In the analysis the 2 subscale scores and the total stress score from the PSI were used, with the score from the Malaise Inventory.

It was hypothesised that parents of children with cerebral palsy would show higher levels of stress than the normal population. In order to assess the nature and level of stress, descriptive statistics of outcome measures (dependent variables) were computed. These are compared to the published normative data for the outcome measures (see table 1). The difference between mothers' outcome measures and the normative data for the measures was analysed using t-tests.

Table 1. Describing Outcome Measures compared with the Normative Data.

Outcome Measure / Score	**Mothers**			**Normative Data***	
	Mean	**S D**	**Range**	**Mean**	**S D**
Malaise Inventory	5.72	4.07	0 - 16	3.2	-
PSI Total Stress	260.26	40.07	171 - 342	222.8	36.6
PSI Child Domain	121.52	23.12	70 - 171	99.7	18.8
PSI Parent Domain	138.73	20.51	93 - 177	123.1	24.4

Note: Possible ranges of scores: PSI total stress =101-505; PSI child domain =47-235; PSI parent domain =54-270; Malaise Inventory = 0-24.
** Normative data taken from Abidin (1990) (PSI); Rutter et al., (1970) (Malaise Inventory)*

In mothers, the means and standard deviations on the outcome measures were higher than the reported normative data.

Table 2. Showing Outcome Measures related to Normative Data

Outcome Measure	**t-test result**
Malaise Inventory	(t (58) = 4.756, p<.001)*
PSI Total stress	(t (56) = 5.53, p<.001)
PSI Child domain	(t (56) = 2.41, p<.01)
PSI Parent domain	(t (56) = 6.92, p<.001)

* To determine if the sample means on the Malaise Inventory are significantly different from the normative data, the mean and standard deviation are required.

However, only the mean was available for the normative data. Therefore a one-sample *t* test was used (formula below):

$$t = \frac{\bar{X} - \mu}{\sqrt{\frac{s^2}{N}}}$$

Where: t = the t statistic; X = sample mean; μ = population mean; s = sample mean; N = sample size. This requires the assumption that the normative data mean is equivalent to the population mean.

Table 2 shows that on all outcome measures mothers' scores were significantly different from the normative data.

2. Demographic Variables

Some basic demographic variables were checked to see if they had any impact upon the outcome measures. Descriptive data for these variables can be found in the method section, chapter 2. These included age of the child and time since diagnosis, which were analysed using bi-variate correlations. Neither of these variables was significantly related to the outcome measures. Child gender and ethnicity were also analysed using independent t-tests. Child gender was not significantly related to any outcome measures.

Ethnicity was found to be related to one outcome measure. On the PSI child domain the mean for the caucasian group was 118.5; S D = 22.6. For the ethnic minority group, the mean was 135.7; S D = 20.7. (*Note: Possible ranges of scores: PSI child domain = 47-235*) A t-test revealed that these scores were significantly different ($t(55) = 2.21, p<.05$).

3. Stressors

3.1 Child's Abilities

The Vineland Adaptive Behaviour Scales (VABS) were used to measure the child's abilities. The VABS comprises of 4 subscales: communication, daily living skills, socialisation and motor skills. These are combined to form the Adaptive Behaviour Composite.

It was predicted that greater overall severity of the disability would be associated with poor parental outcome, i.e. higher levels of stress. It was also hypothesised that lower levels of communication skills, functional skills, motor skills and socialisation skills would be related to poor parental outcome. These were analysed using descriptive statistics and Pearson's bi-variate correlations (see tables 3 and 4).

Table 3. Describing the child's abilities

V.A.B.S.	Mean	S D	Range
Adaptive Behaviour Composite	55.42	20.88	20 - 104
Communication Domain	67.61	27.22	21 - 122
Daily Living Skills Domain	46.59	25.47	19 - 103
Socialisation Domain	71.37	22.29	24 - 127
Motor Skills Domain	43.93	21.99	19 - 102

Note. Standard domain and composite scores: mean = 100; S D = 15.

Table 4. Showing Child's abilities related to Outcome Measures

V.A.B.S.	Malaise Inventory	PSI Total stress	PSI Child domain	PSI Parent domain
Adaptive Behaviour Composite	r = -.21	r = -.22	r = -.34**	r = -.05
Communication Domain	r = -.22	r = -.22	r = -.32**	r = -.08
Daily Living Skills Domain	r = -.22	r = -.11	r = -.20	r = .01
Motor Skills Domain	r = -.19	r = -.08	r = -.14	r = .00
Socialisation Skills Domain	r = -.11	r = -.30*	r = -.39**	r = -.15

* = $p < .05$; ** = $p < .01$; *** = $p < .001$.

Table 3 shows that as a group, the children had a wide range of adaptive behaviour and abilities within the domains. As a group, the children's skills were best in the socialisation area. Communication skills were also better than other skills. The children had lower daily living skills and their worst skill area was motor skills.

Table 4 shows that the overall severity of the disability as measured by the Adaptive Behaviour Composite was negatively correlated with the PSI child domain score.

Socialisation skills were negatively correlated with the PSI total stress score and the child domain score. Communication skills were negatively correlated with the PSI child domain score. Daily living skills and motor skills were not significantly related to any outcome measures.

Adaptive Levels

The scores for the subscales on the VABS were classified into adaptive levels: High; Moderately High; Adequate; Moderately Low and Low. The proportion of children falling into the 'Low' category for all 4 subscales, 3, 2, 1 and 0 was then computed (see table 5). This was then related to the outcome measures, using analyses of variance.

Table 5. Showing Distribution of 'Low' adaptive level on Subscales

'Low' adaptive level on:	**Frequency**	**Percentage**
4 subscales	28	47.5
3 subscales	6	10.2
2 subscales	14	23.7
1 subscale	5	8.5
0 subscales	6	10.2

Table 5 shows that the majority of children fell into the 'Low' adaptive level on all 4 subscales. Approximately one quarter were in the 'Low' adaptive level category on 2 subscales.

The number of subscales in the 'low' adaptive level were not significantly related to the Malaise Inventory (F (4,54) = .98, n.s.); the PSI total stress score (F (4,52) = 1.32, n.s.); the PSI child domain score (F (4,52) = 1.98, n.s.) and the PSI parent domain score (F (4,52) = .62, n.s.).

3.2 Child's Behaviour

The VABS includes a maladaptive behaviour domain that may only be administered to children aged 5 years or older. It yields 3 maladaptive behaviour levels: non-significant, intermediate and significant. It was predicted that behaviour problems would be associated with poor parental outcome, i.e. higher levels of stress. Table 6 shows the distribution of the maladaptive behaviour domain. Descriptive statistics are then described for these maladaptive levels related to outcome measures, in table 7.

Table 6. Showing the Distribution of the Maladaptive Behaviour Domain

Maladaptive Level	**Frequency**	**Percentage**
Non significant	9	21.4
Intermediate	14	33.3
Significant	19	45.2
Total	**42**	-

Table 6 shows that of the 42 children for whom the Maladaptive behaviour domain was completed the majority showed maladaptive behaviour at a significant level. One third of these children were in the intermediate level category.

Table 7 Showing Maladaptive Behaviour Level related to Outcome Measures

Outcome Measure / Score	**Non-significant Level**		**Intermediate Level**		**Significant Level**	
	Mean	S D	Mean	S D	Mean	S D
Malaise Inventory	3.5	4.2	6.3	5.0	6.7	3.7
PSI Total Stress	214.6	28.0	259.7	27.3	283.4	32.1
PSI Child Domain	93.5	12.4	122.0	17.3	136.5	14.2
PSI Parent Domain	121.1	18.6	137.7	15.9	146.9	20.1

Table 7 shows that for each outcome measure the mean level of stress increases with the increase in the level of behavioural problems.

Differences between the groups were examined using analyses of variance and post-hoc Bonferroni test to identify group-by-group differences. The child's behavioural problems were significantly related to the PSI total stress score in mothers (F (2,37) = 14.83, $p<.001$). The 'intermediate level' group is significantly different from the 'non-significant level' group, and the 'significant level' group is also significantly different from the 'non-significant' level group (Bonferroni, $p<.01$).

The child's behavioural problems were also significantly related to the PSI child domain stress score in mothers (F (2,37) = 22.37, $p<.001$). The 'intermediate level' group is significantly different from the 'non-significant level' group, and the 'significant level' group is significantly different from the 'non-significant level' group (Bonferroni, $p<.01$).

In addition, the child's behavioural problems were significantly related to the PSI parent domain stress score in mothers (F (2,37) = 5.42, $p<.01$). The 'significant level' group is significantly different from the 'non-significant level' group (Bonferroni, $p<.01$).

However, the child's behavioural problems were not significantly related to mother's scores on the Malaise Inventory (F (2,39) = 1.77, n.s.).

3.3 Life Events

It was hypothesised that a greater strain from life events would be associated with poor parental outcome. Descriptive statistics showed that the mean score on the life events scale was 31.32; S D = 24.58; range = 0-107. (*Note. Possible range of the scale: 0-420).* This was analysed using Pearson's bi-variate correlations (see table 8).

Table 8. Showing Life Events related to Outcome Measures

Measure	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Life events scale	r = .49***	r = .32**	r = .23	r = .37**

** = $p< .05$; ** = $p< .01$; *** = $p< .001$.*

Thus the life events scale was significantly related to the Malaise Inventory, the PSI total stress score and the PSI parent domain score.

4. Coping Resources

4.1. Personality Variables

Extraversion

It was hypothesised that higher levels of extraversion would be related to good parental outcome, i.e. lower levels of stress. Extraversion was measured using the Extraversion scale from the Eysenck Personality Inventory (EPI).

Neuroticism

It was predicted that higher levels of neuroticism would be related to poor parental outcome, i.e. higher levels of stress. Neuroticism was measured using the Neuroticism scale from the Eysenck Personality Inventory (EPI).

For the Extraversion score the mean for the group was 11.55; S D = 4.51; range = 3-20. Regarding the Neuroticism score, the mean was 9.66; S D = 4.64; range = 1-22. (*Note: Possible ranges of scores: Extraversion and Neuroticism = 0-24.)* This was analysed using Pearson's bi-variate correlations (see table 9).

Table 9. Showing Extraversion and Neuroticism related to Outcome Measures

E. P. I.	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Extraversion	r = .08	r = .00	r = .10	r = -.11
Neuroticism	r = .69***	r = .46***	r = .30*	r = .56***

* $= p< .05$; ** $= p< .01$; *** $= p< .001$.

Table 9, above, shows that mothers' Extraversion scores were not significantly related to any outcome measures. However, mothers' Neuroticism scores were significantly related to the Malaise Inventory, the PSI total stress score and the PSI parent domain score. They were related at a less significant level to the PSI child domain scores.

4.2 Social Support

Satisfaction with and availability of social support was measured using the Social Support Questionnaire (SSQ). It was predicted that higher levels of satisfaction with and availability of social support would be related to good parental outcome, i.e. lower levels of stress. Descriptive statistics showed that for the Satisfaction score the mean was 4.96; S D = 1.31; range = 0-6. For the Availability score the mean was 19.56; S D = 11.93; range = 0-54. (*Note: Possible ranges of scores: Satisfaction = 0-6; Availability = 0-54.)* This was analysed using Pearson's bi-variate correlations.

Table 10. Showing Social Support related to Outcome Measures

S.S.Q.	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Satisfaction	r = -.26*	r = -.23	r = -.15	r = -.28*
Availability	r = -.12	r = -.23	r = -.17	r = -.25*

* = *p< .05;* ** = *p< .01;* *** = *p< .001.*

Table 10 shows that the mothers' satisfaction with social support was significantly related to the Malaise Inventory and the PSI parent domain score. The availability of social support was also significantly linked to the PSI parent domain score.

4.3 Support Services

4.3.i Unmet Service Need

Unmet service need was measured using the Perceived Needs Scale (PNS). It was hypothesised that lower levels of unmet service need would be related to good parental outcome, i.e. lower levels of stress. The mean for the PNS was 7.33; S D = 4.72; range = 0-17. (*Note. Possible range of scores: 0-23.)* This was analysed using Pearson's bi-variate correlations (see table 11).

Table 11. Showing Unmet Service Need related to Outcome Measures

P.N.S.	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Unmet Service Need	r = .46***	r = .41***	r = .38**	r = .36**

* = *p< .05;* ** = *p< .01;* *** = *p< .001.*

Thus the unmet service need scale was significantly related to all outcome measures.

4.3.ii. Family 'Link' Person

Descriptive statistics were performed to examine how many families had a family 'link' person.

Table 12. Showing Distribution of Families with 'Link' Person

Family 'Link' Person	**Frequency**	**Percentage**
Present	5	8.5
Absent	43	72.9
Missing data	11	18.6

Table 12, shows the majority of mothers reported that they did not have a family 'link' person.

4.4 Maternal Employment

It was predicted that maternal employment would be related to good parental outcome, i.e. lower levels of stress. Employment status is described in table 13. Descriptive statistics are then described for employment status related to outcome measures in table 14. Differences between the groups were examined using analyses of variance.

Table 13. Showing Distribution of Maternal Employment

Employment / Unemployment	**Frequency**	**Percentage**
Full-time employment	13	22.0
Part-time employment	10	16.9
Unemployed	36	61.0

Table 13 shows that the majority of mothers did not work. Approximately one fifth of mothers worked full time and a smaller number worked part time.

Table 14. Describing Maternal Employment and relationship to Outcome Measures

Outcome Measure	**Full time**		**Part time**		**Unemployed**	
	Mean	**S D**	**Mean**	**S D**	**Mean**	**S D**
Malaise Inventory	4.2	2.6	7.9	3.8	5.6	4.3
PSI Total stress	262.0	40.0	270.2	14.8	256.8	45.0
PSI Child domain	119.8	22.3	124.3	11.9	121.3	26.0
PSI Parent domain	142.1	21.3	145.9	9.8	135.5	22.1

Table 14 shows that for the Malaise Inventory and the PSI child domain, the lowest mean scores were for the mothers in full time employment. Regarding the PSI total stress score and the PSI parent domain score, the means were lowest for the unemployed mothers. Mothers who were employed part time had the highest mean score on all outcome measures.

Maternal employment status was not significantly related to the Malaise Inventory (F (2,56) = 2.41, n.s.); the PSI total stress score (F (2,54) = .43, n.s.); the PSI child domain score (F (2,54) = .10, n.s.) and the PSI parent domain score (F (2,54) = 1.21 n.s.).

4.4.ii. Type of work; Desire to work; Partner support work

a) Exploratory analysis was completed in mothers who worked, to examine the type of work mothers undertook. This was analysed using a standard occupational classification.

Table 15. Showing Distribution of Occupation skills

Occupational Classification	**Frequency**	**Percentage**
Professional	5	21.7
Managerial and Technical	7	30.4
Skilled	8	34.8
Partly Skilled	1	4.3
Unskilled	2	8.7

Table 15 shows that the majority of mothers who worked were in ‘skilled’ employment. Approximately one third worked in ‘managerial or technical’ employment, and a further fifth worked in ‘professional’ employment.

b) In mothers who did not work, exploratory analysis was completed to examine whether they would like to work and whether their partner would support them in this (if a partner were present).

Table 16. Showing Distribution of Desire to Work and Partner Support.

Desire to work	Frequency	Percentage	Partner support	Frequency	Percentage
Yes	15	41.7	Yes	17	63.0
No	11	30.6	No	1	3.7
No preference	10	27.8	Abstain	9	33.3

Table 16 shows that of mothers who did not work, the majority said that they would like to work. Approximately one third said they did not want to work and approximately one quarter said they had no preference.

Regarding partner support, nearly two thirds of mothers said that their partner would be supportive if they wished to work. One third of mothers abstained and only one mother said that her partner would not support her.

4.5 Socio-economic Circumstances

It was hypothesised that higher levels of deprivation, would be related to poor parental outcome, i.e. higher levels of stress. Deprivation was measured by examining employment status of both parents (if there were two parents). Families were assigned to the 'employed' category if one parent or both parents were employed. The 'unemployed' category was used if a single parent was unemployed, or if both parents were unemployed. Thus category allocation was based on whether income from employment (part/full time) was being brought into the family. Table 17 shows the distribution of employment status and table 18 describes employment status related to outcome measures including t-test analysis.

Table 17. Showing Distribution of Employment Status

Employment Status	**Frequency**	**Percentage**
Employed	51	86.4
Unemployed	8	13.5

Table 18. Showing Employment Status related to Outcome Measures

Outcome Measure	**Employed**		**Unemployed**		**t-test result**
	Mean	**S D**	**Mean**	**S D**	
Malaise Inventory	5.2	3.8	8.5	4.4	(t (57) = 2.13, *p*<.05.)
PSI Total stress	258.0	38.6	275.8	49.8	(t (55) = 1.10, n.s.)
PSI Child domain	120.5	22.4	128.8	28.0	(t (55) = .89, n.s.)
PSI Parent domain	137.5	19.8	147.0	24.8	(t (55) = 1.14, n.s.)

Table 18 shows that socio-economic status, as measured by employment status, was significantly related to the Malaise Inventory.

5. Coping Strategies / Style

5.1 Use of Practical / Problem-focused Coping

It was hypothesised that greater use of practical and problem-focused coping would be related to good parental outcome, i.e. lower levels of stress.

5.2 Seeking of Professional / Informal Support

It was also hypothesised that greater seeking of professional / informal support would be related to good parental outcome, i.e. lower levels of stress.

5.3 Wishful Thinking

It was predicted that greater use of wishful thinking would be related to poor parental outcome, i.e. higher levels of stress.

These were all measured using the appropriate scales from the adapted version of the Ways of Coping (Revised) Questionnaire (WCQ). The results were analysed using descriptive statistics and Pearson's bi-variate correlations.

Table 19. Showing Relative Scores for Coping Styles

WCRQ (adapted)	Mean	S D	Range
Practical Coping	.17	.07	.0 - .37
Seeking Professional / Informal Support	.22	.08	.0 - .08
Wishful thinking	.11	.06	.0 -.32

Note: Possible range of scores: 0-1

Table 20. Showing Coping Styles related to Outcome Measures

WCRQ (adapted)	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Practical Coping	r = -.11	r = -.31*	r = -.24	r = -.34**
Seeking Professional / Informal Support	r = -.40**	r = -.35**	r = -.21	r = -.43***
Wishful thinking	r = .48***	r = .39**	r = .30*	r = .42***

* = $p < .05$; ** = $p < .01$; *** = $p < .001$.

Table 20 shows that practical coping was negatively correlated with the PSI parent domain score and the PSI total stress score. Regarding seeking professional / informal support, this was negatively correlated with the PSI parent domain, the PSI total stress score and the Malaise Inventory. Wishful thinking was positively correlated with all outcome measures.

6. Multiple Regression Path Analysis

To obtain information about the relative impact of the independent variables on the dependent (outcome) variables a linear multiple regression path analysis was completed. This analysis was also used to elucidate the relationships between the groups of independent variables presented in the model of stress and coping. The following variables were selected from within the groupings of the model:

Table 21. Showing variables entered into the multiple regression path analysis

Outcome Variables	**Coping resources**	**Coping Strategies / Style**	**Stressors**
• Malaise Inventory • PSI Total Score	• Extraversion • Neuroticism • Unmet service need • Maternal employment status • Socio-economic status • Satisfaction score (SSQ)	• Practical coping • Seeking support (Professional & informal) • Wishful thinking	• Child's global ability score • Child's behaviour score • Parental life events

The path analysis was conducted by regressing each variable on those that it could precede in an assumed causal sequence (Davis, 1985, provides a rationale and review of this procedure). Thus the outcome variables were regressed on all prior variables, coping resources on all except the outcome variables, and coping strategies on stressors.

Variables which did not present a significant relationship to the variable under test were discarded and the analysis re-run. This process was repeated until only significant variables remained. Paths reliable at $p<.05$ and above are reported. These relationships are presented graphically in a path diagram, at the end of the section.

The arrows between variables indicate the direction of causation, and numbers written on the arrows represent effects in the form of regression coefficients, or rather in this case, path coefficients. The causal ordering, as specified by the path diagram, is derived from the model of stress and coping and not from the data.

The results showed a direct path from life events to the Malaise Inventory outcome measure ($\beta = .31, p<.001$). Neuroticism had a direct effect on the Malaise Inventory outcome measure ($\beta = .60, p<.001$). These two variables accounted for 58% of the variance on the Malaise Inventory.

A direct effect was observed for the coping strategy practical coping, on the Parenting Stress Index ($\beta= -.31, p<.01$). This was an inverse association, which accounted for 9% of the variance on the PSI.

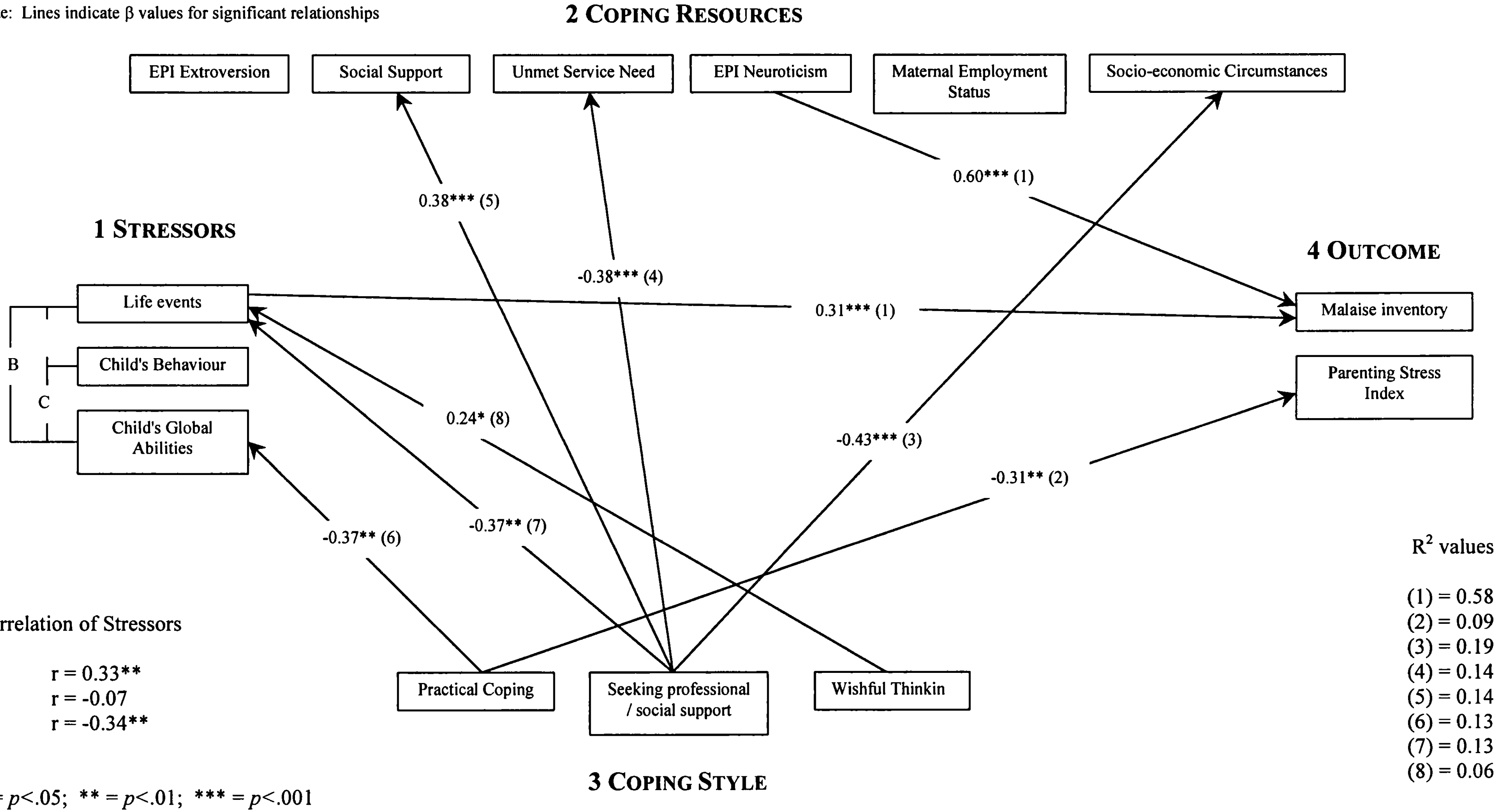
The remainder of the path model refers to the relationships between the independent variables. The coping strategy seeking professional / informal support was inversely associated with unemployment (socio-economic status) ($\beta = -.43, p<.001$), accounting for 19% of the variance. It was also inversely associated with the Perceived Needs Scale ($\beta = -.38, p<.001$), accounting for 14% of the variance. Seeking professional / informal support was positively associated with the satisfaction score from the Social Support Questionnaire ($\beta = .38, p<.001$), accounting for 14% of the variance. It was also inversely associated with life events ($\beta = -.37, p<.01$), accounting for 13% of the variance.

Wishful thinking was positively associated with life events (β = .24, p<.05). Practical coping was inversely associated with the child's overall abilities (β = -.37, p<.01), which accounted for 13% of the variance.

Correlations of stressors showed that parental life events was positively correlated with the child's behaviour (r = .33, p<.01) and that the child's global abilities were negatively correlated with the child's behaviour (r = -.34, p<.01).

Results of Multiple Regression Path Analysis

Note: Lines indicate β values for significant relationships



Correlation of Stressors

A r = 0.33**
B r = -0.07
C r = -0.34**

$* = p<.05$; $** = p<.01$; $*** = p<.001$

R^2 values

(1) = 0.58
(2) = 0.09
(3) = 0.19
(4) = 0.14
(5) = 0.14
(6) = 0.13
(7) = 0.13
(8) = 0.06

SECTION TWO: FATHERS

1. Outcomes

It was hypothesised that parents of children with cerebral palsy would show higher levels of stress than the normal population. Descriptive statistics shows the nature and level of stress in fathers, on outcome measures. These are compared to the published normative data for the outcome measures (see table 22).

Table 22. Describing Outcome Measures compared with the Normative Data.

Outcome Measure / Score	Fathers			Normative Data *	
	Mean	**S D**	**Range**	**Mean**	**S D**
Malaise Inventory	4.6	4.3	0-21	3.2	-
PSI Total Stress	249.0	51.1	179-347	222.8	36.6
PSI Child Domain	116.7	24.3	70-157	99.7	18.8
PSI Parent Domain	132.3	30.6	78-190	123.1	24.4

Note: Possible ranges of scores: PSI total stress =101-505; PSI child domain =47-235; PSI parent domain =54-270; Malaise Inventory = 0-24.

** Normative data taken from Abidin (1990) (PSI); Rutter et al., (1970) (Malaise Inventory)*

The mean results for outcome measures in fathers were generally higher than the reported normative data.

Table 23. Showing Outcome Measures related to Normative Data

Outcome Measure	**t-test result**
Malaise Inventory	(t (24) = 1.62, n.s.)*
PSI Total stress	(t (24) = 3.01, p<.01)
PSI Child domain	(t (24) = 2.94, p<.01)
PSI Parent domain	(t (24) = .55, n.s.)

* A one-sample *t* test was used in this analysis (see section one for details).

Thus table 23 shows that for fathers the PSI total stress score and the PSI child domain score were significantly different from the normative data.

2. Demographic Variables

Some basic demographic variables were checked to see if they had any impact upon the outcome measures. These included age of the child and time since diagnosis, which were analysed using bi-variate correlations. Gender of the child and ethnicity were also analysed, using independent t-tests. None of these variables were significantly associated with any of the outcome measures. Thus these variables will not be considered further in the analysis.

3. Stressors

3.1 Child's Abilities

It was predicted that greater overall severity of the disability would be associated with poor parental outcome, i.e. higher levels of stress. It was also hypothesised that lower levels of communication skills, functional skills, motor skills and socialisation skills would be related to poor parental outcome. The child's abilities as measured by the Vineland Adaptive Behaviour Scales are described in the table below. These were analysed using Pearson's bi-variate correlations (see table 25).

Table 24. Describing the child's abilities

V.A.B.S.	Mean	S D	Range
Adaptive Behaviour Composite	60.0	18.6	20-93
Communication Domain	76.7	26.9	21-122
Daily Living Skills Domain	51.4	24.8	19-103
Socialisation Domain	80.0	21.3	28-127
Motor Skills Domain	45.4	19.5	19-79

Note. Standard domain and composite scores: mean = 100; S D = 15.

Table 24 shows that as a group the children had a wide range of adaptive behaviour and abilities within the domains. As a group the children's skills were best in the socialisation and communication areas. The children had lower levels of daily living skills and motor skills.

Table 25. Showing Child's abilities related to Outcome Measures

V.A.B.S.	Malaise Inventory	PSI Total stress	PSI Child domain	PSI Parent domain
Adaptive Behaviour Composite	r = -.11	r = -.43*	r = -.51**	r = -.31
Communication Domain	r = -.03	r = -.40*	r = -.49**	r = -.28
Daily Living Skills Domain	r = -.36	r = -.39*	r = -.34	r = -.38
Motor Skills Domain	r = -.20	r = -.28	r = -.32	r = -.21
Socialisation Skills Domain	r = -.03	r = -.35	r = -.40*	r = -.27

* = $p< .05$; ** = $p< .01$; *** = $p< .001$.

Table 25 shows that the overall severity of the disability as measured by the adaptive behaviour composite, was significantly related to the PSI child domain score and to the PSI total stress score.

Communication skills were negatively correlated with the PSI child domain score and the PSI total stress score. Daily living skills were negatively correlated with the PSI total stress score. Socialisation skills were also negatively correlated with the PSI child domain score. Motor skills were not significantly related to any outcome measures.

Adaptive Levels

The scores for the subscales on the VABS were classified into adaptive levels: High; Moderately High; Adequate; Moderately Low and Low. The proportion of children falling into the 'Low' category for all 4 subscales, 3, 2, 1 and 0 was then computed (see table 26). This was then related to the outcome measures using analysis of variance.

Table 26. Showing Distribution of Low adaptive level on Subscales

'Low' adaptive level on:	**Frequency**	**Percentage**
4 subscales	7	28
3 subscales	4	16
2 subscales	9	36
1 subscale	2	8
0 subscales	3	12

Table 26 shows that approximately one third of children fell into the 'Low' adaptive level on 2 subscales, and roughly one quarter fell into the 'Low' adaptive level on all 4 subscales.

The number of subscales in the 'low' adaptive level were not significantly related to the Malaise Inventory (F (4,20) = .44, n.s.); the PSI total stress score (F (4,19) = .39, n.s.); the PSI child domain score (F (4,19) = .77, n.s.) and the PSI parent domain score (F (4,19) = .14, n.s.).

3.2 Child's Behaviour

It was predicted that behaviour problems would be associated with poor parental outcome, i.e. higher levels of stress. The child's behaviour as measured by the Vineland Adaptive Behaviour Scales are described in the table below. Differences between the groups were examined using analyses of variance.

Table 27. Showing the Distribution of the Maladaptive Behaviour Domain

Maladaptive Level	**Frequency**	**Percentage**
Non significant	4	28
Intermediate	6	42
Significant	4	28
Total	**14**	-

Table 27 shows that the Maladaptive behaviour domain was completed for 14 children. The majority of these showed maladaptive behaviour at the intermediate level.

Table 28. Showing Maladaptive Behaviour Level related to Outcome Measures

Outcome Measure / Score	**Non-significant Level**		**Intermediate Level**		**Significant Level**	
	Mean	S D	Mean	S D	Mean	S D
Malaise Inventory	4	2.9	7	7.3	6.3	3.0
PSI Total Stress	230.8	13.4	260.7	61.3	289.3	29.6
PSI Child Domain	101.8	11.3	120.5	30.1	141.0	6.9
PSI Parent Domain	129.0	16.1	140.2	33.7	148.3	23.5

The child's behavioural problems were not significantly related to the Malaise Inventory (F (2,11) = .38, n.s.); the PSI total stress score (F (2,10) = 1.41, n.s.); the PSI child domain score (F (2,10) = 2.64, n.s.); and the PSI parent domain score (F (2,10) = .44, n.s.).

3.3 Life Events

The life events scale was completed individually by mothers and fathers. Descriptive statistics showed that the mean was 32.9; S D = 30.9; range = 1-130 (*Note. Possible range of the scale: 0-420).* It was hypothesised that greater strain from life events would be associated with poor parental outcome. This was analysed using Pearson's bi-variate correlations (see table 29).

Table 29. Showing Life Events related to Outcome Measures

Measure	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Life events scale	r = .61***	r = .35	r = .14	r = .47**

* = $p < .05$; ** = $p < .01$; *** = $p < .001$.

Thus the life events scale was significantly related to the Malaise Inventory and to the PSI parent domain score.

4. Coping Resources

4.1. Personality Variables

Extraversion

It was hypothesised that higher levels of extraversion would be related to good parental outcome, i.e. lower levels of stress

Neuroticism

It was predicted that higher levels of neuroticism would be related to poor parental outcome, i.e. higher levels of stress.

For the Extraversion score, the mean for the group was 12.8; S D = 4.6; range = 5-20. Regarding the Neuroticism score, the mean was 8.2; S D = 5.6; range = 0-21. (*Note: Possible ranges of scores: Extraversion and Neuroticism = 0-24.*) This was analysed using Pearson's bi-variate correlations (see table 30).

Table 30. Showing Extraversion and Neuroticism related to Outcome Measures

E. P. I.	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Extraversion	r = .02	r = .28	r = .13	r = .37
Neuroticism	r = .73***	r = .51**	r = .34	r = .59**

* = *p*< *.05;* ** = *p*< *.01;* *** = *p*< *.001 .*

Table 30 shows that the father's Extraversion score was not significantly related to any outcome measures. However, the father's Neuroticism score was significantly related to the Malaise Inventory, the PSI total stress score and the PSI parent domain score.

4.2 Social Support

It was predicted that higher levels of satisfaction with and availability of social support would be related to good parental outcome, i.e. lower levels of stress. Descriptive statistics showed that for the Satisfaction score, the mean was 5.2; S D = 1.0; range = 3-6. For the Availability score, the mean was 18.4; S D = 12.5; range = 3-49. (*Note. Possible ranges of scores: Satisfaction = 0-6; Availability = 0-54.)* This was analysed using Pearson's bi-variate correlations.

Table 31. Showing Social Support related to Outcome Measures

S.S.Q.	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Satisfaction	r = -.28	r = .01	r = .30	r = -.22
Availability	r = -.39	r = .06	r = -.03	r = .12

* = *p*< *.05;* ** = *p*< *.01;* *** = *p*< *.001.*

Table 29 shows that the father's satisfaction with and availability of social support was not significantly related to any outcome measures.

4.3 Support Services

4.3.i Unmet Service Need

It was hypothesised that lower levels of unmet service need would be related to good parental outcome, i.e. lower levels of stress. The mean for the PNS was 8.9; S D = 6.0; range = 0-23. (*Note. Possible range of scores: 0-23.)* This was analysed using Pearson's bi-variate correlations.

Table 32. Showing Unmet Service Need related to Outcome Measures

P.N.S.	**Malaise Inventory**	**PSI Total stress**	**PSI Child domain**	**PSI Parent domain**
Unmet Service Need score	r = .51**	r = .49**	r = .44*	r = .47*

* = $p < .05$; ** = $p < .01$; *** = $p < .001$.

Thus the unmet service need scale was significantly related to the Malaise Inventory and the PSI total stress score ($p<.01$). It was also significantly related to a slightly lesser extent to the PSI child domain and parent domain scores ($p<.05$).

4.5 Socio-economic Circumstances

It was hypothesised that higher levels of deprivation, would be related to poor parental outcome, i.e. higher levels of stress. All the families of fathers participating fell into the 'employed' category and therefore further analysis with outcome measures was not possible.

5. Coping Strategies / Style

5.1 Use of Practical / Problem-focused Coping

It was hypothesised that greater use of practical and problem-focused coping would be related to good parental outcome, i.e. lower levels of stress.

5.2 Seeking of Professional / Informal Support

It was also hypothesised that greater seeking of professional / informal support would be related to good parental outcome, i.e. lower levels of stress.

5.3 Wishful Thinking

It was predicted that greater use of wishful thinking would be related to poor parental outcome, i.e. higher levels of stress.

These measures were analysed using descriptive statistics and Pearson's bi-variate correlations (see tables 33 and 34).

Table 33 Showing Relative Scores on Coping Styles.

WCRQ (adapted)	**Mean**	**S D**	**Range**
Practical Coping	.22	.06	.12 - .37
Seeking Professional / Informal Support	.18	.08	.00 - .29
Wishful thinking	.11	.05	.01 - .18

Note: Possible range of scores: 0-1

Table 34. Showing Coping Styles related to Outcome Measures

WCRQ (adapted)	Malaise Inventory	PSI Total stress	PSI Child domain	PSI Parent domain
Practical Coping	r = -.11	r = -.45*	r = -.33	r = -.48**
Seeking Professional / Informal Support	r = -.15	r = -.29	r = -.13	r = -.39*
Wishful thinking	r = .19	r = .39*	r = .24	r = .45*

** = p< .05; ** = p< .01; *** = p< .001.*

The table above shows that practical coping was negatively correlated with the PSI parent domain score and the PSI total stress score. Seeking professional / informal support was negatively correlated with the PSI parent domain. Wishful thinking was positively correlated with the PSI parent domain and total stress score.

6. Multiple Regression Path Analysis

A linear multiple regression path analysis was performed on the variables in the same way as for the mothers. Only one relationship appeared to be significant. Neuroticism showed a positive association with the Malaise Inventory outcome measure ($\beta = .73$, $p <. 001$, $R^2 = .54$). This direct effect accounted for 54% of the variance in the Malaise Inventory.

SECTION THREE: MOTHER AND FATHER DYADS

The 25 mother and father dyads were analysed to investigate whether there were any significant differences between mothers and fathers. Analysis was performed on measures that may be considered to be more independent of the child.

1. Outcomes

Mothers and fathers were compared on outcome measures using descriptive statistics and t-tests.

Table 35. Describing Mother and Fathers on Outcome Measures.

Outcome Measure / Score	**Mothers**		**Fathers**	
	Mean	**S D**	**Mean**	**S D**
Malaise Inventory	5.7	4.2	4.6	4.3
PSI Total Stress	251.5	38.9	249.0	51.1
PSI Child Domain	113.3	22.3	116.7	24.3
PSI Parent Domain	138.1	19.5	132.3	30.6

Note: Possible ranges of scores: PSI total stress =101-505; PSI child domain =47-235; PSI parent domain =54-270; Malaise Inventory = 0-24.

Table 35 shows that on the outcome measures, mothers generally showed higher levels of stress than fathers (apart from the PSI child domain score).

Table 36. Showing Mothers compared to Fathers on Outcome Measures

Outcome Measure	t-test result
Malaise Inventory	(t (48) = .92, n.s.)
PSI Total stress	(t (47) = .19, n.s.)
PSI Child domain	(t (47) = .50, n.s.)
PSI Parent domain	(t (47) = .79, n.s.)

Table 36 shows that there were no significant differences between mothers and fathers on outcome measures.

2. Stressors

2.1 Life Events

Descriptive statistics of the life events scale showed that the mean for mothers was 28.4; S D = 19.11. For fathers the mean was 32.9; S D = 30.97. A t-test revealed that these scores were not significantly different (t (48) = .62, n.s.).

3. Coping Strategies

3.1 Personality Variables

Extraversion

Descriptive statistics showed that on the extraversion score of the EPI, for mothers the mean was 11.4; S D = 4.2. For fathers, the mean was 12.8; S D = 4.6. A t-test revealed that fathers and mothers were not significantly different on extraversion scores (t(48) = 1.12, n.s.).

Neuroticism

On the neuroticism score of the EPI, the mean for mothers was 10.7; S D = 5.4. For fathers, the mean was 8.2; S D = 5.6. A t-test revealed that fathers and mothers were not significantly different on neuroticism scores (t(48) = 1.65, n.s.).

3.2 Social Support

Satisfaction

Descriptive statistics showed that on the satisfaction scale of the social support questionnaire the mean for mothers was 5.2; S D = 0.8. For fathers the mean was 5.2; S D = 1.0. These scores were not significantly different (t(45) = .10; n.s.).

Availability

Descriptive statistics showed that on the availability scale of the social support questionnaire the mean for mothers was 18.5; S D = 9.2. For fathers the mean was 18.4; S D = 12.5. These scores were not significantly different (t(45) = .03; n.s.).

4. Coping Strategies

4.1 Practical Coping

Descriptive statistics showed that the mean for mothers was .17; S D = .07. For fathers the mean was .21; S D = .06. These were significantly different (t(48) = 2.26, p<.05).

4.2 Seeking Professional / Informal Support

The mean score for mothers was .22; S D = .07; and the mean score for fathers was .17; S D = .08. These were significantly different (t(48) = 2.24, p<.05).

4.3 Wishful Thinking

The mean score for mothers was .13; S D =.06; and the mean score for fathers was .10; S D = .04. These were not significantly different (t(48) = 1.63, n.s.).

CHAPTER FOUR: DISCUSSION

OVERVIEW

This chapter will initially provide a brief summary of the research questions, and main findings of the study. It will then discuss and interpret the findings of the research. A discussion of the limitations of the study will then follow with some suggestions for future research. Finally the implications of this research are outlined.

A note of caution. This study reports results as being significant at the $p<.05$ level of significance. In considering the non-independent data of mothers and fathers and the somewhat exploratory nature of the study this is a generous way of examining the data. A more cautious approach would be to reduce the level of significance to $p<.01$.

SECTION ONE: SUMMARY OF RESEARCH QUESTIONS AND MAIN FINDINGS

1. Outcome

It was hypothesised that the parents of children with cerebral palsy would show higher levels of stress than the normal population, on the Malaise Inventory and the Parenting Stress Index. For mothers, all outcome measures were significantly higher than the normal population. Fathers were significantly higher than the population norms for overall parenting stress and the parenting stress from the characteristics of the child.

2. Demographic Variables

The data was checked for the effects of demographic variables on outcome measures. Mothers from ethnic minorities were found show higher levels of parenting stress from characteristics within the child.

3. Stressors

3.1 Child's Overall Abilities

It was predicted that greater overall severity of disability would be associated with poor parental outcome, i.e. higher levels of stress. For mothers and fathers the child's overall level of ability was negatively correlated with parenting stress from characteristics of the child. For fathers it was also negatively correlated with total parenting stress.

3.2 Child's Specific Abilities

It was hypothesised that lower levels of communication skills, functional skills, motor skills and socialisation skills would also be related to poor parental outcome.

Socialisation skills were negatively correlated with parenting stress from characteristics of the child in both mothers and fathers, and also to the total parenting stress in mothers.

Communication skills were negatively correlated to parenting stress from characteristics of the child in both mothers and fathers, and also to total parenting stress in fathers.

Functional / daily living skills were only negatively correlated to total parenting stress in fathers.

Motor skills were not significantly related to any outcome measures.

3.3 Child's Behaviour

It was predicted that behavioural problems would be associated with poor parental outcome. In mothers this was significantly related to the total parenting stress, and stress from parental / situational, as well as child characteristics. For fathers there was no significant association with the child's behaviour.

3.4 Life Events

It was hypothesised that greater strain from life events would be associated with poor parental outcome. This was positively correlated with the Malaise Inventory and the stress from parental / situational characteristics for both mothers and fathers. For mothers it was also significantly related to the total parenting stress. In mothers life events significantly predicted stress on the Malaise Inventory.

4. COPING RESOURCES

4.1 Personality

4.1.i. It was predicted that higher levels of extraversion would be related to good parental outcome, i.e. lower levels of stress. This was not significantly related to outcome measures in mothers or fathers.

4.1.ii. It was hypothesised that higher levels of neuroticism would be associated with poor parental outcome. For both mothers and fathers this was significantly related to the Malaise Inventory, total parenting stress and parenting stress from parental / situational characteristics. In mothers it was also significantly associated, to a lesser degree, with the parenting stress from the characteristics within the child. For both mothers and fathers neuroticism significantly predicted stress on the Malaise Inventory.

4.2 Social Support

It was predicted that higher levels of satisfaction and availability of social support would be associated with good parental outcome. In mothers satisfaction with social support was negatively correlated with the Malaise Inventory and parenting stress emanating from parental / situational characteristics. Availability of social support was also negatively correlated with parenting stress from parental / situational characteristics in mothers. For fathers social support was not significantly associated with outcome measures.

4.3 Support Services

4.3.i. It was hypothesised that lower levels of unmet service need would be associated with good parental outcome. This was positively correlated with all outcome measures for both mothers and fathers.

4.3.ii. The majority of families in the study said they did not have a family 'link' person.

4.4 Maternal Employment

4.4.i. It was predicted that maternal employment would be related to good maternal outcome. However, maternal employment, whether full or part time, was not significantly associated with any outcome measures.

4.4.ii.a) Mothers who worked mostly undertook skilled employment. Large proportions of the mothers in the sample also worked in managerial and technical as well as professional employment.

4.4.ii.b) The majority of mothers who did not work said they would like to work. A large majority of mothers also said that their partner would support them in their desire to work.

4.5 Socio-economic circumstances

It was hypothesised that higher levels of deprivation, as measured by employment status, would be related to poor parental outcome. For mothers, socio-economic status was related to the Malaise Inventory. Analysis for fathers was not possible.

5. Coping Strategies / Style

5.1. Practical Coping

It was predicted that greater use of practical coping strategies would be related to good parental outcome. This was negatively correlated with total parenting stress and parenting stress from the parental / situational characteristics for both mothers and fathers.

5.2 Seeking Professional / Informal Support

It was hypothesised that greater seeking of professional / informal support would be associated with good parental outcome. In mothers and fathers this was negatively correlated with parenting stress from the characteristics of the parent / situation. For mothers it was also negatively correlated with total parenting stress and the Malaise Inventory.

5.3 Wishful Thinking

It was predicted that greater use of wishful thinking would be related to poor parental outcome. In mothers this was positively correlated with all outcome measures. In fathers it was positively correlated with parenting stress emanating from characteristics of the parent / situation and overall parenting stress.

6. Mother And Father Dyads

Analysis of the mother and father dyads showed that there were no differences in outcome measures. Analysis of independent variables revealed that mothers and fathers were significantly different in their use of coping strategies: specifically practical coping and seeking professional / informal support.

SECTION TWO: INTERPRETATION OF THE FINDINGS

1. Outcome

This study found that mothers were significantly more stressed than the normal population. Fathers were also found to have more overall stress from parenting and parenting stress from characteristics of the child. These results are consistent with the findings of Philp & Duckworth (1982), amongst others, who have shown that parents of children with disabilities are more likely to suffer stress as well as anxiety and depression than other parents. The fact that the results for fathers were not as significant as the results for the mothers may reflect the differences in the parental roles where the mother may be shouldering the main burden of care for the disabled child. It may also reflect the small number of fathers in the study.

2. Demographic Variables

Mothers who were from ethnic minority groups were found to have significantly more parenting stress from characteristics within the child than parents from non-ethnic minority groups. This may be related to findings from previous research studies, which have shown that parents from ethnic minorities in particular, do not receive all the services to which they are entitled (e.g. Murray, 1992). In considering this it is important to be mindful of the way in which formal support services are accessed. It usually involves parents making the initial action to instigate some input from services. Parents from ethnic minority groups may not only have difficulties speaking and reading English, but may also be unaware of the general functioning of the healthcare and related systems.

The child with cerebral palsy could also be considered as facing a double stigma in not only having a physical and / learning disability, but also coming from an ethnic minority group.

Further research is needed to explore ways in which ethnicity may be linked to parenting stress. The absence of similar findings in fathers in this study, again, may be related to the difference in parental roles and / or the small numbers of fathers in the study.

3. Stressors

3.1 Child's Overall Abilities

There was a wide range of abilities within the group of children with cerebral palsy. In both mothers and fathers the severity of the disability was related to parenting stress, particularly from factors within the child. In mothers it was also related to parenting stress as a whole. This is supportive of Sloper & Turner's (1993) findings, in research with physical disability, and does not corroborate the findings of Wallander, Pitt & Mellins (1990). In examining the origins of the parenting stress it was emanating from the child, which may be expected in a child with disabilities who may require more of the parents' time and energy than other children. The severity of the disability was also indicative of parenting stress as a whole in fathers but not mothers. The reason for this difference is unclear.

The children were split into groups according to the number of domains that fell into the ‘Low’ adaptive level. For the mothers the majority of children fell into the ‘Low’ adaptive level on all 4 domains. Regarding fathers, the majority of children were in the ‘Low’ adaptive level on 2 domains. This was not related to outcome measures.

3.2 Child's Specific Abilities

Within the group of children with cerebral palsy, there was a wide range of abilities in each of the different skill areas. As a group the children’s skills were best in the communication and socialisation areas, which is consistent with Graham's (1986) clinical description of verbal skills being more highly developed than non-verbal skills.

With respect to socialisation skills, this study found that in both fathers and mothers low socialisation skills were predictive of parenting stress from characteristics within the child. Low socialisation skills were also related to total parenting stress in mothers. These are interesting findings, which have not previously been reported to be indicative of poor parental outcome. It appears that socialisation skills are not generally measured in research studies of this nature. It may demonstrate the fact that socialisation skills are an important aspect of functioning in children with disabilities, which has been somewhat overlooked. This would support the need for using comprehensive measures of functioning such as the Vineland Adaptive Behaviour Scales. Further research into socialisation skills would be required to corroborate these findings.

The communication skills of the child were predictive of parenting stress in both mothers and fathers, and more specifically stress from characteristics within the child. In fathers it was also related to overall parenting stress. These results support the findings from Frey et al., (1989) in their study with children with physical disabilities. The fact that low communication skills was indicative of overall parenting stress in fathers may reflect the differences in parental roles. If the mother is mostly caring for the child with disabilities, then it may be that the most salient deficit impacting upon the father are the child's communication skills.

Regarding functional skills, this study found that low functional skills were related to the overall parenting stress in fathers. In research with children with severe learning difficulties Sloper et al., (1991) amongst others found that functional skills appear to be predictive of poor outcome. Approximately half of children with cerebral palsy also have learning difficulties in addition to the physical disabilities. Therefore, the research into children with learning disabilities can also be applicable to this sample of children with cerebral palsy. However, it is unclear why low functional skills was predictive of parenting stress in fathers but not mothers.

Motor skills did not appear to be significantly related to any measures of stress in mothers or fathers. It may be that motor abilities *per se* are less important than other skill deficits in the impact they have on outcome in parents.

3.3 Child's Behaviour

In the children aged 5 years and above 45% had significant behaviour problems, which is consistent with Rutter et al., (1970b) who reported a 40% rate of behavioural problems in children with cerebral palsy.

The results showed that behaviour problems in the child were predictive of overall parenting stress in the mother. It was also predictive of parenting stress from characteristics within the child and parent / situation. In research with children with learning disabilities, Sloper et al., 1991, amongst others, also found that behaviour problems were related to poor parental outcome. Although these findings have not been supported in research into physical disability, this may reflect the fact that cerebral palsy is often concomitant with learning disabilities. Moreover, it may reflect something more specific about cerebral palsy itself. The absence of any relationship between the child's behaviour problems and outcome in fathers may result from the fact that the Maladaptive behaviour domain could only be administered to children aged 5 and over. This, coupled with the small number of fathers in this study, may account for the difference.

3.4 Life Events

This study found that a greater strain from life events was related to poor parental outcome, in mothers and fathers, on a measure of emotional distress (Malaise Inventory). A greater strain from life events was also related to parenting stress from parental and situational characteristics in both mothers and fathers and overall parenting stress in mothers. These results support the recent findings from research in both learning difficulties (Sloper et al., 1991) and physical disabilities (Sloper & Turner, 1993). It appears that parental life events produce greater emotional distress than other stressors. This is somewhat understandable from a parent-related as opposed to a child-related stressor. In looking at parenting stress life events was also related to parenting stress from parental / situational characteristics, which would also be consistent with a parent-related stressor. For mothers it was also related to overall parenting stress, which may be related to the fact that they are usually the main carers for the child. A greater strain from life events may impact upon the mother's parenting role, rendering this in turn more stressful. In the path analysis, life events were found to significantly predict emotional distress in mothers. Thus life events are an important stressor when considering parental well being.

4. Coping Resources

4.1 Personality

4.1.i. This study did not find that extraversion was associated with good parental outcome, i.e. lower levels of stress. There has been limited research into extraversion and how this may affect parents. Extraversion was found to be positively associated with maternal adaptation (Sloper & Turner, 1993) and acceptance of a physically disabled child. The parents' acceptance of the child is measured within the Child domain of the Parenting Stress Index, although this forms only one of the subscales within this domain. The lack of significant findings in this study may be related to the small sample size.

4.1.ii. Neuroticism was associated with emotional distress and overall parenting stress, including stress from parental / situational characteristics in both mothers and fathers. In mothers it was also significantly related, although to a lesser extent, to parenting stress from characteristics of the child. These findings support research by Sloper et al., (1991) who found that with parents of children with learning difficulties neuroticism significantly predicted mental and physical health as well as satisfaction with life for both mothers and fathers. In the path analysis neuroticism had a direct effect on emotional distress for both mothers and fathers. Thus neuroticism is an important predictor of emotional distress. Longitudinal research on personality and stress (Bolger, 1990) seems to indicate that neuroticism increases vulnerability and reactivity to stressful events. Bolger (1990) found that neuroticism was related to the amount of wishful thinking and self-blame coping strategies, although this was not found to be a significant relationship in the path analysis.

4.2 Social Support

This study found that in mothers decreased satisfaction with social support was associated with emotional distress, and parenting stress from parental / situational characteristics. A decrease in the availability or number of social supports was related to parenting stress again from parental / situational characteristics. In fathers there was no significant relationship between social support and outcome measures. Despite some significant results these are not as significant as one would expect from the literature on results from previous studies.

Quine & Pahl (1985), amongst others, found that lack of social support can be one of the most stressful factors in caring for a disabled child. In families of children with learning difficulties the severity of behaviour problems was related to the size of the parents' formal and informal support networks (McGrath & Grant, 1993). Sloper & Knussen (1991), amongst others, have found that spousal support appears to be the most significant form of social support predicting positive outcome. Beresford & Lawton (1993) also demonstrated the importance of the extended family.

However, this study used a measure of social support (SSQ), which only measures support resources and support appraisal. However, an important aspect of social support is the support mode (Vaux, 1992). People can help each other in a variety of ways, which may involve different activities and serve different functions. It is generally considered that approximately six modes of support can be identified: financial support; practical assistance; advice / guidance; emotional support; social reinforcement and socialising (Vaux, 1992). Specifying support modes is crucial, since help is context-specific. However, the SSQ does not distinguish which modes of support are sampled. It provides a broad sampling of situations, although most of these are related to emotional support. Thus, the SSQ may be somewhat crude in measuring the construct of social support. Specific measurement of the different modes of social support may have proved useful.

The fact that social support did not appear to be related to outcome in fathers may again be linked to the mother's role in usually caring for the disabled child. If the mother carries the main burden of care for the child, it may well be that social support is a more important coping resource for her than for the father. Of course, the absence of a significant relationship may also reflect the small number of fathers in the sample.

4.3 Support Services

4.3.i. The findings from this study showed that increases in unmet service need were positively correlated with all outcome measures for both mothers and fathers. This demonstrates that services are a crucial area in considering the stress associated with parenting a disabled child and the emotional impact that this has. In mothers the results were more powerful than in fathers, which may again reflect mothers' roles within the family. Sloper & Turner (1991) also found that in families of children with learning difficulties levels of unmet service need were more strongly related to maternal adaptation than the total number of needs, whether or not the needs were met. They concluded, therefore, that services can have a positive effect on maternal adaptation.

4.3.ii. The provision of a 'link' person was recommended in a number of official reports (Warnock Report, DES, 1978) to provide the most appropriate mix and timing of services for individual families. This study found that over 70% of families reported that they did not have a 'link' person. Sloper & Turner (1991) found that 45% of families did not have access to such a person. Furthermore, this study found that fewer than 10% of families reported having a 'link' person and approximately 20% did not answer the question. It may be that parents did not answer the question because they had not heard of such a service provision. Thus it appears that services are still not following the recommended guidelines. However, further research would be needed to examine the reasons for this.

4.4 Maternal Employment

4.4.i. This study found that maternal employment was not related to any outcome measures. This does not support the findings of amongst others, Hirst (1984) who have found that maternal employment was predictive of well being.

The lack of significant results may be related to low-power, i.e. there was a poor chance of detecting an effect that was actually present. The sample was split into 3 subgroups and the distribution of the sample was such that that there were only small numbers of mothers in the full and part-time groups, with the majority of mothers falling into the unemployed group. Thus larger subgroups of full and part-time employed mothers would be needed to increase the chance of detecting an effect. Hence, the results may overlook some important effects of maternal employment status, and thus it cannot be assumed that these findings are representative of the population.

4.4.ii. a) In mothers who worked the majority of mothers undertook 'skilled' work, which encompasses such jobs as clerical and secretarial work. However, approximately half of the mothers that worked had professional or technical / managerial positions. These jobs may be somewhat demanding, thus potentially adding to the stress of parenting a child with disabilities. This could account for the findings of increased stress in mothers in this study. It is possible that jobs which are less demanding may have quite a different impact upon mothers.

4.4.ii.b) In mothers who did not work, the majority expressed a desire to work. However, a large proportion of mothers said they did not wish to work and another large percentage abstained. Pahl & Quine (1987) found that the reason for wanting to work in employed mothers was to increase social contact and to have a break from the burden of caring for a disabled child. In the light of the findings in this study it would have also been helpful to ask working mothers if they were happy with their employment status.

In mothers who did not work and who were living with partners, the majority said that their partner would support them in their desire to work. However, a large proportion of mothers abstained from answering this question. The reasons for this are unclear. With hindsight, it would have been helpful to ask working mothers whether their partner would support them in stopping or reducing work if they wished to do so.

It seems that this question regarding partner support may have been somewhat ambiguous. Partner support could refer to specific encouragement in obtaining employment and / or support in the household chores and / or the care of the disabled child. With this lack of clarity, it is difficult to conclude anything meaningful.

4.5 Socio-economic circumstances

This study found that socio-economic circumstances were related to emotional distress in mothers. However, these results are not as significant as would be expected from the research literature, with only one measure showing a significant relationship. Sloper & Turner (1993), amongst others, found a strong link between deprivation and high levels of stress. This study used employment status of both parents (if there were two parents) as a measure of deprivation, which may have been somewhat crude. Other studies have also measured financial difficulties, parental educational level, house ownership, and car ownership.

5. Coping Strategies / Style

5.1 Practical Coping

It was found that the use of practical coping strategies was negatively associated with overall parenting stress and parenting stress related to parental / situational factors in both mothers and fathers. This supports findings from Frey et al. (1989) in research with parents of both physical and learning disabled children.

In the path analysis for mothers the overall abilities of the child were inversely associated with the use of practical coping strategies. Thus the lower the abilities of the child, the more parents use practical coping strategies and vice versa. This appears to make good sense. In mothers path analysis also found that the use of practical coping strategies was inversely associated with overall parenting stress. Thus, this study suggests that the use of practical coping strategies is an important factor in reducing stress from parenting a child with disabilities, especially if the child has low ability levels.

5.2 Seeking Professional / Informal Support

The findings of this study showed that seeking professional / informal support was negatively associated with parenting stress from parental / situational characteristics in both mothers and fathers. In mothers it was also negatively associated with overall parenting stress and emotional distress. This supports the findings of Trute & Hauch (1988) who found that seeking social support was related to successful adaptation in the parents. Thus seeking support, whether professional or informal, is an important coping strategy particularly in mothers. The difference between mothers and fathers results may reflect the different roles within the family.

In mothers, the path analysis showed that seeking professional / informal support was also inversely associated with unmet service needs. The needs of the child would remain unmet if the mother did not seek any professional support. Path analysis also showed that life events in mothers were inversely associated with seeking support. This may be consistent with Quine & Pahl's (1985) findings with learning disabled children, that some families were so overwhelmed with stress they were not able to seek or use social support.

In mothers, path analysis found that social support was positively associated with the coping strategy of seeking of professional / informal support, which appears to make good sense.

In the path analysis for mothers seeking support was also inversely associated with unemployment (socio-economic circumstances) in the family. These findings support Wallander et al., 1989, who found that family income was positively associated with social functioning (participating in social and leisure activities) in mothers of children with cerebral palsy or spina bifida. Thus money may have a facilitative effect in seeking informal social support.

5.3 Wishful Thinking

This study found that a wishful thinking coping style was positively associated with all parenting stress measures and emotional distress in mothers. In fathers it was positively related to overall parenting stress and parenting stress associated with parental and situational characteristics. This research supports the findings of Sloper & Turner (1993) with children with physical disabilities, where wishful thinking was found to be a maladaptive coping strategy in mothers. However, wishful thinking did not predict outcome in fathers in their study. The reason for the differences between fathers in these two studies is unclear.

In the path analysis, wishful thinking was found to be positively associated with life events for mothers. Thus greater use of wishful thinking was related to greater strain from life events. It is possible that 'wishful thinkers' may have rated their life events as more stressful than people who did not use wishful thinking. In someone who uses a wishful thinking coping style, the occurrence of life events may be dissonant with what the person would have wished had happened.

6. Mother And Father Dyads

This study found that there were no differences in outcome measures between mothers and fathers. However, mothers and fathers were significantly different in the use of coping strategies. Fathers were found to use more practical coping strategies than mothers. Mothers used seeking professional / informal support more than fathers. This may be related to the difference in parental roles where the mother may be mainly responsible for the care of the disabled child. The beneficial effects of these coping strategies have been shown in a number of studies (e.g. Frey et al., 1989; Sloper & Turner, 1993). However, further research is needed to confirm these differences between mothers and fathers.

There were no other differences found in the independent variables examined. The lack of significant differences may be a reflection on the small number of couples used in the dyadic comparison of this study.

SECTION THREE: LIMITATIONS OF THE STUDY

1. Generalising from the findings

This study incorporated only 56% of the 108 families that were originally approached to participate. Although some families were never successfully contacted for various reasons, some families did not want to participate and other families initially agreed to participate but later cancelled. It is important to acknowledge that some parents may not have wanted to participate because they were stressed, indeed at least three parents gave this reason for not wanting to participate. Parents that initially agreed to participate and who later cancelled, had usually been sent the questionnaires before they decided to cancel. It appears that some parents felt that the nature of the questionnaires was too personal, and others were deterred by the number of questionnaires that they were being asked to complete. Again, this could have been because parents felt stressed or overloaded already. This could mean that the very people whom this study was targeting were not participating and, therefore, the results of the study may be skewed towards parents that are not as stressed and / or coping better. Thus, because of sampling bias caution must be taken in generalising from the findings of this study.

The inclusion criteria which stipulated that at least one parent was fluent in English, was a further limitation of the study. It is known that at least one family was unable to participate in the study for this reason, and two partners of participants were also unable to participate because of this. Furthermore, this may have been a factor in parents not being willing to participate or later cancelling having received the questionnaires. This will have led to a lack of representation from ethnic minority groups who were unable to read and /or speak English. It was necessary to exclude these people because the measures used were standardised for English speaking people. Thus, again, caution must be taken in generalising from the findings of this study.

The participants all came from the London / Greater London area and therefore the sample may be biased through regional differences, such as in the type of support services that they receive.

The study had a small sample size, with 59 mothers and 25 fathers. Therefore, caution needs to be taken in interpreting the results and generalising from this sample to other populations, particularly with respect to fathers.

It is important to acknowledge that this study did not measure a number of areas, which have previously been found to be important factors in similar studies. These are discussed in chapter one, and include such things as previous coping experiences, beliefs about locus of control and the family environment. When reflecting on the findings of this study, it is important to remember that the areas examined form only a selection of possible variables that may impact upon parental outcome.

2. Research Design

The cross-sectional design has limitations for the internal validity of the findings of the study. The findings are limited in that it is not possible to go beyond associations between variables to make any causal inferences about predictor and outcome variables. A longitudinal research design would be required to examine causality.

3. Measures

Parental adaptation was measured in this study using negative outcome measures, focusing on distress. Successful outcome however, may not simply be marked by the absence of distress. Thus it may have been appropriate to use some additional outcome measures, which measure other aspects such as the quality of life and adaptation to the disabled child.

The measurement of socio-economic circumstances through employment status appeared somewhat crude and may not have been a sensitive enough measure for this purpose. Further, more detailed information would be required to adequately address this area.

The measurement of social support also appeared somewhat crude. It may have been more prudent to use a measure, which examined specific modes of social support in addition to support resources and appraisal.

SECTION FOUR: FUTURE RESEARCH

These suggestions broadly correspond to the limitations of the study, described above.

1. Generalising from the Findings

It would be desirable to replicate this study with a higher proportion of families approached participating in the study. Another study might allow for more time and resources to be spent on achieving a greater uptake of families participating. One possibility would be for families to be contacted by someone who already knew them, perhaps a member of the local health services or education system, to explain the study rather than receiving a letter and then a telephone call from a stranger. Another possibility would be to provide some form of incentive for participating in the study e.g. money / book token. A further aim would be to have more fathers participating in the study. Conducting the home visit at a time when more fathers are at home may improve upon the response rate. It would be desirable for future research to address the lack of representation from ethnic minorities, although this remains a thorny issue if standardised measures are to be used. It would also be desirable to replicate the study over a wider geographical area, perhaps not in the London / Greater London area.

2. Research Design

A longitudinal study or a series of follow-up studies would be helpful in looking at causality regarding predictor and outcome variables. There may also be changes over time, perhaps reflecting the age or life stage of the child, which may impact upon the variables examined.

3. Measures

It is recommended that future research should also include outcome measures that are not negative, such as measuring the quality of life of parents. A more sensitive measure of socio-economic circumstances would also be recommended. In measuring social support, it is suggested that future research should include an analysis of the different modes of social support. Further research is needed to examine maternal employment. It would be helpful to ask mothers who work whether they are happy with their employment status. The results of this study do not support the recent research; thus it would be helpful to elicit further details to elucidate this area. It may be that seeking qualitative information would provide the most useful approach in understanding the impact of maternal employment.

SECTION FIVE: CONCLUSION AND IMPLICATIONS OF THE STUDY

The process model of stress and coping was used to understand and organise this research in looking at parenting a child with cerebral palsy. This study found that parents of children with cerebral palsy are significantly more stressed than other parents.

The model can be used to understand how interventions should be organised with these families. It emphasises that parents are actively coping with their circumstances and seeking ways to alleviate their situation. Interventions should build upon the existing strengths and skills of parents (Bregman, 1980). Beresford (1994), proposes that interventions should be twofold, aiming at coping resources as well as parents' coping skills. This study has shown that knowledge about the impact of stressors could also be used to aid assessment and inform intervention.

The overall abilities of the child were significantly related to levels of stress in both parents. In particular, low levels of communication and socialisation skills were significantly related to stress in mothers and fathers. This was notwithstanding the fact that for the group of children with cerebral palsy their skills were highest in the communication and socialisation areas. This knowledge could alert clinicians about the impact that a particular child's level of functioning may have upon the parent despite apparent skills in some areas. It could also indicate that an intervention based on improving particular areas of the child's skills, such as communication and socialisation, would be helpful.

In studies of this nature, which have included fathers there has been little evidence to show that child-related factors are stressful. However, this study has shown that in parents of children with cerebral palsy these indeed appear to be important factors related to fathers' functioning. These results may reflect the use of a more sensitive measure of parenting stress.

This study found that 45% of the children with cerebral palsy had significant behavioural problems and this was significantly related to stress in mothers. Thus assessment of the child's behaviour problems is essential in considering parental well being. Clinical psychologists themselves could be directly involved in interventions aimed at managing behaviour problems in the child and thereby reducing stress in the mother.

In studies of parents of children with disabilities, research into life events as potential stressors have been somewhat limited. However, this study corroborates the findings of this limited recent research in identifying life events as an essential factor relating to stress in both mothers and fathers. Thus it is important that services involved with the family are always mindful of other family issues, which may not be related to the child, and that these issues are also considered and perhaps addressed.

High levels of neuroticism were related to increased levels of stress in both mothers and fathers. Neuroticism was a vital factor in predicting stress in both mothers and fathers. It appears that personality may increase vulnerability and reactivity to stressful events. Thus assessment of neuroticism may identify parents at risk, so that interventions can be aimed at helping these parents.

With respect to support services, the level of unmet service need was related to levels of stress in both parents. Hence services have a crucial role to play in mediating the impact of stress in not only mothers but also fathers. Despite recommendations for a family 'link' person to be appointed to each family, this study found that at least 70% of families did not have access to such a person. This is an area which services need to address.

In both mothers and fathers, the use of practical coping strategies and seeking professional or informal support was related to lower levels of stress. This knowledge can help clinicians to target interventions aimed at increasing these coping strategies in parents. The use of wishful thinking was related to higher levels of stress in both mothers and fathers. Again, this knowledge could be used by clinicians with the aim of decreasing the use of wishful thinking in parents and promoting other forms of coping.

In conclusion, the results of this study provide an insight into the nature and types of stressors, coping strategies and resources, in parents of children with cerebral palsy. This information may be used to enable clinicians to develop specific, more effective support for families with a child with cerebral palsy.

APPENDIX

Contents of Appendix

Letters of Ethical Approval

Initial Invitation Letter

Letter Confirming Home Visit

Project Information Sheet for Parents

Parental Consent Form

Adapted Version of Ways of Coping (Revised) Questionnaire

Perceived Needs Scale

RIVERSIDE RESEARCH ETHICS COMMITTEE
CHELSEA & WESTMINSTER HOSPITAL
Lower Ground Floor
Regional & District Pharmacy Offices
369 Fulham Road, London SW10 9NH
Tel: 0181 846 6855 Fax: 0181 846 6860

Ms Katie Richardson
Clinical Psychologist in Training
Clinical Health Psychology
University College, London
Gower Street
London WC1E 6BT

4 August 1997

Dear Ms Richardson

RREC 1446 - Stress, coping and the use of support services in parents of children with cerebral palsy.

Thank you for your submission. This has been carefully considered and now approved by the Chairman.

Please note the following conditions which form part of this approval:

[1] This approval is for one year only. For projects with an expected duration of more than one year, a letter from the principal investigator will be required in order to further extend consent. This will enable the Committee to maintain a full record of research.

[2] Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee's approval.

[3] The Committee should be notified immediately of any serious adverse events or if the entire study is terminated prematurely.

[4] You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, e.g., extra work for laboratories. Approval by the Committee for your project does not remove your responsibility to negotiate such factors with your colleagues.

Cont/2...

Cont/2...**RREC 1446 - Stress, coping and the use of support services in parents of children with cerebral palsy.**

[5] You must ensure that nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

[6] Pharmacy must be told about any drugs and all drug trials, and **must** be given the responsibility of receiving and dispensing any trial drug.

[7] The Committee must be advised when a project is concluded and should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

May I take this opportunity to wish you well in your research. However, if any doubts or problems of an unexpected nature arise, please feel free to contact me at any time.

Yours sincerely

J. N. Harcourt-Webster

J Nigel Harcourt-Webster MD FRCPath
Chairman - RREC

Seen and Approved	
Submission 23-05-97 with letters 27-06-97 & 1-08-97 and letter from Dr M Box.	Signed Initials: J.N.H-W.
Protocol	Signed Initials: J.N.H-W.
Information Sheet Letter to Parents (see letter of 27-06-97)	Signed Initials: J.N.H-W.
Consent Form	Signed Initials: J.N.H-W
Questionnaires Scales and Questionnaires	Signed Initials: J.N.H-W
Letter of Indemnity	Signed Initials: —
CTX/DDX/Licence	Signed Initials: —

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GKK/JCW

15 September 1997

Ms K Richardson
Clinical Psychologist in Training

Dear Ms Richardson

STRESS, COPING AND THE USE OF SUPPORT SERVICES IN PARENTS OF CHILDREN WITH CEREBRAL PALSY

I am pleased to advise you that at its meeting on 10 September the Local Research Ethics Committee approved the above study subject to receiving confirmation that the letter to parents would have a letter heading to enable them to know how to contact you. As the interviews would take place in the home it was agreed to waive the inclusion of a space for a witness signature on the consent form as the Committee appreciated that this would be difficult to obtain.

Yours sincerely

Geoffrey Knowles

Dr G K Knowles
Chairman
Local Research Ethics Committee

Chairman Roy Galley *Chief Executive* Richard Gibbs

<phone number>

<date>

Dear <name>,

You are being invited to participate in a research project, which is taking place in the Department for Children with Special Needs. This project is an investigation into the experience of parenting a child with cerebral palsy. We know that it can be very stressful bringing up a child with a disability. It is hoped that if we can understand more about the specific experiences of parents, it will enable clinicians to develop more effective and more appropriate support, to meet the needs of families with a child with cerebral palsy.

You will be contacted shortly, by phone, to answer any questions you may have and to see if you wish to take part in the study.

Taking part in the study involves parents filling in some questionnaires, which will take up to an hour. An appointment will be made for me to visit the parents at home, to help them complete the questionnaires. Prior to the visit, some of the questionnaires will be sent in advance, through the post, so that parents have the option of completing them, if they are able to do so, before the visit.

You should only take part in the study if you are willing to do so. If you decide not to your child's treatment will not be affected in any way. All information obtained will be strictly confidential; it will not be traced back to any hospital notes or be available to any other clinic staff.

If you have any questions, please do not hesitate to contact me at the number printed above.

Katie Richardson

Clinical Psychologist in Training

<phone number>

<date>

Dear <name>,

Thank you for agreeing to participate in the research project. Please find the enclosed questionnaires, which I would be very grateful if you would complete before my visit. Please complete the questionnaires separately; it is important that we get both mother's and father's views.

The questionnaires look at a range of areas, including use of services, the family environment, stress, social support, different ways of coping, etc... These are all-important aspects in our lives, which may affect how we feel. The project looks mostly at psychological aspects. It is hoped that the information that you give will help us to provide more effective services, on a wider scale, to parents of children with special needs.

Please remember any information you give is entirely confidential; it will be used for research purposes only and will not be traced back to you or your child. I realise that you are busy people; your time and effort will be very much appreciated.

If you need to get in touch before the visit, I can be contacted at the above number, where there is also an answering machine.

I look forward to meeting you on <appointment date & time>.

Yours sincerely,

Katie Richardson

Clinical Psychologist in Training

INFORMATION SHEET FOR PARENTS

You are being asked to participate in a research project. This project is an investigation into the experience of parenting a child with cerebral palsy. We know that it can be very stressful bringing up a child with a disability. It is hoped that if we can understand more about the specific experiences of parents, it will enable clinicians to develop more effective and more appropriate support, to meet the needs of families with a child with cerebral palsy.

Taking part in the study involves parents filling in some questionnaires, which will take up to one and a half hours. An appointment will be made for the researcher to visit the parents at home, to help them complete the questionnaires. The researcher will be a clinical psychologist in training. Prior to the visit, some of the questionnaires will be sent in advance, through the post, so that parents have the option of completing them, if they are able to do so, before the visit.

You should only take part in the study if you are willing to do so. If you decide not to your child's treatment will not be affected in any way. All information obtained will be strictly confidential; it will not be traced back to any hospital notes or be available to any other clinic staff.

PARTICIPANT CONSENT FORM

Title of the project:

Stress, coping and the use of support services in parents of children with cerebral palsy.

Please read the following statement. If you agree with it and are willing to take part in the study, please sign below:

I have read the Information Sheet and have asked and received satisfactory answers to any questions I had. I understand that the study involves filling in some questionnaires and that any information given in those questionnaires will not be traced back to any hospital notes and that my child's treatment will not be affected in any way. I have received adequate information about the study and I agree to take part.

Signed ....

(Name in block capital letters) ....

Date ....

COPING WITH PROBLEMS

Folkman & Lazarus 1985 (Knussen et al. 1992)

Instructions:

In this section, we would like to get some idea of how parents cope with problems in bringing up children with disabilities. It is important for us to find out the ways parents have coped with problems in order to help others who may have difficulty. Therefore, even though this is a long section and some questions may appear silly, it would be very helpful for us if you could fill it in.

Please read each item and think about whether you use this way of dealing with problems in bringing up your child. By problems we mean such things as sleeping difficulties, embarrassing behaviours, worries about the child's future, your own feelings about having a handicapped child or anything which you yourself feel to be a problem.

Please tick one of the first four spaces opposite each item to show whether you DO or DO NOT use this way.

	Thought / Action	Not Used	Used somewhat	Used quite a bit	Used a great deal
1	I just concentrate on what I have to do next, the next step.				
2	I try to analyse the situation in order to understand it better.				
3	I turn to work or substitute activity to take my mind off things				
4	I feel that time will make a difference - the only thing to do is wait.				
5	I do something that I don't think will work, but at least I feel I'm doing something.				
6	I talk to someone to find out more about the situation.				
7	I criticise or lecture myself.				
8	I try not to burn my bridges but leave things somewhat open.				
9	I hope a miracle will happen.				
10	I go along with fate; sometimes I just have bad luck.				
11	I go on as if nothing has happened.				
12	I try to keep my feelings to myself.				

	Thought / Action	**Not Used**	**Used some-what**	**Used quite a bit**	**Used a great deal**
13	I look for the silver lining, so to speak; try to look on the bright side of things.				
14	I accept sympathy and understanding from someone.				
15	I tell myself things that help me to feel better.				
16	I am inspired to do creative things.				
17	I try to forget the whole thing.				
18	I try to get professional help.				
19	I try to change or grow as a person in a good way.				
20	I wait to see what will happen before doing anything.				
21	I make a plan of action and follow it.				
22	I accept the next best thing to what I want.				
23	I let my feelings out somehow.				
24	I accept that I bring problems on myself.				
25	I try to come out of experiences better than when I went in.				

	Thought / Action	**Not Used**	**Used some-what**	**Used quite a bit**	**Used a great deal**
26	I talk to someone who can do something concrete about the problem.				
27	I get away from it for a while; try to rest or take a holiday.				
28	I try to make myself feel better by eating, drinking or smoking.				
29	I try to make myself better by taking medication.				
30	I take big chances or do things that are very risky.				
31	I try not to act too hastily or follow my first hunch.				
32	I find new faith.				
33	I maintain my pride and keep a stiff upper lip.				
34	I rediscover what is important in life.				
35	I change something so things will turn out all right.				
36	I avoid being with people in general.				
37	I don't let it get to me; I refuse to think too much about it.				

	Thought / Action	Not Used	Used some-what	Used quite a bit	Used a great deal
38	I ask relatives or friends I respect for advice.				
39	I keep others from knowing how bad things are.				
40	I make light of the situation; I refuse to get too serious about it.				
41	I talk to someone about how I am feeling.				
42	I stand my ground and fight for what I want.				
43	I take it out on other people.				
44	I draw on my past experiences.				
45	I usually know what has to be done, so I keep up my efforts to make things work.				
46	I refuse to believe that it has happened.				
47	I make a promise to myself that things will improve next time.				
48	I think up a couple of different solutions to problems.				
49	I accept it since nothing can be done.				

	Thought / Action	Not Used	Used some-what	Used quite a bit	Used a great deal
50	I try to keep my feelings from interfering with other things too much.				
51	I wish I could change what has happened.				
52	I wish that I could change how I feel.				
53	I try to change something about myself.				
54	I daydream or imagine a better time or place than the one I am in.				
55	I wish that the situation would go away or somehow be over with.				
56	I have fantasies or wishes about how things might turn out.				
57	I pray.				
58	I prepare myself for the worst.				
59	I go over in my mind what I might say or do.				
60	I think about how a person I admire would handle this situation and use that as a model.				
61	I try to see things from the other person's point of view.				

	Thought / Action	**Not Used**	**Used some-what**	**Used quite a bit**	**Used a great deal**
62	I remind myself how much worse things could be.				
63	I try to make myself feel better by exercising or getting involved in something.				

PERCEIVED UNMET SERVICE NEED SCALE

Here is a list of some help which children with special needs sometimes need. Do you feel you need more professional help with any of the following?

Please tick only one of the boxes.

Type of help	**Getting enough help**	**Getting help but would like more**	**Not getting help but need it**	**Not getting help but do not want it**	**No problem**
1. Information about services for your child					
2. Chance to discuss your child's progress regularly.					
3. Help with teaching your child self-help skills.					
4. Help with teaching other new skills.					
5. Emergency service for times of difficulty.					
6. Advice and information about your child's condition.					
7. Help with babysitting or childminding.					
8. Classes or workshops to learn how to help your child.					
9. Help in dealing with night time disturbance.					
10. Help in dealing with your child's behaviour.					
11. Help with management problems.					
12. Help with inappropriate social behaviour.					

Type of help	**Getting enough help**	**Getting help but would like more**	**Not getting help but need it**	**Not getting help but do not want it**	**No problem**
13. Help with mobility problems.					
14. Help with problems regarding your child's appearance.					
15. Help with developing communication skills.					
16. Assistance with child care at home.					
17. Help with coming to terms with your child's handicap.					
18. Help with marital problems.					
19. Help with housing problems.					
20. Help with financial problems.					
21. Help with hearing problems.					
22. Help with sight problems.					
23. Help with transport problems.					

Quine & Pahl (1989).

Thankyou.

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