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## **PROFESSIONAL DOCTORATES**

**Coping strategies and psychological adjustment of children and adolescents with severe chronic renal failure.**

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**COPING STRATEGIES AND PSYCHOLOGICAL ADJUSTMENT OF  
CHILDREN AND ADOLESCENTS WITH SEVERE CHRONIC RENAL  
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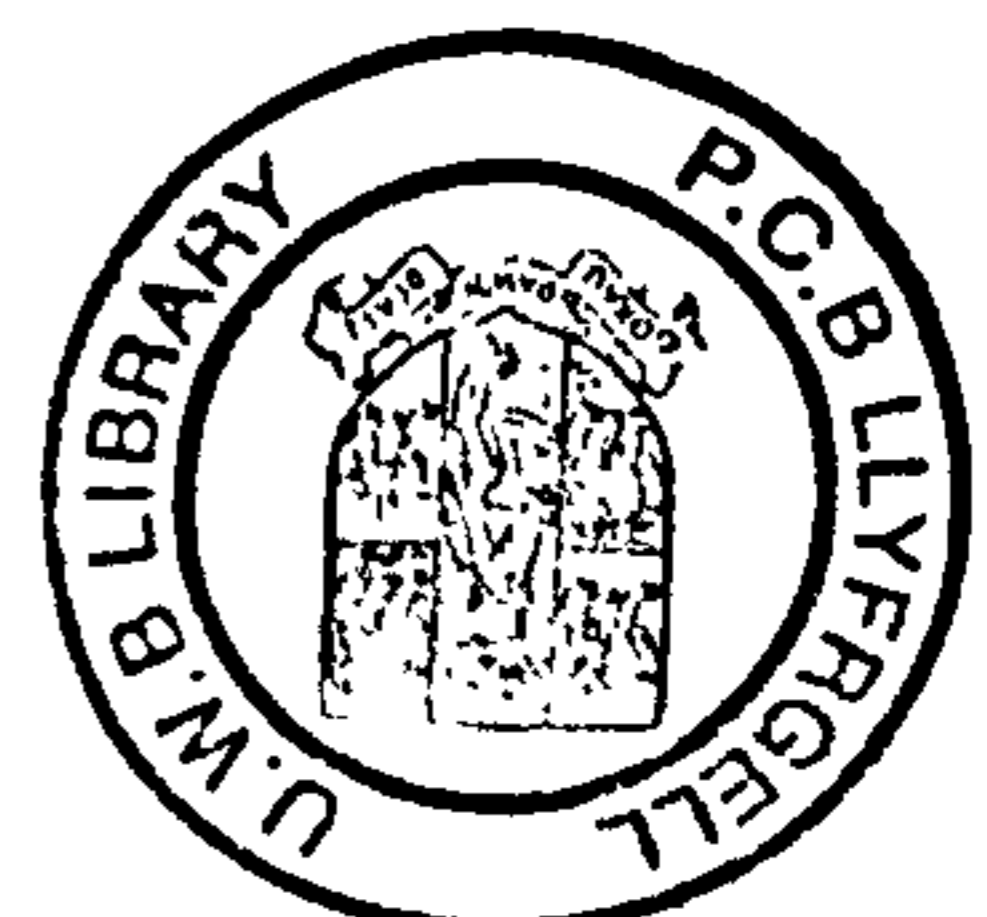
**Shelagh Madden**

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Submitted for the Doctor of Clinical Psychology to University of Wales,  
Bangor 2000.



## **SUMMARY**

In an exploratory study, the influence of severity of illness and coping style was examined in 86 children and adolescents with severe chronic renal failure. Psychological outcome was measured using the Strengths and Difficulties Questionnaire and The Harter Self-Perception Profile for Children. Parents completed child outcome measures and a questionnaire about their own coping strategies and their distress (using the Coping Health Inventory for Parents and the General Health Questionnaire.).

Measures of illness severity included a composite measure regarding the child's treatment, illness and hospital attendance, and a self-report health and social functioning measure. Children's coping with their illness was evaluated using the Kidcope Questionnaire and 4 coping styles were identified using factor analysis.

Findings from previous research suggest that factors affecting adjustment to illness are interactive and have resulted in models of adjustment that need to be applied to field research. Therefore, coping was examined both as a moderator and a mediator of the effect of severity of illness on psychological outcome.

Descriptive findings indicated significantly higher levels of psychological difficulties in these children compared to normative values, supporting previous findings of other children with chronic disease, but no differences in mean levels of self-esteem. An effect of illness severity on outcome was seen for the self report measures of illness severity only.

Maternal variables did not have an effect on child's coping, although there were some effects of gender on coping strategies endorsed.

Coping acted as a mediator in one circumstance, where a maladaptive coping style mediated the relationship between social functioning and psychological adjustment.

Coping acted more consistently as a moderator when higher levels of maladaptive coping style moderated the relationship between self reported illness severity and psychological outcome.

The findings, though tentative, have implications for further research and clinical practice.

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**DECLARATION**

This work has not previously been accepted in substance for any degree and is not currently submitted in candidature for any degree.

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This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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## CHAPTER 1 INTRODUCTION

### Prevalence and Incidence of Chronic Illness in Children.

Chronic illness and chronic physical disabling conditions have been estimated to affect between 10% (Pless 1968; Pless & Douglas, 1971) and 19% (Newacheck & Stoddard, 1994) of children under 18 years of age. Of this number of children, the majority are only mildly to moderately affected, that is the conditions have minimal limitations to their usual activities and everyday life (Newacheck & Taylor, 1992).

The type of illness varies in its prevalence. Asthma is by far the most common chronic illness, with a prevalence estimate of 38 per 1000 children; chronic renal failure is one of the most rare chronic conditions with prevalence estimates of 0.08 per 1000 children (Garrison & McQuiston, 1989). In addition to variation in the prevalence, chronic illnesses differ in the prognosis. Estimated proportions of children surviving to age 20 range from as little as 25% for children with chronic renal failure to 98% for children with moderate to severe asthma. Spina Bifida and Acute Lymphocytic Leukaemia have survival rates of between 40 and 50% (Gortmaker & Sappenfield, 1984).

However, the recent medical advances in many areas of illness, particularly in the areas of cancer and cystic fibrosis and more recently in renal medicine, have greatly improved the longevity and prognosis for children with chronic illness. As these children are surviving longer than they did in the past, health professionals have begun to shift their attention away from the singular focus of mortality to considering the range of psychosocial effects of chronic illness (Eiser, 1993; Nolan & Pless, 1986).

### Psychosocial effects of chronic illness

There has now been a considerable amount of research that has generally concluded that children with ongoing health conditions are at a greater risk of mental health problems compared with healthy peers. ( e.g. Breslau, 1985; Cadman, Rosenbaum, Doyle & Orfford, 1991; Nolan & Pless, 1986; Rutter, Tizzard, & Whitmore, 1970; Wallander, Varni, Babani, Banis & Wilcox, 1988). However, there is a wide variation in individual functioning of children with chronic disorder, and there is also variation between disease types.

One large-scale report reviewed 50 studies examining psychological outcome of children with a broad cross-section of physical disorders including diabetes, cystic fibrosis, visual and hearing impairments and neurological disorders (Nolan & Pless, 1986). The studies included case studies without controls (n = 17) case studies with controls (n = 19), three prevalence surveys, age follow-up studies and three intervention studies. The aim of this review was to conduct a meta-analysis, although it was not carried out because the authors felt that the diversity of outcome measures, study designs and analysis made this impracticable. However, the authors concluded that a relationship existed between a chronic disorder and later emotional problems in children and that the incidence of diagnosed psychiatric disorder in children with chronic physical illness compared to healthy children was approximately 2.2 to 1.

However when individual studies are examined, results are frequently contradictory and confusing, particularly in the measurement of adjustment. Breslau (1985) reported about a group of 304 children with a variety of major physical disorders, for example, cystic fibrosis, cerebral palsy, myelodysplasia. These children were compared with 360 healthy children in the same age range. Mothers completed a psychiatric screening inventory about their children. The rate of severity of psychiatric impairment was nearly 2 1/2 times greater amongst the disabled children compared to the controls (27% versus 11%). The most severely emotionally affected were those children who had central nervous system involvement but there were no other differences of importance noted between disease groups themselves.

In contrast to the above another study (Kellerman, Zelter, Ellenberg, Dash & Ridler, 1980) examined a population of children who had different conditions; a total of 168 children with oncology, cardiology, diabetes, cystic fibrosis, nephrology and rheumatology illness. Their results led to the contrary conclusion that children with physical disorders were not at risk of psychological maladjustment. However, the measures used in this study were not particularly sensitive to overall psychological distress; being measures of trait anxiety, self-esteem and locus of control. Trait anxiety and self-esteem of the group of sick children were not significantly different to a group of 349 healthy peers who were not aged matched and in fact were significantly younger than the illness group.

In an attempt to provide an overview of the incidence of psychological adjustment problems in children with chronic illness, meta-analysis combines individual studies in an attempt to find a common thread of the effect of chronic illness. One such analysis was carried out by Lavigne and Faier-Routman (1992) who assessed the correlates of psychological adjustment amongst chronically ill children in 87 studies. The analysis aimed to provide comparisons across disease types and also according to non-categorical illness criteria. Whether or not paediatric physical disorders differ from each other in their psychological effects is important in developing a rationale for formulating approaches and models investigating the mechanisms behind psychological adjustment to illness. The effect size for overall adjustment for all groups of illnesses combined, was significantly different from zero (mean effect size = 0.62,  $p < 0.01$ ). There were also significant effect sizes for higher levels of internalising and externalising symptoms and lower levels of self-esteem. Lavigne and Faier-Routman (1992) also noted that there were differences in the effect size of psychological adjustment according to whether studies used normative data or control groups. They concluded that there was a tendency for studies without controls to minimise differences in adjustment between children with physical disorders and healthy controls, whereas studies relying on normative comparisons tended to overestimate effect sizes.

Meta-analysis examined levels of adjustment across specific disease groups and in addition the authors divided disease types into four broad groups; sensory, neurological, fatal and non-fatal disorders. They concluded that the risk of psychological adjustment problems varied across disease groups, although the degree to which this occurred was uncertain. Effect sizes were small both between disease groups and between the broader non-categorical groupings, with effect sizes for sensory disorders being significantly higher than either non-fatal or fatal illnesses. Whilst neurological disorders also showed largest effect sizes these were not significantly higher than the other three categories. The authors suggested that the absence of large differences were due to considerable intra-disorder variation in outcome and that other factors such as social class, age, sex and race may have contributed to variations across diseases. The authors note that the total number of high-quality studies being conducted in any single disease group was still very small. However despite these findings, the authors conclude that the mean change in effect sizes in overall psychological adjustment of children who are ill would result in essentially doubling the number of children in the population that would be expected to have psychological problems compared to healthy peers.

Children with renal disease provide a good opportunity to explore the general psychological effects of a discrete illness group. In addition, as this disease has specific stages of illness and treatment episodes, it has a good variation in severity. Therefore it should be possible to examine the adjustment of children within both the specific illness perspective and from an important non-categorical aspect that appears to be associated with adjustment to illness, the severity of illness.



## **Renal Disease in children**

Children who have severe chronic renal failure will have a lifelong chronic illness. Those families of children whose kidneys fail completely, have to live with the knowledge that the disease whilst seemingly chronic in nature, is in fact life threatening. The complexity and nature of treatment of renal disease varies in accordance with the child's level of renal failure. However treatment for total renal failure is life dominating. The timing of the course of the illness is unpredictable, thus alteration of treatment regimens and lifestyle changes may occur at short notice. With such a challenging agenda for the family to come to terms with, the study of psychosocial effects of renal failure is important in order to provide insight into the psychological care of these children and their families.

In order to understand the psychological challenges facing these children it is helpful to have some knowledge of the background of the medical care required for them. This will provide a basis for an understanding of the psychosocial issues that face the child and family with end-stage renal failure.

### **Medical Implications.**

The incidence of children who have disease which results in failure of the kidneys, known as end stage renal failure is relatively rare. The causes of the kidney failure are varied but in children it is commonly due to hereditary, congenital or urological factors.

The frequency rates of children in end stage renal failure in Europe show a mean of three new paediatric cases per year per million-child population aged 0 to 15 years. (The European Dialysis and Transplantation Association, E D T A; Loiriat, Ehrich & Geerlings, 1994).

Although the course of the end stage renal failure is predictable, the timing of this is not. In the early stages children have chronic renal failure. This means that the kidneys have a functioning capacity of between 25 and 50%. Loss of functioning in the kidneys of under 50% rarely has

consequences for patient, but with decreasing function there is a parallel increasing need for therapeutic intervention to maintain the functions of the body that the kidneys provide. Besides the maintenance of fluid and electrolyte balance of the body, the kidneys contribute towards the control of blood pressure, through metabolism and red blood cell formation.

Intervention in chronic renal failure requires diet and medication to compensate for or to maintain these functions. A specific diet with a large increase in protein and carbohydrate requirements is particularly important for children with renal failure because of the need to maintain optimal growth. A cocktail of medication is also required some of which taste unpleasant to the child. Adherence to this restrictive regimen can delay the onset of end-stage renal failure.

As the renal failure progresses, the child requires increasingly frequent visits to a specialist paediatric nephrology centre, which may be a considerable distance from their home. End stage renal disease is defined when the kidneys are functioning with only 10 -25% and the child's symptoms of renal disease cannot be alleviated by medicine and diet. These children then require renal replacement therapy either in the form of dialysis or a kidney transplant.

Renal dialysis results in a very restrictive lifestyle for the child and their family. The child needs to attend hospital three times a week in order to have haemodialysis (this is filtration of the blood by attachment to a haemodialysis machine). Alternatively and more commonly, the child is dialysed at home using his peritoneum as the filter with exchange of toxins being carried out by osmosis. This is known as peritoneal dialysis. The child has a sterile tube inserted into his abdomen to allow exchange of dialysis fluid; they are then typically attached to a peritoneal dialysis machine overnight. In order to maintain this regimen one or both parents are actively involved in this highly technological process which requires considerable amounts of time in the administration and maintenance of the machine. In addition, children who are on dialysis take a large amount of medication and keep to a restricted diet in order to maintain their health. Often poor appetite

will result in the child having at least part of their diet administered via nasogastric or gastrostomy tube. One of the most difficult consequences of dialysis may be the strict fluid restriction, meaning that a child may not be allowed to drink much more than one to two cups of fluid a day, as overloading the body with fluid will result in serious medical consequences.

Renal transplantation is considered the preferred treatment of end stage renal disease; survival rates are good, with a 90% survival rate at 1 year and 75% at 5 years (Waraday, Hebert, Sullivan, Alexander & Tejani, 1997) with transplanted kidneys lasting for periods of up to 10 years (Ettinger, 1990). The lifestyle of the child who is transplanted is better than those who are on dialysis and a child who has a good functioning implant can appear generally very healthy (Brownbridge & Fielding, 1994; Garralda et al., 1988; Reichwald-Klugger et al., 1984). However, following transplant, it is necessary for the child to have close medical monitoring and scrupulously adhere to immuno-suppressive medication for the life-span of the kidney. Unfortunately, unwanted side effects of taking the immuno-suppressive medication particularly in the initial months following transplantation include weight gain, swollen facial features and unwanted facial and bodily hair, in addition to mood and behaviour changes.

The failure of the transplanted kidney results in the child recommencing dialysis and going back onto the waiting list for a kidney. Rejection episodes, hypertension and recurrence of the kidney disease contribute towards the shortening life-span of the kidney, as well as psychosocial causes such as non-adherence to medication. Whilst repeated transplants are possible, it becomes increasingly difficult to find a matching kidney with each successive transplant as the body builds up more antibodies making it more likely to reject a new transplant.

### **Psychosocial sequelae of renal disease**

Although there appears to be a reasonable amount of research examining the psychological consequences of renal disease in childhood, a closer evaluation of the studies reveals less in terms of concrete data and robust findings (Schweitzer & Hobbs, 1996). One of the major difficulties in pursuing

psychological research in this disease group is the rarity of this illness. Hence although there is the opportunity to examine within group differences according to severity of illness, low numbers of children with this disease frequently make this impossible. What is clear from a search of journal papers is that there is much concern about how of children receiving this relatively new intensive treatment are faring psychologically but a paucity of research studies seeking to scientifically answer this question.

The effects of renal disease encompass a wide range of psychological and psychosocial consequences. Research evaluating these effects tends to fall broadly into two areas; evaluation of the disease effects on the cognitive functioning of the child and the effects of illness on the psychosocial functioning of the child and family. This review deals with the second area whilst recognising the effect the disease state and developmental factors will contribute towards the child's cognitive and hence psychological functioning (Fenell et al., 1990).

The findings and questions arising from the research regarding psychosocial consequences of renal illness for the child and family tend to reflect those found in other psychological studies of paediatric patients. However, there is a particular focus of studies around the effect of disease severity and the burden of care placed on families. In addition, with the long-term medical outcome still being inconclusive, there has been increasing interest in reporting this aspect of psychosocial consequences. The psychosocial studies are almost exclusively descriptive in nature, and the findings are discussed below.

#### Renal versus control comparisons and the effect of disease severity.

Studies that have evaluated psychiatric morbidity in this group of children suggest the diversity of psychological sequelae have also been shown in children with other types of disease.

Results of research examining psychological distress in children with renal failure demonstrate a higher level of psychiatric morbidity in children with end-stage renal failure compared to healthy controls (Korsh et al., 1973, Reynolds et al., 1988, Rosenkranz et al., 1992). In addition, there appears to

be a relatively robust relationship between disease severity and therefore treatment condition and level of psychiatric morbidity in this group of children.

In an early study (Korsh et al., 1973) children with renal transplants had increased problems in social adjustment, high levels of anxiety and lower self-esteem than healthy children. However, they did not show an increased level of personality disturbances compared to other children with less severe medical illness.

Garralda et al. (1988) found greater psychiatric maladjustment of children on dialysis when compared with children with chronic renal failure. This group in turn had higher levels of maladjustment compared to healthy controls. Using a composite measure of interview and the Rutter A questionnaire (Rutter et al., 1970) they found a different pattern of adjustment between the groups of children; with definite and marked disturbance in 32% of dialysis patients. Mild psychological difficulties were present in 59% in the non-dialysis chronic renal failure group. Healthy controls had lower incidence of problems, 21% had a definite disorder and 24% had mild problems.

Similar conclusions have been drawn when self-concept and social impairment have been used as outcome measures. Brownbridge and Fielding (1991) found that children who are on dialysis had consistently higher incidence of psychiatric morbidity and lower self-concept than those children who had been transplanted. The authors suggested that there was an improvement in mood and self-concept in parallel with improvement in general physical health following transplantation of these children.

Brownbridge and Fielding (1991) examined children who had been transplanted with those on dialysis (hospital dialysis versus home dialysis). The highest scores of psychological dysfunction were found in the hospital dialysis group. Depression scores were highest in hospital dialysis children, with no difference between home dialysis and post transplantation groups. On the Rutter A (Rutter et al., 1970) questionnaire 11% scored as cases in the post transplant group, 20% in the home dialysis group and 28% in the hospital dialysis group. This suggests that an additional factor here may be the effect of

restriction on lifestyle as a consequence of illness severity, given that the disease and treatment modality are similar between the dialysis groups. In a more recent study, the same authors (Fielding & Brownbridge, 1999) assessed 60 children and their families on dialysis. Children were found to be at increased psychological risk of adjustment difficulties, anxiety and depression when there was greater functional impairment caused by the illness.

In 1991 Reynolds, Garralda, Postlethwaite and Goh followed up a group of 29 children with an age range of 2-17 years who had received functioning renal transplants. Measures used were the Rutter A (Rutter et al., 1970), a self-concept scale and a self-report depression questionnaire. Parents were also asked about changes that had occurred in their children and family life as a consequence of transplantation. The study compared the 29 transplanted children with data from their earlier study of 22 children on haemodialysis, 22 children with chronic renal failure and 31 healthy controls. (Garralda et al., 1988). As a result, there was an overlap of children in the treatment groups so that seven of the dialysed children, and four of those with chronic renal failure were also in the transplantation group. Thus, there may have been a problem of non-independence of sampling, which should be born in mind when interpreting the results.

In parent self-report ratings of children's change in health and behaviour, most rated a change in the child health and behaviour following transplantation. None rated their children as having serious problems although 39% rated their children as having minor behavioural problems. This compared favourably with the other treatment groups where one third of parents reported severe problems with behaviour .

These self-reported results were not fully supported by the Rutter A questionnaire which showed scores of 39% reaching the threshold for psychiatric cases (although usually having minor symptoms), compared to 28% of children with chronic renal failure and 13% of healthy controls.

Child self-report scales indicated children who were transplanted reported no severe worrying compared to 30% of the haemodialysis group who rated themselves as having severe worries and 40% of the chronic renal

failure group also said they worried severely. In addition, in the self-rating depression scale, 8% of children following transplant rated themselves as depressed compared to 20% of those on haemodialysis and 20% in chronic renal failure. This was in comparison to 4% in healthy controls. The authors concluded that overall transplanted patients were the better adjusted patients.

#### Adherence Issues

There is a conundrum regarding the difficulty for the child and family in adhering to the complex treatment requirements on one hand with the severe medical consequences as a result of non-adherence on the other hand. This has resulted in some exploratory work regarding this issue in older children and adolescents.

AS far back as 1971, a study by Korsch, Fine, Grushkin and Negrete, showed that children who had been transplanted having depression, poor self-esteem and non-adherence to treatment, in addition to the preoccupation with the side-effects of the medication and growth.

Brownbridge and Fielding 1994 examined adherence to dialysis in a group of 60 children with a wide age range. Non-adherence was correlated with increasing age, higher scores of anxiety and depression in the child and parent, family variables and length of time on dialysis.

In a qualitative study, Harwood and Johnson (1999) described adolescent experiences and adherence problems following their kidney transplant. They concluded that following an initial period after transplant adolescents were more selective in their adherence to their regimen based on their perceptions of the risks involved. The authors concluded that the modifications made to their regimen did at times place the adolescents' health at risk.

#### Self-report data on children with Renal Disease.

The majority of studies of children with renal failure collect most if not all of their outcome measures of children's status from parents, not least because of the wide age range in studies may make self-report data unreliable. However in studies where self-report and informant data are reported, the self-report data may add weight to findings or show a different perspective. In the above

study by Reynolds et al. (1991), self-report data supported parent report data that transplanted patients were better adjusted than chronic renal failure patients.

Reynolds, Wood, Eminson and Postlethwaite (1995) evaluated the psychosocial effects of an organic consequence of renal failure; short stature. All children were well below norms for height in this study and were having growth hormone. There was a difference in perception in this study between parent and child worries, with friendship problems being reported by half of this group, so somewhat surprisingly, growth and short stature was reported to be a preoccupying worry for only 28% of the children, but more of the parents. Due to age and developmental delay, just half the children completed the self-report data.

Only one study has been carried out looking specifically at coping strategies in children with renal failure. Brem, Mcgrath and Spirito (1988) carried out a small study ( $n = 12$ ) of children treated with dialysis; with six of the children on hospital haemodialysis and six children on home peritoneal dialysis. Measurements of the children's self-esteem, locus of control of mood and adaptive functioning were recorded as well as the Adolescents Coping Orientation Problem Scale (A-cope; Patterson & McCubbin, 1983). This yielded scores in 12 patterns of coping for example self-reliance, avoidance, and relaxation. Differences in coping style between peritoneal and haemodialysis patients were assessed as well as comparisons made with a control group of 50 age-matched students attending a local high school. The self-esteem scores showed no difference between the controls or those children on haemo and peritoneal dialysis. There were no significant differences in either personal or social adjustment scores between haemodialysis and peritoneal dialysis patients. However, two-thirds of the children fell below the 50th percentile rank for personal adjustment and all of the children fell below the 50th percentile rank for social adjustment. The authors suggest that these low scores in personal and social adjustment indicate a lower quality of life in this patient group which may give more sensitive information than psychological adjustment scores. There were some



differences in coping mechanisms; those children on peritoneal dialysis used low levels of activity, self-reliance, and more friendship strategies more than those on haemodialysis. When compared to the healthy control group the dialysis patients were significantly more likely to forge emotional bonds both within and outside the family unit. In addition, despite their disability, dialysis patients showed higher levels of activity and humour.

Studies which have examined self-esteem, rely entirely on self-report as the concept is pivotal to the individual's perceptions. Findings showing a relationship between disease factors (such as severity and disability) and lower self-esteem have not been fully substantiated. (Henning, Tomlinson, Rigden, Haycock & Chantler, 1988; Reynolds et al., 1995). Generally there does not appear to be an overall mean difference in self-esteem in children with renal failure. (Postlethwaite, Garralda, Eminson and Reynolds 1996; Brem et al., 1988). Even in children who were hypothesised to be more vulnerable, such as those with very short stature, this was not the case (Reynolds et al., 1995). The numbers of studies using self-esteem as an outcome measure within this group are small, and the number of subjects in each study is low, for example, in Reynolds et al. n=14, and in Brem et al. n=12.

#### Long term Psychosocial consequences of Renal Illness

The long-term psychosocial consequences of survival of these children is now becoming more relevant as mortality rates associated with the disease and treatments decrease. At present, there are no longitudinal studies examining this; studies rely on cross-sectional data at indistinct time sampling points. Of those studies results from Reynolds, Morton, Garralda, Postlethwaite and Goh (1993) show no increased psychiatric morbidity in 45 young adults with life long illness when compared to healthy matched controls. Postlethwaite et al. (1996) subsequently concluded that the psychological difficulties experienced by these children were minor and of a transient nature.

However in other follow up studies, findings reflect the general child paediatric studies showing the majority not having major maladjustment but an increased risk of psychological or adjustment problems compared to the

healthy population (Henning et al. 1988, Roscoe et al.1991.) Methodology is not thorough, with most measures of adjustment tending to be at most a broadband subjective evaluation made by the researcher or parent about the overall functioning of the child or adolescent. In one of the more detailed studies Henning et al. (1988), followed up all children from one tertiary hospital that had had dialysis and transplantation between the ages of 4-14 years. Of the 46 patients 14 (31%) had died and the mean age of the survivors at follow up was 22 years. A structured questionnaire asked about their life style, personal and social lives. The results were compared with a group of diabetics. Compared to the diabetic group, the renal patients had lower educational achievements and incidence of employment and were more likely to live with their parents. 76% of the diabetics were in long term relationships compared to 28% (n=8) of the renal group. Sexual difficulties were reported by five of this group. 34% of this group had seen a doctor for a persistent emotional or psychiatric problem in the last five years. Overall, a more objective standardised measure of mental health may assist in this issue.

#### Renal studies and parental adjustment.

There are certainly more papers regarding the burden of care and subsequent psychological distress of parents caring for the children with renal problems, than there is of children reporting about their perception of being treated for renal failure.

Again the results indicate that psychological effects of the burden of care is commensurately related to the intensity of treatments needed for the children. For example, in Reynolds et al. (1991) study, 30% of mothers of chronic renal failure children had raised scores on the General Health Questionnaire (GHQ) (Goldberg, 1978). In addition, 40% of mothers of haemodialysis children, and 26% of mothers of transplanted children had raised scores compared with 28% of controls of mothers of healthy children. There was a significant difference between mothers of children on haemodialysis and those who had been transplanted. Douglas, Hulson and Trompeter (1998) also report over one third of mothers of younger children who had kidney transplants, scoring above the clinical threshold on the GHQ.

In contrast, in a slightly different patient group of children with renal failure with very short stature using growth hormone, only 18% of parents scored above the threshold in the GHQ (Reynolds et al. 1995).

In Brownbridge and Fielding's study (1991) The Leeds Anxiety and Depression scale was used which found that parents scores were higher if their child was on hospital haemodialysis compared with peritoneal home dialysis. However it is not clear whether this is higher than a normal population sample. In another study Watson (1997) evaluated parents stress, anxiety, depression and information needs longitudinally. Families were also rated by medical caregivers on a "burden of care assessment". In families who had an initial high burden of care score there was a positive correlation with maternal stress and anxiety. Parents of older children requiring renal replacement therapy had more stress than those parents of younger children. These findings that relate parental mental health to child severity illness were not supported by Hauser et al. (1996) who investigated 28 families of children with renal problems. Families with children who had been transplanted had more psychological problems than families with children on peritoneal dialysis or those with chronic renal failure.

There is minimal reported research on examining relationships between the maternal level of care or distress on their child's psychological outcome. However, in a recent study Fielding and Brownbridge (1999) identified by correlational analysis a number of important parental factors associated with child's poor adjustment to dialysis. Risk factors were parents with low socio- economic status, parents' with large families, parents with limited support and parents of young children.

There has been just one study examining the coping strategies of parents of children with renal problems. Douglas, Hulson and Trompeter (1998) used the Coping Health Inventory for Parents (CHIP), (McCubbin et al., 1983) and the Family Crisis Oriented Personal Evaluation Scale (F-Copes; McCubbin et al., 1981) to evaluate parents of 14 children up to three years following renal transplantation. Scores on the CHIP for mothers and fathers were both within the ranges expected for parents of chronically ill

children. Mothers had higher scores than fathers on two of the three sub scores; those which involved integration of self-esteem and optimism within family life and those that involved communication with medical staff regarding their child's care. The F-copes scores of parents demonstrated a wide variation in the types of coping mechanisms with the particular high score in the use of passive appraisal. The relationship between parental coping and any child's outcome measures was not reported in this study.

### **Critique of Renal Psychosocial Research.**

Overall there is a paucity of results examining the psychosocial effects of renal failure in children in comparison with the data available on adults (Beidal et al., 1987). Taken as a whole, there does appear to be agreement that the severity of renal disease is related to psychosocial adjustment in children, and that the type of treatment that the child has in end-stage renal failure will have an effect on the child's psychological adjustment to the illness.

Unfortunately, it is difficult to come to unequivocal conclusions about the psychosocial effects on illness, because of some of the methodological problems in the research with this group of children.

Firstly the comparative rarity of this disease (it is 100 times less common than children with cystic fibrosis) makes it difficult to recruit adequate numbers to study. As a result of the low level of numbers, researchers tend to ignore developmental issues by placing children of all ages in the same group. Thus the effects of disease severity will not have the developmental perspective evaluated within the study because this will reduce numbers for analysis. For example in Reynolds et al. (1991) study looking at the changes in psychosocial adjustment of the renal transplantation, the age range of the 29 subjects were between 1 and 17 years. The findings that disease severity affect psychosocial adjustment need further examination, particularly for any interacting variables that could contribute towards understanding the role that severity plays in psychological adjustment.

With such small numbers it is also very difficult to examine any differences in psychological adjustment using other such non-categorical

criteria such as age at onset of illness and duration of illness. Other variables such as socio-economic, cultural and family factors are also difficult to examine with small numbers of children. In particular, research studies that are likely to have small numbers must guard against selection or bias of patient groups to be studied, unless this is part of the study design. For example Douglas et al (1998) reported a cross-sectional study of 14 families following transplantation. Standardised outcome measures indicated that the mean score of children's outcome was not abnormal. However, this group of families were a self selecting group from a larger group of 27 families, with no comparison data available with the families who declined to participate.

Secondly, there is an issue regarding measures that evaluate psychological outcome. Some studies which purport to examine "psychological outcome" report only on children's school or educational status (Riechwald-Klugger et al., 1993; Koewn, Shackleton & Ferguson, 1992; Rosenkranz et al., 1992) thus neglecting very large area of psychological adjustment.

In addition measures used throughout studies are frequently not reported in depth. Normal standardised measures of outcome seem to be the exception rather than the rule. Many measures seemed to rely on self-report or non-standardized scales (Watson, 1998; Roscoe et al., 1991; Henning et al., 1988). Whilst self-report measures can be very useful in pointing out exact issues that are pertinent with a patient group, it is very difficult to make comparisons across studies of overall outcome of families and children. Without reporting these measures in depth or in the appendix of the journal paper it is unlikely they will be validated with other patient groups. For example Watson's (1997) study asks parents about their stress, anxiety, depression, and information needs but failed to describe in detail the questionnaires used for this. Measures of health severity have tended to focus on simple division of children into treatment groups, rather than taking other variables into account. Whilst severity may appear to be related to outcome, the mechanism behind this has not systematically been evaluated. In an exception to this pattern, Brownbridge and Fielding (1994) have used a self-

report health status questionnaire, which has been validated with severity of illness, suggesting that there is a relationship between these two measures.

Again with an important question regarding the psychological issues around parents donating a kidney to their child, evaluation of psychological data were collected with self-report non-standardised, descriptive questionnaires (Karrfelt, Berg, Lindblad & Tyden, 1998).

In all, renal research on psychological outcome remains very much in its early stages with results reporting and describing the type of consequences that face these families. There is a general lack of theoretical basis from which to place current findings or from which to base future studies. What is needed is research-based theory that is clinically applicable, so the findings of results can be applied to interventions. Besides looking at the psychopathology associated with this group it would be refreshing to re-focus on those children who appear to be coping with their illness, and explore and understand the mechanisms behind this. Aims of the future should include an examination of the more complex nature of the psychosocial effects in these families; looking at both the risk and resilience factors that will predict psychological outcome. The types of models that could provide this basis are described in the next section.

### **Theories of Adjustment in Chronic Illness.**

In order to proceed in understanding the mechanisms behind psychological adjustment in this group, research needs to be more firmly based in theory. Whilst the prevalence of psychopathology in children with chronic illness does appear to be higher than that of healthy children there is a large proportion of children who do not show psychological difficulties and therefore have adjusted to the stresses that are undoubtedly associated with living with a chronic illness. One can conclude therefore, that children with a chronic disorder are a population at risk of psychological difficulties, but that these difficulties are not inevitable and are not determined solely by a single mechanism such as the child's diagnosis or severity of illness.

This shift away from psychopathology as the focus is a relatively new concept, and one theme in the literature to account for the differences between individuals' adjustment has been the exploration of psychosocial risk and resilience factors that influence both the child and family's adjustment. With an accumulation of evidence of the type of psychosocial factors that influence adjustment, it has become clear that the mechanisms underlying adjustment are not simple, linear or easily predictable. Different variables contribute towards the overall picture and interact together to offer a greater or lesser contribution to the child or families overall adjustment.

One of the most promising theoretical models is that proposed by Wallender, Varni, Babini, Banis & Wilcox, (1989b) who endeavoured to integrate three theories into a single conceptual model; Pless and Pinkerton's model, (1975), Moos and Shaefer's Crisis Theory (1984), and Lazarus and Folkman's model of stress and coping (1984).

Pless and Pinkerton's model (1975) proposed that adjustment is a dynamic process that throughout childhood continues to be applied, shaped and influenced by feedback loops. They hypothesised that genetic, social and family factors determined a large part of a child's attributes e.g. temperament or personality. In turn, these attributes interact with characteristics of the disease such as severity and location. Results of these interactions determined the child self-concept and coping style and hence the child's overall adaptation.

Moos and Shaefer's crisis theory (1984) is concerned with responding and coping with major life crisis. The diagnosis of illness in the child is seen as a crisis and as a consequence the individual tries to re-establish equilibrium by employing problem-solving strategies. Non resolution of these problems will result in the individual suffering a crisis, and non-resolution of this crisis in maladaptive responses becoming established. A number of risk factors influence the individual's appraisal of the situation and their subsequent use of coping strategies which include demographic, personal, illness, and environmental variables.

### Lazarus and Folkman's model of stress and coping (1984)

hypothesised that stress and coping involve continuous interactions and adjustments between the person and their environment. Stress is said to occur when the demands on a person exceed the present resources or ability to cope. Coping is hypothesised to be behaviour or cognition by which people attempt to manage the demands with the resources available. The individual initially appraises whether the demands threaten their well being and if they have the resources to cope with this. Having appraised the problem the individual seeks to master the situation by selecting coping strategies or a mechanism which aims to change the situation for the better and also to manage the subjective components of stress related emotions.

The integration of the above models into Wallender et al.'s (1989b) model of Child and Maternal Adaptation to Chronic Conditions initially makes the assumption that the presence of a chronically sick or handicapped child does not necessary represent an adverse event for the family. Rather that as a consequence of having a child with a disorder the family are confronted by increased number of potentially stressful situations, which can lead to difficulties, if not managed successfully.

In seeking to explain the variability in child and family adjustment to chronic illness the model by Wallender, Varni, Babini, Banis and Wilcox, (1989) places particular emphasis on the role of stressors and the individuals competence (see figure 1). Competence is viewed as "the effectiveness of the coping responses indicated when an individual is confronted with problematis situations."(Varni & Wallander, 1988, p. 215) . The model hypothesises that risk and resilience influence adjustment. Variables that increase the risk of poor adaptation fall into three categories. These are disease and disability parameters, (for example severity and sensory loss); the level of functional independence of the child, (how able the child is to carry out everyday activities); and psychosocial stressors (including stresses related to the disease as well as other independent problems).

The impact of these risk factors on adjustment is modified by three sets of resistance factors, which are intra personal (e.g. temperament and



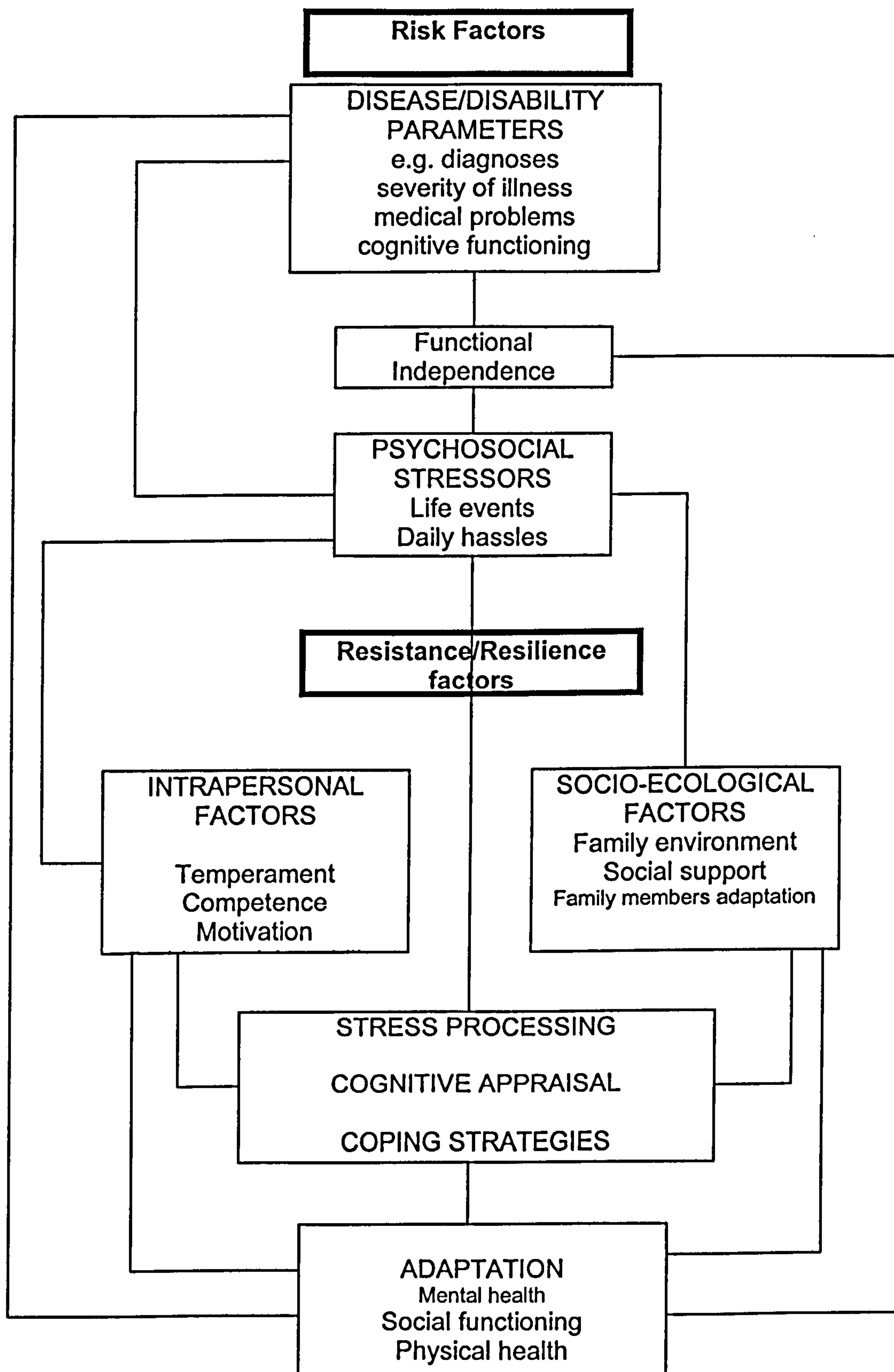
motivation), social-ecological (e.g. family environment and social support), and coping resources (e.g. cognitive appraisal and coping strategies).

Wallander et al. (1989b) hypothesised that these factors influenced adaptation in both direct and indirect ways. Thus this model offers a much more complex and multi-factorial explanation of the individual differences that have been observed in children's adjustment to chronic illness. In particular they emphasise the interdependence of risk and resilience factors and move away from the suggestion that adjustment is solely a function for example, of coping skills, or child self-concept.

The multi-factorial nature of this model whilst being its strength, has the drawback of being too complex to be able to validate the model as a whole. Wallander (1992) argues that it is only feasible to analyse single or small groups of variables within the model to see if they operate in the hypothesised direction. Wallander and Varni (1992) also support the non-categorical approach to study the effects of chronic disease. Thus they argue that their model is applicable to any paediatric disorder and so can be used as a basis for research projects evaluating psychological adjustment in paediatric psychology.

Figure 1.

Wallander and Varni's conceptual model of child adjustment to paediatric chronic physical disorders. From Wallander, Varni, Babini, Banis and Wilcox (1989).



### The Application of Wallander et al.'s (1989b) Model of Child and Maternal Adaptation to Maternal and Child Chronic Conditions

A series of studies were carried out by the authors of the model, (Wallander et al., 1989b) to test aspects of their theoretical model. Specifically they aimed to evaluate whether disease or disability had a mediating effect on child and maternal adjustment (Wallander et al., 1988; Wallander, Feldman, & Varni 1989; Wallander et al., 1989a; Wallander, et al., 1989c).

In 1988, Wallander et al. examined the impact of specific diagnosis on children's adjustment. The results indicated that there was a fivefold increase in psychological problems in children who had a chronic disease (cerebral palsy and spina bifida) in comparison to healthy peers; generally children's scores of behavioural disorder did not vary as a function of the diagnostic group. These findings supported the assertion (Wallander, Varni, Babini, Banis & Wilcox, 1989) that adjustment problems were not necessarily disease specific and a non-categorical approach was the way forward. However, these findings were not substantiated in a later study (Wallander et al., 1989a) investigating the role of disability parameters with a measure of the child's functional status (ratings made by the researcher) in a population of children with cerebral palsy or spina bifida. Again, children were rated as having significantly more emotional and social functional problems compared to a normative sample. However, the authors failed to establish any significant associations between level of disability and maternal and child adjustment problems.

In a further study, Wallander, Feldman, and Varni (1989) used a more detailed measure to determine a child's physical health status. This included data from medical records of the underlying causes of the child's disability, plus parameters of mobility. However, this still did not predict the behavioural and emotional adjustment difficulties reported.

The same research group examined whether the child's functional impairment would have some bearing on maternal adjustment. In these two

studies (Wallander, Pitt & Mellins 1990; Wallander et al., 1989c) groups of mothers of children with physical or sensory disorders were compared to mothers of physically handicapped children. Again they failed to find unequivocal support for their model showing increasing disability in the child related to increasing maternal adjustment.

Thus it can be seen that to achieve evidence within the clinical field to support a conceptual model was difficult, given that the authors of the model themselves found it difficult to substantiate. Bradford (1997) suggests there are weaknesses in the model and also in the methodological investigations to substantiate this. In examining the conceptualisation of risk and resilience factors Bradford suggests that for example family environment, although conceptualised as a resilience factor, did in fact appear to act as a risk factor. Hence an effect of family environment was seen when this was maladaptive. Again one could see that other so-called resilience factors may in fact, act to make a child more at risk; for example, maladaptive coping strategies. Wallander and his colleagues do not precisely define what is meant by risk and resilience, and some of their categories make it possible to transpose what are resistance into risk factors. Bradford (1997) goes on to suggest that this could be addressed by more precise labelling of the interactive variables that make up the risk and resilience factors and thus specifying which dimensions of each factor are important.

Methodologically, the above studies (Wallander et al., 1988; Wallander, Feldman, & Varni, 1989; Wallander et al., 1989a; Wallander et al., 1989c) have relied on one main outcome measure - the Child Behaviour Checklist (Achenbach & Edelbrock, 1983). The use of this measure with chronic illness populations has been criticised (Perrin, Stein & Drotor, 1991). In addition the measurement of health status may not have been sensitive enough to detect differences between children. Carrying out the research studies concurrently as is suggested by the publication dates may have meant that Wallander et al. (1988, 1989a,b,c,) were less able to reflect on methodological shortcomings from project to project. Finally, in

investigating the contributing factor of disease and disability parameters as mediators of adjustment, Wallander and Varni (1998) imply that they account for most of the effect seen in variances in levels of adjustment. It is possible that other variables outlined in the model also contribute towards the overall outcome.

However, despite its lack of support within clinical research Wallander et al.'s (1989) acknowledgement of the interaction of factors influencing child and family adaptation to chronic illness still represents the most coherent theory to date. Further investigation of some of the factors and how they contribute is warranted to see whether there is support for the hypotheses generated from this model, and whether it is possible to evaluate the multi-factorial nature of the model in a more satisfactory way.

#### **Further Examination of Risk and Resilience Factors.**

##### **The health status of the child.**

Although there is no simple answer to the question of whether severity of the physical illness influences psychiatric risk, the balance of evidence generally favours a link between severity and psychiatric adjustment in more severely affected children with problems such as asthma, eczema, diabetes and chronic renal failure (Garralda et al., 1988; Pless & Nolan, 1991). The issue around the relationship between illness severity and psychological outcome needs further examination. Wallander et al. (1989b) support the non-categorical model of illness thus implying that it is the effects of the illness rather than the diagnosis that will contribute towards psychological difficulties. However in the studies cited above, there was no evidence supporting their hypotheses around non-categorical factors being related to psychological outcome. This could be due to methodological problems with the studies. For example Wallander et al. (1988) reported using only objective measures of illness, made primarily by the researcher. Alternative parallel measures such as those that tap different dimensions of illness severity, for example, the effects of the child illness on their social and physical functioning may have shown some effect in the analysis. Lavigne and Faier Routman's (1992 ) meta analysis

emphasises that a simple measure of severity of illness or diagnosis is not enough to predict differences in the child's outcome. Rather it is the effect that the illness has on the child that is more likely to show an effect. Thus they suggest a measure of the child's functioning is the critical factor leading to psychological outcome.

Other studies which indicate a relationship between health status and adjustments have included this type of measure (Kahn et al., 1995; Orr, Weller, Scatterwhite & Pless, 1984). A study by Perrin, Williams, MacLean and Perrin (1989) evaluated health status and the psychological adjustment of 46 children with asthma using two types of health measure. A composite health status measure was made up of information regarding medication frequency, frequency of asthmatic attacks and days missed from school. In addition, parents rated their own perceptions of the child's illness. Although there was some correlation between parental and objective health status measures, on analysis this was only significant with the amount of medication the child took and not the other categories of the composite health status measure. When these two results were correlated with a measure of child psychological adjustment, there was a significant relationship between parental rating of child severity and scores of psychological distress, whereas the relationship was not significant for the composite health measure. The authors suggest that the mechanisms may be the parent's attitudes towards the child illness influencing the children's response to illness and hence the psychological adjustment. This study clearly shows perceptions as more important than more concrete measures of the child's illness. Thus further investigation of what is meaningful about this measure is important, and should also include the child's perceptions of their illness.

#### Coping resources

An important factor that seeks to explain individual differences in adjustment both in theoretical models such as Wallender et al., (1989) and in clinical applications is the concept of coping. The concept of coping in itself has a large body of literature that attempts to define the mechanisms, processes and

behaviours of coping. Hence the definition and difficulties of measuring this concept will be discussed, before application of this within the above model.

### The Concept of Coping

Coping strategies are one of the resources used to manage the effect of adverse events. A broad stress and coping framework is useful in specifying a number of variables and research questions that concern adaptation to stressful events. The diagnosis and adjustment to living with chronic illness is considered such a stressful event. A stress framework model refers to process in which individuals encounter adverse events within the environment (stressors), interpret these events as threatening to their well-being (appraisals) and utilise coping strategies and social resources to manage their effect and/or attempt to change the situation (Lazarus & Folkman, 1984).

Lazarus and Folkman (1983) emphasised that stress was derived from a negative quality of events rather than from change in itself; change per se would predict that positive as well as negative events are predicted to be stressful. Studies have concluded that it is the negative undesirable and not desirable events that relate to high levels of psychological symptoms in children and adolescents (Rowlesson & Felner, 1988; Sandler, Wolchick, MacKinnon, Ayers & Roosa, 1997).

Several models have proposed causal relations between stressful events and adjustment problems (Dohrenwend & Dohrenwend, 1978). Stressful events are hypothesised to have a direct causal effect on increasing children's adjustment problems, with both major and minor events having additive effects over time. Alternatively another model is one of a bi-directional nature that is children's adjustment problems interact with their environment in a causal relationship (Roosa, Beals, Sandler & Pillow, 1990).

The two key concepts in Lazarus' and Folkman's (1984) model are the appraisal of the situation followed by the application of coping strategies. According to this model, the critical process that leads to a stress response

(and therefore coping) is the individual's appraisal that the event has negative implications for one's well being. Lazarus (1993) identified three components to appraising the implications of specific events. These corresponded to three questions; goal relevance (should I care?), goal congruence (is this positive or negative?), and type of ego-involvement (in what way am I involved?). Although the construct of appraisal is pivotal to this model, it has received considerably less research than the construct of coping.

Coping focuses on how children respond once they have made a threatening appraisal. Lazarus and Folkman (1984) defined coping as "constantly changing cognitive and behavioural efforts to manage the specific external and/or internal demands that are appraised as taxing and are exceeding the resources of the person" (p. 141). Lazarus and Folkman hypothesised five types of coping resources from which to utilise coping strategies; utilitarian, which includes socio-economic status and available resources; health energy or morale; social networks, including interpersonal relationships; general and specific beliefs, which include self-efficacy and self-esteem, and problem-solving skills including cognitive, intellectual and problem solving abilities. The resulting execution of coping styles have two major functions. Firstly to change the situation for the better and so solve the problem from the perspective of the individual. Secondly, to manage the somatic and subjective components of the stress related emotions. These two functions can either oppose or support each other. Their model emphasises that coping should be viewed as *all* cognitive and behavioural efforts that are used to respond to specific external and internal demands, regardless of the outcome.

### Children's Coping Strategies

As discussed above, Lazarus and Folkman (1984) identified two broad dimensions of the intended functions of coping. Problem focused strategies are aimed at changing the problematic situation, whilst emotion focused strategies are aimed at managing or reducing the emotional distress associated with the situation. Nearly all theoretical models embrace a two factor model



thus defining coping strategies into very broad categories. Other examples describing this construct in broad dimensions are repression - sensitisation (Krohne & Rogner, 1982) and monitoring - blunting (Miller, Brody & Summerton, 1988).

Another two factor theoretical framework is based on focusing coping either towards or away from the situation (Ebata & Moos, 1991). Approach coping involves cognition; for example, positive reappraisal directs behaviour that focuses on the stressful situation. Avoidance strategies involve cognitive or behavioural efforts not to think about and avoid encountering the stressful situation.

In the clinical field however it is also important to study the details of coping efforts, and these may be missed because of very broad categorisation of coping dimensions. More recently researchers have empirically identified more narrow bands of dimensions of coping, using factor analytic approaches. Using this technique Ayers, Sandler, West & Roosa (1996) found a four-dimensional model of coping consisting of: Active Coping, Avoidance, Distraction, and Support Seeking. This provided a better fit to their data than an approach versus avoidance or problem focused versus emotion focused models. In Ayers et al.'s findings, active coping includes both emotional focused strategies (positive thinking) and problem focused strategies (direct action). Distraction strategies are distinguished from cognitive efforts (avoidance) in dealing with the situation.

In another study, children's coping strategies were examined following a hurricane (Vernberg, La Greca, Silverman & Prinstein, 1996). The Kidcope coping checklist (Spirito, Stark & Williams, 1988) was used which focussed on the coping strategies used for the specific stressor of a hurricane. A factor analysis of the Kidcope responses indicated four factors of coping strategies. These were: Positive Coping, where efforts to maintain or regain a positive emotional state were used, Blame and Anger, Wishful Thinking and Social Withdrawal. Children's coping strategies accounted for 21% of additional variance in symptoms of post-traumatic stress disorder. There was a positive

relationship between greater psychological distress and greater use of all coping efforts. In addition, results also suggested that the use of blame and anger as a way of coping had the strongest negative ramifications to children's levels of distress, with the blame and anger factor accounting for 36% of the total effects of the coping variables.

In terms of the predictable quality of coping strategies for mental health outcomes there is consistent evidence that it is the dimension of active coping that includes problem solving and positive cognition about a stressful situation are related to lower mental health problems. For example, researchers have reported that problem focused coping is significantly related to several developmental outcomes such as self-efficacy, self-esteem, and perceived self-confidence (Causey & Dubow, 1992; Brodzinsky et al., 1992)

There is relatively consistent evidence that the use of avoidance type coping strategies is related to high mental health problems in children and adolescents (Ebata & Moos, 1991; Sandler, Tein & West, 1994; Ayers et al., 1996). For example Sandler et al., (1994) found that anxiety predicted higher avoidance coping leading to the interpretation that anxiety leads to the high use of avoidance coping rather than the reverse causal direction.

Research evidence is not yet conclusive concerning the relationship of support seeking coping with problem outcomes. However, Causey and Dubow (1992) did not find a significant relationship between the support seeking and children's adjustment. Ayers et al. (1996) and Sandler et al. (1994) also did not find any significant relationship between support seeking coping and child adjustment in their studies.

### **Coping as a State or Trait Variable**

Besides the concept of coping mechanisms, Lazarus and Folkman (1984) emphasise in their definition that coping mechanisms are situation specific; in other words they are not consistent from situation to situation for the individual. There are differing opinions regarding the emphasis of the contribution of the importance of the temporal and contextual influences. Some researchers view coping style as a stable trait of the individual, with the

same coping strategies being applied across a wide range of stressors (Carver, Schier & Weintraub 1989; Miller, 1982.). Studies have attempted to examine this issue further, and one way of assessing this is by examining the effect of coping patterns of children or adolescents across situations and over time within the same contexts.

Spirito et al. (1988) has developed a coping strategies questionnaire which specifies the situation in which the child apply their coping strategies. He has carried out studies examining the stability of situation specificity of coping strategies (Spirito, Stark, Gil & Tyc, 1995). Using the Kidcope to identify types of stress reported by chronically ill children, they investigated whether coping was a state or trait factor. The children in this study had diagnoses of sickle cell, diabetes, cancer, migraine, and cystic fibrosis.

Results compared inpatients and outpatients with different types of stresses (illness versus non-illness problems) and the frequency with which they were reported. There were no differences in number and type of stressors reported by gender or disease category. There were age differences with older children choosing problems associated with their illness. Spirito et al. (1995) found domain effects for age, gender, illness problem, and anxiety. ANOVAs revealed significant differences between individual coping strategies.

Differences in coping strategies were found when type of problem was interacted with gender e.g. resignation was used as a coping strategy more frequently by adolescents who selected pain as a problem and boys used cognitive restructuring and self-blame more than girls who used emotional regulation and social support.

Spirito et al., (1995) analysed whether coping was more strongly affected by individual traits (using age & gender) than situations. They reported that there was only small consistent age effects across the two sets of problems described, although there were some gender effects for coping strategies used in illness problems but not in non-illness problems.

In exploring the situational specificity effect of coping strategies,

Spirito et al. (1995) analysed the variability in coping expressed by the same subject both in the problems reported associated with everyday life, and also in problems associated with their illness. Some coping strategies remained consistent between everyday problems and illness reported problems suggesting coping strategies had some stability in individuals across situations.

He then reported a study of situation specificity testing out coping strategies over time. Using the same questionnaire and situation three days apart results showed consistency between the two time points. In contrast, using the same questionnaire but with differing situations, this time 10 weeks apart, results showed low test re-test correlations as would be predicted by a situation specific hypothesis.

Spirito et al. (1995) concluded that there was a combined effect of both stability and situation variability influencing children's coping strategies therefore both needed to be taken into account in measuring and reporting coping strategies.

Pretzlick (1997) also found good test re-test reliability for self-reported stress also using the Kidcope (Spirito et al. 1988). Eight out of ten of the coping strategies used in the same situation showed consistency with no mean differences reported in the frequency or perceived helpfulness of coping strategies between the two time periods seven days apart.

Thus this concept is a major issue in the measurement of coping, and links to criticisms in previous research on coping which is around methodology. Questionnaires frequently result in inconsistent responses, as most make it unclear regarding the context in which they are asking questions both from situation to situation and over the course of time. For a predictable pattern of coping to be measured, not only must the individual differences of the children be taken to account but also the type of stressor needs to be specified, so for example, in paediatric illness even though the stressor is expected to be illness related there is a need to specify that coping is being measured in relation to illness variables.

### **External Influences of Coping.**

In addition to examining coping style and its relationship to psychological adjustment it is important also to consider what are the determinants of child coping. The relationship between high levels of parental and associated child psychological distress has been substantially investigated (Pound, Cox, Puckering & Mills, 1985; Breslau, Staruch & Mortimer, 1982). However, research studies of the influence of parental coping on child adjustment or child's coping are more scarce. Sanger, Copeland and Davidson, (1991) found that in children with cancer whose parents maintained family integration had an optimistic definition of illness and fewer psychological difficulties. Similarly Frank, Blount and Brown (1997) examined the influence of attribution and coping style in 86 paediatric oncology patients. He also evaluated parental coping using the Coping Health Inventory for Parents (CHIP, McCubbin et al., 1993). They found that the use of a coping pattern (family integration) associated with lower child adjustment scores. Relationships between parental and child coping were not reported in this study.

The relationship between parental and child coping has been specifically examined in few studies with the results being rather tentative. A study examining 28 long-term survivors of paediatric leukaemia (Kupst et al., 1995) found that ten years following the treatment, both patients and families were assessed as being well adjusted to their outcome. The researcher evaluated the individual's ability to manage emotionally and practically a number of lifestyle issues, and made a measure of "adequacy of coping". A hierarchical multiple regression analysis was conducted showing that mothers coping adequacy and perceived adjustment were the strongest indicators for child survivors coping adequacy and perceived adjustment. The authors suggest the children may well have learned to cope with distress through their mothers modelling of coping behaviours.

Kliewer and Lewis (1995) examined the contribution of parenting and

family variables to the general coping processes of 39 adolescents with sickle cell disease. Parents rated their own coping assessment and also a measure in which they rated the extent to which they encouraged 50 coping behaviours in their children. Children filled in their own coping strategy questionnaire and a level of hope scale. Results indicated that parents own coping explained a significant proportion of the variation in children's avoidance coping, with parental cognitive restructuring negatively related to child's avoidance. In addition, parents' active coping suggestions were associated with children's level of hope. A measure of family cohesion was also positively related to active coping. The above results followed the researchers expectations and suggest that the coping messages parents give their children affect how the children feel about the circumstances of their lives and how families influence children's coping. An additional result however, was in the opposite expected direction, as parents' active coping was positively associated with their child's avoidance coping. They suggested that this strong relationship may be due to the parents taking more care of the children's problems thus the children assumed a more passive role in responding to stressful situations.

### Summary

The need to examine the effects of chronic illness from a theoretical framework has become increasingly important as findings regarding the relationship between psychological distress and chronic illness suggest that this is a complex one with many influencing factors. The use of a model such as Wallender et al. (1989b) has influenced the exploration of influencing factors such as the role of the severity of illness. Findings point to this as an important factor in considering psychosocial outcome, although the way in which this is measured bears a strong impression on the outcome results. More recently research has started to look at other factors which influence the positive psychological outcome of these children with coping strategies exploring how these families adapt and cope with their illness. The theoretical and research findings in the coping field have provided a basis for exploring

this variable in paediatric research. The following section describes what research has been carried out on children's coping strategies within the chronic illness framework, and then goes on to examine how links between coping, adjustment and severity to illness could be further clarified and scientifically explored.

### **Children Coping with Illness**

As research studies have moved away from the assumption that chronic disease would inevitably have an adverse effect on the patient and family (Gayton, Freidman, Tavormina & Tucker, 1997), studies began to examine coping strategies of the child and parent as a predictor for psychological adjustment.

Initially, the bias to research was identification of coping strategies associated with maladjustment, as it was felt the identification of high risk groups was important in developing preventative and therapeutic approaches (Pless & Nolan, 1991).

For example, Dalamater, Smith, Lancaster and Santiago (1988) carried out a study that examined the contribution of coping to the adjustment of 47 children with insulin dependent diabetes mellitus. They found that several diabetes specific coping measures were significantly associated with worse metabolic control. Higher scores in the coping strategies of Self-Blame, Keeps to Self, and Wishful Thinking were related to worse control. In children with the same disease, Hanson et al. (1989) found that avoidance coping was unrelated to metabolic control in 135 adolescents but that this coping strategy was significantly related to lower regimen compliance.

In a different disease group, Thompson, Gil, Burbach, Keith and Kinny (1993) found that children's strategies for coping with pain explained an additional 21% of the variation in child reported behaviour symptoms after accounting for illness complications, pain frequency, gender and age. Specifically, negative thinking in children was associated with greater levels of behaviour problems.

In 1996 Kronnenberger et al. found that avoidance and distraction

coping strategies were associated with higher aggression, anxiety, withdrawal and depression in children having bone marrow transplant. Kronnenberger et al., also evaluated positive coping strategies such as cognitive restructuring, social support, and problem solving but they found that these were unrelated to child adjustment scores. In this study, parental distress was correlated with higher levels of children's problems and the children using avoidance coping strategies.

The identification of maladaptive coping strategies has led to concurrent identification of positive coping strategies which could act as protective factors for psychological outcome in children with chronic illness. With the acknowledgement that treatment strategies need to be designed and evaluated for the children identified as at risk of maladjustment (La Greca & Varni, 1993) there has been increasing focus on identification of positive coping strategies.

Ebata and Moos (1991) investigated the relation between coping and adjustment in 45 adolescents with rheumatic disease. Adolescents who used coping strategies such as positive reappraisal and problem solving and conversely less avoidance coping were more psychologically healthy.

Band and Weisz (1990) found coping significantly related to medical adjustment in a group of older children with mixed diseases and ages. Primary (similar to problem focused) coping was associated with more favourable adjustment. In addition coping style was uniquely predictive of parent rated behaviour and conduct problems.

Spirito et al. (1988) have adapted The Ways of Coping Questionnaire (Lazarus & Folkman 1986) to become more situation specific. As discussed above, the issue over whether coping is a state or trait variable is important in trying to predict behaviour patterns within individuals and situations. Lazarus and Folkman (1983) argue that coping is situation specific, therefore questionnaires that measure the specificity of coping strategies would be particularly usefully applied within the health and illness framework. The resulting Kidcope (1988) examined negative and positive coping strategies,



which has been used in studies of children with illness. Spirito et al. (1988) compared paediatric patients who had been referred for psychological evaluation with diabetic patients in a summer camp. Paediatric patients used social withdrawal and distraction more than diabetic children or healthy controls. They also noted that the healthy children used self-criticism significantly more frequently than the paediatric or diabetic children.

In a comparison study using hospitalised versus chronically ill children (the chronically ill children being the ones reported in the above study), Spirito, Stark and Knapp (1992a) found that acute children were more likely to use distraction, self-blame, and wishful thinking than the chronically ill children.

In summary, as in the general studies of coping, problem focused coping appears to be more adaptive in this population, resulting in better adjustment to chronic illness. Avoidance coping and self-focused coping appear to be associated with poorer adjustment. These consistent findings suggest that the factors are important ones in the adjustment to illness equation. However, the relationship between coping and outcome is not unequivocal, and there is a need for a better conceptualisation of the process for further research studies to clarify this relationship. Although the contribution of coping as a resilience factor is addressed in Wallander et al.'s (1989) model, the process of how this variable influences outcome needs further exploration.

Nevertheless, as discussed above, coping and the severity of illness consistently seem to have an effect on many patient groups in paediatric psychology. Most studies have taken a "main effects" approach when exploring associations between variables and adjustment (Kliwer, 1997). What is needed is a re-examination of these variables within a tighter framework than the theoretical perspective offered by Wallander et al. (1989) which aims to examine the mechanism of the interactive effects that variables have on the child's adjustment to chronic illness.

The contribution of variables as moderator and mediators can

contribute to the understanding of such processes. The models describing these, and how coping could be fitted to these concepts are described below.

### Mediating and Moderating Models

Two conceptually distinct processes give rise to a theoretical basis for examining how the influence of the stress of chronic illness may impact upon psychological outcome. Mediators and moderators can be characteristics of the child, the child's family, or larger environment that determine *the degree to which* a stressor may impact upon child outcomes (Garmezy, 1985). In themselves, mediators and moderators can explain how the risk and resilience factors may affect the child as suggested in the Wallander et al. (1989b) model, but the process by which they act on the child is more clearly conceptualised. What the moderator and mediator concept can do is to explain how the variables classified as risk and resilience factors by Wallander et al. need not to be confined to one or other category as described in the model. They can, in fact, through the process of moderation or mediation fit either category. For example both coping strategies and family environment are defined as resilience factors in the model, yet their own findings (Wallander et al., 1989c) suggest that family environment acts as a risk factor (Bradford, 1997). Intuitively, coping strategies could be defined as either risk or resilience factors according to whether they are adaptive or maladaptive. Moderator and mediators do not categorise factors but offer how one variable may act upon another, influencing outcome. Although both moderators and mediators explain the link between a stressor and outcome they are distinct concepts, and act in different ways from each other.

Moderators alter the strength of the relation between exposure to a stressor and its outcome. A stressor may have little or no affect in the presence of moderator but may greatly increase or decrease that likelihood of negative outcomes in the absence of moderator. For example the presence of social support from adults has been shown to reduce the negative effects of

life stresses in children in divorced families (Wolchick, Ruelhman, Braver & Sandler, 1989). Thus social support is considered a moderator (in this case a protective factor) that reduces the strength of the relation of a stressor to its outcome.

Moderators can also act as vulnerability factors so that the presence of these can increase the strength of the relation of a stressor to its outcome. Typically researchers identify moderators by finding variables that interact with a stressor to influence adaptation (Rutter, 1985).

Moderators in themselves are not influenced by the occurrence of the stressor, therefore they explain the circumstances under which there is a relationship between the stressor and outcome.

Mediators, on the other hand, are affected by the presence or strength of major stressors. Mediators are then in turn related to mental health outcomes, either in a positive or negative direction. For example positive parenting behaviours are positively related to child mental health. However, these parenting behaviours can be mediated through exposure to high levels of stress and the subsequent diminished quality of parenting can increase the child's likelihood of developing mental health problems (Roosa, Tein, Groppenbacher Michaels & Dunka, 1993). Again mediators can act like moderators and reduce or enhance risk, hence it explains the link between a stressor and outcome.

Baron and Kenny (1986) have statistically distinguished the properties of moderator and mediator variables, so it is possible to clarify the different ways in which these conceptual variables account for differences in people's behaviour. Coping therefore could act as a mediator or a moderator in the face of a stressor such as illness severity, which will act upon the psychological outcome of the child.

When coping acts as a moderating variable, it would examine under what conditions the relationship between health status and adjustment might exist. The moderating effect is typically expressed as the interaction between the predictor and criterion variables. Figure 2 illustrates the essential

properties of the moderator. There are three causal paths directed into the outcome variable: the predictor or independent variable (path a) the moderator variable (path b) and the interaction or product of both of these (path c). The Moderator hypothesis is supported if the interaction along path c) is significant. If there are some significant findings indicating a moderating effect, then the moderating variables that are contributing to the effect need to be further examined in order to explain the direction of influence behind the contributing factor.

In the mediator model, the mediating variable coping, examines the link between severity of illness and adjustment (see figure 3). In order to prove this an initial relationship between the predictor (severity of illness) and outcome (adjustment) needs to be established (path c). There also needs to be a proven relationship between the mediator (coping) and the outcome (adjustment), (path b). A relationship also must be seen between the predictor and the mediator (path a). When the effects of the mediator on the outcome are controlled, the mediator model is substantiated by the relationship between the predictor (severity of illness) and outcome (adjustment) (path c) being significantly reduced. In other words, coping is statistically accounting for or “carrying the effect of” the relationship between health status and adjustment.

Figure 2  
Direction of Relationship Between Variables in the Moderator Model.  
(Baron & Kenny, 1986).

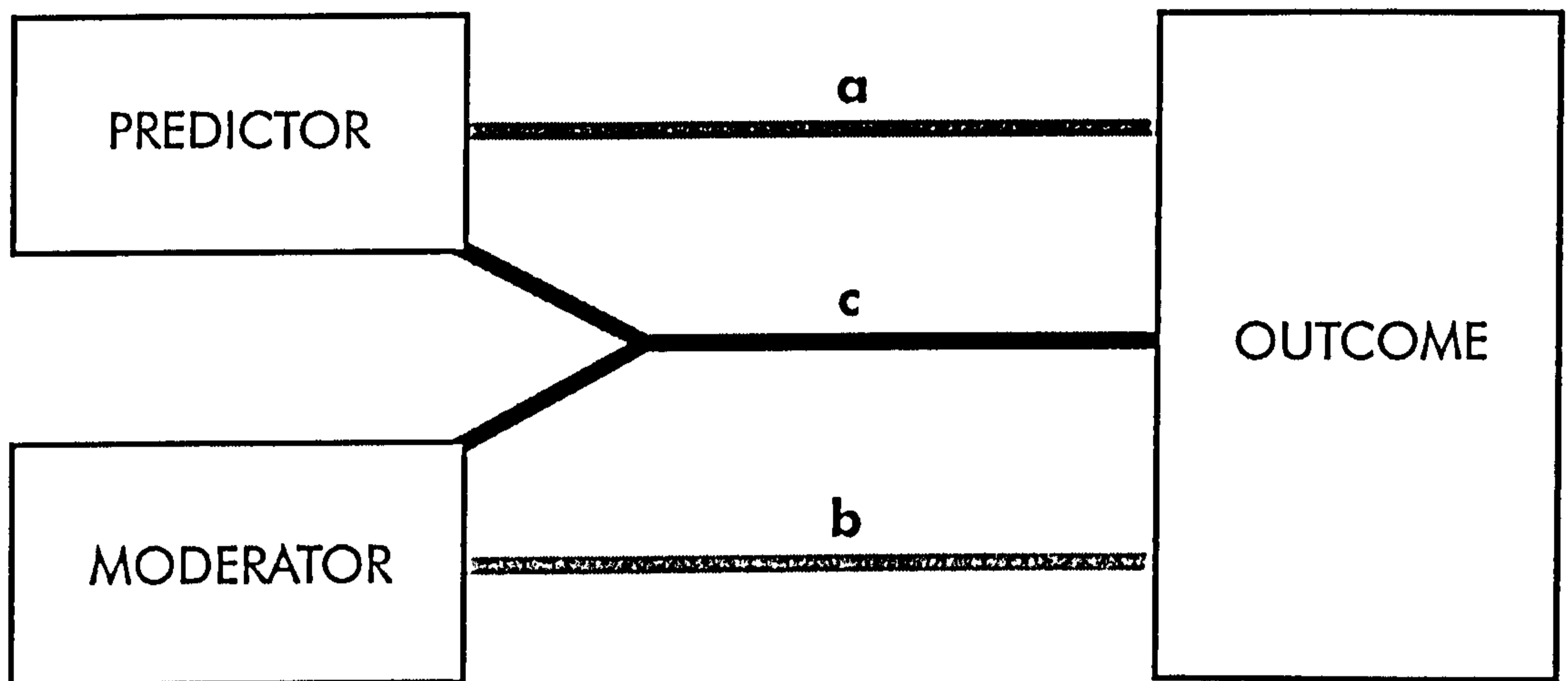
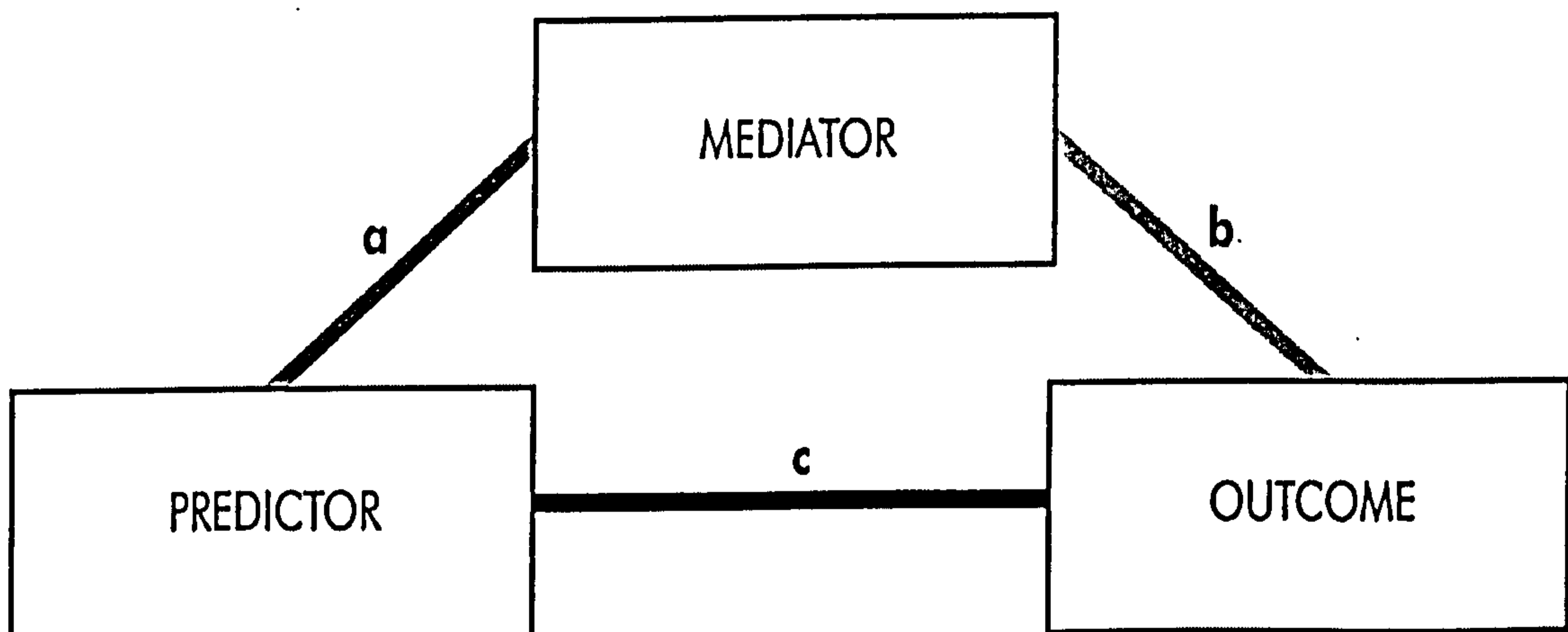


Figure 3  
Direction of Relationships Between Variables in the Mediator Model.  
(Baron & Kenny, 1986)



### **Studies Investigating these Models**

In a search of the literature, few studies were found which examined the contribution of variables using either moderators or mediators as a framework in predicting adjustment. Of these studies, there has been a tendency to focus on the main effects of interactions that have a disposition to be referred to as moderator or mediators interchangeably as if the terms had the same meaning. However, from the moderator/mediator framework the differentiation between moderators and mediators are important, explaining the process of interaction (Baron & Kenny, 1986).

One such study suggested that a mediation process accounted for independent and significant increments in the variance of adjustment in mothers who had adolescents with cystic fibrosis (Thompson, Gustafson, Hamlett & Spock, 1992). They hypothesised that poor adjustment in mothers would be due to higher levels of perceived stress, palliative coping, and poorer levels of family support rather than to illness and demographic variables. Hierarchical multiple regression analysis was undertaken to address the unique and combined contributions of variables of stress and coping to adjustment. Order of entry into the regression was based on the Thompson stress and coping model (Thompson, Gustafson, George & Spock, 1984) with severity of illness entered first. The proposed “mediators” or variables of daily stress, family support and palliative coping added significant increments to the variance that together accounted for 53% of the variance of maternal depression. This study does not clearly differentiate between moderator and the mediator processes as described by Baron and Kenny's (1986) model. Instead it looks simply at the amount of contribution a number of variables makes to psychological outcome of these parents, which are more likely to be moderators rather than mediators. In addition, this study relies overly on self-report data for all variables.

Whilst the above study lacks clarity and methodological sophistication in its exploration of interactive variables, two studies have looked in detail at their data distinguishing the contribution of moderator and

mediator variables.

Lewis and Kliever (1996) analysed whether coping acted as a moderator or mediator between hope and adjustment in children with Sickle Cell disease. The predicted effect of coping strategies on the relationship between hope (conceptualised as generalised cognitive appraisal) and adjustment in was examined. Standardised measures of hope (Snyder, 1989), coping strategies, children's depression and anxiety were used to measure the variables. Using a structured pain interview with the child's caregivers an assessment of functional measures of adjustment was made. (Gil, Williams, Thompson and Kinny, 1991). The links between hope, coping and adjustment within a mediating model were examined. In analysis, in which the significant relationships between coping, hope and adjustment needed to be established (Baron & Kenny, 1986), both anxiety and active coping were significantly related to hope. In the mediating analysis, after controlling for the effects of active coping on adjustment the relationship between hope and adjustment was not significantly reduced. Therefore coping did not mediate the relationship between hope and anxiety in this study.

When a moderator analysis was performed on the same data, Active Coping, Support Coping and Distraction Coping factors significantly interacted with hope to affect anxiety with interaction terms explaining an additional 8 to 11% of the variance in anxiety. Further analysis of the moderating variables showed a strong negative relationship between hope and anxiety for children who used high levels of active coping support and distraction, with these coping strategies appear to protect the child from high levels of anxiety. There were no such relationships for those using the low levels of active coping support and distraction strategies. Therefore the authors concluded that hope was negatively related to anxiety but coping strategies moderated this relationship. As the authors point out, this is an important study as it examines alternative models in the relationships between the variables that makes clear the mechanism of coping between hope and adjustment. Limitations of the study are with sample size ( $n = 39$ ),

and the heavy reliance of all measures on self-report. The authors themselves suggest that observational or objective data would also complement self-report measures in this study.

A second study examined the direct and moderating influences of family and individual variables on the adjustment of 64 children and adolescents with diabetes mellitus (Kager & Holden, 1992). The child and mothers' coping skills were hypothesised to act as a buffer between the stress of disease related family disruption and child's type of behaviour pattern with outcome variables of metabolic control and global self-esteem. Hierarchical multiple regression analysis were computed which evaluated the contribution of the interactive term of stress x family or child variable. Main effects illustrated disease related maternal coping was negatively related to child's general self-worth, suggesting that mothers attempts to manage distress associated with having a chronically ill child appeared to be more helpful when their child had lower self-esteem. Gender was also a significant contributor to diabetes adjustment with girls showing better adjustment. In addition higher levels of negative life events were associated with poor adjustment. Whilst there was not a direct relationship between "Type A" behaviour and higher levels of glucose in the blood i.e. poor control, children who exhibited "Type A" behaviour had poorer metabolic control than "Type B" (a calmer and less demanding behavioural style) children at low levels of stress. However at high levels of stress children with "Type B" behaviour showed poorer metabolic control compared to children with "Type A" behaviour.



### Summary

- There is substantial research supporting an increased risk of psychological problems in children with chronic illness. However, it is also clear that the effects of illness differ substantially from child to child, with the predictors of adjustment being far from clearly defined.
- Children with chronic renal failure appear to have an increased risk of psychological problems associated with the illness, but in addition there is a relationship between illness severity and psychological problems. However research with this illness group tends to be explorative in nature and certainly not theoretically based. Therefore it has not examined in detail what other factors could contribute towards these findings; for example how coping strategies explain the differences in adjustment.
- As research has developed, conceptual theories have been developed in an attempt to explain the current findings. Increasingly sophisticated models aim to account for what appears to be the multifactorial nature of influencing factors on the adjustment of children with chronic disease. Wallander et al.'s (1989b) study currently attempt to take into account both risk and resilience factors that would contribute towards the adjustment of children with chronic illness. However its major weakness is that it does not explain how the factors may inter-relate.
- The contribution of coping towards adjustment to illness has been reported more frequently in recent years. In addition coping theories are influential within the adjustment models; however the mechanism explaining how they work has not been thoroughly explored. Models of coping e.g. Lazarus and Folkman (1984) proposed that individuals' coping strategies will be situation specific with the individual interacting with their environment appraising distress demands then seeking to master the

situation by selecting coping strategies. Wallander et al. (1989b) interpret coping strategies as resilience factors protecting the child in the face of their stress so that theoretically it is difficult to account for maladaptive coping strategies.

- In addition to exploring the mechanism behind coping and adjustment exploratory work regarding the effect of environmental or individual influences have on coping strategies will provide additional information regarding the mechanism of the coping strategies themselves. Hence this will inform the type therapeutic input that may be appropriate.
- Models derived from examining the contribution of variables via moderation or mediation processes serve as a way forward to explore the mechanism that explains the contribution of coping within clinical field research.

### Aims of the Study

There are two areas that are to be examined in this study. Firstly to expand the knowledge base of the psychological effects of a relatively rare chronic illness, severe chronic renal failure.

Secondly, to explore the role of coping as an intervening variable that accounts for the relationship between severity of illness and psychological outcome.

### Psychological Adjustment in Children with Renal Disease

The second set of hypotheses aim to evaluate the psychological impact of a specific illness i.e. severe chronic renal failure on children and adolescents.

There is particular scope for the improvement of methodology from previous studies using this patient population. Firstly, with how representative the sample aims to be. Previous studies have used small numbers of children (Douglas, et al., 1998) or a wide age range (Reynolds et al., 1991). This study aims to examine psychological adjustment within a specific developmental group as this will permit any findings that are age sensitive to be noted that may not have been found in other studies. The specific psychological impact of renal disease on older children and adolescents has not been examined, hence this study aims to have as representative a group as possible, in order to be able to generalise the findings. In addition, one of the variables of interest, coping strategies has been found to be age sensitive (Spirito et al., 1988). Therefore, a study group with a narrow age band should control for age sensitive measures.

Large numbers of children with severe chronic renal failure will also enable the examination of non- categorical effects of illness variables within a heterogeneous diagnostic group. Thus we can see whether this is the most appropriate method to categorise patients within this diagnostic group, rather than for example, by age or gender. In addition, examination of adjustment

between severity of illness categories may enable the results to be compared to other groups with similar non-categorical variables.

Given the equivocal findings of the effect of severity of illness on psychological outcome in other research (Garralda et al., 1988, Pless & Nolan, 1991), this study will develop a more comprehensive severity of illness measure. The aim will be that this will be more sensitive to the power of the variable, as it is this that may have accounted for the equivocal findings in previous studies. This study aims to use a more comprehensive measure as the criteria of severity of illness rather than just using one variable. In the majority of previous renal research, measurement of severity of illness has only been by treatment group. A more comprehensive measure should include information on other variables that contribute to illness severity such as additional aspects of illness, and frequency of hospital appointments. In addition, a self-report measure of perceived illness severity will tap into another factor that has been found to be related to outcome in sick children and will allow these two types of measure to be compared with each other (Khan et al., 1995; Orr et al., 1984).

The evaluation of adolescents themselves, rather than by parent report, will result in a first-hand account of adolescents' perception of the effects of their illness on their self-esteem, their health and social status. It is important to assess the best informant to gain the most valid and accurate data. La Greca and Lemanek (1996) propose that these depend on developmental level and the construct being measured. They suggest that from midadolescence both adolescents and adults are important sources of information, with externalising problems being reported more accurately by parent or other informants, but internalising or subjective behaviour being best reported by the children themselves. Additional data from other informants by the child's parent will help methodologically in addressing reporter bias and substantiating findings from self-report data.

### **Coping in relation to adjustment within chronic illness**

It may be possible to improve the design of studies examining coping strategies and adjustment to illness through focusing on specific questions derived from a theoretical basis.

Initially the first step is to explore the frequency, distribution and efficiency of coping strategies within a group of chronically sick children. As there is increasing evidence (Spirito et al., 1995; Pretzlick, 1997) that coping strategies are specific rather than a stable trait of the child, the measurement of coping strategies used by children with chronic illness needs to be improved. This could be done by the use of a measure that specifies the context under which the coping strategies are applied. The Kidcope coping strategies questionnaire (Spirito et al., 1988) not only focuses on a context in regard to eliciting coping strategies from a child, but it permits the child to answer the questionnaire pertaining to a problem that they perceive to be the most troublesome. This “reality testing” is more likely to result in valid responses made by the child as the questionnaire will be more meaningful to them. Thus from a single questionnaire it is possible to have a representation of the range of problems that are concerning to a specific group of children, and also to have data of the type of coping strategies used by children when dealing with the most difficult aspect of their illness.

The collection of data regarding the range of coping strategies that children use within the specific context provides two methods from which to explore the data. Firstly, the opportunity to explore the frequency and distribution of individual coping factors used by children and secondly to examine whether the coping strategies used can be grouped into meaningful categories for example into adaptive and maladaptive groupings. The Kidcope, (Spirito et al., 1988), for example, which is made up of 11 coping strategies does not have definitively structured factor pattern, although some patterns have emerged in previous studies (Spirito, 1996; Vernberg et al., 1996). The present study aims to gather sufficient data to enable a factor

analysis of the coping strategies and hence to examine whether patterns of coping are associated with variables of interest in this study, such as illness severity and psychological outcome.

Coping strategies in themselves are likely to be affected by extraneous variables, and the underlying reasons why a child may adopt a particular coping strategy needs to be explored, as this would contribute towards the understanding of the process of coping. Possible reasons may stem from child individual differences or from the system in which the child operates (Sangler Copeland Davidson, 1981; Frank et al., 1997). Hence, this study also aims to explore whether the individual factors of age gender have an influence on children's coping strategies. More specifically, whether there will be an overall reduction of number of coping strategies with increased age (Wertlieb, Weigal & Feldstein, 1987; Pretzlick & Hindley, 1993). In previous research of coping in children with chronic illness, (Spirito et al., 1995), girls used more social support strategies than boys and boys used cognitive restructuring and self-blame more than girls.

In addition, this study will examine whether the external effects of parental coping strategies will have a relationship with children's coping strategies. Findings of relationships between parental and child coping are still rather tentative but suggest that positive parental coping strategies are related to adaptive child coping (Kuspt et al., 1995; Kliwer & Lewis, 1995).

In seeking why there may be a lack of consistent results between illness severity and psychological adjustment, this study aims to explore whether coping has an influence between these two variables using a theoretical framework. The increasing likelihood of there being a complex relationship between illness variables that contributes to adjustment have resulted in a number of models attempting to incorporate the multifactorial nature of variables (e.g., Wallander et al., 1989). The theoretical framework of many of these models stem from the concept of risk and resilience factors. Coping is considered a resilience factor within the Wallander et al. (1989) model, whereas illness severity is considered a risk factor. An aim of this

study is to explore whether coping acts as a risk or resilience factor by examining its interaction with severity and psychological adjustment. Furthermore, in order to address the lack of clarity in the process of variables such as coping in Wallander et al.'s model, this study aims to investigate the mechanisms that elucidate the relationship between severity of illness and psychological adjustment using a moderating and mediating framework (Barron & Kenny, 1986). The distinction between whether variables moderate or mediate is important in interpreting findings in studies. As a mediator, coping will account for the relationship between severity of illness and outcome and Figure 5 illustrates the hypothesised direction of results when coping acts as a mediating process.

When coping acts as a moderator, it will describe under what conditions the relationship will occur. Previous preliminary research suggests that coping is more likely to act as a moderator rather than a mediator, with findings showing that type of coping influences adjustment in this way (Lewis & Kliever, 1996). Figure 4 illustrates the hypothesised direction of results when coping is acting as a moderating process between severity of illness and psychological adjustment.

Figure 4  
Hypothesised Direction of Results when Coping Acts as a Mediator

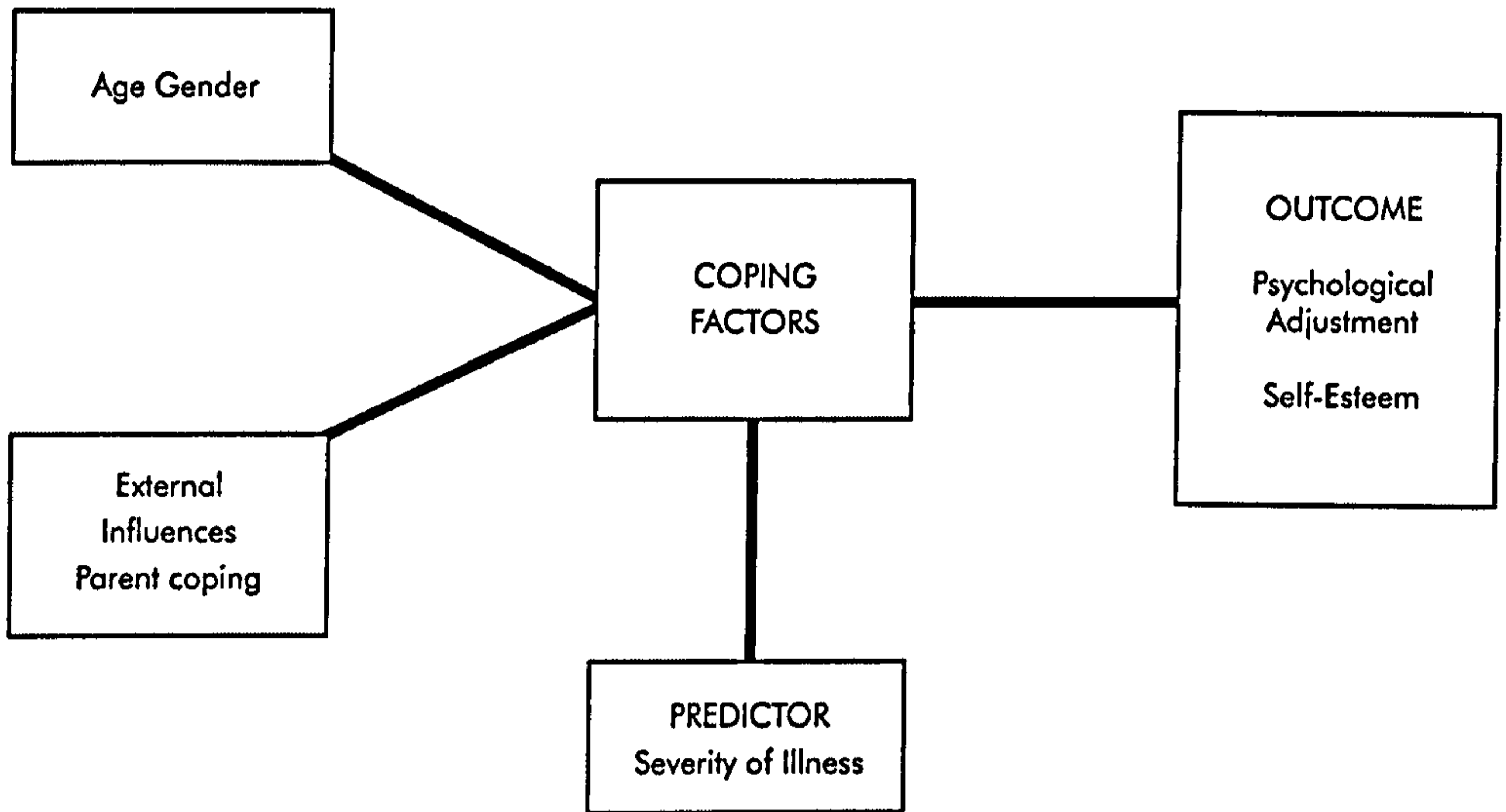
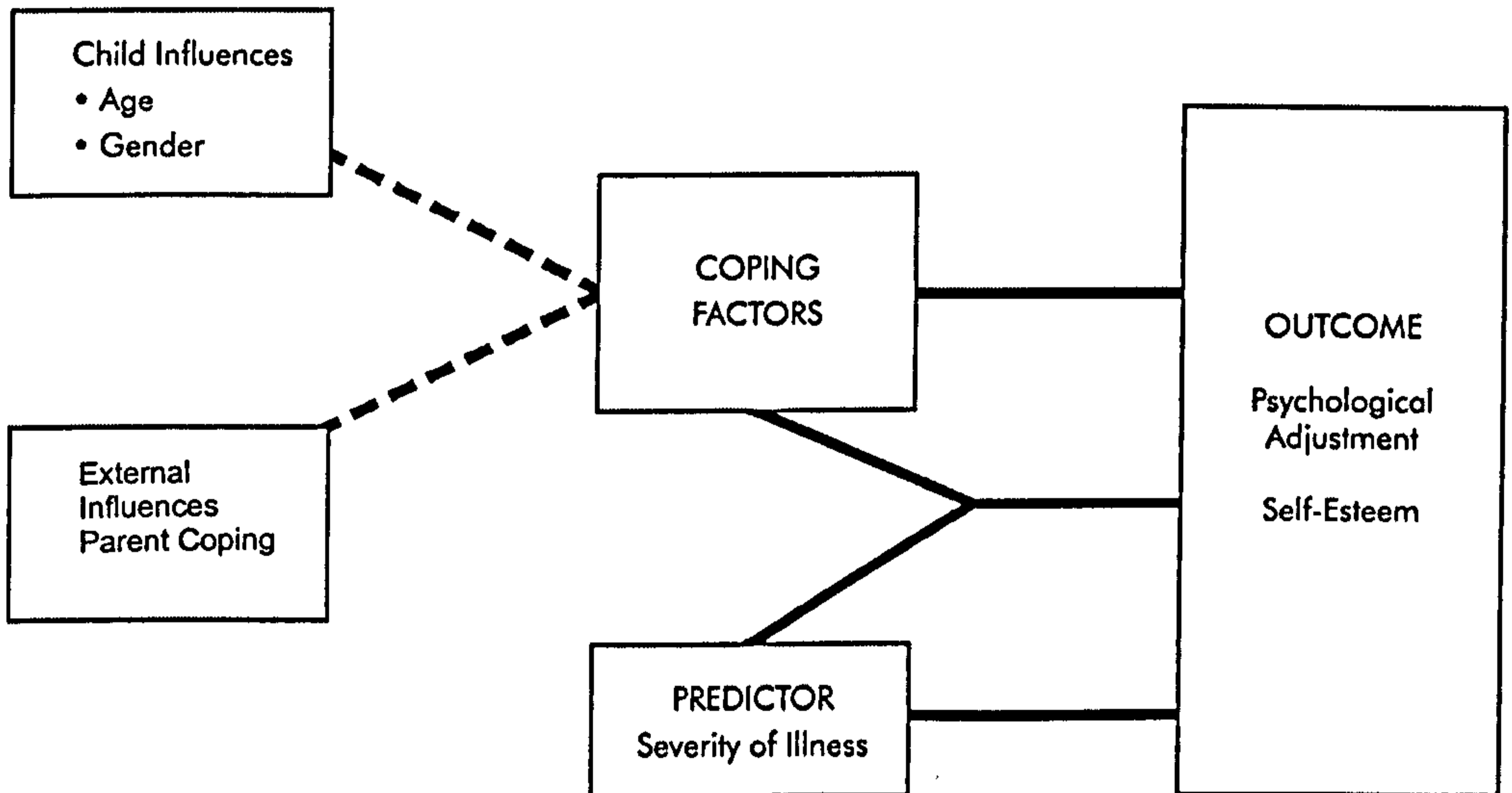


Figure 5  
Hypothesised Direction of Results when Coping Acts as a Moderator





### Hypotheses of the Study

- 1. The hypothesis predicts that children with severe chronic renal failure will show higher levels of psychological difficulties and lower levels of self-esteem than the norms for healthy children in the community.**
- 2. The hypothesis predicts that severity of illness will discriminate levels of psychological distress within a heterogeneous group of renal patients. Children who have higher levels of illness severity will show higher levels of psychological distress and lower self-esteem.**
- 3. From existing research, the hypothesis predicts that there will be an effect of the child's age and gender on coping patterns (with an increased use of cognitive coping strategies with increasing age and an overall reduction of number of coping strategies with increasing age). The effect of gender on coping will show girls using social support more frequently than boys and boys using cognitive restructuring and self-blame more than girls.**
- 4. Based on previous research, parental coping patterns and psychological distress will also have a relationship with children's coping patterns, so that there will be positive associations between parents adaptive coping patterns / low levels of psychological distress and coping patterns adopted by children.**
- 5. The hypothesis predicts that there will be some effects of the type of coping patterns that will be associated with outcome measures of psychological adjustment. From existing research the hypothesis predicts that coping strategies that have been categorised as adaptive such as primary, problem solving, or active coping skills will be associated with lower levels of psychological distress and higher levels**

of self-esteem. Concurrently, coping strategies that have been labelled as maladaptive such as avoidance, blaming or emotion focused will be associated with higher levels of psychological distress and lower levels of self-esteem.

6. The mediator hypothesis predicts that coping will act as an intervening variable and account for the relationship between illness severity and adjustment. Thus there will be a significant relationship between the variables of illness severity, coping and psychological outcome. However, the relationship between illness severity and outcome will become non significant once coping has been controlled for, demonstrating that coping is mediating between severity of illness and psychological outcome.
7. The moderator hypothesis predicts under what conditions coping will act as an intervening variable between health status and psychological outcome. Thus when maladaptive coping is high, illness severity will be strongly associated with psychological outcome. Concurrently, when adaptive coping factors are little used, there will be a similar strong association between illness severity and psychological distress. Conversely when maladaptive coping is low, and when adaptive coping is high there will be little association between illness severity and psychological distress.

## **CHAPTER 2**

### **METHODS**

#### **Participants**

##### **Sampling Procedure**

Children and adolescents aged 11 through 16 years with chronic or end stage renal disease and who were attending outpatients at Great Ormond Street hospital for children were eligible for the study. Children with severe developmental delay and little understanding of English were excluded as they would have been unable to complete the questionnaires.

For clarity and brevity the children and adolescents will be referred to as 'the children' for the remainder of this document.

There were 146 children of eligible age derived from a hospital database of 295 children of all ages with renal failure. Details of the child's age, date of birth, date of assessment, medical consultant, medical background and treatment were all obtainable from the child medical notes. Those participants who were invited to take part in the study were those who had clinical outpatient appointments during the six months that data were collected. If there were more than 4 eligible families attending a single clinic (which was rare) then the families were randomly chosen to participate. However, in order to achieve a balance of treatment groups within the whole sample, all those children who were treated with haemo or peritoneal dialysis were targeted as a priority as there were lower numbers in these groups than other treatment groups.

##### **The Children**

A total number of 103 children and their parents were recruited for this study. Of the 43 children not approached, 4 children were excluded because of severe developmental delay, 3 because of known language difficulties and the remainder either did not have or cancelled appointments on the days that data were collected. In total 86 children participated and 17 (16%) families declined to be seen. There were 33 (38%) girls and 53 (62%) boys. The mean

age of the children was 14.67 years ( S. D. = 1.87). The ethnic origins of the children were as follows; 23 (26%) were of Indian subcontinent origin, 5 (6%) were black African or Caribbean, and the remainder (68%) were white caucasian.

All children were registered in the hospital that is a tertiary centre for paediatrics and were being treated for chronic illness related to renal problems. The diagnosis of the children fell into sixteen categories; the most common diagnoses were Renal Dysplasia, Vesico Ureteric Reflux, Pelvic Urethral Valves (PUV) and Nephrotic syndrome (see Table 1).

Furthermore, 38% of children had an additional illness. This included another illness separate to their renal problem or additional problems associated with their underlying diagnosis. This included urological disorders which required daily treatment, and children with neurological and sensory impairment.

The form of treatment needed for their illness varied according to the stage of their renal failure (see Table 2); 24 (27.9%) children had chronic renal failure that was maintained on drugs and diet alone, 24 (27.9%) children had good functioning renal transplants for more than one year. Twenty-two (25.6%) children had medical difficulties which were associated with recent transplants (n=6,) or other problems with their transplants (n=8,) or were in the end stages of chronic renal failure (n=8). Finally there were sixteen (18.7%) children receiving dialysis; 12 of these were on peritoneal dialysis, and four of these on haemodialysis.

The children were under the care of one of 4 consultant paediatric nephrologists. Attendance at outpatients was required weekly or fortnightly by 14% of children, 44% attended every one to two months, and 41% every 2 months or less.

Table 1

Underlying Medical Diagnosis of the Children (N= 86)

	Renal Dysplasia	Pelvic Urethral Valves	Nephrotic Syndrome	Vesico Ureteric Reflux	Other diagnoses	Additional Illness
Number of Children	13	10	11	13	39	33

Table 2

Treatment Group of Children. (N = 86)

	Chronic Renal Failure	Transplant over 1 yr.	Transplant Problems	End Stage Renal Failure	Peritoneal Dialysis	Haemo Dialysis
Number of Children	24	24	14	8	12	4

Table 3

Family Variables of Participating Children (N=85)

	Parental Status		Number of Siblings				
	Single	Partner	0	1	2	3	4 or more
Number of Children	12	73	9	28	22	16	10

The Families

The majority of children (84.9%) were living in families where there were two parents, this would be the child's natural or reconstituted family. Over half of the children (58%) had one or two other siblings at home, however, 10 children were from larger families with four or more siblings living at home (see Table 3).

A total of 73 parents took part in the study. Of the 13 parents who did not complete their questionnaires; five of these parents did not attend the hospital appointment with their child as their child was considered old enough to be responsible to relay messages regarding treatment back home. These parents did not respond when contacted by post with further prompts regarding the study. The other eight parents were unable to complete the questionnaires because of difficulties in understanding the meaning even with the researcher's assistance. 57 mothers, 15 fathers and one grandfather completed the questionnaires.

### **Non Participants**

Demographic details and treatment group of the 17 families who declined participation were available. Their mean age was 14.4 years (SD 1.95), with 8 (47%) boys and 9 (53%) girls. There was a bigger proportion of girls refusing than boys, given the predominance of boys in the participating group. The reasons for this are not clear. These children were spread across the treatment groups, with the majority of them (n=9) being treated conservatively for chronic renal failure, 5 had been transplanted for more than 1 year. There was one child in each of the treatment groups of transplantation less than 1 year, other transplantation problems, and haemodialysis. There were no children who refused to participate in the peritoneal dialysis or transplant problems groups.

## Children's Measures

The following demographic and psychological measures were taken of the children and are discussed below.

1. **Index of Medical Severity.**
2. **Child Questionnaire Measures. (Please see appendices 1-7 for copies of each questionnaire).**
  - **Background Information, (self-report).**
  - **The Health Status Questionnaire, (self-report), Brownbridge & Fielding, 1991).**
  - **The Kidcope, (self-report), (Spirito et al., 1988).**
  - **The Self-Perception Profile for Children -Compency scale, (self-report), (Harter 1985).**
  - **The Self-Perception Profile for Children -Importance scale, (self-report), (Harter, 1985)**
  - **The Strengths and Difficulties Questionnaire, (self-report and parent report version), (Goodman, 1997)**

### Index of Medical Severity

A composite measure making up an index of medical severity about the child's illness and treatment was calculated. Children were categorised into treatment group by their medical consultants onto the hospital renal database. The rating of severity of each treatment group was based on their consultant's evaluation of the type of treatment needed for each child. The more intensive the input needed for the child, the higher the rating of the scale. The ratings and a description of the categories are summarised in Table 4, with the least severe having a rating of one, and most severe four. This variable of treatment score was combined with two others to create the index of medical severity; the presence of additional illness and the frequency of outpatient attendance. The overall medical severity score was expressed as an addition of the Z scores of each variable so that equal weight could be given to all of the three

variables. High scores indicated increased medical severity.

Table 4  
Description of Ratings of Treatment Group Variable

Scale	Type of Treatment
1.	Chronic Renal Failure. Health maintained by medication and may have some dietary restrictions or supplements.
2.	Post transplantation. Scrupulous maintenance of medication regimen and monitoring of physical health, with close follow-up from hospital.
3.	Medical problems with transplant, needing more intensive treatment & monitoring; or transition of treatment to dialysis as kidneys nearing end stage renal failure.
4.	Child on Peritoneal or haemodialysis. Restricted lifestyle, medication, diet and fluid restriction required.

### Child Questionnaire Measures

Each child participating in the study was assisted in the completion of the self-report measures below.

#### Background Information of Obtained From the Child

The child was asked information about the following subjects. (see Appendix 1).

- The child's school year.
- The composition of their family living at home.

#### The Health Status Questionnaire

A self-report measure of the severity of the child's illness was taken using the health status questionnaire (Brownbridge & Fielding, 1991), (see Appendix 2). This measure evaluated two areas; the child's functional impairment and their social functioning. The questionnaire measure has been designed and used for assessment of children with renal failure (Brownbridge & Fielding, 1991). There are 6 items making up the functional impairment scale which



cover tiredness aches and pains, feeling ill, sleep problems, ability to walk unaided, and the ability to run.

The five item social impairment scale asked whether the child's state of health affects them in the following areas; friends, hobbies or interests, family, school or work, and holidays. Each scale item requires a yes or no response which was scored one or zero; the maximum impairment scores obtainable were six for functional health status and five for social impairment, with higher scores indicating increased impairment. The measure is designed to be self-completed by older children and adolescents.

The measure has been validated and shown to differentiate in both scales between those children having higher amounts of medical care and those children who had less medical input (Brownbridge & Fielding 1991). In addition a significant correlation was found between high scores of the functional impairment scale and depression, anxiety and behavioural disturbance in children. This supported their hypothesis that children with good functioning renal transplants would have less social and emotional difficulties compared to children on dialysis. There is no published reliability data.

The Health Status Questionnaire together with the index of medical severity provided a multi-modal assessment of illness severity so that it would tap the different perspectives of the child's illness and the effect of the illness on the child. Thus the study would be able to evaluate which measures were more sensitive in evaluating illness severity in relation to outcome measures. Intercorrelations of the 3 measures used to evaluate illness severity are shown in Table 5. The measures show only small correlation with each other suggesting that these variables are in fact tapping different aspects of illness severity.

**Table 5**  
**Intercorrelations Between Scales of Illness Severity.**

Scale	1.	2.	3.
1. Functional Impairment	--	0.21	0.25*
2. Social Functioning		--	0.28*
3. Index Medical Severity			--

\*  $p < 0.05$

### **The Kidcope (Spirito et al., 1988)**

The Kidcope is a checklist that measures children's cognitive and behavioural coping strategies (see Appendix 3). It is derived from The Ways of Coping Questionnaire for adults (Folkman & Lazarus, 1980). The older version (recommended for ages 13 to 18 years) and the anglicised version (Pretzlick & Hindley) of the Kidcope was used for all the children in this study. The checklist lists 11 coping strategies. These are; Distraction, Social Withdrawal, Cognitive Reframing, Self-Blame, Blaming Others, Problem Solving, Emotional Upset, Emotional Calming, Wishful Thinking, Social Support and Resignation.

When completing the Kidcope the child was initially asked to choose a specific stressor within the context of their illness; thus each child was asked to describe what most bothered or hassled them about their illness. The child answered the questionnaire keeping in mind the stressor described.

Firstly, the child rated their level of distress and their attitude to the problem, secondly the child rated each of 11 coping strategies according to whether they had used the particular item. This was scored on a scale of 0 = never to 3 = almost all the time, (the frequency score). Finally for each item that the child indicated they used, the child rated how helpful they perceived

this item to be on a scale of 0 = not at all helpful to 4 = very much, (the efficiency score).

#### Psychometric Properties of the Kidcope

The validity of the Kidcope has been reported by Spirito et al. (1988) who compared the Kidcope with two other coping questionnaires for children. The Coping Strategies Inventory (CSI), (Tobin, Holroyd & Reynolds, 1984) has eight factors similar to the Kidcope coping strategies. Correlation between the Kidcope and the CSI showed significant results for seven out of eight factors.

Spirito et al. (1988) also administered the Kidcope and the Adolescent Coping Orientation for Problem Experiences (ACOPE), (Patterson & McCubbin, 1983) to a group of school children and six of the Kidcope coping strategies were significantly correlated with 12 ACOPE factors.

The cross validity for the distress measures was established in a study by Pretzlick and Sylva (1995) who showed significant correlations between the distress measures and an observed objective measure of distress.

The reliability of the Kidcope is more difficult to demonstrate given the context of coping which by definition is seen to vary across different contexts. However Spirito et al, (1988) reported undertaking two successful test retest studies using the Kidcope check-list in which he obtained moderate to high correlations ( $r = 0.4-0.8$ ) when subjects rated the same stressor three days apart. Lower test re- test correlations were found in another study reported in the same paper in which children completed the Kidcope questionnaire 10 weeks later but this was also in response to another stress.

Pretzlick (1997) also reported reliability in the Kidcope questionnaire when repeated measures were taken seven days apart for the same context; 8 out of ten of the coping strategies showed significant reliability coefficients, illustrating test re-test reliability within the same context.

#### Use of the Kidcope in paediatric research

The Kidcope was initially designed and validated for sick children (Spirito et al., 1988). It has been used in a number of studies looking at the coping strategies of children with illness (Spirito et al., 1988, 1995; Kronenberger et

al., 1996; Frank et al., 1997; Brown, et al., 1991). The children investigated in the studies had a wide range of chronic illness, ranging from diabetes, leukaemia, bone marrow transplant and cystic fibrosis. Results from the studies show some gender differences with boys using cognitive restructuring and self-blame more than girls (Spirito, Stark, Gil & Tyc, 1995). In terms of analysis of the frequency of specific coping strategies Spirito et al. (1992) found acutely ill children were more likely to use distraction, self-blame and wishful thinking than chronically ill children. He also noted that self-criticism was used less by chronically ill children than by healthy controls. Brown et al. (1991) found problem solving, wishful thinking and emotional regulation the three most frequently used coping strategies by a group of children with leukaemia. None of the above studies report examining the type of coping strategies with child adjustment outcome. However a study by Kronenberger et al. (1996) exploring the psychological adjustment of children in the pre-transplant phase of bone marrow transplant; avoidance and distraction scores on the Kidcope were associated with more aggression and anxiety, withdrawal and depression in the Child Behaviour Check-list (Achenbach & Edelbrock, 1983). Pretzlick (1997) noted that an increase of children's self-rating of distress regarding their reported problem was related to an increase of number of coping strategies endorsed by children.

#### Factor Analysis of the Kidcope

There is no overall total score of the Kidcope, the reasons given by the authors is because the questionnaire's primary purpose was to provide a clinically useful exploratory check-list to systematically examine coping styles in children and adolescents (Spirito, 1996). However, as there is a need in the research field to reduce the number of variables, factor analysis of the coping strategies can address this issue. In his own research Spirito has noted that different factor structures have emerged which vary from context to context. For example, a five item single factor structure was found in adolescents who thought about coping with a suicidal friend and an eight factor dimension when the problem was around adverse medical procedures. Spirito points

out that these results should not be surprising, because coping is theorised to be situation specific. Hence he suggests that factor analysis could be carried out within individual studies (Spirito, 1996).

Another factor analyses of this questionnaire has been reported. Vernberg et al. (1996) in researching PostTraumatic Stress Disorder (PTSD) in children following a natural disaster, noted a 4 factor analysis of the Kidcope. The factors were labelled Positive Coping, Blame and Anger, Wishful Thinking and Social Withdrawal. Blame and Anger accounted for 36% of the total effects of coping variables and this coping strategy was also linked to the highest level of PTSD symptomatology.

Factor analysis may be especially useful in research rather than in the clinical situation, as there is need to reduce the number of variables measured for data analysis. In addition as coping is just one variable to be measured alongside many others as one of the research aims is to examine the contribution of several different factors to the outcome.

Factor analysis was carried out on the Kidcope efficiency scores. These are the child's self-rating regarding how helpful they regarded each coping item that they used. Although most reported work has been carried out on the frequency scores of the Kidcope, the efficiency scores were thought more likely to parallel another measure used in the study, The Coping Health Inventory for Parents, (CHIP), (McCubbin et al., 1983) which asks parents to rate the helpfulness rather than the frequency of coping strategies used. In addition, asking a more in depth question of how helpful a coping strategy is, suggests that the child may have more fully analysed their the true use of each strategy, (as indicated by the theoretical definition of coping "cognitive and behavioural efforts to manage the stressor" p. 141 (Lazerus & Folkman, 1984), rather than more simple response behaviours.

Overall, research using the Kidcope has shown that the frequency scores are closely correlated with the efficiency scores (Spirito et al., 1988). Pearson rank correlation of the frequency scores with the efficiency scores in this data were also significant, with all correlations between questions being

$p < 0.0001$  (see Table 6). However, examination of the results suggested that the efficiency scores were more statistically valid for a factor analysis procedure.

Table 6

Correlation of Scores of the Kidcope Frequency with Efficiency Questions (N=70)

<u>Question Number &amp; Descriptor</u>	<u>r</u>
1. Distraction	0.73***
2. Withdrawal	0.81***
3. Cognitive Re-framing	0.87***
4. Self-Blame	0.86***
5. Blaming Others	0.60***
6. Problem Solving	0.94***
7a. Emotional Upset	0.80***
7b. Emotional Calming	0.89***
8. Wishful Thinking	0.52***
9. Social Support	0.89***
10. Resignation	0.66***

\*\*\*  $p < 0.001$

The assumptions underlying the factor analysis were that the relationships among the coping variables should be described with as few factors as possible, and that the factors derived should be meaningful.

A principal component analysis with a varimax procedure indicated four factors from the 11 Kidcope strategies. The results of the factor loadings are shown on Table 7. Items loading at 0.45 or above on one factor, but less than 0.45 on all others were considered as contributing to distinct subscales of the coping items. The four factors were as follows;

1. The first factor contained 3 items (Emotional Upset – "shout, scream or hit something", Blaming Others and Emotional Calming - "try to calm down by talking to myself or going for a walk"). For ease of communication this was labelled "Emotional Externalising".
2. The second factor, which contained the items of Problem Solving, Distraction, and Social Support, was labelled "Active Coping" as the strategies all involved making active attempts to deal with the stressor.
3. The third factor, which contained the items of Self-criticism, Social Withdrawal and Wishful Thinking, was labelled "Internalising" because of the isolating nature of the items.
4. The fourth factor was labelled "Acceptance" as it contained the Cognitive Restructuring item of "trying to see the good side of things" and the Resignation item "I just accepted the problem". This factor suggested that the child had reached a decision to live with their illness rather than being either hostile or actively involved in coping with it.

These four factors accounted for almost 60% of the variance in coping scores (see Table 7).

Table 7  
Factor Analysis of the Kidcope Efficiency Ratings (N=70).

Kidcope Coping Items	Coping Factor			
	Factor 1 Emotional Externalising.	Factor 2 Active Coping	Factor 3 Internalising	Factor 4 Acceptance
7a. Emotional Upset	0.82			
5. Blaming Others	0.73			
7b. Emotional Calming	0.57	0.74		
6. Problem Solving		0.68		
1. Distraction		0.53		
9. Social Support			0.70	
4. Self- Blame			0.68	
5. Social Withdrawal			0.49	
8. Wishful Thinking				0.77
3. Cognitive Restructuring				0.68
10. Resignation				
% Total Variance Explained	15.98	15.12	14.60	12.51



## The Self-Perception Profile for Children (S.P.P.C.) (Harter, 1985)

### Competency scale

This questionnaire (see Appendix 4) aims to elicit domain specific judgements of competency or adequacy into five separate domains as well as global self-worth. The five domains or sub-scores are scholastic, physical appearance, behavioural, conduct, athletic, peer /social, in addition to a global self-worth score.

There are a total of 36 items, six items within each domain of which three items reflect high competency and three low competence.

The questionnaire is constructed in such a way that aims to reduce the frequency of socially desirable responses. The respondents choose which of two opposite statements is more like them, and then decide whether or not the chosen statement is only 'sort of true' or 'really true' for them. The questions are presented so that the initial statement is keyed positively or negatively an equal amount of times. Their answers are scored from one to four where a score of one indicates low perceived competency and four reflects a high perceived competency.

The Harter SPPC Competency scores have been validated with a group of 600 Scottish school children (Hoare, Elton & Kerly, 1993), allowing comparison with a British population. The questionnaire has also been used in paediatric populations (Hoare & Mann, 1994; Holden, Chiemlewski, Nelson & Kager, 1997).

The global self-concept score correlates with all other domains (Harter 1993). Therefore the global self-concept was used as the primary score in analysis of the child's self-concept in order to avoid large numbers of statistical tests

### Use of the SPPC Competency scores in paediatric research

This questionnaire has not been used extensively in paediatric research. However results do not show any conclusive evidence of a difference between the mean scores of chronically ill children and the norms of healthy population, but appear to show differences between types of illness and in illness severity.

In 1995 Reynolds et al. reported results of the global self-concept scale of the Harter self-perception profile in a group of 14 children with renal failure

having hormone replacement therapy. All children were of extremely short stature. Results were unexpected, and showed that the mean scores of the global self-concept were not significantly different to norms for Scottish schoolchildren (Hoare et al., 1993).

Holden et al. (1997) measured self-esteem using the Harter SPPC with children who had asthma and diabetes. Holden reported means of all domain scores for this group of children (50 with diabetes and 40 with asthma). Children with asthma displayed higher scholastic self-competency scores than children with diabetes. In addition age of child and number of hospitalisations were significantly associated with global self-esteem.

In another study (Hoare & Mann, 1994) the Harter SPPC competency scales and the Child Behaviour Check-list (Achenbach & Edleberg, 1983) were used on children with epilepsy and diabetes. Means for the Harter scales are reported for both groups. Within each illness group there was a wide variation in scores of self-esteem. Significantly lower scores for children with epilepsy were found compared to diabetic children in five of the six sub scales with the physical appearance not being significant. There was also an effect of gender when boys and girls' data were analysed separately. When the domains of the Harter were correlated within the each group the behavioural and global sub scales were most consistently correlated with the other sub scales with the strongest association between appearance and global self-worth. Those with epilepsy group showed more psychological disturbance (on the behavioural scores) whilst those with diabetes were within norms. The authors concluded that the children with chronic epilepsy carried a higher risk of behavioural disturbance than children with chronic illness such as diabetes. In addition, the duration of treatment and male gender were the most important contributions to the variance found in this study.

### **The Self-Perception Profile for Children (Harter 1988)**

#### **Importance Scales**

Besides measuring the child's perceived self-competency, The Harter self-perception profile for children can also measure the child's rating of the

importance of self-worth in each of the specific domains (see Appendix 5). This allows the child to have lower competency scores in some domains but not necessarily have lower self-esteem, as they do not deem these domains important and “discount” these domains when evaluating overall self-esteem. The measure constructs a discrepancy score between importance ratings and competence ratings of each domain.

This measure is made up of ten questions with two questions addressing each of the five domains used in the competency questionnaire. The format and scoring is in the same as in the self-concept scale with the child asked to choose which of two opposite statements is more like them, and then to decide whether or not the chosen statement is only 'sort of true' or 'really true' for them. Their answers are scored from one to four where a score of one indicates low perceived importance and four reflects a high-perceived importance. The Importance scores in the domains are subtracted from the child's competency scores to give a total discrepancy score.

The larger the discrepancy scores (with a negative sign), the more the child's importance ratings exceed his competence scores and so these scores should be associated with low self-worth.

#### Use of the SPPC Importance scales in paediatric research.

One of the reasons for the overall unequivocal results of the Harter competency scores may be that some children retain a high level of self-esteem despite predictions by "discounting" one or more areas of low self-esteem as described in the above importance questionnaire. The use of the importance scores have not been reported as frequently in research as the Harter competency scores, and they are reported rarely in paediatric study groups. However, both the competency and importance scores have been reported in a study with young people with spina bifida (Appleton et al., 1994). The hypothesis of this study that young people with spina bifida would place lower importance values on appearance scales in order to maintain their self-esteem was not supported in this study. Despite having large discrepancies between their importance and competency scores, their overall

self-esteem scores were not lower than controls as would have been expected from earlier work by Harter and Rennick (1988).

### **The Strengths and Difficulties Questionnaire (Goodman, 1997)**

The strengths and difficulties questionnaire (SDQ), is a brief behavioural screening questionnaire for children that asks about 25 attributes, some positive and others negative (Goodman 1997). This Questionnaire has two versions, a self-report version for older children (see Appendix 6) and informant version (for parents and other carers), (see Appendix 7). The design and structure of each version is the same.

Of the 25 attributes, 10 would generally be thought of as the strengths, and 14 would generally be thought of as difficulties and one item is considered neutral. The 25 SDQ items are divided between five scales of five items each, as outlined below.

- The hyperactivity scale e.g.; negative item, "restless, overactive, cannot stay still"; positive item, "thinks things out before acting".
- Emotional symptoms scale e.g.; negative items, "often complains of headaches stomach aches"; "often unhappy, down hearted or tearful"; "nervous or clingy in new situations, easily loses confidence." (all negative items in this scale).
- Conduct problems scale: e.g.; negative item, "often has temper tantrums or hot tempers"; positive item, "generally obedient usually does what adults request".
- Peer problems scale; e.g.; negative item, "rather solitary tends to play alone"; positive item; "has at least one good friend".
- Prosocial scale: these are all positive items, e.g.; "considerate of other people's feelings", "often volunteers to help others".

Each item can be marked as "not true", "somewhat true", or "certainly true", and is scored zero, one or two respectively if the item is negative. The scores are reversed for positive items. The prosocial scale has all items that are scored in the positive direction.

A total difficulty score ranging from 0 to 40 is calculated by summing the scores for hyperactivity, emotional symptoms, conduct problems, and peer problems. The prosocial score is not incorporated in the reverse direction into the total difficulties score, since the absence of pro social behaviours is seen as conceptually different to of the presence of psychological difficulties (Goodman, 1997).

#### Psychometric properties of the informant/parent version

The psychometric properties of the SDQ have been investigated in several papers. The SDQ (informant version) has been validated with the established Rutter parent questionnaire (Goodman, 1994) demonstrating comparable predictive validity.

The internal reliability of parent completed SDQ scales have been investigated in a sample of 900 Swedish children (Smedjie, Broman, Hetta & von Knorring, 1999) with Chronbach's alpha being 0.76 for total score.

The SDQ and the child behaviour checklist (CBCL) (Achenbach & Edelbrock, 1983) are also highly correlated with each other (Goodman & Scott, 1999) and the questionnaire is able to discriminate between children drawn from high and low risk samples. In addition parents were significantly more likely to prefer completing the SDQ to the CBCL probably because of the brevity and more emphasis placed on children's strengths in the SDQ questionnaire (Goodman and Scott, 1999).

#### Use of the questionnaire with paediatric population

There is as yet only one patient group with published studies reporting on the use of this questionnaire with paediatric patients. Goodman and Graham (1996) Goodman, (1998) reports a longitudinal survey of children with hemiplegia. Initially the Child Behaviour Checklist (Achenbach & Edlebrock, 1983) was completed; the children were followed up four years later using an early version of the strengths and difficulties questionnaire. Psychiatric disorder affected 54% of children at initial assessment. At follow-up the mean level of problems score did not significantly change with the exception of hyperactivity scores. Continuity of psychiatric problems was seen with 70% of

children who were psychiatric cases previously and still cases four years later. In addition 30% of children who were not cases initially have become psychiatric cases four years later. Goodman and Graham (1996) suggest the high rate of psychiatric problems may be at least partly due to low IQ and the linked predictor of neurological severity. However the authors emphasise the general vulnerability of this group, as psychiatric disorder was still 39% amongst the 28 children who had a mild hemiplegic disorder attending a normal school and had an IQ within the normal range.

Gjaerum & Heyerdahl (1998) reviewed mental health assessment of sick children using screening questionnaires. Whilst endorsing the potential of the SDQ, they suggested that the usefulness of the strengths and difficulties questionnaire has yet to be shown thus requiring more research with this instrument and subject group.

#### The psychometric properties of the self-report version

The self-report version of the SDQ is designed for completion by young people aged 11 through 16 years. The 25 items cover the same attributes as the informant rated SDQ. The only difference between the two is a grammatical change from the third person to the first person.

Goodman, Melzer, and Bailey (1998) have investigated the validity of for the self-report SDQ. 83 parents and children of a community sample, and 116 parents and children in a child and adolescent mental health clinic completed the SDQ. The scores showed significant discriminate validity between the clinic and community sample and inter-rater correlation between parent report and self-completed questionnaires were significant. However, in the clinic, attendees self-report questionnaires had more scores in the normal or borderline range, even though their parents or teachers reported a high level of symptoms. Overall, however, this study showed satisfactory levels of cross informant agreement and internal reliability of the self-report SDQ.

Provisional banding of the self-report version of this questionnaire has been selected by Goodman (1998) so that 80% of 11-16 year olds in the community are in the 'normal' group, 10% borderline and 10% in the

abnormal range for scores on the Strengths and Difficulties scale.

### **Parental Measures**

Parent data were all obtained through self-report questionnaires.

#### **Parental Self-Report Questionnaires (see Appendices 8-10)**

- **Background Information.**
- **The Coping Health Inventory for Parents, (McCubbin et al., 1983).**
- **The General Health Questionnaire (GHQ-28), (Goldberg & Williams, 1989).**

#### **Background Information**

The following information was obtained from the parent (see Appendix 8).

- The length of their child's illness.
- Their child's current treatment.
- The frequency of attendance for appointments.
- The amount of time that their child had missed from school the previous term.

#### **The Coping Health Inventory for Parents (CHIP), (McCubbin et al., 1983)**

The coping health inventory for parents (CHIP) was developed by McCubbin et al. (1983) to measure parental coping styles (see Appendix 9). It was primarily aimed to assess parents perception of the helpfulness of behaviours that they were currently utilising to manage family life when they had a child that was chronically ill with cystic fibrosis. The 45 items can be conceptualised into three coping scales. These are:

- Coping pattern I; maintaining family integration, co-operation and optimistic definition of situation.
- Coping pattern II; maintaining social support, self-esteem and psychological stability.

- Coping pattern III; understanding the medical situation through communication with other parents and consultation with the medical staff.

The CHIP is self-administered, with parents rating the helpfulness of the range of coping behaviours. A four-point likert type scale is used with 0 equalling not helpful and 3 equalling extremely helpful. The anglicised version of the CHIP developed by Eiser and Havermans (1992) was used in this study.

The number of items making up each sub-scale of coping is not the same. There are on 19 items for coping pattern 1 (family integration); 18 items for coping pattern II (social support and self-esteem); and eight items for coping pattern III (medical support). The authors obtained data from 300 mothers and fathers with a chronically ill child and have produced some normative data. The theoretical base from which the scoring is derived is the McCubbin's double ABCX model of adaptation (McCubbin & Patterson, 1981) so that the more coping behaviours that are utilised by a family the less stress they would experience. Thus higher pattern scores indicate more adaptive styles of coping.

The internal consistency of the three coping patterns was found satisfactory with Cronbach's alpha coefficients of .79, .79, and .71 respectively. (McCubbin et al., 1983). McCubbin et al. also identified factor ratings for the items within each of the three patterns identified, thereby demonstrating acceptable construct validity.

Discriminate validity has been demonstrated in a small number of studies. Flynt and Wood (1989) found the CHIP sensitive to race and maternal age when used with mothers of children with severe learning difficulties. Powers, Gaudet & Powers, (1986) found differences in the coping pattern II sub-scale between Anglo-American and Hispanic-American mothers of chronically ill children.

Brown et al. (1992) used the CHIP over 3 time periods with parents of children with cancer. They did not note any differences in parents' scores at diagnosis, during therapy and following treatment. Age of mother was related



to the use of the medical communication factor, with younger parents endorsing this factor less frequently.

**The General Health Questionnaire, GHQ-28 (Goldberg & Williams 1989)**

The general health questionnaire is a self-administered screening test aimed at detecting psychiatric disorder among respondents in community and non-psychiatric clinical settings (see Appendix 10). The questionnaire was designed to be easy to administer, short, and acceptable to respondents.

The questionnaire has a split half reliability of 0.95, and internal consistency alpha coefficient ranging from 0.82 to 0.93. (Goldberg & Williams, 1989.)

The GHQ-28 is a scaled version of the full 60-item questionnaire and is based on the results of principal component analysis and result in four sub scales. These are; somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. These sub scales represent dimensions of symptomology and do not necessarily correspond to psychiatric diagnosis.

Use of this version allows for investigation of these four dimensions of symptoms within the GHQ as well of giving an overall score. A number of validation studies have been carried out using the GHQ-28 (Parkes, 1982, Patton & Elton, 1987).

The GHQ has been administered to a wide range of respondents allowing for comparison of norms across different groups of respondents. Threshold scores for the GHQ 28 show a variance from 4/5 up to 11/12 in 16 validity studies (Goldberg & Williams, 1987), with a cut off of 5 being the most common. As the parents of this study are not ill themselves, it is not necessary to use a higher threshold to avoid somatic symptoms, therefore the most commonly reported cut-off score of 5 will be used in the analysis.

Other studies that have carried out the GHQ with parents of children with renal disease have used 5 as a cut-off, showing varied frequency of parents scoring above this range. Reynolds et al., (1995) interviewed parents and children with very short stature, 18% of parents scored > 5 on the GHQ. Higher levels of mental distress was observed using the same measure

(Reynolds et al., 1991) comparing children and adolescents in different stages of treatment for their renal disease. The percentage of parents scoring above threshold ranged from 26% for those parents of children with transplantation to 40% (those parents of children on dialysis).

## **Procedure**

### **Ethical Approval**

Ethical approval was obtained from Great Ormond Street Hospital /Institute of Child health Ethics Committee (research and development registration number 98BS16) (see Appendix 11) and University of Wales, School of Psychology Ethics Committee (see Appendix 12).

### **Administration of measures. (Copies of all measures can be found in Appendices 1-10)**

Potential subjects were identified from the renal database available in the hospital and these were cross-referenced with appointment waiting lists. Prior to the family attending for in the outpatient appointment they were contacted in advance with letter (see Appendix 13) and information sheet (see Appendix 14) explaining the study and asking if they would participate. One week before the appointment, telephone contact was made by the researchers and if agreement to participate was achieved an arrangement was made to see the family during their routine outpatient visit.

On the arrival to their outpatient appointment the child and parent was seen again by the researchers and a reminder of the method and purpose of the study was given. Written consent was obtained if agreed for both the child and parent (see Appendix 15). The parent was given a set of questionnaires and an explanation about how to complete the forms. They were left to complete these as far as they was able whilst the child was interviewed by a researcher.

The clinical psychologist or research assistant conducted the

interviews. The research assistant had training in interview skills given by the clinical psychologist and was observed by the clinical psychologist collecting data prior to them independently collecting data sets. All interviews were conducted in a quiet room or corner of the outpatient clinic, away from their parents. All questions were read out to participants who responded verbally or indicated their answer on the questionnaire for themselves. The interview took between 30 and 45 minutes. Parent completion of the data took from 15 to 25 minutes.

## CHAPTER 3

### RESULTS

Data were analysed using the Statistical Package for Social Sciences (SPSS), version 8.0 for windows.

An Alpha level of 0.05 was used for all statistical tests, unless stated differently in the text.

The presentation of the results will follow the sequence of the hypotheses, with the appropriate descriptive data needed to examine evidence for each hypothesis also being described in the relevant section.

**Hypothesis 1. That children with severe chronic renal failure would show higher levels of psychological difficulties and lower levels of self-esteem than norms available for healthy children.**

In order to examine evidence for the above hypothesis descriptive analysis of the children's psychological outcome variables was carried out.

#### **The Strengths and Difficulties Questionnaire- the Self-Report Version.**

The mean total score of the self-report version of the SDQ was 11.73 (SD = 5.25). Scores ranged from 1 to 26 out of a maximum of 27. The overall scores of 13% in the borderline and the 7.2% in the abnormal range reflect that of Goodman et al.'s (1998) study of a community population showing 10% of children in the each of the borderline and abnormal categories. Compared to the normative scores for this questionnaire (Goodman et al., 1998), the number of children in the study group scoring in the borderline or abnormal range for the total and sub scores were not significantly different using the Binomial test of proportions. There were no gender differences between the total SDQ scores ( $t(82) = 0.84$ , ns.); however within the sub-scales, girls scores were higher than boys in the prosocial scale ( $t(82) = -0.26$ ,  $p < 0.01$ ) and the emotional scales ( $t(82) = -2.28$ ,  $p < 0.05$ ). Thus girls rated themselves

as having more positive social behaviours and also more emotional problems.

The percentages of children falling into the abnormal or borderline range for psychological difficulties for the total and sub scales are shown in table 8.

Table 8

Distribution of the Children's Self-Report Scores of the Strengths and Difficulties Questionnaire (SDQ)

SDQ Scale	Normal Range (%)	Borderline (%)	Abnormal (%)
Prosocial	68	23	9
Hyperactive	73	9	18
Emotional Problems	86	8	6
Conduct Problems	72	11	17
Peer Relationships	87	5	8
Total Difficulties Score	86	13	7

**The Strengths and Difficulties Questionnaire - Parent Report Version.**

The mean total score of the parent report version was 11.96 (SD = 6.08), with scores ranging from a 0 to 26. Using Goodman's (1997) normative scores, 11% of children rated by the parents were in the borderline range and 27% in the abnormal range, thus this number of children was greater than the expected 20% (Goodman, 1997). This difference was significant using the binomial test; as was differences in the sub scales of emotional, conduct and peer relationship difficulties, with these sub-scores being higher than norms (Table 9).

There was also a significant gender difference in the parent report

total score ( $t(69) = 2.45, p < 0.05$ ) and in the hyperactivity scale ( $t(69) = 3.12, p < 0.01$ ) with boys scoring significantly higher than girls. Gender differences in these two scales were also found in a study testing the psychometric properties of the strengths and difficulties questionnaire in Sweden (Smedje et al., 1999).

Table 9

Parent Report of Frequency of Abnormal & Borderline scores in the Strengths and Difficulties (SDQ) Questionnaire. Comparison with Normative Values.  
(N =84 )

SDQ Scales	Observed Probability	Test Probability
Pro social	0.86	0.8
Hyperactive	0.76	0.8
Emotional Problems	0.55***	0.8
Conduct Problems	0.62***	0.8
Peer Relationships	0.21***	0.8
Total Difficulties	0.62***	0.8

\*\*\*  $p < 0.001$ .

### The Harter Self-Perception Profile for Children

#### Competency scale.

The Harter self-perception profile for children mean global score was 3.06 (SD. = 0.60) Scores ranged from 1.67 to the maximum of 4. Hoare et al. (1993) suggests that a score of over 2.5 (the mid-point) indicates higher self-esteem. The frequency of the distribution of the global scores suggest that most children in his study group were in the higher range for self-esteem; with just 15% of the study group score below 2.5 suggesting a lower self-esteem.

Normative scores are available from Scottish schoolchildren for each year group and gender of children ranging from eight to sixteen years (Hoare et al., 1993). However dividing the study group children in such away reduced the cell sizes for calculation to an unacceptably low level with eight of fourteen cells having an  $n < 5$ . Therefore the mean score across the age range in the Scottish normative sample was used as a comparison; and at 2.97, this did not significantly differ from the study group ( $t(80) = 1.4$ , ns.).

The Harter global self-esteem has been reported for children with diabetes and epilepsy (Hoare & Mann, 1994). These were used for comparison with this study group. The children with renal failure had a significantly higher global self-esteem than children with epilepsy ( $t(80) = 1.96$ ,  $p < 0.05$ ) but they were not significantly different to those children who had diabetes ( $t(80) = -1.43$ , ns.).

#### Importance scale.

The mean discrepancy score for the importance questionnaire was  $-0.55$  ( $SD = 0.52$ ). The scores ranged from  $-1.83$  to  $2.45$ . This calculates whether the child evaluates the domains at which they do not rate themselves very competently as being important. A large negative discrepancy, (maximum of  $-2.0$ ) between their perceived competency and importance scores would place them at risk of low self-esteem. Harter does not publish norms for the importance scale, with these being regarded as indicators of vulnerability to self-esteem. Harter (1986) has demonstrated a linear relationship between Importance discrepancies and global self-worth, with larger negative domain discrepancies being associated with lower self-worth. In this study there was a significant correlation between Harter Global scores and mean discrepancy scores ( $r(78) = 0.412$ ,  $p < 0.001$ ), in the same direction as Harter's (1982) findings, with children with large negative discrepancy scores having associated lower self-esteem scores.

Therefore there was some evidence for the support of the hypothesis with higher levels of psychological distress, but not lower levels of self-esteem being associated with the children in the study.

**Hypothesis 2. The severity of illness will discriminate levels of psychological distress within a heterogeneous group of renal patients**

The two types of measures (the composite index of medical severity and the self-report health status) were used to explore the hypotheses that there was a relationship between an increase of severity of illness and an associated increase in psychological distress. These variables were then correlated with psychological outcome measures.

**The Health Status Questionnaire – Descriptive Analysis.**

**The Functional Impairment Scale.**

80% of children reported some impairment of functional health status in at least one area of the six areas asked about. 10% of the children had difficulties in four or five of these areas indicating high levels of functional impairment. Children's functional health status was positively correlated with index of medical severity, so that children needing more treatment (such as those on Dialysis) were more likely to have higher impaired functional health status ( $r(80) = 0.25, p < 0.05$ )

**The Social Functioning Scale.**

70% of children reported they had some impairment in social functioning with 20% rating impairment in three or more out of five areas.

Children's social functioning was also correlated with their index of medical severity, with children needing more treatment having higher levels of impaired social functioning ( $r(80) = 0.28, p < 0.05$ ).

Social functioning was not significantly correlated with functional impairment ( $r(80) = 0.21, ns.$ ), suggesting that these were 2 distinct measurements. (see Table 5, p. 62, in Methods).

**Illness and Outcome Variables – Univariate Analysis**

The variables associated with illness were correlated with those of outcome (Table 10).

The index of medical severity score (treatment category, additional



illness and frequency of hospital attendance) was not significantly correlated with the outcome variables of psychological adjustment (SDQ scores) or with children's self-esteem (Harter Global and Importance score).

However there was a relationship between children's self-report health status questionnaire and some of the outcome measures. Children's health status was significantly correlated with their self-report SDQ, ( $r(84) = 0.42$ ,  $p < 0.001$ ), but was not significantly correlated with any other outcome measure.

Table 10

Correlations between Severity of Illness and Psychological Outcome

Outcome Measure	Illness Measure		
	Medical Severity Index	Functional Health	Social Functioning
Parent SDQ	0.04	0.18	0.23
Self-report SDQ	0.17	0.42***	0.29**
Harter Global Score	-0.05	-0.18	-0.23*
Harter Importance Score	-0.08	-0.13	-0.33**

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$

Children's social functioning was significantly correlated with their self-report strengths and difficulties questionnaire ( $r(84) = 0.23$ ,  $p < 0.01$ ). In addition social functioning was significantly negatively correlated with the Harter global self-esteem score ( $r(81) = -0.25$ ,  $p < 0.05$ ), and the Harter Importance score ( $r(78) = -0.33$ ,  $p < 0.01$ ). Thus the hypothesis of relationships between severity of illness and psychological outcome is partially substantiated for self-report scores of severity of illness. Hence if the child perceived themselves to have social or health functioning difficulties they were also likely to rate themselves as having psychological problems

and lower self-esteem. As the composite measure of index of medical severity did not show this relationship the hypothesis was not supported for this measure. In addition, the outcome measure of parent report SDQ was not correlated with any of the illness measures.

**Hypothesis 3. That there would be an effect of age and gender on childrens coping patterns**

In order to examine this hypothesis the frequency, type and distribution of the scores on the coping questionnaire needed to be analysed, using descriptive analysis. Following this univariate analyses were used to explore relationships between coping patterns and child variables of age and gender.

**The Kidcope – Descriptive Analysis**

The children were asked to generate a problem associated with their illness that bothered them most. Their responses were categorised into 5 groups (see Table 11). The most common worry generated was about carrying out their medical regimen with 34 (39%) children naming this as their prime worry. Issues about school life such as falling behind their peers academically and socially was nominated by 29 (34%) of children. Other worries were around peer relationships 13 (15%) children, and 5 (6%) of children had problems related to body image. Just one child named family or a home problem related to their illness, and the four (5%) remaining children named other problems.

Table 11

**Type of Problem Described Using the Kidcope (N = 86)**

	Medical regimen	Schooling	Peers	Body Image	Family	Other
% of Children	39	34	15	6	1	5

In responding to questions regarding their generated problem, children firstly rated how distressed they felt about the problem. From a possible total of 12, the mean score was 3.18, (S D. 2.82).

The children then were asked to rate the frequency of their use of the 11 coping strategies listed for their problem. If the child endorsed the use of a coping strategy they were then asked how helpful that coping strategy had been for them. Results on Table 12 show the mean scores of the frequency of the strategy used, and the mean scores of their rating of the helpfulness of that coping strategy, if used. Note that the frequency scale is scored 0 to 3, whilst the efficiency scale is scored 0 to 4.

The most commonly used coping strategy was resignation, with children also rating this as the most helpful. Other strategies most frequently used were, Distraction, Problem-Solving, Emotional Calming, Wishful Thinking and Social Support. It can be seen from Table 12 that in some coping strategies there is more of a discrepancy between evaluation of frequency and helpfulness so that although children say they use a coping strategy, they do not necessarily evaluate it as being helpful. This occurs in Wishful Thinking, when the mean efficiency score is less than the frequency.

Table 12

Mean Scores of Children's Frequency and Efficiency of each Coping Strategy in the Kidcope Illness Questionnaire. (N = 70)

Question. Number and Descriptor	Frequency Mean score (scale 0-3)	Efficiency Mean score (scale 0-4)
1. Distraction	0.8	1.0
2. Withdrawal	0.52	0.51
3. Cognitive Re-framing	1.31	1.79
4. Self-Blame	0.29	0.29
5. Blaming Others	0.16	0.06
6. Problem Solving	0.59	0.87
7a. Emotional Upset	0.30	0.27
7b. Emotional Calming	0.69	1.08
8. Wishful Thinking	1.04	0.70
9. Social Support	0.89	1.43
10. Resignation	1.91	1.94

In contrast, Cognitive Reframing and Social Support when used is evaluated as very helpful. However, despite these discrepancies, there was high overall agreement between frequency and efficiency scores of all coping strategies, as they are all correlated at the  $p < 0.001$  level (see Table 6, in methods).

The frequency of the four coping categories (Internalising, Emotional Externalising, Active Coping, and Acceptance) generated by the factor analysis are shown in Table 13. The most frequently used factor was Acceptance with 93% of the children endorsing this, whilst both Internalising and Emotional Externalising was used less at 64% and 65% respectively.

Table 13

Frequency and Means of Coping Factors. (N= 70)

Coping Factor	<u>M</u>	<u>S.D</u>	% Frequency
Emotional Externalising	1.43	1.43	65
Active Coping	2.77	2.77	77
Internalising	1.49	1.50	64
Acceptance	3.73	3.73	93

Child Variables Related to Coping

The individual factors hypothesised to relate to children's coping were child age and gender.

The four coping categories of Internalising, Emotional Externalising, Active Coping and Acceptance generated by the factor analysis were used to examine the relationship with these variables. Age, although correlated with decreasing frequency of coping strategies was not significant ( $r(70) = -0.067$ , ns) unlike previous findings (Spirito et al., 1998). In addition age was not correlated with any of the coping factors or individual coping strategies.

However there was a significant difference in gender within the coping factor of Internalising, ( $t(68) = 2.28$ ,  $p < 0.05$ ) with boys evaluating social withdrawal within this coping factor as being significantly more

helpful ( $t(68) = 2.19, p < 0.05$ ). Boys also had higher mean scores in Self-Blame than girls but this was not significant. There was a small difference in the mean scores in Active Coping strategies between boys and girls ( $t(68) = -1.56, n.s.$ ), with girls evaluating this coping strategy as being helpful more frequently than boys. The gender difference in this coping factor is due to the coping item of seeking social support as there is a significant difference between girls and boys in the scores of this item ( $t(68) = -3.17, p < 0.01$ ) with girls endorsing this item more frequently.

Thus there was some support for the hypothesis that there would be a relationship between gender and coping pattern, but not between age and coping pattern.

**Hypothesis 4. That parental coping patterns and level of distress would have a relationship with children's coping patterns**

To explore the hypothesis the patterns of parental coping and distress were descriptively analysed and then univariate analysis between these variables and child coping were examined.

**The Coping Health Inventory for Parents – Descriptive Analysis.**

64 parents were able to complete the Coping Health Inventory for Parents (CHIP). Parents who declined to complete this measure found the questionnaire ambiguous and difficult to understand especially if English was not their first language.

The mean scores of the parents three coping patterns were summarised and compared with the norms available (McCubbin et al., 1983), and are shown in Table 14. Mothers coping pattern I (family integration), and pattern II (support self-esteem) did not differ significantly from the norms. However in the third coping pattern (medical information and communication), the mothers mean scores were higher than norms ( $t(51) = 2.98, p < 0.01$ ). As higher scores in all of the CHIP coping patterns are indicative of better coping (McCubbin et al., 1983), this score may reflect the needs of parents of the

children with this disorder to communicate effectively with the doctors regarding the typically complex care of the child at home.

The mean scores of fathers coping pattern I (family integration) were significantly above norms ( $t(11) = 3.50, p < 0.01$ ), indicating that for the group of fathers who completed the questionnaire they used coping strategies of maintaining family integration, co-operation and an optimistic definition of the situation more frequently. By virtue of attending clinic appointments with their children this group of fathers were likely to have been biased towards these type of coping strategies which suggests that they were more fully integrated into the day to day care of their children in the home. Fathers mean scores for coping pattern II and III were also higher than normative scores but not significantly so.

Table 14

Means of Parents' CHIP Scores Compared with Normative Scores.

CHIP Pattern	Parent Scores		Norms		t
	M	SD	M		
	mothers n=52				
Pattern I Family Integration	41.78	9.92	40		1.29
Pattern II Support & Self-esteem	27.61	12.16	28		0.23
Pattern III Medical & communication	16.76	4.27	15		2.98**
	Fathers n=12				
Pattern I Family Integration	42.66	6.5	36		3.50**
Pattern II Support & Self-esteem	29.16	9.32	25		1.54
Pattern III Medical & communication	15.0	5.6	12		1.85

\*\*  $p < 0.01$

### **The General Health Questionnaire – Descriptive Analysis.**

30% of parents scored above the threshold of 5 used as the cut-off in this study. The highest frequencies of scores were reported in the anxiety and insomnia scale, with 50% of parents endorsing at least one symptom. This result is comparable with some of the previous research carried out with this patient group (Reynolds et al., 1991).

### **Parental Coping, Psychological distress and Child Coping patterns - Univariate Analyses**

Parents' coping pattern scores of the CHIP were correlated with the Kidcope individual efficiency scores and also with the four coping factors. There was no significant correlation noted for any of the scores.

In addition the GHQ total and sub scores were correlated with the Kidcope coping factors. Again no significant correlation was found. Thus the hypothesis that parents distress or coping factors will affect children's coping factors was not supported.

### **Hypothesis 5. That there would be a relationship between childrens' coping patterns and their psychological outcome**

To explore the above hypothesis, the four coping factors identified from the Kidcope were correlated with the children's psychological outcome measures.

### **Relationship of Children's Coping with Outcome – Univariate Analysis.**

From the above analysis there were two significant correlations (Table 15). Firstly the coping strategy Internalising (Self-Blame, Social Withdrawal and Wishful Thinking) was significantly correlated with the self-report SDQ ( $r(69) = 0.39, p < 0.001$ ), thus an increase in use of this coping strategy paralleled an increase in the level of psychological distress.

Secondly, the coping factor Acceptance (Cognitive Reframing and Resignation) was significantly associated with global self-esteem scores ( $r(69) = 0.286, p < 0.05$ ). Hence the use of these coping strategies would be



accompanied with a higher rather than lower level of self-esteem.

These findings partially substantiate the hypothesis that maladaptive coping strategies such as Internalising would be associated with higher levels of psychological distress, whilst more adaptive coping strategies such as Acceptance would be associated with more positive psychological outcome such as higher self-esteem.

Table 15

Correlation of Children's Coping Factors and Psychological Outcome

Outcome Measure	Coping Factors			
	Emotional Externalising	Internalising	Active Coping	Acceptance
Parent SDQ	0.17	0.24	0.07	0.23
Self-Report SDQ	0.13	0.387***	0.09	-0.15
Global Self-Esteem	0.08	-0.22	-0.08	0.29*
Importance Score	-0.10	0.14	-0.18	0.18

\* $p < 0.05$ , \*\*\*  $p < 0.001$

**Hypothesis 6. The mediator analysis predicts that coping will account for the relationship between illness severity and adjustment**

In the mediator model, the mediating variable (coping), explains the link between health status and psychological adjustment.

The strategy for analysing coping as a mediator involves two main steps:

Step 1- Correlations are carried out between the independent, dependant and potential mediating variables, examining whether there are any

significant relationships between illness severity and coping, illness severity and psychological outcome and coping and psychological outcome.

Step 2-Where there are significant correlations, regression equations are used to describe mediation relationships. Three regression equations provide the tests of the links to the mediation model and in order to function as a mediator the variable must meet the following specific conditions (Baron & Kenny, 1986).

- Variations in the levels of the independent variable illness severity significantly account for variations in the hypothesised mediator (path a, in figure 3.)
- Variations in the mediator significantly account for variations in psychological adjustment. (path b)
- When coping is controlled for in these conditions, a previously significant relationship between Illness Severity and the adjustment variable (path c) is no longer significant or is at least much reduced.

A significant reduction along the path between the independent and dependent variables demonstrates that a given mediator is indeed potent.

Thus the following variables were applied to analysis of the mediation model. Coping factors (as defined in the factor analysis) of Internalising, Emotional Externalising, Active Coping, and Acceptance were tested as mediators.

The independent variables of Illness Severity examined were Social Functioning, Health Status, and the index measure of Medical Severity.

The dependent variables of psychological adjustment were the total scores of the self-report and parent report Strengths and Difficulties Questionnaire, and the Harter SPPC Global competency and importance score.

#### **Coping as a Mediator – Multivariate Analysis.**

Associations were found in the predicted direction between severity of illness, coping and outcome enabling the data to be analysed within the mediator framework.

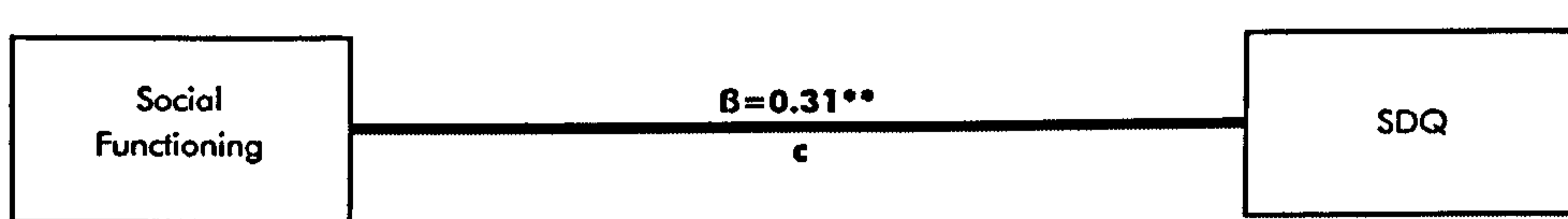
On analysis there were significant correlations in the 3 paths of the

above model in 2 circumstances. These were when the coping variable of internalisation was acting upon the dependent variable of self-report SDQ with the two independent variables of functional health status and social functioning. However when the effect of coping was controlled for, there was a significant reduction in the effect of health status on adjustment only in one circumstance. This occurred between social functioning and self-report SDQ, with the pathway between social functioning and SDQ being reduced from  $\beta = 0.31, p < 0.01$  to  $\beta = 0.19, ns.$  when Internalising coping factor acted as a mediator (see diagram 6a). However when health functioning acted as the independent variable, there was no significant change in the pathway when Internalising was controlled for in the regression. (See diagram 6b).

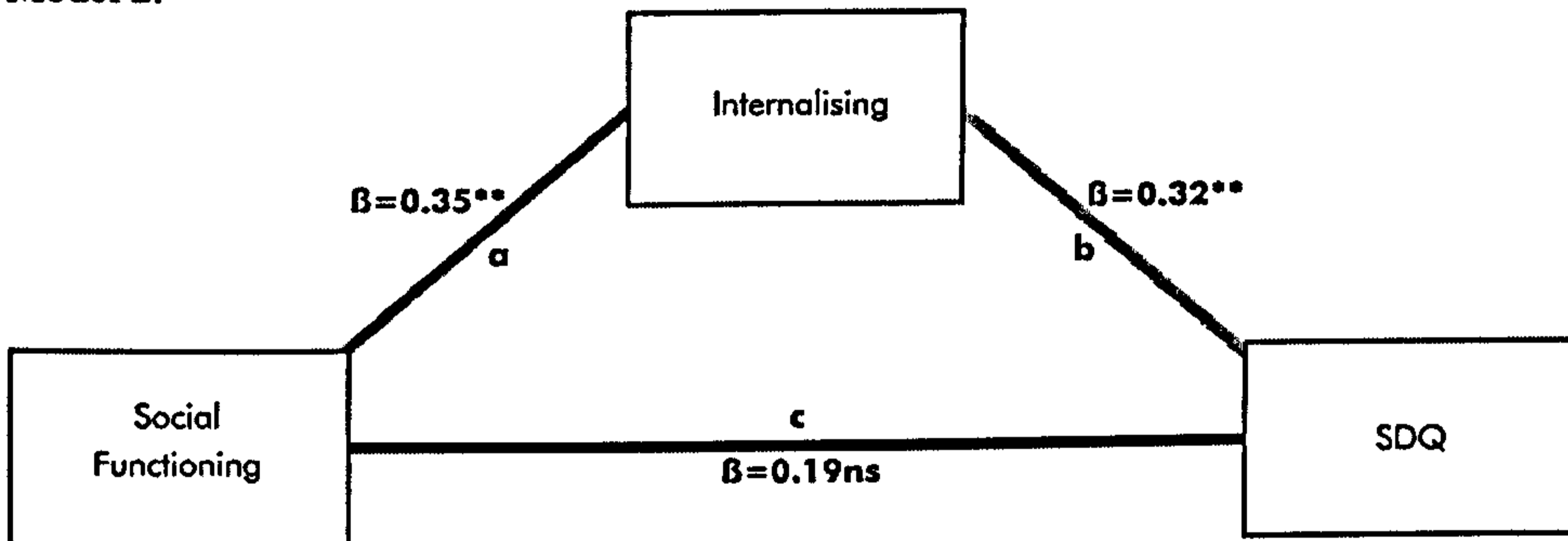
Thus the hypothesis which suggests that coping may act as a mediator is substantiated only in one circumstance when one construct of coping acts as a mediator between social functioning and SDQ . As mediators explain how external effects take on internal psychological significance, they are explaining how or why such effects occur (Baron & Kenny, 1986). The content of the measures is probably relevant to this result and will be discussed in more detail in the discussion chapter.

**Figure 6**  
**Relationships between Health Status and SDQ when Internalising Acts as a Mediator**

**a) With Social Functioning as the Independent Variable.**  
**Model 1.**



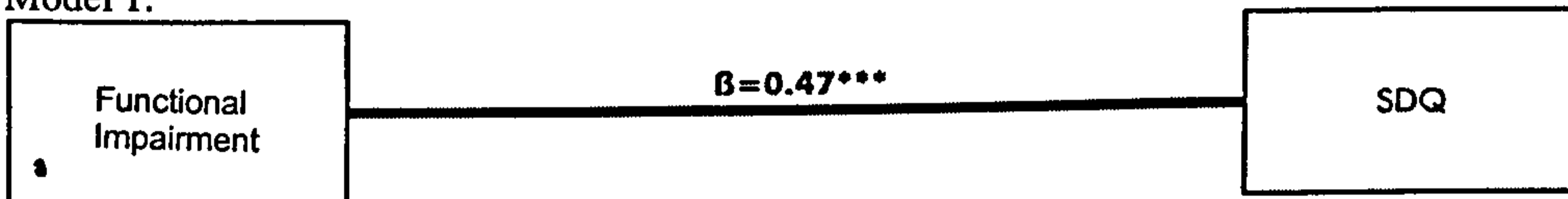
**Model 2.**



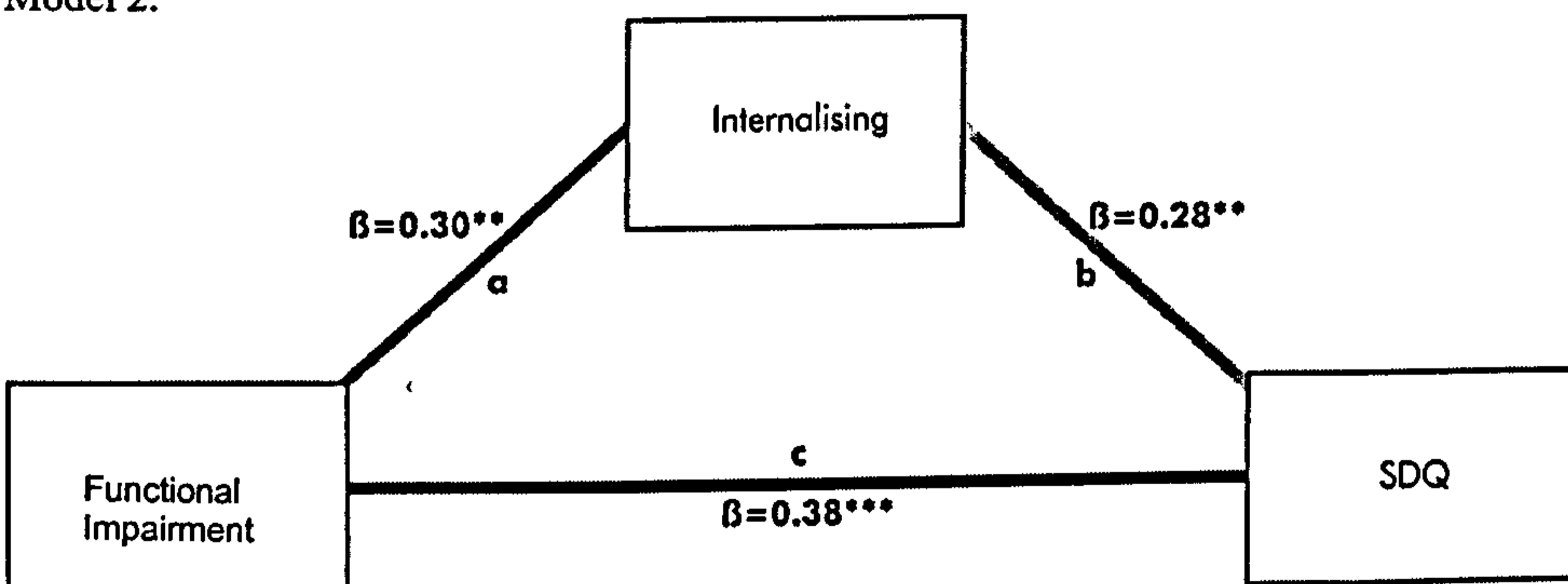
Note: Pathway c decreases to become non significant when coping is controlled for in Model 2.

**b) With Health Functioning as the Independent Variable**

**Model 1.**



**Model 2.**



Note: Pathway c does not reduce in significance when coping is controlled in Model 2.

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ .

**Hypothesis 7. When coping acts as a moderator it will explain the circumstances under which there is a relationship between severity of illness and psychological adjustment**

**Coping as a Moderator - Multivariate Analysis.**

In the Moderator model the moderating variable (coping) moderates or explains under what conditions there is a relationship between illness severity and psychological adjustment.

In order to test the differential effects of moderation, there are two steps to the analysis using regression equations.

Firstly, the main effects of severity and coping are examined to see if there is a predicted outcome. Secondly, severity, coping and the interaction of severity and coping are entered into the equation to see whether the interaction is contributing a significant amount to explained variance and hence there is evidence for moderation.

If there is evidence for moderation, the interaction will be examined to determine the direction of the effect.

The criterion variables of adjustment were as follows; the moderating factors of coping examined were; Internalising, Emotional Externalising, Active Coping and Acceptance.

Dependent measures were child and parent report total Strengths and Difficulties score, the Harter SPPC Global self-esteem score and Importance score. The predictor variables of illness severity, were the Medical Severity Index, Functional Impairment, and Social Functioning.

**Statistical considerations.**

In order to statistically test for moderating effects, the level of statistical significance of the interaction effect needed to be reconsidered. This is because the detection of moderator effects within field research is known to be extremely difficult, even though experimentalists frequently detect strong

interaction effects (McCelland & Judd, 1993). This is frustrating for the field researcher who may have compelling theoretical reasons for expecting moderator effects and the knowledge of how to identify such an effect statistically (Morris, Sherman and Mansfield, 1986).

The differences found in the level of interaction effects between laboratory experiments and field studies can be explained. Firstly, overall model error is frequently lower in experiments because these are conducted under more controlled conditions. Experimentalists are also less likely to be affected adversely by measurement error which can be controlled in laboratory settings. In addition, there are often theoretical constraints on the nature of the interaction in field studies so that the moderator cannot be presumed to be strong enough or isolated enough to account for all interactions found.

Perhaps not unsurprisingly even when reliable moderator effects are found, the reduction in model error due to adding the product term is often disconcertingly low. Evans, (1985) for example, concluded that moderator effects are so difficult to detect that even those explaining as little as 1% of the total variance should be considered important. In a review of the social science literature Champoux and Peters (1987) reported that field study interactions typically account for about 1 to 3% of the variance.

Therefore there are implications for the level of significance reported in field research designs. Thus in this study a relatively conservative approach will be taken with exploration of any interaction effects of 3% of variance or more, which in the context of field studies constitute a large effect (Champoux & Peters, 1987). The criterion of percentage of variance has been set in preference to an absolute p value in order to reduce type II errors (hence the exact p value will be reported in these circumstances). Obviously this will mean accepting the possibility of higher rates of type I errors and this needs to be acknowledged. In addition, the large number of regression analyses needed for the analysis will also increase the chance of type 1 errors, but as this is an exploratory study it is important not to miss any pertinent results.

Subsequent to finding any relevant interaction effects, further studies

could explore ways of re-examining these to ensure that there is a truly significant interaction. For example,

McCelland and Judd (1993) suggest a strategy of over-sampling extreme observations which will result in a sub-sample close to an optimal design.

In the circumstances where the interaction of coping and severity explains or moderates 3% or more of variance of the outcome, then the effect of coping needs further exploration to examine the directional cause of the moderator. By using a median split, the subjects using a moderating coping strategy would be divided into two groups; those that are highly endorsing the use of the coping strategy, and those who are scoring little or none. Each groups' severity of illness scores would be correlated with their psychological adjustment to examine the direction of the relationship.

Overall, using the above criterion, predictor, and moderating variables, there were five analyses where the percentage of variance was over 3%.

#### **1. Emotional Externalising as a moderator of the relationship between functional health status and parent report total strengths and difficulties**

Table 16 shows the regression coefficients for these variables when Emotional Externalising moderates between functional health status and parent report SDQ. The change in the  $R^2$  between the 2 models was over 6%. The subjects were divided using a median split by high and low scores in Emotional Externalising. Correlation of the functional health status and Strengths and Difficulties scores of each of these groups was carried out. For those children with high scores of externalising there was a significant positive correlation between functional health status and the parent total difficulties score ( $r(29) = 0.40, p < 0.05$ ). This suggested that high scores in maladaptive coping strategies were more likely to result in maladaptive adjustment scores when functional health status was poor. Comparison with those with low scores on externalisation indicated that there was not such a strong relationship between health status and adjustment ( $r(28) = 0.22, ns$ ).

Table 16

Summary of Hierarchical Regression Analysis for Emotional Externalising as a Moderator of the Relationship Between Functional Health and Parent Report Total SDQ.

Model	Variables entered	B	$\beta$	p
One $R^2 = 0.10$	Severity-Functional health status	1.73	0.28	<0.05
	Coping-Emotional Externalising	0.58	0.19	0.42
Two $R^2 = 0.17$	Severity-Functional Health status	1.61	0.26	<0.05
	Coping-Emotional Externalising	0.22	0.04	0.76
	Severity x Coping	1.53	0.28	<0.05

$\Delta R^2$  model one to model two = 0.07.

**2. Emotional Externalising as a moderator of the relationship between social functioning and parent report total strengths and difficulties**

Table 17 shows the regression coefficients for the variables when Emotional Externalising moderates social functioning and parental total SDQ. The difference of the  $R^2$  between the 2 models was over 4%. The subjects were again split by high and low scores of Emotional Externalising. Correlation of the social functioning and parental SDQ of each of these groups was carried out. For those children scoring highly on externalising there was a higher positive correlation between functional health status and the parent total difficulties score ( $r(29) = 0.32, ns$ ) than those children with lower scores.



This suggested that high scores in maladaptive coping strategies were more likely to result in maladaptive adjustment scores when social functioning was low. Comparison with those with low scores on externalisation indicated that there was not such a strong relationship between social functioning and adjustment ( $r(28) = 0.18, ns.$ ).

Table 17

Summary of the Hierarchical Regression Analysis when Emotional Externalising Moderates the Relationship Between Social Functioning and Parent Report Total SDQ.

Model	Variables entered	<u>B</u>	$\beta$	p
One $R^2 = 0.07$	Severity-Social Functioning	1.20	0.28	0.13
	Coping-Emotional Externalising	0.67	0.13	0.36
Two $R^2 = 0.11$	Severity-Social Functioning	1.30	0.22	0.10
	Coping-Emotional Externalising	6.99E-02	0.01	0.93
	Severity x Coping	1.30	0.24	0.11

$\Delta R^2$  model one to model two = 0.04.

### **3. Emotional Externalising as a moderator of the relationship between social functioning and Harter Global Self-Esteem score.**

Table 18 shows the regression coefficients when Emotional Externalising moderates between social functioning and the Harter SPPC global self-esteem. The difference of the  $R^2$  between the 2 models was 5.8%. The externalising scores were divided into high and low scores. Although there were no significant correlations between social functioning and the global self-esteem score, there was a larger correlation for those with low externalising scores ( $r(31) = -0.29, ns.$ ) than those with high externalising scores ( $r(38) = -0.068, ns.$ ). This result is not in the predicted direction, as this suggests that children with low scores in Emotional Externalising (a maladaptive coping strategy) would be more likely to have a relationship between low social functioning and lower self-esteem rather than those children with higher scores of Emotional Externalising.

The groups scoring high or low in Emotional Externalising were scrutinised for any overt reasons for this result. The coping strategies making up the coping factor (Blaming Others and Emotional Regulation) all followed the same predicted direction, with those who had a high score of Emotional Externalising all scoring significantly higher in each strategy. In addition those with high scores were more likely than those with low scores to rate themselves as more distressed about the problem they had described, suggesting that they found it more difficult to cope with their problem, which follows the predicted direction for this coping factor. The implications for these results will be considered in the discussion.

Table 18

Summary of Hierarchical Regression Analysis of Emotional Externalising Moderating Between Social Functioning and Harter Global Self-Esteem.

Model	Variables entered	B	$\beta$	p
One $R^2 = 0.23$	Severity-Social Functioning	-0.14	-0.22	0.07
	Coping-Emotional Externalising	7.23E-02	0.12	0.33
Two $R^2 = 0.29$	Severity-Social Functioning	-0.14	-0.23	0.07
	Coping-Emotional Externalising	3.08E-02	0.05	0.70
	Severity x Coping	0.11	0.19	0.15

$\Delta R^2$  model one to model two = 0.06

**4. Internalising as a moderator of the relationship between social functioning and the Harter SPPC Importance scores**

Table 19 illustrates that the regression coefficients when Internalising acts as a moderator between social functioning and the importance score of Harter self-esteem. The difference in the  $R^2$  between the 2 models was over 7%. When the group was split into high and low scores, those children who had high scores of Internalising had a larger negative correlation between low social functioning and the importance score ( $r(35) = -0.321, ns.$ ) [compared to those who had low Internalising scores ( $r = -0.197, ns.$ )]. Thus children who more frequently endorsed this coping strategy were more like to have large discrepancies between their ideal and real self-esteem when their social functioning was low, therefore making them vulnerable to low self-esteem.

This result reflected some support for the hypothesis that Internalising acted as a maladaptive coping factor.

Table 19

Summary of Hierarchical Regression Analysis of Internalising  
Moderating Social Functioning and the Harter SPPC Importance Scores.

Model	Variables entered	B	$\beta$	p
One $R^2 = 0.32$	Severity-Social Functioning	-0.39	-0.27	<0.05
	Coping-Internalising	-0.16	0.11	0.41
Two $R^2 = 0.39$	Severity-Social Functioning	-0.35	-0.23	0.06
	Coping-Internalising	-6.59E-02	0.05	0.73
	Severity x Coping	-0.29	0.24	<0.05

$\Delta R^2$  model one to model two = 0.07

**5. Active Coping as a moderator of the relationship between social functioning and parent report total SDQ score.**

Table 20 shows the regression coefficients when Active Coping acts as a moderator between social functioning and parents report total SDQ score. The difference between the  $R^2$  between the 2 models was over 4.5%. The subjects were split by high and low scores in Active Coping strategies. Correlation of social functioning and SDQ scores of each of these groups was carried out. For those children scoring highly on Active Coping there was a larger positive correlation between social functioning and the parent total difficulties score ( $r(25) = 0.390, p < 0.05$ ) compared to those children with lower scores ( $r(32) = 0.036, ns.$ ). This suggested that high scores in this coping strategy

were more likely to result in maladaptive adjustment scores when social functioning was low.

Table 20

Summary of Hierarchical regression Analysis of Active Coping strategies  
Moderating the Relationship Between Social Functioning and Parent Report  
SDQ Total Score.

Model	Variables entered	B	$\beta$	p
One $R^2 = 0.06$	Severity-Social Functioning	1.32	0.23	0.94
	Coping-Active Coping	0.22	0.04	0.78
Two $R^2 = 0.10$	Severity-Social Functioning	1.45	0.25	0.06
	Coping-Active Coping	2.05E-02	0.00	0.98
	Severity x Coping	1.51	0.22	0.10

$\Delta R^2$  model one to model two = 0.05

As the results of this correlation were not in the predicted direction the coping factor was further scrutinised. The individual coping strategies making up the Active Coping factor were examined to explore whether there was a loading of a single coping strategy in the children who had high Active Coping scores that could account for their high levels of distress. For all three coping strategies (Problem Solving, Distraction, and Social Support) the mean score was significantly higher in those with high Active Coping scores thus confirming the earlier predictions that those children employ and utilise all three of the coping strategies that make up the factor of Active Coping. There

was however a significant difference between those scoring high or low in Active Coping in their ratings of distress associated with the problem described on the Kidcope. Those with high scores in Active Coping although utilising coping strategies were still significantly more distressed about the problem than those with low Active Coping scores ( $t(68) = -2.1, p < 0.05$ ). In addition, there was a difference between the groups scoring high or low in Active Coping in the type of problem they generated for the Kidcope. Those scoring highly in active coping were more likely to find school issues a problem than those with low scores in active coping (Man-Whitney  $Z = -2.51, p < 0.01$ ). The implications of these results will be considered in the discussion.

Thus there is some tentative evidence for the hypothesis that coping strategies act as a moderator between illness severity and psychological adjustment. However the results are seen under specific circumstances. Firstly the coping factor that acts the most frequently as a moderator is more likely to be a maladaptive one, most commonly Emotional Externalising. Secondly the measure of illness severity that shows results is the self-report measure of Health status - a rating of both functional impairment and social functioning. Lastly, the most clear outcome measures in this moderating model are with the parental report SDQ, although there are some additional findings using the Harter SPPC. The implications of these results will be discussed in the next chapter.

## **CHAPTER 4**

### **DISCUSSION**

Discussion of the results of the study will be as follows:

1. Each of the hypotheses made in the introduction of the study will be examined in relation to the results to evaluate the level of support for that hypothesis. The relevant research and associated methodological issues for each hypothesis will also be discussed.
2. Further methodological and design issues relevant to the study will be discussed.
3. Further implications for future research studies based on the findings of this study will be discussed.
4. Finally the clinical implications from the results of the study will be discussed.

#### **Substantiation for the Hypotheses**

The evidence for the hypotheses related to the psychological adjustment of children with renal failure is presented, followed by the hypotheses related to coping.

#### **Hypothesis 1: Children with end-stage renal disease will show higher levels of psychological difficulties and lower levels of self-esteem compared to normative data for healthy children**

The incidence of psychological difficulties reported in this group of children using the parent report strengths and difficulties questionnaire, supported the hypothesis that children with chronic renal failure would have significantly higher levels of psychological distress than population norms. 38% of children were rated as having borderline or abnormal scores, which was significantly higher than community norms (Goodman, 1997). The data support findings of higher levels of psychological difficulties in children with chronic illness (e.g.

Pless & Nolan, 1986). Studies using the SDQ as an outcome measure in the paediatric population have not been extensively published, however they have been published for a group of hemiplegic children (Goodman & Graham, 1996); the incidence of above normal scores in this patient group was 55%. Goodman and Graham's study included children with cerebral palsy and the high incidence of psychological distress in this study was suggested to have been due to the added risk factor of the presence of neurological impairments (Garraida, 1994).

In contrast to the above findings, a recent study used the SDQ to evaluate children receiving bone-marrow transplants and their siblings donating the bone-marrow (L'win, Dunn and Stevenson, 1999, personal communication). The parent report scores of the SDQ were made at the time of transplantation. These were within normal ranges for both the children receiving and donating bone-marrow for transplantation.

The SDQ has been validated with the Rutter A behaviour questionnaire (Rutter et al., 1970), which has been used more extensively within paediatric populations, hence the current results can also be compared with this measure when used with similar populations.

Comparison of these results with other studies of children with renal disease shows that there are similar findings within this patient group. For example Reynolds et al. (1991) used the Rutter A behaviour questionnaire. 39% of children who had had renal transplants had behavioural problems reported by their parents using this questionnaire; and 28% of children with chronic renal failure also scored above the norms.

Interestingly, in the Reynolds et al. (1991) study the children's self-reported strengths and difficulties questionnaire did not score above norms. In all 20% of children rated themselves in the borderline or abnormal range, exactly reflecting the Goodman et al. (1998) study of a community sample. It appears that children with renal failure did not rate themselves as having as severe psychological symptoms as their parents did, hence they did not reach the threshold for "psychiatric caseness".



The Harter global self-esteem scores did not significantly differ from the norms available for Scottish school children (Hoare et al., 1993). In addition, the scores did not differ from those of a group of diabetic children, but did differ significantly from the self-esteem of a group of children with epilepsy (Hoare et al., 1994). It is possible that self-esteem scores do not appear to be sensitive enough to be useful as measures of overall outcome, certainly in this group of patients. In addition, other renal studies also show no difference in mean scores. Lavigne & Fair Routman (1992), argue that findings that indicate increased levels of lower self-esteem in paediatric patient population studies are inconclusive.

The importance score, which examines the individuals vulnerability to low self-esteem, was correlated with the Harter global self-esteem score, suggesting that those children whose ideal self was very different to their real perceived selves were more likely to have low self-esteem. These findings suggest that one way in which some of this population could be maintaining levels of self-esteem within the norms is by using 'discounting' as described by Harter (1985). This occurs when children with overall higher self-esteem have smaller discrepancies between the importance and competency scores. Hence children with low self-esteem fail to discount the importance of a domain even when they see themselves as having low competencies in that domain.

Further examination of the individual domains and the importance scores of the Harter would be interesting and could provide some further evidence to help understanding of this patient population, but this is not within the scope of the present study question.

**Hypothesis 2: The effect of the severity of illness will discriminate between levels of psychological distress in a heterogeneous group of renal paediatric patients**

The study examined the opportunity for evaluation of the non-categorical effect of severity of illness within a diagnostically specific group. This would clarify whether categorising this population into treatment /severity groups for

future research would be justified. Categorising renal patient groups this way has been the predominant method in past studies and this categorisation may have been at the expense of variables such as developmental status.

Severity of illness was rated in two different ways. Firstly, a composite measure that took into account treatment input, additional illness, and frequency of hospital attendance, this measure aimed to embrace the multiple nature of this concept in an attempt to make it as valid and reliable as possible. Secondly a self-rating measure was taken of two concepts of the child's health status; their functional health rating and their perceived social functioning. Results of the composite measure with the parent and self-report SDQ total scores indicated that there were no significant associations between these measures.

However, both the measures of the children's Health Status Questionnaire were significantly correlated with their self-report strengths and difficulties questionnaire meaning that increased impairment in health functioning and higher levels of social difficulty were correlated with higher levels of self-reported psychological distress. There were no corresponding associations when parental SDQ score was the outcome measure.

There were small but significant associations between Harter global self-esteem and the social functioning measure and also a larger correlation between the importance score and social functioning. The relationships are in the predicted direction, with a lower level of social functioning associated with lower levels of self-esteem and larger negative discrepancy scores. There are no associations between the functional impairment score or the index of medical severity with self-esteem. The significant associations are possibly due to the social functioning measure being associated with the same type of concepts that make up the domains of the self-esteem measure. For example, the social functioning questionnaire asks about the child's social life in terms of friends, family, and schoolwork.

The difference in the findings between the two measures of severity of illness merits some discussion.

Inconsistencies between illness severity and psychological outcome have been seen in previous research. Findings that there is a more consistent relationship between *perceived* illness severity and other measures of illness severity has also been found in other studies (Khan et al, 1995, Orr et al., 1994). As discussed in the introduction, one possible reason that explains these differences is of the tendency towards the use of unrefined measures of illness severity. The more thorough measure of the index of medical severity made in this study was chosen to address this issue, but this did not show the anticipated results. Thus the associations with psychological outcome do appear to be due to the importance of the perception of the severity of illness rather than a consequence of the sophistication of the measurement used. There does appear to be a difference between the measures regarding what is being measured, with the self-reported measures evaluating the effects of the illness on the child, and the medical index measure being a more direct measure of the illness itself.

Another reason why the composite measure of illness severity did not show any main effects may have been because it was moderated by another variable. Coping was examined as a possible moderator with this variable and the results are discussed below. However, there may have been other moderating variables that could have made this measure more meaningful, for example, it may be moderated by a parent variable such as family functioning.

The findings in this study do not support those of previous studies of this particular population of a relationship between treatment status (a crude measure of illness severity) and psychological outcome (Davies, Tucker & Fennell, 1996; Garralda et al., 1988; Schweitzer & Hobbs, 1996). The different measure of illness severity may have accounted for the difference in results between these studies.

The above hypothesis is supported for the relationship between the perception of health and social functioning and psychological outcome, and studies using this measure have also shown a relationship in the same direction (Brownbridge & Fielding 1991, Fielding & Brownbridge, 1999).

This measure has only been validated for this particular diagnostic group. Although results suggest validation, there has not been any documented research regarding reliability (for example repeated measures). Further studies need to examine this measure and validate it with different patient populations and with other measures of health functioning.

Thus, despite the more thorough measure of medical severity used in this study, the findings suggest one of two consequences; firstly that there is no relationship between this measure of medical severity and outcome in this population, or secondly that there are no main effects, but a more complex framework explaining the relationship between this variable and outcome.

**Hypothesis 3: There will be an effect of external variables on the pattern of the children's coping strategies; so that child's age and gender will be related to their coping**

An effect of age on the frequency and efficiency of coping strategies was not seen. Spirito et al. (1995) found main effects for age in their study of chronically ill children. However, the age range of the children investigated was wide, from 7 to 18 years, and age effects were seen when the groups were divided into younger age groups of 7 to 12 years, and an older group aged 13 to 18 years. Thus, the null effects of age in this study may have been due to the narrower age band of children completing this questionnaire.

There were some gender differences found in regard to the children's coping strategies. Whilst there was no overall difference in the mean scores of frequency and efficiency of coping strategies between the boys and girls, there were differences in the frequency of type of coping strategy endorsed between boys and girls. Boys were significantly more likely to have higher Internalising factor scores than girls. Girls were more likely than boys to use the coping strategy of social support. This difference between boys and girls seemed to be in their social functioning, as boys were more likely to use social withdrawal coping strategy (within Internalising), in contrast girls seek socialisation via social support. Spirito et al. (1995) also found that girls were also more likely to seek social support than boys, and boys also used self-

blame more frequently, which is another of the Internalising coping factors.

**Hypothesis 4: Parental coping patterns and psychological distress would have a relationship with patterns of children's coping**

The failure to identify any associations between parental coping factors and children's coping was unexpected. No relationship was found between the CHIP coping patterns and parental distress using the GHQ and the Kidcope item scores or coping patterns.

The reasons why this may be so for the coping questionnaires can be examined from both a theoretical perspective, and from the methodological issues regarding the measurements of parent and child coping questionnaires.

Findings that children will adopt their parents coping strategies supports the belief that coping strategies are trait rather than state variables. With the research indicating that coping strategies are at least a combination of state and trait variables (Spirito et al., 1992a), any result showing correlated parental and child coping strategies would be expected to be relatively weak.

Thus, in this study if situation specificity was an important influence, it is possible there was not a direct measurable influence from parental to child coping as parents and children may have applied their coping strategies within different situations. Whilst we know from the Kidcope the specific content of the children's worries, we are not aware of the specific parental worries; only that they would be associated with their child illness. For example, parents may be applying their coping strategies around the organisation and time management demands of the child illness, which is different to many of the children who were using their coping strategies around other aspects of their illness, such as school and friendship issues. Thus a questionnaire which parallels the Kidcope in terms of asking parents about coping strategies around a specific problem may have resulted in coping strategies being reported that had a relationship with their child's coping. Thus future research needs to look at more closely allied parent and child coping measures, particularly if they are context specific measures.

There were some fundamental differences between the Kidcope and

the CHIP. Firstly the CHIP items are made from 45 coping strategies which are grouped into three coping patterns; all of which have been rated as useful to parents coping with a sick child (McCubbin et al., 1983). The Kidcope items are made up of a broad spectrum of coping strategies, which have theoretically or in previous research been defined as adaptive or maladaptive. Thus it is not possible to directly measure any specific type of coping strategy or pattern across parent and child. The patterns of coping in the CHIP are predominantly a list of the types of resources they used, which is different to the types of factors identified in the Kidcope which have a more cognitive bias.

There were some practical issues associated with collection of the data. The CHIP was the most difficult questionnaire for the parents to complete, with the lowest number of completed forms for this measure (n=64). Criticisms of the layout and instructions regarding this questionnaire have been made in the past (Eiser & Havermans, 1992), and although the Anglicised version of the CHIP was used (McCubbin, McCubbin, Nevin et al., 1983), the instructions to the parent may still appear ambiguous. The respondent is asked to rate the helpfulness of every coping strategy listed, and there is no option to rate whether coping strategies were not used. There is an implicit assumption that the parent will have used all 45 coping strategies. Thus, it is likely that some parents may have answered the questionnaire inaccurately and in a somewhat generalised way.

**Hypothesis 5: There would be a relationship between coping style and outcome measures. Adaptive coping strategies would be related to lower levels of psychological distress and higher levels of self-esteem whilst maladaptive coping strategies would be associated with higher levels of psychological distress and lower self-esteem.**

The high numbers of coping strategies used in the Kidcope were evaluated using a factor analysis technique. This aimed to address the statistical difficulty of analysing multiple variables within a research study, whilst still addressing the need to broaden the categorising of individual coping strategies

away from the unsatisfactory two-dimensional approach upon which coping theories have been based. Studies using factor analysis of coping strategies have tended to derive different numbers of dimensional structures. For example Ayers et al. (1996) found a four dimensional model which they labelled as Active Coping, Avoidance, Distraction, and Support Seeking; Gil et al. (1991) identified three coping factors labelled Coping Attempts, Negative Thinking, and Passive Adherence.

The lack of a stable factor structure in research studies of coping strategies has been identified as one of the major problems in coping strategy research (DeRidder, 1997). This review argues that the use of factor analysis relies too much on using a bottom up approach, at the expense of ignoring the elaboration of theoretical rationale of coping dimensions. Unfortunately, the theoretical concepts of coping strategies in themselves are not clearly defined, and frequently rely on two-dimensional broad band definitions (e.g. Lazarus & Folkman 1984; Ebata & Moos 1991). Hence it is difficult much other than to examine the data and see under which categories coping strategies fit. For this study, using this population, the factor analysis of the 11 coping strategies supported the four distinct groups of coping factors labelled Emotional Externalising, Active Coping, Internalising and Acceptance. Future research using a similar population could validate that these four factors are appropriate for this patient group with their described problems.

However, one of the undisputed aims of computations of coping strategies is to differentiate between adaptive and maladaptive coping strategies. Research has been able to identify some strategies that clearly fit into each category with adaptive coping strategies generally being considered problem focused and positive thinking, and maladaptive strategies being avoidance or blaming. (Ayers et al., 1996, Ebata & Moos, 1991, Sandler et al., 1994). The efficacy of some specific coping strategies (for example, distraction) have, yet to be clearly defined, and probably are dependent upon the context of the stressor.

Identification of different dimensions of coping that are related to

lower or higher levels of associated distress will enlighten further research and clinical applications of the results. In the current study, of the four coping factors identified, the two factors labelled Internalising and Emotional Externalising appeared to fit theoretical and research findings, suggesting that these would be maladaptive coping strategies.

Two of the three coping strategies that made up the factor labelled Active Coping, have, in previous research found to be adaptive strategies (Sandler et al., 1994). Findings regarding distraction, the third strategy making up this factor, are conflicting, as this has been considered as a maladaptive strategy (Ebata & Moos 1994).

The fourth coping factor in this study, labelled Acceptance, is made up of the strategies of cognitive restructuring and resignation. Both hypothesised to be adaptive particularly within the context of these children's severe long-term chronic illness over which they had little control.

Reinterpretation of the coping factors within the problem focused/emotion focused framework (Lazarus & Folkman 1984) suggested that the coping factors of Internalising and Emotional Externalising had predominantly emotional coping strategies which have been associated with poor psychological outcome. However, the other two strategies had a combination of emotion and problem orientated strategies so could not be fitted into this framework.

In examining the effect of childrens' coping factors with outcome, Internalising, a maladaptive coping strategy, was significantly correlated with increased levels of psychological distress on the self-report SDQ, supporting the hypothesis that the coping strategies making up Internalising are indeed maladaptive. In addition, there was a relationship between the coping factor of Acceptance and global self-esteem suggesting that this coping factor is adaptive, and contributed towards self-esteem. The adaptive /maladaptive distinction between coping factors was further addressed within the moderating and mediating frameworks and will be addressed in the next sections. Overall, it is the coping factors of Internalising and Emotional



Externalising that remain the most consistent in their associations with other variables as maladaptive coping factors, where-as the adaptive coping factors of Active Coping and Acceptance show less consistency in their findings.

The distribution of the use of coping strategies may be meaningful in understanding why the maladaptive coping factors have stronger statistical relationships between health status and psychological distress compared to adaptive coping factors that did not appear to have a positive effect. There is an overlap of children using both adaptive and maladaptive coping strategies and, additionally, the high frequency of use of adaptive strategies may explain why it is difficult to find a relationship between adaptive coping strategies and psychological outcome.

It can be seen that the frequency of the use of Internalising or Emotional Externalising is much lower in the group as a whole, with the strategies not being used by 45% of children. On the other hand, the adaptive coping strategies were used by most children with 80 and 90% for Active Coping and Acceptance respectively. Thus, it could be hypothesised that adaptive coping strategies, whilst useful in adjusting to their chronic illness, lose their impact in the face of maladaptive coping strategies. Thus, the maladaptive coping strategies in the circumstances appear to act as a risk factor for the adjustment of these children. Nearly all children were using adaptive coping strategies, but as no relationship was found between these and the strengths and difficulties scores, these do not appear to act as resilience factors, certainly in the presence of the maladaptive coping factors. Thus they do not fit into the model of resilience factors as proposed by Wallender, et al. (1989b).

**Hypothesis 6: The Mediator hypothesis predicted that coping would account for the relationship between illness severity and adjustment.**

In order to prove a variable is acting as mediator, there needs to be an initial strong association between the mediating variable and the stressor, in this case between illness severity and coping strategy.

In this study the Internalising factor mediated between social

functioning and psychological distress using the self-report SDQ. The link between social functioning and the coping strategies making up Internalising make intuitive sense, and these two variables could be linked to each other in either direction. However for the mediating model, it is hypothesised that lower levels of social functioning, for example having few friends, would predict coping behaviours such as social withdrawal, self-blame and wishful thinking, which in themselves appear to be isolating types of behaviour. Within these circumstances then, these coping strategies would act to increase the level of psychological distress of the children. What is pertinent is the relationship of Internalising with *social functioning*, as the same coping factor did not mediate between functional impairment and psychological distress, despite there being the underlying statistical associations between this measure, Internalising and SDQ. Hence, there is only one very specific circumstance under which Internalising has a mediating effect.

Given that there was just this one occurrence when coping had a mediating effect, it is possible that this result is an anomaly of statistical calculations - type I error due to the number of regression analyses carried out. However, the highly significant difference in the regression analysis (see figure 6, p.96,) suggests that this result is unlikely to have occurred by chance.

As there is very little support in any other studies for the possibility that coping may typically act as a mediator, this result may have been due to the items measuring social functioning and Internalising. The items of Internalising – (social withdrawal, self-blame and wishful thinking) also appear to be descriptors suggesting low use of social skills or social relationships, and hence a strong relationship between Internalising and social functioning would be expected, which in turn would link with psychological problems.

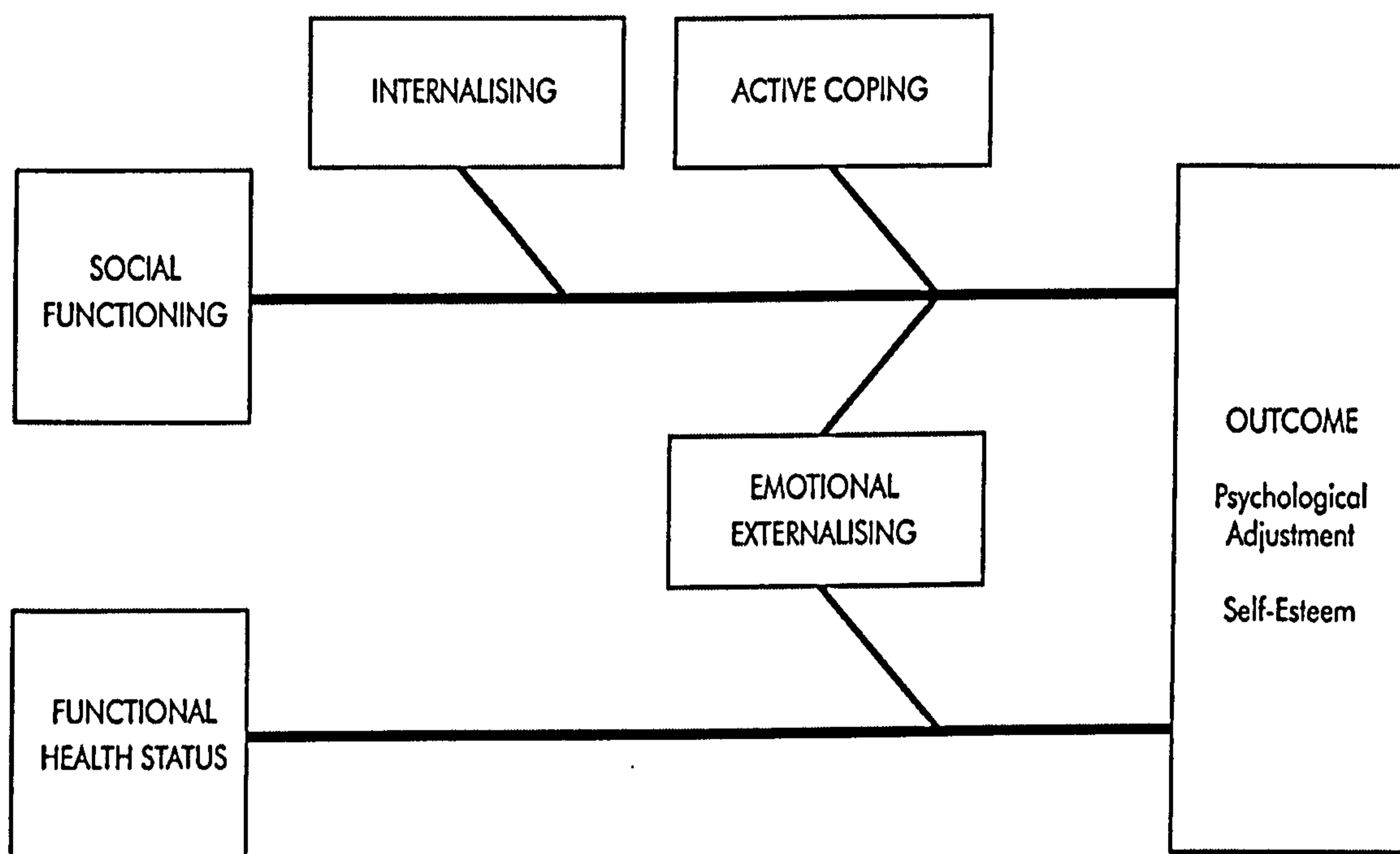
**Hypothesis 7: The moderator hypothesis predicts that when maladaptive coping is high, illness severity will be strongly associated with psychological outcome. Concurrently, when adaptive coping factors are little used, there will be a similar strong association between illness severity and psychological distress.**

When coping acts as a moderator, it is explaining under what circumstances it will have an effect between health status and psychological outcome. From the multi factorial models now being proposed (e.g. Wallander et al., 1989b) explaining the influence of coping as a resilience factor, it makes good intuitive sense that the mechanism of coping is as a moderator .

Figure 7 summarises the findings of this study when coping acts as a moderator. The relationship between severity and outcome in these circumstances depends on the high versus low use of particular coping factors. Emotional Externalising moderated both functional health status and social functioning, affecting the outcome measures of the parent report strengths and difficulties questionnaire. Results showed that those children who had high scores in this coping strategy were more likely to have correspondingly high scores in the strengths and difficulties questionnaire, supporting the findings that this is a maladaptive coping strategy.

Emotional Externalising also moderated social functioning and global self-esteem, however, when the mechanism behind this relationship was examined the findings were not as predicted. Although there was a relationship between Emotional Externalising and self-esteem in the predicted negative direction, the high versus low level of scores acting on self-esteem as seen in the psychological distress measure were in the opposite predicted direction. Thus those children with low scores of Emotional Externalising had a stronger association with low self-esteem compared with those scoring higher levels of Emotional Externalising. There is no obvious explanation for this, and the examination of the coping questionnaire did not help. However, it could be hypothesised that any level of Emotional Externalising has a negative, although not cumulative, effect on lowered self-

Figure 7

Study Findings when Coping Acts as a Moderator.

esteem; or indeed that the measures of self-esteem are not sensitive enough to detect differences in the level of Emotional Externalising.

The coping factor of Internalising when acting as a moderator between health status and psychological outcome did not have a relationship at the required statistical level. However, Internalising moderated the relationship between the social functioning and the Harter Importance scores. Again, the direction of results suggest that high levels of these coping strategies were maladaptive, resulting in high negative scores, which is associated with lower levels of self-esteem.

The coping factor labelled Active Coping acted as a moderator between social functioning and the parents report SDQ. However, the hypothesis that high scores of Active Coping would predict lower scores of psychological distress was not substantiated in the moderating model with the relationship in fact being in the opposite direction. It was hypothesised that the individual coping strategies within the Active Coping factor may account for this difference (for example, the distraction strategy may have been high with those with high scores thus contributing towards this being a maladaptive factor). There were no differences in the frequency of the three coping strategies between those with high and low active coping scores. Thus in the light of these results we cannot say that Active Coping is an adaptive coping strategy for these children.

Indeed in evaluating the level of distress experienced by these children in regards to the problem they nominated on the Kidcope, children using higher levels of Active Coping were significantly more distressed regarding the problem, than those using lower levels of these coping strategies. Additionally, those with high active coping scores were more likely to evaluate school as a problem compared to those with low active coping scores. This finding suggests that there is a relationship between this factor, anxiety and type of problem, and that in the face high anxiety about school problems Active Coping strategies were not useful.

The moderating model provides a valid and interesting framework

from which to explore the influence of these coping strategies. Although this study can only be seen as exploratory in nature, the interaction terms of coping with severity accounted for reasonable levels (4 -7%) of variance (Champoux & Peters, 1987). The findings and conclusions outlined must be seen as tentative due to the statistical considerations of a lower percentage of variance being accepted and the large number of regression analyses carried out. Hence there is a need for a stronger research design in order to explore the hypotheses further. For example, subjects could be selected on the basis of scoring extremes in their coping strategies (McCelland & Judd,1993) and evaluated to see if higher levels of statistical differences were found.

### **Further Methodological and Design Issues**

#### **The Participants**

One of the aims of this study was to have a population sample that was as representative as possible. Glasgow and Anderson (1995) suggest that one of the most frequent limitations of sample considerations is the lack of a representative a sample, with many paediatric psychology studies containing relatively small convenience samples such as hospitalised children or volunteer families. They suggest that better samples should be recruited through the use of procedures such as consecutive patients attending out patient visits or national data banks or registries.

Initial recruitment of families from a hospital held database meant that all patients were considered for recruitment. The database is voluntarily kept; without this, recruitment of eligible patients would have had to be carried out with arduous cross-referencing between appointment waiting lists, doctors' recollection for patients' diagnosis and treatment and hospital medical notes. The recruitment of patients was randomly allocated according to outpatient attendance lists. Whilst this meant that those patients recruited were more likely to attend more frequently, this in fact was necessary in order to ensure as even a distribution of children in each treatment group as possible, as those

who attended most frequently made up the smallest treatment group - the dialysis patients.

The bias of gender, with more boys than girls in this study group simply reflects the bias in the renal population, with more boys than those girls having renal failure.

The low refusal rate, and narrow exclusion criteria resulted in a high proportion of available subjects participating and therefore it is likely to have resulted in a truly representative population of children with renal failure being seen, including a diversity of ethnic groups. However, one drawback in using very narrow exclusion criteria is the issue of missing data. In this study the largest section of missing data was within the parental questionnaires, thirteen of the parents did not complete any part of the parental questionnaires, and in the completion of the CHIP, 22 of the parents were unable to complete this questionnaire. Although it is not possible to conclusively say that the failure to complete the parental questionnaires was due to language problems or cultural issues in understanding some of the concepts, anecdotal information from the collection of data suggests that there may have been some loss of ethnic diversity in the parental questionnaires scores.

The developmental focus of this study was within the adolescent age range. This is a relatively narrow age band for paediatric renal psychological research; as most other studies cover a wider age range (e.g. Reynolds et al. 1991-age range from 2-17 years) in order to have higher numbers from which to analyse results of their study.

La Greca and Lemanek (1996), in a review concerning assessment in paediatric psychology, suggest that efforts should be made to study more cohesive developmental groupings. Developmental or chronological age is a global measure that represents a spectrum of processes that evolve throughout childhood. In the anxiety to include larger numbers for analysis issues around developmental process affecting the outcome variables may be set aside. In particular, with variables such as coping strategies that have been shown to be age sensitive, it was important in this study to have a narrow age band in

order to exclude possible confounding effects of developmental stage. In this study there were no age effects with coping strategies or in psychological outcome, even though the age range of 11 through 16 years could be considered broad. The lack of any difference in age range could be partly attributed to this population of children being less socially and physically mature in comparison with their peers, a common finding in children with chronic renal failure.

The constitution of the family in which the child was living showed that just 15% of children were living in single parent households. The information gained was current status of households and in those households with two adults it was not possible to discriminate between those children living with both natural parents and those living with step parents. Hence it is not possible to draw any conclusions about the effect of the child's illness on parental partnership status. This could only be achieved with a more detailed family history in future studies. In addition, there is no information regarding families socio-economic status, as it was felt that questions regarding this were not specifically related to the questions of the study and therefore would be intrusive. However, because the sample was representative of the population, it would have included families drawn from a wide breadth of socio-economic status.

In conclusion, the high numbers of patients agreeing to participate in this study in addition to the sampling procedure makes this a good representative group of adolescents with end-stage renal failure from which to draw generalised conclusions from the results.

#### Non-Respondents

There were no significant differences between those 17 families who declined and those who participated in age and treatment group. Exceptionally more girls than boys refused. There is no good reason to account for this gender difference; although it is possible to speculate anecdotally that one reason might have been more teenage girls than boys felt anxious about participating in an interview such as this and therefore refused. However, there are no



particularly strong gender effects in the data, suggesting that this difference between non-respondents and participants should not have had a significant overall effect.

### **Illness Variables**

The children's diagnoses were commensurate with renal paediatric population, with the most common conditions reflecting congenital or hereditary conditions. The small numbers of children in some diagnoses categories reflected the rarity of some underlying illnesses causing renal failure. The rarer the underlying diagnosis, the more likely they would be referred to this specialist tertiary hospital, which may explain why nearly half of the children had diagnoses spread over 12 categories. However, by the time the children were recruited to the study, underlying diagnosis was less important at this stage, explaining only the underlying cause of their chronic renal failure. The important medical variable at this stage was that these children shared the secondary diagnosis of severe chronic renal failure.

There was a high incidence of additional illness, with 38% of children having this. Whilst this is high, it is not abnormally so in a population of children with renal failure. Multiple disorders in children with chronic renal failure have been reported in other studies at approximately one-third of patients (Rosenkranz et al., 1992; Rizzoni, Ehrich, & Broyer, 1992).

### **Treatment Group**

The lower number of children in the dialysed group reflected the existing patient population within the renal unit, and is representative of the treatment phases of end-stage renal failure. Besides being life dominating for both the child and family, dialysis is expensive to the health service, hence there are dual pressures to have this carried out for the minimum time possible.

Dialysis is seen as a transitory phase prior to transplantation and the aim of treatment for end stage renal failure is to progress from dialysis to transplantation as soon as medically feasible. Hence there will be many fewer children on dialysis compared to transplantation and chronic renal failure.

## Coping

### The Distribution of Worries Generated by the Kidcope

The most frequent answer to the type of problem generated by children associated with their illness was concerning coping with their medical regimen. 39% of children reported this was the biggest problem associated with their illness. Other studies of children with paediatric disorders have similarly found that children frequently have problems associated with the administration of treatment of their illness. Spirito et al. (1995) reported that pain associated with disease was the most frequently reported problem in children with a variety of diagnoses (although the majority had sickle cell disease) and Pretzlick (1997) found medically related issues reported by 83% of younger children with leukaemia using the Kidcope.

What is unusual in this study is the high incidence of problems reported by the children regarding school issues. 34% of children reported that issues associated with missing school and falling behind in school work worried them most. The reasons for this response may be twofold. Firstly with this population of older children missing out school can occur during the crucial time prior to GCSEs meaning they are more likely to have worries associated with their schoolwork.. Additionally because these are older children, if they are not receiving additional input in school they maybe expected to seek out help and catch up with their missing work themselves.

Secondly, the issue of missing school sessions may be somewhat more of a problem with the cumulative nature of school absences that long-term chronic disease may bring. If the child is absent for a substantial period, the school is obliged to check upon and rectify if possible the gaps in their school work. The motivation of the child, family and schoolteachers is likely to be higher in the novel situation of missing school. Long-term sporadic absences may make the sustained motivation needed for catching up more

difficult for teachers, parents and pupils alike. With school skills building on previously learnt skills that have been missed out on earlier in their illness career, whole areas of achievement may be neglected for a child.

The weight put on the importance of the child in gaining academic qualifications may vary from parent and teacher to child. The importance of keeping up with schoolwork may be important from the child's point of view because of their desire not to appear different to their peers. In contrast, the parent or teacher may feel that focusing on the child's academic gaps may put further stress on a child who already has enough to contend with a life threatening illness.

The finding that problems associated with body image were reported as being the most important for only 6% of group is unexpected. This was surmised to be much more of a problem based on the clinical input to these children who frequently have very short stature, have multiple operation scars from dialysis sites and corrective surgery to their renal and urological systems. In addition, if they are on immuno-suppressive treatment following transplant they may have cushionoid appearance and unwanted additional facial or bodily hair. It is possible that body image may have been a problem but not a priority to this group, as only the most important worry was reported with the Kidcope. In their study on the effects of short stature of children with renal problems, Reynolds et al. (1995) also found that stature was not an overwhelming issue for this group of children compared to their parents. It is possible that this group of children had an ability to integrate the reasons for their difference in appearance into their own identity and thus did not perceive it is as much of a difficulty as their carers may do so.

### Coping Assesment

The criticisms of coping assessment fall into three broad areas. Firstly, the definition of the concept of coping; secondly, the definitions of dimensions of coping strategies; and thirdly, the debate regarding whether coping is a trait or state process concept continues. All these have implications for the measurement and interpretation of coping in this research study.

The lack of a tight definition of the concept of coping intrudes into major issues about coping measurement. Critics of Lazarus and Folkman's (1984) theory of transactional processes of coping is that the key concepts are not well-defined (Stone, Greenberg, Kennedy-Moore & Newman, 1991). One criticism is the omission of the impact of the determinants of coping such as the individual's goals, commitments, and other personal and social resources, which may shape the coping responses (Moos & Shaefer, 1993). This argument may help to explain some of the weakness of the current results. In the future coping itself may need to be examined using the type of model examined in this study so that for example, factors which moderate or mediate coping style could be evaluated. One factor that has already been associated with type and frequency of coping strategies is age. Thus one could formulate a model to be tested in which age is examined as a moderator between active problem coping strategies and psychological outcome.

The quandary of accurately assessing coping strategies, but not having too many variables to analyse, has led to factor analytic strategies being used with coping strategy questionnaires. However, the lack of stable factor structure in research has been criticised, with suggestions that the use of factor analytic techniques to identify relevant coping factors are inappropriate for something inheritantly variable (DeRidder, 1997, Stone et al., 1991). What appears to be needed are measures that move on to categorise coping strategies from more than two broad bands. Folkman (1992) argued that the critical number of coping dimensions should be between two and eight; as two dimensions may mask the variety of coping, where as more than eight poses of the problem of an overwhelming number of combinations for statistical analysis.

The difficulty in allocating specific coping strategies to particular factors remains a problem, with coping strategies fitting into either, neither, or all factors according to sample and study. Hence the definition of coping strategies themselves needs further consideration. Sandler et al. (1997) proposed re-categorising of coping variables into three broad groups which

will have a bearing on each other; firstly, *coping resources* refer to the relatively stable characteristics of the individual that influence how children cope in specific situations. They are, for example, children's temperament, personality, and beliefs about themselves in the world including their self-esteem. Secondly, *coping style* refers to generalised coping strategies such as typical preferences for ways of approaching problems. These coping styles may be the type of dimensions that have previously been described such as monitoring and blunting. Thirdly, *coping efforts or strategies*; these are the cognitive and behavioural actions that occur in specific stressful situations that are intended to manage or improve the problematic situation.

Rather than concentrating solely on the contribution of coping strategies, Sandler et al. (1997) suggest that studies should focus on the relationship between resources, style and efforts. They suggest that the coping resources may directly influence children's use of coping strategies or even make them more efficient in carrying out specific strategies (Lengua & Sandler, 1996). Initial research examining these types of relationships has found that adolescents with a more active temperament use more approach coping whilst those with the temperament of higher negative emotionality used more avoidance strategies (Ebata & Moos 1994). In this study it is possible that coping resources such as self-esteem may show more of an effect on coping strategies than it did as a measure of outcome. Future studies again should look at the more complex associations between coping that can incorporate at least two of the above points. For example, self-esteem could be explored as a moderator of the coping style or strategies.

The third factor that affects coping assessment is the stability of the strategy or style within situations. This issue has already been referred to in the Introduction and influenced the choice of coping measure used in the study. However it is important for research studies to define whether coping style or process is being measured. Lazarus (1993) defined coping as a dynamic situation specific reaction to stress, and therefore suggested it is an unstable situational process. The major strength of the Kidcope is its ability to

be specific about coping strategies used within a situation. However, there is some research now indicating that it is not strategies per se that are situation specific but that some strategies are influenced this way whilst others remain more stable. For example, social support appears to be a situation dependent response compared to positive reappraisal which appears to be a more a stable coping strategy (Folkman et al., 1986). Future research needs to focus on the development of questionnaires that would sample items across different populations and in different conditions to control for the influences of external factors and the internal individual differences on coping strategies.

Pertinent to collecting data regarding coping strategies, is the question: to what extent are the subjects able to reflect on their attempts to deal with the adverse conditions? They must also be able to re-construct these attempts to fit the desired responses on coping strategy questionnaires, and additionally, the influence of social desirability may also affect their responses. Thus observational data or parent report data may have added weight to this measure thus supporting the use of particular coping strategies.

Although the Kidcope has advantages over other measures in terms of its situation specificity, there are some drawbacks in using this questionnaire. The Kidcope has no norms for individual coping strategies or even for a coping total. There is also no suggested format for categorising coping strategies. Spirito (1996) argues that the reason for this is that the Kidcope is designed as a clinical and not a research tool, however, as he reports his own results of the Kidcope within a research context this argument is rather weak. In addition there is value in collecting and reporting normative scores and coping factors as this would be pertinent in clinical work in screening for potential vulnerable patients and designing treatment strategies.

The factor analysis of the Kidcope into the four coping factors described in this study appears to have face validity but there is a question of how this could be explored further given each different study results in different strategies being categorised into factors. The data using the Kidcope could be revalidated in a further study, and/or qualitative information could be

collected from a sample of the population, to check the validity of the coping factor being measured.

In this study it was the coping factors of Internalising and Emotional Externalising which moderated the effect of severity on outcome, so further research could focus on lowering the impact of these in this population. The coping factors of Active Coping and Acceptance did not appear to have an impact, probably due to the ceiling effect of use of these coping strategies. The construction of these factors should be re examined to see if it is possible to discriminate between different levels of strengths of these particular coping strategies, in order to see whether there are some other factors affecting the use of these in the study population.

#### **Statistical Issues in Using the Moderator and Mediator Models.**

The difficulty in detecting moderating effects in field research will continue to add to the challenge in this area of research. With the percentage of variance contributed to the interaction term continuing to be too low to be statistically significant according to traditional probability values, there may be a difficulty in disseminating these research findings in peer review journals. The methods for accepting findings of note described in this study will result in higher rates of type I errors. This type of strategy not usually acceptable to journal editors (McCelland & Judd, 1993). McCelland and Judd point out that factors contributing to the reduction in variance of an individual predictor in field studies include restrictions on its range, a clustering of observations in the centre rather than the extremes and multiple categories of measures between the extremes. The solutions to these problems are not simple within field studies, but they also suggest one strategy may be to over-sample extreme observations so that one sub-sample is close to an optimal design which will result in a higher percentage of variance. It is important that these statistical considerations are understood and discussed by journals publishing applied research in order to disseminate knowledge regarding the testing of moderating and mediating variables.

In terms of the overall variance explained, only small amounts are

being contributed by medical severity and coping strategies. There is the possibility that there are more significant factors (for example family functioning) contributing towards adjustment of children with chronic illness, or at least contributing towards the relationship between illness severity and psychological outcome. However, intervention packages specifically focusing on coping strategies may be more effective in showing change than intervention around general family traits, but expansion of these questions would be the topic of further research studies.

The other issue that needs to be acknowledged when testing for moderating and mediating variables, is the issue of multiple testing. The large number of regression analyses carried out increases the likelihood of type I errors, something which has to be taken into account when examining the results. The multiple testing needed in order to test mediating or moderating variables needs to be borne in mind when interpreting the results. One way of addressing this issue is to make more stringent criteria for the probability test value. This was not carried out in this study given the high possibility of type II errors in field studies detecting moderating variables (McCelland & Judd 1993). However, there does need to a consolidation of these initial and tentative results in further research studies in order to draw firm conclusions about the findings.

### **The Strengths and Difficulties Questionnaire**

One of the strengths of the study design was to use independent sources of data whenever possible. Data gathered solely from one source lacks independence of measurement, and same source reporting data is likely to result in inflated associations and bias to the scores. Therefore a combination of sources of data should result in more valid findings. As outcome results of the Parent Strengths and Difficulties Questionnaire support findings of the moderating effect of coping on severity of illness and outcome, this is reassuring especially as the coping strategy and health status are self-report measures.

However, findings of a concordance of results between parent report



and self-report SDQ are weak. There is a small but significant correlation between the child self-report and the parent self-report questionnaire, which is comparable to the community sample quoted in a study validating the self-report version of the SDQ (Goodman et al., 1998). However, there was a higher correlation between parent and child informant scores for those children attending a psychiatric clinic in the same study (Goodman et al., 1998). Despite the reported high correlation in that study however, 25% of clinic attending children rated by parents as being in the borderline or abnormal range had been rated by the children themselves as being in the normal range. Although this study discriminated between cases of children in the community and those attending a psychiatric clinic, the validation of the self-report version of the SDQ is still in its early stages. These results may indicate there are still some reliability and validity issues between the two versions of the questionnaires.

Whilst the threshold for cut-off with the parent report SDQ appears to be discriminating for this patient population (with the levels of distress supported by previous studies of this patient population), the self-report questionnaire appears to be not sensitive enough for detecting "caseness" in this current study. Given the significant positive correlation of the self-report SDQ with measures of health status, it appears to be sensitive as measure of distress in testing this relationship. Further validation of the self-report measure with other psychological children's self-report measures would clarify the accuracy of the threshold scores of this questionnaire.

### **Further Implications for Future Research**

There is a need to continue to carry out paediatric psychological research from a theory driven perspective that it is also sensitive to clinical needs. This will enable other research studies to build on earlier findings. This is particularly important because of the increasingly complex nature of models explaining adjustment to illness. Drotar, (1994) and Wallender and Varni (1992) suggest

that research questions based on a conceptual framework have the best chance of yielding information about psychological processes that affect children's health and well-being. The move away from examining main effects of predictor variables is likely to become increasingly common because of the significant number of research studies that have failed to find such effects, thus supporting the theoretical/research process of more complex frameworks.

One of the main aims of this study was to move on from earlier renal research, which focuses on descriptive work describing psychopathology to the exploration of interaction of factors that help these families in difficult circumstances to adjust to the demands required from them. The findings fit in more readily with the notion of risk and resilience. This concept allows for creative thinking around the process of adaptation of the child and family to stressors, in this case long term chronic illness. Garmezy (1991) emphasises the flexibility of resilience as a concept in that it does not reflect "an imperviousness" to stress rather it gives another strength that can enable the child and family to adapt to their circumstances over time.

Wallender et al.(1989b) have viewed the combined effects of risk and resilience resulting in the ability of the child and family to cope with illness more or less well. What is needed to enable this model to become more useful is an understanding of the mechanisms of the factors contributing to risk and resilience. At present the model (see figure 1; in the Introduction) suggests that coping strategies are factors that contribute to the child's resilience. The findings of this study suggest that coping factors could be risk or resilience factors with the maladaptive coping strategies acting as risk factors. The implications for further research, based on this model (Wallender et al, 1989b), could re-examine whether the categorisation of variables into either risk or resilience is useful. Each factor could be examined for its risk or resilience potential and then the mechanism behind the actions explored. This could be done from the mediator/moderator framework, with research focusing on the contribution of the variables that make up risk and resilience factors in moderating the effects of chronic illness.

The testing of potential moderating effects could lead to the identification of subgroups of subjects that are more resilient or more vulnerable under certain conditions. The identification of the circumstances under which children in this group are more vulnerable to psychological distress could inform future research focusing on these groups exploring how or why these links are conditional. In this study, both self-report measures of illness severity (functional health status and social functioning) acted as a predictor with maladaptive coping strategies moderating the relationship between this and psychological outcome. Future research from these findings could focus on the subgroup of subjects who appeared to be at risk because of the presence of maladaptive coping strategies. In particular, a pertinent question might be why the presence of adaptive coping strategies in this group of children does not come into play in these circumstances. One option may be to design an intervention study that manipulates a coping strategy in order to more clearly understand the direction of the mechanism. The pre and post measures taken in association with an intervention programme may clarify the direction of the relationship between the coping strategy and severity of illness.

The increasing complexity of theoretical models explaining adjustment to illness means that there needs to be greater precision in asking the research question so that it reflects the main construct of interest. Research questions which in themselves seek to clarify constructs that are ambiguous in their meaning in the field of paediatric psychology would help re-formulate a tighter next question. For example, rather than referring to global coping strategies, future research questions may specify the associations that arise with specific coping styles or strategies. La Greca and Lemanek (1996) and Lemanek, (1994) emphasise the need to base studies from a conceptual rationale, with clear research questions and implementing focused assessments to answer these questions.

The need for further testing for validity and reliability of the self-report health status questionnaire would result in a standardised measure that could

be used to allow comparison across studies. This research served to confirm that illness severity is not a unitary construct, as seen by the small relationship between the index of medical severity and the child perceived health status. The index of medical severity may show results as a predictor with other variables, so that the need for multi-dimensional multi-method instruments to measure this construct should continue in research projects. Validation of these instruments would assist in assessment of their usefulness in further research. In addition the use of previously standardised measures wherever they are available and are appropriate to research question should be encouraged, as this should facilitate further comparison across studies resulting in more meaningful meta-analytic reviews.

Future research in which research design is prospective and longitudinal collection of data, would address defined issues such as the stability of measures and their predictive value. Longitudinal data collection could also contribute to clarification regarding the direction of effects. Recruitment and retention of subjects for this sort of research is frequently more difficult than for subjects of cross-sectional studies, however, implications that can be drawn from this type of research design are likely to be stronger than those from correlational studies.

Finally, the questions asked regarding the relationship between coping strategies and severity of illness are pertinent across the paediatric psychology field. Hence, there is the need to ask these questions within a different population group. Besides testing the stability of the individual variables, by using different patient population we would contribute to questions about the influence of non-categorical variables in paediatric psychology.

### Clinical Implications of this Study

One of the implications for clinical practice arising from this study are those that result from the shift away from, and evaluation of child adjustment solely through the outcome measure of psychological distress. Instead, this study moves towards evaluating the mechanisms behind those variables that may offer protection or make the child more vulnerable in the face of adversity. Clinically this suggests input of a proactive and preventative nature instead of the reactively led input that is traditionally associated with clinical psychology. Most research in paediatric psychology has been seeking subgroups that are at greatest risk to maladjustment. Implicit in the research with risk factors is the notion that this will improve the ability to intervene effectively. As paediatric psychology is a relatively new field there is a place for exploring variables that may be related to maladjustment (in particular in new patient groups). However, the cumulative results of many studies, including meta-analysis which aims to provide an overview of research findings, there is a lack of clear consistent evidence pointing to overwhelming particular risk factors. Therefore, the notion of moderating variables provides the concept of risk and resilience. The exploration of how coping moderates what has been an intuitively important and thoroughly researched risk factor of severity of illness has been central to this study. Therefore it is important to use the concept of moderating or mediating variables to inform clinical work.

The implications from this study for clinical practice fall into two broad categories. Firstly there are implications in the assessment of children with chronic disease to screen for intervention and prevention programmes in helping them adjust to and to cope with their chronic illness. Secondly, there are implications for the intervention or prevention programmes themselves, so that the efficacy of such interventions can be augmented. Results from the study suggest that two of the measures may be particularly useful in assessing and applying interventions for children with chronic illness. These are the

coping questionnaire, the Kidcope, and the self-report health status questionnaire. Each questionnaire would have value in informing clinical work on their own, but also when used together have value in increasing specificity of assessment and intervention.

### **Implications for Assessment Procedures**

The use of the Kidcope for a patient population of this type can be of valuable clinical use on several levels. Firstly in generating the context in which their illness is the most difficult to cope with for the child is an important building block on which to construct further assessment and intervention strategies in the therapeutic situation. The type of intervention planned may well be biased according to the contextual situation that the child needs to cope with. For example, in this study, the majority of the children's problems arose from either their medical regimen or their schooling situation, and not from problems around family issues or body image.

The screening of coping strategies used by chronically ill children serves two purposes, prioritising and prevention. Thus, in children who are already experiencing distress associated with their chronic illness, screening for use of coping strategies addresses the question of whether the lack of or maladaptive coping strategies may be contributing towards their psychological distress. Besides coping strategies having a moderating effect on psychological distress, it is quite possible that the mechanism behind raised levels of psychological distress in children may be due to other influences due to contributing factors of the parent, child or external circumstances. The screening of the presence or not of maladaptive coping strategies will assist in the formulation of the problem.

The findings in this study regarding the moderating effects of coping strategies, suggest that it is the presence of maladaptive coping strategies that act as vulnerability risk factors making the difference to levels psychological distress even in the presence of adaptive coping strategies. The dual use of adaptive and maladaptive coping strategies need to be screened for in order to confirm the repertoire of coping strategies already available that could make

the difference in the current problem.

In addition, the information may be useful when screening in the future but within a different context. At this stage it would be possible to evaluate which specific coping strategies had been useful or not for that particular child. For example the finding on assessment that school problems was associated with anxiety for those children despite them using Active Coping. This group of children could be reassessed using a different context to see if Active Coping was more adaptive in different circumstances or whether their anxiety was due to their particular coping style in a particular context.

The issue of when to screen for coping strategies is an important one, given the specificity of the application of coping strategies.

Spirito et al. (1992b) suggests that initial screening may be useful shortly after the diagnosis of illness, as by that time the child is likely to have been exposed to a number of illness related stressors. He also recommends screening at milestones in the disease course and /or at particular developmental transitions stages. Another very useful element to the assessment of coping strategies is recommended by Spirito et al. (1992b) which would have pertinent clinical implications is to carry out an assessment of the child when the stressor is not anticipated to determine whether coping strategies are available in optimal circumstances. Then it is suggested that an assessment is made immediately prior to the child being exposed to the stressor, as this will help determine whether the coping strategies are available to the child under stressful conditions. Any mis-match between the two situations could be rectified therapeutically to provide an increased repertoire of appropriate coping strategies that are already available to the child.

The use of the health status questionnaire to determine the child's perception of functional impairment and the social functioning would also serve as a predictor to increase levels of psychological distress. The brevity of this questionnaire is its strength as it could be used within busy clinical settings, and unlike the Kidcope could be administered by staff who are untrained in psychological assessment. Besides the results being of interest to

those using psychological interventions, the information gained from this questionnaire may be clinically useful to the medical practitioner assessing the current status of the child. The findings from this questionnaire challenge the previously held belief by clinicians within the renal medicine field that the children most vulnerable to psychological distress are those who have intensive levels of treatment; in other words particularly those children who are on Dialysis. What is more probable is that those children who are on Dialysis and experiencing psychological distress are likely to be identified from the clinical situation, not least because they are seen very frequently. It is those children who are not seen as frequently that are not picked up from medical clinical contact that results in the assumption that it is those children with frequent clinical contact who have the greatest amount of psychological problems. Thus, screening the children with a rapid measure such as the health status questionnaire who have less frequent contact with the clinical services is likely to be more important for identifying those children who may need further psychological assessment.

For those children who have lower scores in social functioning, further assessment could be made to evaluate whether this result is making them vulnerable to psychological difficulties.

The ability to assess children using both the coping strategies and health status questionnaire would result in the increased likelihood of identification of sub groups of children with vulnerability to higher levels of psychological distress. As many children and their families spend lengthy times waiting to be seen in the clinic, this would not be impossible. And, because the psychological resources will always be limited it is important to avoid a high level of false positives detected in screening.

### **Implications for Intervention Packages**

The findings of this study has implications for different aspects of interventions. Pless and Stein (1994) describe interventions in the context of a three-dimensional matrix. These are described as the target of intervention, the type of modality of intervention and the timing of intervention. Pless and



Stein also emphasise the need to identify risk factors to assist in the planning of intervention packages.

The target of intervention is typically the child, and the emphasis of the findings of this study which are mostly around the child orientated measures suggest that stress reduction intervention could be targeted at the individual. However, interventions can also be targeted at the systems affecting the child. Although this study did not show an effect of parental distress or coping strategies affecting child coping strategies, recruiting the parents as co-therapists could support interventions aimed at changing the child's coping strategies. In addition knowledge gained from the Kidcope and the social functioning questionnaire can help provide intervention targeted at the wider system. Thus for example for those children whose concerns were oriented around school issues, intervention aimed at the child's school peers or teachers may make the difference to the child's ability to cope with the situation. Similarly, difficulties around the child's medical regimen may be partially resolved with discussions with the child's doctor exploring whether there is any flexibility in the treatment regimen for the child.

The modality of intervention involves the type of treatment provided for the child and family. In addition the type of treatment also relates to what target behaviour or aspect of the child's functioning is being sought for change. The more specific the behaviour being targeted for change, the more specifically designed the treatment or intervention package can be. This is a pertinent point for stress reduction intervention packages, as evaluation of intervention packages for the reduction of stress for children have not generally been successful in showing large desired changes in children or parental levels of distress (Nolan, Zvagulis & Pless, 1987).

The type of treatment package can be tailored according to the information gained in assessing the child's coping and social functioning. Education of the child, either individually or within a group situation, regarding the types of coping strategies that have been used by children in similar situations may provide the child with additional resources to cope with

the current difficulties. As many of the coping strategies are cognitive in nature, individual interventions addressing the child's belief system may enable a child to change the focus of their coping strategies. The value of understanding the coping mechanisms used in different contexts may also be useful, the child or family may need direction to apply previously functional coping strategies to a different context to see if they will be beneficial. The value of using previously used coping strategies is that there will be a reinforcing of self-efficacy for the child on his family for dealing with the current difficult situation.

The interpretation of the results of the health status questionnaire combined with an analysis of coping strategy could, for example result in a treatment strategy designed to generally increase a specific aspect of the child's psychological functioning. This could have a knock on effect by offering resilience in the face of stressors associated with their illness. For example, in this study, children with low levels of social functioning and who also used socially isolating coping strategies (Internalising) were more vulnerable to psychological distress. It is possible that their use of socially isolating coping strategies reinforced their low levels of social functioning. Thus a prosocial skills intervention programme may be more likely to show an effect for this specific group of children. Ladd (1985) designed an intervention package for a group of children who were rejected by their peers that was specifically aimed at a subgroup of children rather than a more broadly defined group. The content of the intervention programme was closely matched to the particular social difficulties of the children which resulted in a subsequent success rate exceeding those of more generic interventions. The information gained by assessment prior to an intervention package would ensure focused direction of limited resources to groups of children most likely to show most improvement by that particular intervention strategy.

The need to evaluate intervention programmes based on this and other study findings is important. This will provide further evidence of the impact of the moderating or mediating effect of coping strategies by the manipulation

of this variable through a treatment programme. Concurrently, these findings suggest that coping is likely to be just one moderating variable acting upon the child's psychological status hence the ease of intervening with this variable needs to be assessed in terms of cost benefits. Where an intervention programme competes with another moderating variable or intervention programme the value of this intervention needs to be known.

In addition to psychological intervention programmes, the knowledge gained by psychosocial variables affecting medical treatment can be used in decision-making regarding options available within medical care. Thus for example, knowledge of the child's ability to cope in the face of a very complex treatment regimen can influence how this regimen may be implemented. Hence for a child and family at the limit of their coping abilities the streamlining of the medical regimen, whilst not providing the absolute optimum of medical care, may enable the family to carry out enough of the required care to remain as healthy as possible.

### Conclusion

This study is exploratory in nature and hence the conclusions can only be seen as tentative. However, despite the need for caution in interpreting the significance of the study results it is useful to explore these variables in relation to the moderating and mediating frameworks because of the clinical implications. Identification of such variables as a potential explanation of why an independent variable has an effect on a dependent variable is important in the design and evaluation of future intervention programmes.

The possibility of screening children using the very brief self-report measure of health status and the Kidcope questionnaire is clinically very feasible. Understanding the direction of the effect of coping strategies would reduce the number of potentially vulnerable patients to a manageable number for further assessment and intervention.

These tentative conclusions need to be followed up in future research

studies.

**Appendix 1. Child Background Information Sheet****Child Information Sheet**

Child project number:.....

Age:.....

School year:.....

Family Structure: (who lives at home)

**Appendix 2. The Child Health Status Questionnaire.**

Child project number:.....

**The children's health Status Questionnaire****Tick one answer**

- |  |     |    |
|--|-----|----|
| 1. Do you often feel tired?            | Yes | No |
| 2. Do you often have aches and pains?  | Yes | No |
| 3. Do you often feel ill?              | Yes | No |
| 4. Do you often have trouble sleeping? | Yes | No |
| 5. Are you able to walk unaided?       | Yes | No |
| 6. Are you able to run?                | Yes | No |

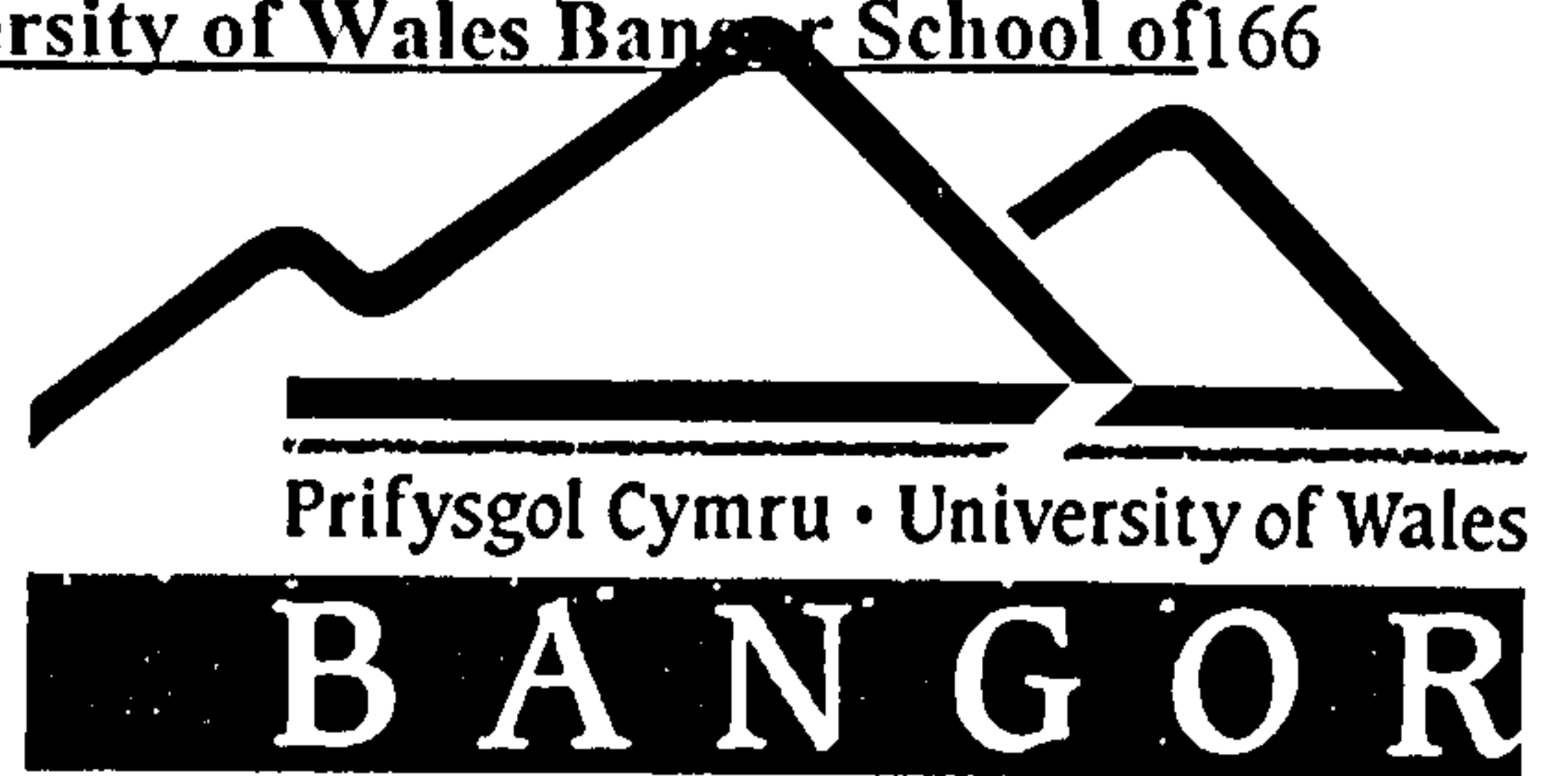
Does your state of health now affect your health in any of the following areas?  
(give examples where necessary)

**Tick one answer**

- |                                 |     |    |
|---------------------------------|-----|----|
| 1. Friends                      | Yes | No |
| 2. Hobbies or interests         | Yes | No |
| 3. Family                       | Yes | No |
| 4. School (or college, or work) | Yes | No |
| 5. Holidays                     | Yes | No |

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Appendix 12. Letter of Approval from University of Wales Bangor School of Psychology Ethics Committee.



c.c. Dr. Robert Jones

Ysgol Seicolog Prifysgol Cymru Bangor Bangor, Gwynedd LL57 2DG Ffôn: Bangor (01248) 382211 Ffôn Rhyngwladol: +44 1248 382211 Ffacs: (01248) 382599 Ffacs Rhyngwladol: +44 1248 382599	School of Psychology University of Wales Bangor Bangor, Gwynedd LL57 2DG Tel: Bangor (01248) 382211 International Tel: +44 1248 382211 Fax: (01248) 382599 International Fax: +44 1248 382599
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e-mail: [pss029@bangor.ac.uk](mailto:pss029@bangor.ac.uk)  
<http://www.psych.bangor.ac.uk/>

March 8, 1999

Ms. Shelagh Madden  
Principal Clinical Psychologist  
Department of Psychological Medicine  
Great Ormond Street Hospital for Children NHS Trust  
Great Ormond Street  
London WC1N 3JH

Dear Colleague

**Psychological adjustment in children with renal disease**

Your research proposal (referred to above and on the attached sheet) has been reviewed by the School of Psychology Research Ethics Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines. If you wish to make any substantial modifications to the research project please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if research participants experience any unanticipated harm as a result of participating in your research.

You should now forward the proposal to the GOS/ICH Research Ethics Committee. You may not proceed with the research project until you are notified of their approval.

Yours sincerely

Kath Chitty  
Coordinator - School of Psychology Research Ethics Committee

Athro a Phennaeth yr Ysgol  
Professor and Head of School  
C Fergus Lowe, PhD, FBPSS



Ext. 5561

Dear

We are carrying out a survey about how children with renal conditions cope with their illness in every day life.

Here at Great Ormond Street there is a large group of children whom we could gain information which would help inform us about what it is like living with renal illness.

We are seeking your permission for you and your child to participate in a study which will involve answering some questions. We will see you during one of your outpatient appointments. The enclosed information sheet explains in more detail what the project entails.

You need do nothing yet as one of our psychologists will contact you by telephone in a few days to clarify any details, and if you are in agreement to the proposal, arrange a time to meet you.

Yours sincerely

**Consultant Nephrologist**

**Principal Clinical  
Psychologist**

Shelagh Madden

## **Parent / Carer Information.**

### **A survey of how children cope with their illness in daily life.**

- **The Aim of this study.**

The aim of this project is to find out how children cope with the demands of living with chronic illness, how they see themselves in comparison with other children. We also wish to find out how their parent(s) cope with the demands of caring for a child with chronic illness, to see if there are similarities of coping styles between parents and children.

- **Why is this study being done?**

Whilst we are gaining more information about what contributes to child and family stress when they have a sick child, we have relatively little information about how families cope and manage the situation day by day.

- **Benefits of this study.**

More information would help us advise families like yourselves about living with the medical management and daily stresses of renal health problems within the family. We know that the best people to inform us about these issues are the parents and children themselves, that is why we would like to involve you in this study.

- **How is the study to be done?**

- a) A general description.

A psychologist will interview your child and assist them in filling out some questionnaires. These will ask your child about coping strategies used, and how they see themselves in relation to their behaviour, their school and social life. The child's parent/s will also be asked to

Appendix 14. Parent and Child Information Sheets.

complete some questionnaires about their child and their illness, and their own coping strategies and stress.

- b) Details of what the study will involve.

The study involves a single interview for the child whilst at the same time their parent will be able to complete their questionnaires. The time taken should be about 30 minutes.

We will arrange an interview time most convenient to you, for example on the same day that you are attending an outpatient appointment. We will give you at least a weeks notice prior to the interview, to help you decide whether you would like to participate.

- **Are there risks or discomforts?**

You can stop and withdraw from the study at any time, and your child will be told that they can stop the interview at any time. Refusal to participate will not in any way affect your child's treatment.

If there are any issues that arise for the children or their families as a result of the interviews which they wish to discuss further, the psychologist who interviewed them, or if they prefer, another psychologist will be available to talk to.

- **What other treatments are available?**  
This is not a treatment study, rather a research study to see whether we could improve our service.
- **Who will have access to the research records?**  
No-one with the direct medical care of your child will have access to the interview and questionnaire records. These will only be available to the two psychologists involved in the study. If there is any information that you would like to discuss further with any of the professionals involved with your child's care, the psychologist involved can assist you in this. An information sheet describing the overall results of the study will be available to you by contacting one of the researchers. The researchers hope the results will inform clinical practice both in this hospital and other hospitals.
- **Do I have to take part in the study?**  
If you decide, now, or at a later stage, that you do not wish to participate in the research project, that is entirely your right, and will not in any prejudice any present or future treatment.
- **Who do I speak to if problems arise?**  
If you have any complaints about the way in which this research project has been or is being conducted please in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the chairman of the Research Ethics Committee, by post via the Research and development Office, the Institute of Child Health, 30, Guildford Street, London WC1N 1EH, or if urgent, by telephone on 0171 242 9789 ex 2620 and the Committee administration will put you in contact with him.
- **How do I contact the Researcher?**  
Shelagh Madden and Jasmine Sekhon can be contacted via the Department of Psychological Medicine, at Great Ormond Street Hospital. Phone no 0171 829 8679.

## **Child and Teenager Information.**

### **A survey of how children cope with their illness in daily life.**

We are carrying out a survey to find out how children cope with their health condition in everyday life. We are asking all the older children and teenagers who have renal conditions about their illness, how they deal with it and how they see themselves in terms of their confidence, their school and their social life. We will also be asking one of your parents to fill in some questionnaires about their coping.

If you agree to help us we will ask you to complete some questions during one of your regular outpatient appointment visits to hospital. Anything you say will not be shared with your parents, doctors or nurses, unless there is something you wish us to tell them.

There are more details about this project on a separate enclosed sheet entitled "Parent/Carer Information."

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