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CHILDHOOD NEPHROTIC SYNDROME: CHILDREN'S AND PARENTS' ILLNESS PERCEPTIONS AND PSYCHOLOGICAL SEQUELAE

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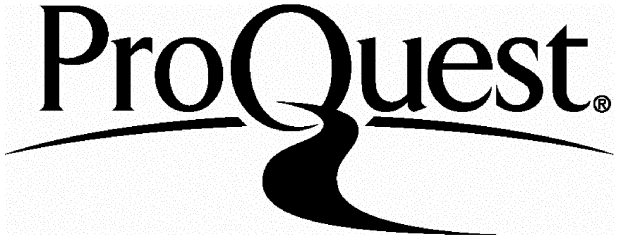

CONTENTS

Page

CHAPTER 1: INTRODUCTION

1.1 OUTLINE OF THE THESIS 1

1.2 CHRONIC ILLNESS IN CHILDHOOD 2

1.2.1 Effects on children 2

1.2.2 Factors affecting adjustment in children 5

1.2.3 Effects on Parents and the Family 8

1.2.4 Factors affecting Parental and Family Adjustment 9

1.3 ILLNESS PERCEPTIONS 11

1.3.1 Illness Representations - Self-regulatory model 11

1.3.2 Illness Representations and Adjustment 12

1.3.3 Carers' Illness Representations 13

1.3.4 Children's Illness Representations 14

1.4 CHILDHOOD NEPHROTIC SYNDROME 16

1.5 THE PSYCHOLOGICAL IMPACT OF CHILDHOOD NEPHROTIC SYNDROME 20

1.6 AIMS AND HYPOTHESES 25

1.6.1 Aims 25

1.6.2 Hypotheses 26

CHAPTER 2: METHOD

2.1 PILOT INTERVIEWS 27

2.2 DESIGN AND VARIABLES 28

2.3 RESEARCH SETTING 29

2.4 PARTICIPANTS 29

2.5 PROCEDURES 30

2.6 OPEN-ENDED QUESTIONS 31

2.7 STANDARDISED MEASURES 31

2.7.1 Parental Measures 31

Illness Perceptions Questionnaire – Carer's Version 31

Strengths and Difficulties Questionnaire 33

Hospital Anxiety and Depression Scale 34

Impact of Event Scale - Revised 35

2.7.2 Child Measures 37

Illness Perceptions Questionnaire – Children's Version 37

Spence Children' Anxiety Scale 38

Birleson Depression Scale 39

Children's Impact of Events Scale 39

2.8 ADDITIONAL INFORMATION COLLECTED 40

2.9 STATISTICAL ANALYSIS 41

CHAPTER 3: RESULTS

3.1 SAMPLE 42

3.2 OPEN-ENDED QUESTIONS 45

3.2.1 Parent Items 46

3.2.2 Child Items 56

3.3 PSYCHOLOGICAL MEASURES 60

3.3.1 Parent Measures 61

Strengths and Difficulties Questionnaire (SDQ) 61

Hospital Anxiety and Depression Scale 63

Impact of Event Scale - Revised 65

3.3.2 Child Measures 66

Spence Children's Anxiety Scale 66

Birleson Depression Scale 66

Children's Impact of Events Scale 66

3.4 ILLNESS PERCEPTIONS 67

3.4.1 Parents 67

Identity Sub-scale 67

Time-line Sub-scale 68

Consequences Sub-scale 69

Control/cure Sub-scale 70

Cause Sub-scale 71

3.4.2 Children 71

Identity Sub-Scale 71

Time-line Sub-scale 72

Consequences Sub-Scale 73

Control/cure Sub-scale 73

Cause Sub-scale 74

3.5 DEMOGRAPHIC AND ILLNESS-RELATED VARIABLES: DIFFERENCES ON PSYCHOLOGICAL MEASURES AND ILLNESS PERCEPTIONS 75

3.6 RELATIONSHIPS BETWEEN PSYCHOLOGICAL MEASURES AND ILLNESS PERCEPTIONS WITHIN PARENT AND CHILD DYADS 77

3.7 ILLNESS PERCEPTIONS AND PSYCHOLOGICAL MEASURES 78

3.7.1 Parent Illness Perceptions and Psychological Measures 79

Parent Illness Perceptions and Anxiety Scores 79

Parent Illness Perceptions and Depression Scores 80

Parent Illness Perceptions and Trauma Symptomatology Scores 81

Parent Illness Perceptions and Reports of Child Behaviour 81

3.7.2 Child Illness Perceptions and Psychological Measures 82

Child Illness Perceptions and Anxiety Scores 82

Child Illness Perceptions and Depression Scores 83

Child Illness Perceptions and Trauma Symptomatology Scores 83

Child Illness Perceptions and Parental Reports of Child Behaviour 84

3.8 DIFFERENCES BETWEEN PARENT AND CHILD IPQ SCORES 85

CHAPTER 4: DISCUSSION

4.1 SUMMARY OF THE FINDINGS 86

4.1.1 Demographic and Illness-related Factors: Relationships with Psychological Symptomatology and Illness Perceptions 86

4.1.2 Open-ended Questions 87

4.1.3 Psychological Outcome 89

4.1.4 Illness Perceptions 91

4.1.5 Illness Perceptions and Psychological Outcome 93

4.2 FINDINGS IN RELATION TO THE LITERATURE 96

4.2.1 Children 96

4.2.2 Parents 98

4.2.3 The Illness Perceptions Model 100

4.2.4 Comparison with Previous Research on Childhood Nephrotic Syndrome 101

4.3 ADVANTAGES AND DISADVANTAGES OF THE CURRENT STUDY 102

4.4 RESEARCH AND CLINICAL IMPLICATIONS OF THE CURRENT STUDY 106

4.5 FURTHER RESEARCH 107

4.6 CONCLUSIONS 108

LIST OF TABLES

Table 1: Provisional Banding of SDQ Scores 34

Table 2: Parent Respondent Demographics 43

Table 3: Child Respondent Demographics and Illness Variables 44

Table 4: Parents' Open-ended Question 1a 46

Table 5: Parents' Open-ended Question 1b 47

Table 6: Parents' Open-ended Question 2 48

Table 7: Parents' Open-ended Question 3 49

Table 8: Parents' Open-ended Question 4 50

Table 9: Parents' Open-ended Question 5 51

Table 10: Parents' Open-ended Question 6 52

Table 11: Parents' Open-ended Question 7 53

Table 12: Parents= Open-ended Question 8 54

Table 13: Parents' Open-ended Question 9 55

Table 14: Children's Open-ended Question 1 56

Table 15: Children's Open-ended Question 2 58

Table 16: Children's Open-ended Question 3 59

Table 17: Distribution of Scores on the Strengths and Difficulties Questionnaire 62

Table 18: Distribution of Parental Scores on the HADS 64

Table 19: Number of Children Identifying Different Causes of their Illness 75

Table 20: Correlations between Parent and Child Scores on Psychological Measures and Illness Perceptions 77

Table 21: Parent IPQ and HADS Anxiety Scores 80

Table 22: Parent IPQ and HADS Depression Scores 80

Table 23: Parent IPQ and IES-R Trauma Symptomatology Scores 81

Table 24: Parent IPQ with Child Gender and SDQ Total Difficulties Scores 82

Table 25: Child IPQ and SCAS Scores 82

Table 26: Child IPQ and BDS Scores 83

Table 27: Child IPQ and IES-8 Scores 84

Table 28: Child IPQ and SDQ Total Difficulties Scores 84

LIST OF FIGURES

Figure 1: Parent Levels of Anxiety and Depression 64

Figure 2: Parent Scores on the IPQ Identity Sub-scale 68

Figure 3: Parent Scores on the IPQ Time-line Sub-scale 69

Figure 4: Parent Scores on the IPQ Consequences Sub-scale 69

Figure 5: Parent Scores on the IPQ Control/Cure Sub-scale 70

Figure 6: Child Scores on the IPQ Identity Sub-scale 72

Figure 7: Child Scores on the IPQ Time-line Sub-scale 72

Figure 8: Child Scores on the IPQ Consequences Sub-scale 73

Figure 9: Child Scores on the IPQ Control/cure sub-scale 74

ABSTRACT

CHILDHOOD NEPHROTIC SYNDROME: CHILDREN'S AND PARENTS' ILLNESS PERCEPTIONS AND PSYCHOLOGICAL SEQUELAE

Childhood nephrotic syndrome is a chronic illness with an unpredictable course requiring long-term medication and treatments. In its mildest form children require steroids over long periods and regular hospital check-ups. In some cases children will experience relapses which require hospitalisation, while others will be unresponsive to steroids and will undergo aggressive chemotherapy treatments. In its most severe form children will have their kidneys removed and will receive dialysis. In the majority of cases children will experience obvious physical changes, such as swelling of the body and may be restricted in their activities. Investigations into the psychological impact of this illness for children and their families are not reported in the literature, although hospital staff working with these children have described anxiety and depression amongst children and their families. The aim of the current study was to explore the psychological sequelae of this disorder in both affected children and their parents. In addition, the potential explanatory value of identifying illness perceptions [Weinman, 1997 #464] as predictors of psychological outcome was examined.

Fifty-seven families with children between the ages of 7 and 18 years, from a total population of one hundred and twenty-one attending a national centre for nephrotic syndrome, participated in the study. One parent and the affected child from each family completed the questionnaires. Open-ended questions derived from pilot interviews were included to obtain information about families' experiences of nephrotic syndrome. Standardised parent measures included the Illness Perceptions Questionnaire - carer's version, the Strengths and Difficulties Questionnaire, the Hospital Anxiety and Depression Scale and the Impact of Events Scale - Revised. Standardised child measures included the Illness Perceptions Questionnaire (adapted

for children), the Spence Children's Anxiety Scale, the Birleson Depression Scale and the Children's Impact of Events Scale.

Open-ended questions revealed a number of factors that appear to affect most of this population, with changes in the child's physical appearance, missing school and being unable to participate fully in activities being reported frequently. Subsequent difficulties such as the affected child being teased, bullied and excluded from social groups were also described by a substantial number of parents. Descriptive and statistical analyses identified elevated levels of anxiety and trauma symptomatology amongst parents, and increased levels of anxiety, depression and trauma symptoms amongst children. Parent and child ratings of psychological symptoms were moderately correlated. In addition, significant numbers of parents reported difficulties with their child's behaviour and these reports were significantly correlated with children's reports of psychological symptoms and parental levels of psychological symptoms. Parent and child ratings of perceived illness identity and consequences were highly correlated, while parents and children showed low levels of agreement as to the duration of the illness and controllability or likely cure of the illness. Multiple regression analyses indicated that children's illness perceptions were predictive of child psychological outcome and similarly, parents' illness perceptions were predictive of parent psychological outcome.

This study indicates that children suffering from nephrotic syndrome and their parents are at increased risk of developing psychological difficulties. The Illness Perceptions model was found to be a useful construct with good explanatory power.

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CHAPTER 1: INTRODUCTION

1.1 OUTLINE OF THE THESIS

The research study described in this thesis aims to investigate the potential psychological impact of a chronic childhood illness, nephrotic syndrome, on the affected children and their parents. This first chapter introduces the broad area of childhood chronic illness and psychological sequelae amongst ill children and their parents. Factors affecting adjustment and adaptation of parents and children are also presented within this context. A cognitive model of illness representations is presented as a potentially valuable approach in understanding the experience and psychological effects of chronic illness. Much of the literature relating to this model focuses on adults with enduring health problems and this literature is used to describe the model and its application. Children's illness perceptions are much less widely investigated at this stage, and the implications for the application of this model with children are discussed. The nature of childhood nephrotic syndrome and its treatment is then presented, from a medical point of view, highlighting the practical difficulties associated with the illness. Literature relating to children's and parents' experiences of nephrotic syndrome and psychological sequelae are then discussed in detail, and considered in relation to the general literature relating to childhood chronic illness.

The second chapter describes the participants involved in the current study, the design used and procedures followed, and provides detailed descriptions of all measures used. The third chapter presents the statistical analysis of the data and findings of the study. The fourth chapter discusses the findings of the study in relation to the stated aims and hypotheses, and the literature presented in chapter one. Advantages and limitations of the current study and implications of this work for future research are also discussed.

1.2 CHRONIC ILLNESS IN CHILDHOOD

1.2.1 Effects on children

"A chronic physical disorder is one that (1) interferes with daily functioning for more than 3 months in a year; or (2) causes hospitalization lasting more than 1 month in a year; or (3) is thought at time of diagnosis to do either" (Wallander and Varni, 1998). Approximately 10-15% of children below the age of 16 years are affected by chronic, long-term physical problems (Weiland *et al.*, 1992). Eczema is the most prevalent chronic illness in childhood, affecting 8-10% of children, with asthma affecting 2-5%, diabetes 1.8%, congenital heart disease 0.2-0.7% and epilepsy 0.26-0.46%. There are also much rarer conditions such as sickle cell anaemia, cystic fibrosis and rheumatoid arthritis. "Other life-threatening conditions such as kidney disease, metabolic disorders, and neuromuscular conditions are also very rare, which in itself poses an added source of stress to the already serious nature of the condition" (p3; Edwards and Davis, 1997).

The psychological impact of chronic illness in childhood is a field of enquiry that generates a complex picture. Some research studies indicate increased levels of emotional and behavioural problems, while others do not (Bennett, 1994). However, there are numerous reports in the literature of chronic illness being associated with increased levels of psychological symptomatology. Eiser's (1990) review of research investigating the psychological effects of chronic disease leads her to suggest that children with chronic illness are more likely than healthy children to show maladjustment.

Bennett's (1994) meta-analysis of depression among children with chronic illness indicated slightly elevated rates of depression (median prevalence of 9%) compared to 1-5% typically reported for community samples of children (Fleming and Offord, 1990). Bennett (1994)

also suggests (cautiously) that children with illnesses that involve high levels of pain and unpredictability, such as asthma, recurrent abdominal pain and sickle cell disease are likely to show high levels of depressive symptoms. Children with diabetes are also thought to show increased levels of depressive symptomatology over time, but not at a clinical level (Kovacs *et al.*, 1990).

An illness that has received a disproportionate amount of attention in the literature is that of childhood cancer (Eiser, 1990). A relatively early research study (Koocher *et al.*, 1980) identified significant numbers of paediatric cancer survivors with psychosocial difficulties following survival of cancer. A population of one hundred and fifteen children and adults who had been diagnosed with cancer between birth and 18 years and were at least one year post-treatment were interviewed about their hospital and illness experiences and completed self-report depression and anxiety ratings. Ratings of adjustment completed after interview indicated that more than half of the population were considered to have "adjustment problems", with additional self-report evidence of residual depression, anxiety and poor self-esteem. During the interviews "those patients who were able to articulate reasons for their malaise often related it to uncertainties about the future, fear of possible disease recurrence, and inability to "forget" some stressful aspects of their treatment experiences" (p170; Koocher *et al.*, 1980). In contrast to this, Fritz and Williams (1988) completed interviews and self-report depression ratings and found good adjustment and normal levels of depression in their population (8%) of adolescent cancer survivors at least two years post-treatment . However, a strong association was found between relapse and serious adjustment problems. Greenberg *et al.* (1989) also found that overall, their group of one hundred and thirty-eight children between the ages of 8 and 16 years, at least two years post cancer treatment, had adapted well and scored within normal limits on self-report measures of depression. However they were less confident and felt less in control of their lives. Of particular interest was the finding that children with the most visible and serious effects of

treatment were significantly more vulnerable to suffer from depressive symptoms, lower self-concept and more external locus of control. Eiser *et al.* (1995) reviewed the literature relating to factors that contribute to the experience of cancer in children. They identified the following areas as being of importance: physical appearance, interference with activity, peer rejection, integration in school, manipulation or use of the illness to avoid obligations, family support and relationships, preoccupation with illness, anxiety about symptoms, recurrence of disease and impact of treatment.

In recent years, the occurrence of post-traumatic stress disorder in children has been identified following road traffic accidents (Di Gallo *et al.*, 1997; Mirza *et al.*, 1998), earthquakes (Pynoos *et al.*, 1993) and transport disasters (Yule, 1992). It has also become increasingly recognised that physical illness and "medical interventions may occur with sudden onset contributing to a sense of lack of control by the patient and a perceived or actual threat to life" (Jones, 1998) and can therefore be considered to be a traumatic experience. Stuber and colleagues (e.g. Stuber *et al.*, 1994b; Stuber *et al.*, 1994a) suggest survivors of childhood cancer show significant rates of post-traumatic stress. Stuber's (1994a) study involved a group of thirty children between the ages of 8 and 19 years, who were at least twenty-two months post-treatment. Children completed a self-report version of the Post-Traumatic Stress Reaction Index and found that 17% of children reported levels of trauma symptoms in the moderate range, while 30% reported mild levels of trauma symptoms. Additionally, children's appraisal of intensity of their treatment for cancer was significantly positively correlated with reports of post-traumatic stress symptoms.

The evidence described above suggests that children suffering from chronic illness are at increased risk of developing psychological and adjustment problems, including depression, anxiety and post-traumatic stress symptoms. However, it should be noted that although children with chronic illness may be significantly more vulnerable compared to healthy

controls and norms, the majority of chronically ill children do not suffer from psychological and adjustment problems (Wallander and Varni, 1998).

1.2.2 Factors affecting adjustment in children

Stein and Jessop (1982) suggest that the impact of chronic illness in children may not be specific to the medical diagnosis, with the processes involved being common to all chronic illnesses, for example, the burden of health care. In contrast Howe *et al.* (1993) studied one hundred and sixty five families with a chronically ill or disabled adolescent and grouped these individuals according to whether they had a neurological (eighty children) or non-neurological condition (eighty-five children). These two groups were then compared with a group of forty-nine healthy children. Howe *et al.* (1993) completed interviews with adolescents and their mothers and found a distinction between neurological and non-neurological conditions, suggesting that adolescents with chronic illnesses that were not 'brain-based' were comparable with controls in terms of psychological symptoms, while neurologically impaired children had significantly higher levels of symptoms. However, children in both illness groups were compromised in the area of work experience and had lower school achievement scores. It was noted by the authors that the children in their study had 'mild to moderate' levels of disability and were therefore not at a high risk of developing problems. Cadman *et al.* (1991) completed an epidemiological study in Canada, involving more than three thousand children from the general population. They report that children with chronic disease and physical disability were greater than three times more likely to develop psychiatric disorders and were at 'considerable' risk for social maladjustment, compared to healthy children. While those with chronic disease but no physical disability were twice as likely to develop psychiatric disorders but were not more likely to become socially maladjusted.

Severity of illness and adjustment appear to share a complex relationship, although there is some indication that severity plays a role. Parental ratings of moderately severe asthma have been associated with lower levels of adjustment (Perrin *et al.*, 1989), in diabetes poorer health and being within a dysfunctional family has been shown to result in lower levels of adjustment (Johnson, 1988). Children with severe rheumatoid arthritis are reported to suffer from more psychological and physical problems than those with mild forms of the illness (Billings *et al.*, 1987). Chronic renal failure in children is also reported to increase psychiatric maladjustment compared to controls, particularly if the illness was 'severe' (Garralda *et al.*, 1988), while those less severely ill were found to have particular difficulties with school adjustment and loneliness. In addition, children with severe effects following cancer treatment i.e. 'significant restriction on daily activity or severe cosmetic changes', showed significantly greater levels of psychological difficulty (Greenberg *et al.*, 1989).

Factors associated with increased risk of maladjustment in childhood chronic illness include: disorders involving the central nervous system or physical disability; severity of illness (as perceived by parents); age – younger children appear to be more at risk in terms of school achievements, older children in terms of social adjustment (Eiser, 1990). However, Wallander and Varni (1998) suggest that aspects of disease or disability are not the most important influences. Functional independence is thought to be an important factor in adjustment, with poorer overall adjustment (Mulhern *et al.*, 1989) and higher levels of emotional distress and somatic symptoms (Varni *et al.*, 1998) reported for children with cancer. Wallander and Varni (1998) report some of their and colleagues' work including an extensive study involving two hundred and ninety-one children with cancer. This study investigated disease-specific perceived stress in these children, focusing on problems or symptoms associated with the illness and its treatment. These authors report an association between high levels of disease-specific perceived stress and increased rates of behaviour problems (accounting for more than 25% of the variance). Higher levels of general stress

have also been reported as increasing depressive symptoms and lower levels of self-esteem in children with limb deficiencies (Varni *et al.*, 1991).

There are other psychosocial factors that are also associated with adjustment to chronic illness in childhood. Personal characteristics such as locus of control, premorbid psychiatric functioning, psychosocial developmental status, temperament and coping style are intrapersonal factors that may affect adjustment. However, there is little empirical data to clarify their potential influence (Wallander and Varni, 1998). Aspects of family functioning are thought to affect adjustment in children with cancer, with high levels of cohesion and expressiveness predicting better adjustment (Varni *et al.*, 1996). Levels of perceived social support are also considered influential, with low levels of support from school classmates leading to adjustment difficulties in children with cancer (Wallander and Varni, 1998) and limb deficiencies (Varni *et al.*, 1992). Varni *et al.* (1991) also found a strong negative association between social support from classmates and depressive symptoms and suggest that this "may reflect the negative values physically healthy children hold about physical handicaps, which may influence their behavior and projected attitude toward children with limb deficiencies" (p36).

In a group of children with newly diagnosed cancer, their perceptions of their physical appearance have been identified as having direct impact on affective symptomatology, with more positive perceived physical appearance being associated with lower depressive and social anxiety symptoms and higher self-esteem (e.g. Varni *et al.*, 1995b). In contrast to this O'Malley *et al.* (1980) report their findings with childhood cancer survivors, indicating that visible physical impairment did not predict psychosocial adjustment. This finding may have been related to the objective measures of physical impairment used in the latter, as opposed to children's subjective perceptions used in the former. Within the community it has been reported that children's negative perceptions of their attractiveness are significantly

correlated with depressive symptoms (McCabe and Marwit, 1993). In addition, it is has also been reported that a non-clinical group of school children were able to accurately evaluate whether their parents thought they (the children) were too fat, too thin or just right and that this was associated with self-esteem in pre-adolescent children (Pierce and Wardle, 1993). Poor self-image has also been reported as a significant predictor of adolescent depression (Fine *et al.*, 1993).

Overall, it appears that there are many potential factors that might affect a child's adjustment to chronic illness. Issues such as severity of the illness are very complex and not well understood, although there are some indicators that treatment may be a factor within this concept. However, the impact of illnesses that affect appearance, physical integrity and functional independence appear to be most important.

1.2.3 Effects on Parents and the Family

Evidence examining parental adjustment to having a child with a chronic illness is relatively sparse in the literature. Reports of children suffering from anxiety, depression and trauma symptoms have been described above. However Stuber (1996a) reports that parents may be "even more severely affected, possibly because they had a better appreciation at the time of the true dangers posed by the illness and the treatment" (p490). Cadman *et al.*'s (1991) Canadian epidemiological study, involving more than three thousand families in the general pouplation, indicated that parents of chronically ill children were two to three times more likely to receive mental health treatment than parents of healthy children. Mothers of children with sickle cell disease have been found to have high levels of affective symptomatology (Brown *et al.*, 1993) and those of children with sickle cell disease or cystic fibrosis have been found to have poor adjustment over a period of time (Thompson *et al.*, 1994). Stuber and colleagues' (Stuber *et al.*, 1994b) work investigating post-traumatic stress

in thirty families of survivors of childhood cancer, indicate that on self-report measures both mothers and fathers are vulnerable to clinical levels of post-traumatic stress. Interestingly parental levels of post-traumatic stress are not directly correlated with children's levels of post-traumatic stress symptoms. However, children's appraisal of the intensity of their cancer treatment was found to mediate parental levels of post-traumatic stress. Further work by Kazak *et al.* (1997) suggests that parents may be more vulnerable to long-term post-traumatic stress than their child who suffered from cancer. The relationship between parent and child responses to chronic childhood illness are not well documented and clearly require further investigation to clarify these possible interactions.

1.2.4 Factors affecting Parental and Family Adjustment

Wallander and Varni (Wallander and Varni, 1998) review the work they have done with their colleagues to investigate risk factors for parental adjustment but report that relationships with adjustment were not found for severity or type of disability, child's cognitive ability, or dimensions of care strain. However, these authors report disability-related stress and general (major and daily) life events stress as having a strong association with mothers' reports of adjustment problems. Wallander and Noojin (1995) completed a qualitative study investigating what mothers found stressful. They identified disability-related concerns as important (medical and legal issues, child's situation, family functioning and mother's experience), although approximately half of the 'stresses' related to the child's situation, particularly in relation to school.

Research investigating the impact of chronic illnesses on families indicates that there are different effects dependent on the illness studied and the amount of care the child requires. Holroyd and Guthrie (1986) examined levels of stress in parents of children with cystic fibrosis, neuromuscular disease or renal disease. They investigated factors such as parental

health and mood, demands on parents' time, financial implications, activities and family integration, as well as perceptions of the impact of the illness on their child (physical, emotional, occupation and educational 'handicaps'). They found the highest levels of 'stress' for parents with a child that has neuromuscular disease, an illness that places a large burden of care on the family. These parents were reported as being in poor physical and emotional health, financially pressured, felt that they received insufficient support from others and expressed negative feelings about their ill child. Parents of children with neuromuscular disease were also pessimistic about their child's long-term health and viewed their child as multiply handicapped. Cystic fibrosis was associated with 'extensive stress' compared to controls with parental reports of financial stress, insufficient social support, being burdened by their child's physical incapacitation, sensitive about what others think of their child's physical appearance and being concerned about the long-term outcome for their child. Parents of children with renal disease were much closer to matched controls in terms of the stresses they reported, although they did describe financial difficulties, problems with their child's physical incapacities and restrictions on family activities and opportunities. These findings appear to fit with the evidence discussed above that disability-related factors play a role in parental adjustment to their child's chronic illness.

Factors such as family support (Kronenberger and Thompson, 1992) and perceived problem-solving competence (Noojin, 1998) are thought to influence parental adjustment to their child's chronic illness. In addition, the impact of a child's chronic illness on the whole family, and the effects of family functioning are also discussed in the literature, but there is very little research to investigate these systemic effects (Wertlieb, 1993). Clearly, chronic childhood illness will have an impact on the whole family, but the effects and factors that may influence adjustment are not, as yet, well understood.

1.3 ILLNESS PERCEPTIONS

1.3.1 Illness Representations – Self-regulatory model

Responses to illness vary widely from person to person, and these responses are thought to be largely influenced by people's beliefs and attitudes (Sensky, 1997). Weinman and Petrie (1997) discuss the use of an illness perceptions approach as a theoretical, cognitive framework for considering patients' experiences of their illness and describing their own model of their condition. The illness perceptions approach is based upon the work of Leventhal and colleagues (1984) who proposed a self-regulation model that identified patients' illness representations as beliefs about their experiences and their illness. This model incorporates the following illness representation factors: the nature of the condition (symptoms and the actual label of having that illness), the causes of the illness, likely duration, consequences (such as impact on physical, social and psychological functioning) and controllability of their illness. Leventhal *et al.* (1984) suggest that these illness representations are a patient's cognitive response to their illness. They go on to suggest that emotional responses and coping are then determined by these cognitions, with coping acting as a mediating factor between illness representations and outcome (Scharloo *et al.*, 1998).

Weinman and Petrie (1997) describe their illness perceptions model as beginning with a patient's experience of their illness and emphasising the patient's own cognitive model of their condition. "Just as people construct representations of the external world to explain and predict events, patients develop similar cognitive models of the bodily changes that reflect either transient symptoms or more long-term illness. We believe that this approach has a widespread application in psychosomatic medicine, because all patients will construct working representations of their illness" (p113). Ultimately, these illness perceptions will affect patients' coping responses, adaptation and adjustment to their illness (Weinman and

Petrie, 1997). In support of this hypothesis, Weinman and Petrie (1997) describe how different perceptions of an illness of the same objective severity can lead to very different patient responses. Weinman *et al.* (1996) also identified differences in illness perceptions between patients with rheumatoid arthritis and chronic pain, even though the main symptoms (i.e. pain) for these two conditions are very similar.

1.3.2 Illness Representations and Adjustment

Sensky (1997) suggests that "adjustment to illness or symptoms is more accurately predicted by cognitive factors than by 'objective' disease-related variables" (p565). Illness representations have been associated with psychological adjustment in a number of chronically ill populations, with different components of the illness representations model being identified with adjustment. The curability component of illness representations has been associated with later depression for adults with multiple sclerosis, while curability and cause (e.g. the patient being responsible for their illness developing) were related to depression in rheumatoid arthritis sufferers (Schiaffino *et al.*, 1998). Psychological well-being in groups of adults with epilepsy has been associated with patients' perceived ability to contain the effects of their illness (Kemp *et al.*, 1999). In chronic fatigue syndrome strong illness identity, emotional causes, lack of control and serious consequences have been associated with poor psychological adjustment (Moss-Morris *et al.*, 1997). Heijmans (1998) reports supportive findings and suggests that illness representations are stronger predictors of adaptive outcome than coping strategies utilised by patients. Similarly, illness representations in patients with Addison's disease have been found to be better predictors of adaptive outcome than coping strategies, with symptoms experienced, belief in chronicity of the illness and perceived uncontrollability of the illness associated with poorer physical and social functioning, mental health and general vitality (Heijmans, 1999).

1.3.3 Carers' Illness Representations

Those caring for or living with someone who is chronically ill will also have developed illness representations of that illness and will have a belief system about the causes, consequences, duration, control and symptoms of the illness. Weinman *et al.* (1996) investigated 'significant other's' illness perceptions, where spouses were asked to report on their perceptions of a partner's illness. Weinman *et al.* (1996) reported significant but low correlations between patients' and spouses' illness perceptions in terms of consequences, control and duration of the illness, but no correlation between patient and spouse reports of symptoms the patient experiences. These authors suggest that there is "considerable variance in the level of agreement between patients' and significant others' illness representations" (p440), which could be helpful in understanding the role of carers and others within a chronic illness population. Heijmans *et al.* (1999) completed a more detailed study investigating patients' and spouses' representations of chronic illness. They report similar views held by partners in terms of illness identity (symptoms) and cause of the illness, but had significantly different perceptions of the likely duration and consequences of the illness, and one group (those with Addison's disease) differed on perceptions of control or cure of the illness. Overall, spouses tended to exaggerate their partner's illness, being more pessimistic about the duration and control of the illness. However, differences in consequences were found in different directions for different illnesses, that is, spouses of patients with chronic fatigue syndrome were found to minimise the consequences, while spouses of patients with Addison's disease exaggerated the consequences (Heijmans *et al.*, 1999). Heijmans *et al.* (1999) also identified a strong association between dissimilarity in spouses' illness perceptions and aspects of adaptive outcome. When spouses of Addison's disease patients maximised the number of symptoms, duration of the illness and consequences, patients scored higher on measures of physical and social functioning, psychological adjustment and vitality. In contrast, spouses of patients with chronic fatigue

syndrome reporting perceptions of short duration of the illness and maximising consequences were found to have better adaptive outcomes. These findings highlight a number of issues: first, patients and 'significant others' may have significantly different illness perceptions. Second, different illnesses appear to have different effects on the similarity of illness perceptions of 'significant others' and patients. Third, differences in illness perceptions between a patient and a spouse can have a significant impact on adjustment to illness. This is of importance in the study described in this thesis, where children and parents may have differing beliefs and attitudes about the child's illness.

1.3.4 Children's Illness Representations

Children's understanding of illness has been described as following Piaget's stages of cognitive development (e.g. Bibace and Walsh, 1980):

1. Prelogical explanations of illness are phenominism (cause of illness is a remote external concrete phenomenon) and contagion (cause is located in objects or people proximate to the child).
2. Concrete-logical explanations are contamination (illness is caused by an external object/person/action that is 'bad' or 'harmful' for the body) and internalisation (external cause of illness is linked to internal effects)
3. Formal-logical explanations are physiological (cause may be triggered by external events, but the source and nature of the illness lie in specific internal physiologic structures and functions) and psychophysiologic (physiological explanations are described with additional or alternative psychological causes).

However, (Eiser, 1989) suggests the need to consider alternative approaches to understand children's experiences of illness and allow a focus on different aspects of illness rather than just causes.

Application of Leventhal's (1984) self-regulatory model to children's representations of illness has not been as extensively studied as to those of adults. However, Goldman *et al.* (1991) completed a study involving healthy pre-school children and identified the five characteristics of illness representation as discussed in the adult literature: causation, identity, consequence, time-line and cure. Goldman *et al.* (1991) also report that these very young children have less mature notions of illness, compared to older children, which was considered developmentally appropriate. Therefore it could be considered that in pre-school children the cognitive dimensions of illness representations are similar to adults, although the content is less mature and less well informed. This suggestion is supported by the work of Paterson *et al.* (1999) who found that age, verbal intellectual abilities and previous illness experience predicted levels of conceptualisation within an illness representations model. Despite these potential limitations relating to cognitive development, neither of the studies described above reported children having difficulties in understanding the questions being asked of them, about their illness beliefs. In addition Paterson *et al.* (1999) report reasonable levels of reliability and validity for the different dimensions of illness representations in their group of children. The illness representations model therefore appears to be a good theoretical approach that can be used with children and allows for the investigation of a number of dimensions of childhood illness perceptions.

Similar to the research with adults there is some evidence to suggest that children's illness representations have an effect on their behavioural and emotional responses to chronic illness. For example, children who perceive the cause of their illness as being a punishment for bad behaviour are likely to have more negative emotions associated with the illness (Kister and Patterson, 1980).

Issues relating to significant others' illness perceptions were described earlier, and highlighted potential differences between spouses' representations of illness. Very little

research has focused on differences between children's and parents' illness perceptions (Eiser *et al.*, 1995).

Overall, it appears that the illness representations/perceptions model is a useful theoretical framework within which to consider both children's and adults' experiences of chronic illness. This may be of value not only in understanding how the illness is perceived and experienced but how these perceptions are associated with psychological adjustment and illness behaviour.

1.4 CHILDHOOD NEPHROTIC SYNDROME

Nephrotic syndrome (NS) occurs when the kidneys leak large amounts of albumin, and other proteins, into the urine (proteinuria), resulting in lower levels of protein in the blood. This then leads to water passing into tissue and swelling (oedema) occurring (BKPA, 1988). Childhood NS is a rare condition that affects approximately 1 in 50,000 children per year and is twice as likely to occur in boys than in girls (Watson, 1998). The cause of NS is still unknown. However, it has been suggested that reaction to an infection is a possible trigger, and it is more common in families with a history of allergies (Watson, 1998). Complex genetic factors are thought to predispose some children, but these influences are poorly understood and do not affect management of the illness (Haycock, 1994). The highest incidence is in the age range of two to five years, with a smaller peak in later childhood (Haycock, 1994). The course of the illness is unpredictable with eight out of ten children having a relapse and one-third of these children having frequent relapses (Watson, 1998).

The main symptom of NS is oedema, which is generalised and distributed by gravity. Children will often have swelling of the face and around the eyes early in the day and of their ankles in the evening. Without successful treatment severe oedema may result in the

continuity of the skin being breached and fluid oozing from the swollen tissues (Haycock, 1994). Complications associated with NS include: hypovolaemia (reduced volume of blood circulating around the body), thrombosis (formation of a clot in the heart or blood vessels), acute renal failure, hyperlipidaemia (excess fat or lipids in the blood) and malnutrition. In addition, if a child has an infection during relapse this is considered a medical emergency due to nephrotic patients being immunocompromised (Haycock, 1994).

When a child initially presents with NS they will be treated with the corticosteroid prednisolone, until remission is induced (i.e. oedema and proteinuria are no longer present). This will usually take up to two months, and if remission has not been achieved at this point the child is considered to be a 'non-responder' (Haycock, 1994). This leads to the identification of the two main types of NS: steroid sensitive and steroid resistant. A minority of children with steroid sensitive NS will not suffer any relapses and after six months of monitoring their condition, will be discharged without any medically recommended restrictions imposed on their lifestyle. However, most children with steroid sensitive NS will suffer from relapses and their management can range "from relatively straightforward to extremely difficult, depending mainly on three factors: (a) the frequency of relapses; (b) the dose and duration of steroid therapy necessary to induce remission on each occasion; and (c) the tolerance of the individual to long-term steroid treatment, which varies greatly from patient to patient" (p219; Haycock, 1994).

Steroid sensitive NS is categorised into four groups:

i) Non-relapsing

ii) Infrequently relapsing

iii) Frequently relapsing without steroid dependency

iv) Frequently relapsing with steroid dependency

Children in the last two groups are at risk of severe steroid toxicity and treatment side-effects, such as impaired statural growth, disfigurement of facial appearance and behavioural changes (Haycock, 1994). Steroids are also likely to reduce resistance to infections, increase appetite and can increase blood pressure (Watson, 1998). The British National Formulary (BMA, 1998) also includes diabetes, osteoporosis, mental disturbances, muscle wasting and peptic ulceration as potential side-effects of the prolonged use or high doses of corticosteroids (glucocorticoids).

The risks of long-term steroid use may require the introduction of alternative or supplementary medications, usually immunosuppressants. Cyclophosphamide, an alkylating agent, is one option but can lead to side-effects of bone marrow suppression, alopecia, minor gastrointestinal upsets, haemorrhagic cystitis and infertility. Cyclosporin A is also used but is nephrotoxic and can therefore lead to permanent kidney damage with high doses over the long term and regular blood tests are therefore required to monitor levels. In addition, the use of Cyclosporin A is likely to substitute steroid dependence for Cyclosporin dependence. Levamisole has also been reported to be successful for some children with frequently relapsing steroid dependent NS and does not appear to have any significant side effects. It is important to note that none of these medications (including steroids) cure NS, but can be effective in establishing or maintaining remission (Haycock, 1994).

There are also a number of types of steroid resistant NS, largely based on clinical pathology. The three most common types are:

i) Focal segmental glomerulosclerosis is a histopathological diagnosis that describes scarring and degenerative changes of the capillaries within the nephron, which filters urine from the blood. This diagnosis accounts for between 4% (in very young children) and 25% (in older children) of all cases of childhood NS, and can be treated with corticosteroids and cyclophosphamide. Relapse is likely and renal survival is reported as between 45 and 65%.

ii) Mesangiocapillary glomerulonephritis, is a diagnosis with characteristic clinical and histopathological features. Initial clinical presentation is largely in children over the age of 5 years, with haematuria (blood in the urine) and/or inflammation of the kidneys. In addition hypertension and reduced filtration of urine from the blood is likely. This diagnosis accounts for approximately 5% of childhood NS cases. Genetic factors are thought to play an important role in its development. Twenty years after initial presentation 90% of cases have suffered renal failure, 10% will show remission.

iii) Mesangial proliferative glomerulonephritis is another histopathological diagnosis of nephrotic syndrome, characterised by increases in mesangial matrix (mesangial cells are found in the glomerular lobes of the kidneys, they serve as structural supports, may regulate blood flow, are phagocytic and may act as accessory cells, presenting antigen in immune responses). This diagnosis accounts for approximately 5% of childhood NS cases. Effective treatment is not reported but the majority will remit spontaneously.

In cases of steroid resistant NS it is important to provide plasma infusions at twelve hourly intervals until symptoms improve. In addition controlling oedema is necessary through a restriction of dietary sodium intake and increased oral protein intake, combined with diuretic therapy. Children must also be monitored for potential thrombolembolic complications, and bacterial infections (Trompeter, 1994).

This discussion has highlighted the main features and different types of nephrotic syndrome. When a child initially presents with the illness it is not possible to determine its type or what the child's response to treatment will be. For each individual the course of the illness is unpredictable at any stage. Whilst in remission the child's urine needs to be tested daily to check that protein levels are within the normal range. After five years of being in remission it is considered very uncommon for relapse to occur (BKPA, 1988). Overall, it is clear that there is a range of 'severity' of childhood NS in terms of the treatment required, and that in the majority of cases the side-effects of treatment can be severe.

1.5 THE PSYCHOLOGICAL IMPACT OF CHILDHOOD NEPHROTIC SYNDROME

Two studies have focused specifically on the effects of nephrotic syndrome on children (Vance and Pless, 1983) and their families (Vance *et al.*, 1980). In both studies the authors conclude that the impact of nephrotic syndrome is much less than anticipated, although areas of vulnerability were identified in the family study.

The first study (Vance *et al.*, 1980) involved thirty-six families in which a child was suffering from nephrotic syndrome and thirty-six healthy matched control families. Nephrotic syndrome was divided into mild, moderate and severe forms of the illness, although details of how these groups were formed are not reported. An additional 'progress score' was also developed based on the number of relapses, response to steroids, need for non-steroid medication and number of hospitalisations. Parents rated the behaviour of their child (i.e. the sibling of the child with nephrotic syndrome) and siblings completed the 'Self Observation Scales' which provide information about how children perceive themselves and their relationship with peers, home, teacher and school. Teachers completed scales of the child's achievement, ability and behaviour. In addition an interview was completed in which details about the family, its health, child rearing and relationships between parents and siblings were collected, as well as information about problems in the family, and whether these were related to the illness. The main findings of this study suggested that "the frequency of serious problems experienced by the parents or siblings of children with nephrotic syndrome, when compared with matched control families, was much less than had been anticipated" (p951). Family problems that were investigated were financial expenses, overtiredness, extra work, changed sleeping arrangements, changed furnishings, changed housing, parental friction, limited social life, limited travel and interference by relatives. The only significant quantitative differences between the nephrotic and control groups were

that the nephrotic group reported significantly more limited travel while the control group reported significantly more extra work and parental friction. This led to the conclusion that the impact of nephrotic syndrome on families is "less than has generally been assumed in the past" (p953). However, psychological well being and 'stress' in family members was not directly examined in this study.

Sibling health was also examined by Vance *et al.* (1980) and they found that siblings of children with nephrotic syndrome were significantly more likely to be described as having average or poor physical and emotional health by their parents, although they had received fewer routine check-ups and prescribed medications. Siblings' school performance was also significantly more likely to be below average. Teachers' reports also indicated higher levels of underachievement and overachievement in the nephrotic siblings group. Sibling interactions were found to be similar in both groups although siblings in the nephrotic group were more often embarrassed by each other, but were less likely to fight with each other. Analysis of the siblings' self-observation scales was split into three age groups (primary, intermediate and adolescent) and indicated no differences between the nephrotic and control groups on any of its sub-scales: self-security, self-acceptance, school affiliation, social maturity, social confidence, teacher affiliation, peer affiliation, family affiliation, self-assertion. However, when the data for age groups was combined, siblings of children with nephrotic syndrome were found to score significantly lower on measures of self-security and social confidence. Overall, Vance *et al.* (Vance *et al.*, 1980) conclude that, while not greatly disturbed, siblings of children with nephrotic syndrome may be more susceptible to overt psychopathology when additional stressors appear. They also suggest that these families deny stress but siblings show evidence of inhibition (less use of medications, less aggression, poor academic performance and restricted personality profiles) and are therefore a population that may suffer from significant problems.

The study described above (Vance *et al.*, 1980) indicates that families do not suffer a great deal of stress as a result of a child in the family suffering from nephrotic syndrome, restricted travel and increased vulnerability in siblings were identified as potential problems. As noted by the authors the control group was not ideal as it was an atypical group (subscribers of a prepaid health insurance scheme). In addition, the study did not appear to fully explore the psychological implications of chronic childhood illness. Investigation of mood and emotional well being of siblings appeared to be very limited, with a measure (the Self Observation Scales) that does not appear to be reported frequently in the research literature.

The second study reported by Vance and Pless (1983) involved forty-three children with nephrotic syndrome and matched controls. Similar to the previous study a semi-structured interview/questionnaire was completed with parents including parental ratings of the child's behaviour. Teachers reported on academic achievement and children completed the Self Observation Scales. Comparisons on this child measure were completed for only thirty-three pairs of children due to absenteeism.

Analysis of the Self Observation Scales identified no significant differences between the groups or between each group and norms. However, parents of children with nephrotic syndrome were more likely to report that that child did not have enough friends and were less likely to fight with their siblings. Parents of children with nephrotic syndrome also reported poorer health and more medical visits, but fewer routine medical check-ups and acute medical visits. In conclusion, Vance and Pless (1983) describe a group of children who are well adjusted despite suffering from a chronic illness. These authors recommend caution in interpreting the lack of differences reported by children as the measure used was designed to be used in groups and was administered individually in this study which may have resulted in children being more reluctant to divulge any difficulties they were having.

As with the previous study the value of the measures used may be limited, particularly with regard to the investigation of psychological symptomatology.

The literature described in this section suggests that childhood nephrotic syndrome has a minimal impact on children and their families. However, this is in contrast to the clinical evidence that has been reported for the population involved in this study. Staff working with these families have reported observing high levels of distress amongst children and parents, and expressed concern about the psychological and emotional difficulties faced by families in which a child is suffering from nephrotic syndrome. The previous research focused mainly on practical problems experienced by families, and on school achievement, self-perceptions and relationships in affected children and their siblings. These two studies did not directly assess levels of psychological symptomatology in children and their parents.

Taking into account the research indicating increased levels of anxiety, depression and trauma in children (and their parents) suffering from chronic illness, this was considered an important area for further investigation. The previous papers investigating nephrotic syndrome have focused on quantitative measures of potential difficulties for children who are chronically ill and compared them with healthy controls. The current study, in contrast, was considered as an initial exploratory study to describe this population and examine the relationships between child and parent psychological symptomatology and illness perceptions. The exploratory nature of this work led to a preliminary investigation utilising a qualitative approach to guide the main quantitative body of the research.

In recent years the use of qualitative research approaches has increased dramatically, the aim of such approaches being "to understand and represent the experiences and actions of people as they encounter, engage and live through situations" (p216; Elliott *et al.*, 1999). Qualitative approaches can be valuable in providing insights and explanations and "can

illuminate and give a context to otherwise neutral and uninspiring statistics" (p233; Coolican, 1990).

In the context of the current study there was some concern that clinical evidence contradicts, to some extent, previous research and that quantitative approaches with pre-determined hypotheses might lead to important areas being overlooked. This was considered of particular importance given the complexity, variability and unpredictability of an illness that has received limited research attention. Therefore the study was designed to utilise a qualitative approach in the initial stage to explore the face validity of examining psychological symptoms such as anxiety, depression and trauma and to explore other factors and difficulties that might be experienced by the families of children with nephrotic syndrome. This would then guide the main body of the research, targeting a total population, which would utilise a quantitative approach that could be considered as more objective and representative of a greater number of these families. In addition, areas that might be identified through the initial qualitative stage could then be incorporated into the larger scale study.

Taking into consideration the literature described earlier and the initial interviews (described in the method) the following aims and hypotheses were generated for the main quantitative study.

1.6 AIMS AND HYPOTHESES

1.6.1 Aims

The aim of this study is to explore families' experiences of childhood nephrotic syndrome, perceptions of the illness and the psychological impact of the illness on affected children and their parents. This exploratory approach will include investigation of four main areas:

a) levels of psychological symptomatology within this population, to investigate the possible vulnerability of individuals experiencing childhood nephrotic syndrome;

b) relationships between children's and parents' psychological symptomatology. It has been suggested in previous research that there is such a relationship that could affect both child and parent functioning;

c) relationships between illness perceptions and psychological symptomatology. The literature suggests that illness perceptions may predict psychological difficulties and could be a valuable indicator for clinicians working with this population. In addition differences between patient and 'significant other' have been found to predict adjustment and will therefore be investigated in this study;

d) relationships between demographic or treatment factors, illness perceptions and psychological symptomatology. Factors relating to adjustment in chronic illness is a complex area that is not well understood. However, it is important to identify whether demographic and/or treatment factors play a significant role in the development of psychological symptomatology and perceptions of illness.

1.6.2 Hypotheses

1) a) children experiencing nephrotic syndrome will have higher levels of anxiety, depression and trauma symptoms than the general population (as identified through norms)

b) parents of children with nephrotic syndrome will have higher levels of anxiety, depression and trauma symptoms than the general population (as identified through norms)

Hypotheses 1a) and 1b) are based on the reported research evidence.

2) a) children's levels of anxiety, depression and trauma symptoms will be correlated with parental levels of the same symptoms

b) child and parent illness perceptions will be correlated

3) children's and parents' levels of psychological symptomatology will be correlated with parental reports of their child's difficulties

4) children's illness perceptions will predict child levels of psychological symptomatology

5) parents' perceptions of their child's illness will predict parental levels of psychological symptomatology

6) dissimilarity in child and parent illness perceptions will predict levels of child and parent psychological symptomatology

Hypotheses 2 to 6 are exploratory hypotheses derived from suggestions and indications from the general literature and literature describing the potential use of the illness perceptions model with adults.

The literature is very limited with regard to the psychological impact of childhood nephrotic syndrome and research findings paint a very complex picture with regard to factors affecting psychological adjustment in chronic childhood illness. As a result specific hypotheses can not be generated with regard to potential factors that may influence illness perceptions and psychological symptoms. This study will therefore include an exploratory analysis to investigate the potential effect of demographic, illness and treatment variables.

CHAPTER 2: METHOD

This study proceeded with ethical approval from the research ethics committee of the national teaching hospital where this research was carried out (see Appendix 1).

2.1 PILOT INTERVIEWS

The aim of this initial phase of the study was to examine clinical evidence of difficulties experienced by children with nephrotic syndrome and their parents. This was an exploratory stage to investigate a new field of enquiry and establish relevant issues for investigation.

Two families, parents and the affected child, were asked to participate in semi-structured interviews while they were staying on the ward, to provide information of their personal experience of the illness. Three members of staff who have worked for a number of years on the ward and in the community with families in which a child suffers from nephrotic syndrome were also asked to participate in semi-structured interviews, focusing on families' experiences of childhood nephrotic syndrome. The wealth of experience to be elicited by interviewing key staff members was considered of value in outlining the broad range of experiences and observations of families in this situation. The interviews took the form of a brief clinical assessment, addressing issues such as whether family members suffered from symptoms of depression and anxiety and whether there were difficulties that they faced as a result of a child in the family suffering from nephrotic syndrome (see Appendix 2 for information sheets and details of interview questions).

Interviews were transcribed and themes explored. The need to investigate psychological sequelae, in terms of anxiety, depression and possibly even trauma, were identified. Potential risk factors such as changes in physical appearance and the impact on activities and

schooling were also identified. These were considered to be potentially important aspects of childhood nephrotic syndrome that would be of value to explore further and therefore a number of open-ended questions were derived from the interviews that could be included in the main questionnaire study. These open-ended questions are described in Section 2.6 of this chapter.

2.2 Design and Variables

The aim of this study was to investigate families' experiences of childhood nephrotic syndrome, to explore the affected children's and their parents' perceptions of the illness and psychological symptomatology. Given that psychometrically satisfactory questionnaire methods have been developed that describe and measure these variables, it was decided that this study should employ a questionnaire design for the main part of the study. Compared with interview or observation methods, for example, this would allow a larger sample to be accessed, which was considered important for an exploratory study of a population that has received very little attention in the research literature.

This study employed a cross-sectional survey design investigating two different populations:

(1) Parents: accessing parental perceptions of their child's illness and behavioural and emotional strengths and difficulties, as well as parental levels of anxiety, depression and trauma symptomatology.

(2) Children: accessing children's perceptions of their own illness, and levels of anxiety, depression and trauma symptomatology.

The purpose of this study was to investigate the relationships between these variables within a population experiencing childhood nephrotic syndrome. In addition, clinical levels of psychological symptomatology were recorded and compared with norms. However, comparison with a matched control group was not considered appropriate at this stage due to the complexity of factors that would need to be controlled for (e.g. hospital, treatment and physical experiences as a result of different forms of the condition).

2.3 Research Setting

This study was completed at a specialist centre for childhood nephrotic syndrome in a large teaching hospital that treats patients from London and the South of England. One hundred and ninety-six children with nephrotic syndrome are registered at this clinic and have been treated there within the last five years. These children range in age from birth to eighteen years.

2.4 Participants

Given the need for children to complete self-report questionnaires, only those aged over seven years were approached and one hundred and twenty one children were asked to participate in the study. One other exclusion criteria covered children who had received a kidney transplant as the result of nephrotic syndrome. Transplantation is associated with specific physical and emotional difficulties that may have little relationship with the precipitating illness. However, children on dialysis were included in the sample as this could be considered a continuation of the treatment and consequences of their nephrotic syndrome.

2.5 PROCEDURES

For children between the ages of 7 and 15 years, the questionnaire pack sent to families contained a cover letter, two information sheets (one for parents and one for children), a parental consent form and two questionnaires (one for the affected child and one for a parent/guardian to complete) and a return paid envelope. Children between the ages of 16 and 18 years were also sent a consent form for them to complete themselves. The information sheets described the purpose of the study, with details about who to direct queries to. It also explained that responses would remain confidential and that their decision to participate would not affect their medical care. The cover letter gave instructions that one questionnaire was to be completed by the child with nephrotic syndrome, and one to be completed by a parent. If more than one adult was living in the family unit, and they were willing to complete a questionnaire they were asked to contact the researchers (see Appendix 3 for details of all items sent to families).

After one month, thirty-three families had responded to the original request for them to participate in this study. A number of families had also contacted the researchers to enquire about whether they should complete the questionnaire as their child was in remission or had not received treatment for several years. These families were asked to complete the questionnaires considering how they currently feel about nephrotic syndrome and the effects that it may still be having. A second mailing was completed enclosing copies of the information sheets, consent forms and questionnaires. A cover letter included a request to families who had not responded because their child was currently well, to complete the questionnaires from their current perspective (see Appendix 4).

2.6 OPEN-ENDED QUESTIONS

On the basis of the qualitative interviews completed with staff and families, ten open-ended questions were included in the questionnaire for parents, and three open-ended questions for children. For parents these qualitative questions focused on: changes in the child's physical appearance and how this has affected the child and the way other people treat that child; effects on other children in the family; effects on the child's activities, friendships and schooling; effects on the parents' work and activities. In addition parents were asked to describe the worst things about their child having nephrotic syndrome, how they would advise other parents to cope with the illness and how they felt about their child's medical care. Children were asked how nephrotic syndrome had made things different for them, what the worst thing is about having nephrotic syndrome and what their one wish to make things better for them would be.

2.7 STANDARDISED MEASURES

2.7.1 Parental Measures

Illness Perceptions Questionnaire – Carer's Version

The Illness Perception Questionnaire (IPQ; Weinman *et al.*, 1996) is a 26-item measure that assesses cognitive representations of illness, with an additional scale measuring frequency of physical symptoms. This symptom scale can have items added or substituted depending on the population being studied. In the current study an additional ten symptoms central to the medical definitions of the illness and its treatment were included. The questionnaire comprises five sub-scales: identity – the symptoms the patient associates with the illness; cause – personal ideas about aetiology; time-line – the perceived duration of the illness;

consequences – expected effects and outcome; cure/control – how one controls or recovers from the illness. A total identity score is derived by summing the total number of symptoms that are experienced, resulting in a range of scores for the identity sub-scale of zero to twenty-two. All other items are scored on a 5-point Likert scale ranging from 1 to 5. The time-line sub-scale scores range from 3-15; the consequences sub-scale scores range from 7-35; the control/cure sub-scale scores range from 6-30.

Reliability and validity data has been completed on all but the cause sub-scale. Items from the cause sub-scale are not summed as each item represents a specific causal belief and therefore individual items are considered separately. On the remaining four sub-scales (identity, time-line, consequences and control/cure) good levels of internal consistency (ranging from .73 to .82 for the different sub-scales) are reported (Weinman *et al.*, 1996). Test-retest reliability indicated lower levels of reliability for the identity and time-line sub-scales (0.06 and 0.36 respectively) than the consequences and control/cure sub-scales (0.55 and 0.46 respectively). This difference was thought to be because "patients' perceptions of the consequences and cure of their illness are less likely to change over time" (p435 Weinman *et al.*, 1996). Weinman *et al.* also report good levels of concurrent validity, and discriminant validity (discriminating between different illnesses).

A 'significant other IPQ version' has also been developed (Weinman *et al.*, 1996), where the same items are worded to ask about another's illness, this was used in the current study and is referred to as the Carer's version of the IPQ. Heijmans *et al.* (1999) report good internal consistency for the identity sub-scale (α >0.75) and the consequences sub-scale (α >0.70), variable internal consistency for the time-line sub-scale (α 0.58 to >0.70), and control/cure sub-scale (0.63 to >0.70). The possibility that the lower internal consistency scores for the latter two sub-scales was due to the nature of the illnesses being studied was suggested by the authors. This suggests the need for caution in interpretation of the findings from the

carers' version of the IPQ and the need for further research to explore the reliability and validity of this measure.

Strengths and Difficulties Questionnaire

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) is a 25-item measure of a child's cognitive abilities, emotional well-being and behaviour, with peers and others, at school and home, as rated by parents or teachers. Goodman (1997) reports good discriminant validity between 'psychiatric' and 'non-psychiatric' populations. In addition concurrent validity has been established with the lengthier Rutter Questionnaire, with correlation coefficients ranging from 0.78 to 0.88. Goodman (1999) reports good test-retest reliability for the total difficulties scores ($r = 0.85$). Internal reliability scores have not been reported

An expanded version has also been developed (Goodman, 1999) which assesses level of perceived difficulties, chronicity, impact and family burden of a child's difficulties. The burden rating scale correlated well ($r = 0.74$) with interview ratings of burden. In addition the impact score showed improved discriminant validity compared to symptom scores. Test-retest reliabilities produced correlation coefficients of 0.44 for the burden item, 0.62 for the chronicity item, 0.63 for impact rating and 0.70 for the perceived difficulties item.

The questionnaire comprises five sub-scales, each containing five items, investigating emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour. Individual items are scored from zero to two. The total difficulties score is based on all sub-scales excluding the prosocial scale, which is considered as a separate scale measuring the child's strengths. The total difficulties score therefore ranges from zero to forty, and each sub-scale score ranges from zero to ten. Provisional interpretative banding

of SDQ Scores are provided in Table 1. The extended section of the SDQ is scored from 0 to 3 for questions relating to perceived difficulties, impact and burden, and 1 to 4 for the chronicity question. Scores from 0-1 for perceived difficulties and impact items are considered as low, while scores of 2-3 are considered high. This can be used as a valuable discriminator for indicating 'caseness', with scores of 2 or more being highly predictive of clinical status (Goodman, 1999).

Table 1: Provisional Banding of SDQ Scores, as published in Goodman (1997), p586.

These bands, which are not adjusted for age or gender, have been chosen so that roughly 80% of children in the community are normal, 10% are borderline, and 10% are abnormal

	Normal	Borderline	Abnormal
Total Difficulties Score	0-13	14-16	17-40
Emotional Symptoms Score	0-3	4	5-10
Conduct Problems Score	0-2	3	4-10
Hyperactivity Score	0-5	6	7-10
Peer Problems Score	0-2	3	4-10
Prosocial Behaviour Score	6-10	5	0-4

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983) is a 14-item state measure of anxiety and depression which is not contaminated by the presence of physical symptoms. Based on medical outpatient populations, the HADS shows excellent internal reliability and good construct validity (Moorey *et al.*, 1991). Concurrent validity for both sub-scales (i.e. anxiety and depression) of the HADS has been shown, correlating

significantly with other psychiatric ratings (Herrmann, 1997). It has cut-off scores for clinical levels of anxiety or depression, but is also valuable as a clinical indicator of the possibility of disorder (Zigmond and Snaith, 1983), rather than for the specific diagnosis of major depression or type of depression (Herrmann, 1997). It is used here to assess general levels of anxiety and depression.

The scale comprises anxiety and depression sub-scales, each of seven items scored from zero to three. Scores therefore range from zero to twenty-one on each sub-scale. There are two alternative interpretations of scores on this scale, describing either the likelihood of clinical disorder or the severity of symptoms. With the former interpretation, scores of 8 to 10 (on either scale) indicate 'possible clinical disorder', and scores between 11 and 21 'probable clinical disorder'. The latter suggests that scores from 0 to 7 can be said to show 'normal' levels of symptomatology, 8 to 10 'mild', 11 to 14 'moderate' and 15 to 21 'severe'. The value of the HADS in this study was as a measure of overall levels of anxious and depressive symptomatology.

Impact of Event Scale - Revised

The Impact of Event Scale – Revised (IES-R; Weiss and Marmar, 1997) is a 22-item measure of post-traumatic stress disorder symptoms. It consists of three sub-scales measuring intrusion, avoidance and hyperarousal symptoms. It was developed from the original measure, the Impact of Events Scale (IES; Horowitz *et al.*, 1979), a widely used measure assessing post-traumatic symptomatology, which is comprised of two sub-scales: Intrusion and Avoidance. These sub-scales therefore tap criterion B ("the traumatic event is reexperienced" – intrusion) and criterion C ("persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness" – avoidance) of the DSM-IV diagnostic criteria for post-traumatic stress disorder (APA, 1994). Horowitz *et al.* (1979) report

satisfactory internal reliability (Cronbach's α for intrusion = 0.79 and avoidance = .82), and test-retest reliability (correlation coefficients for intrusion = .87 and avoidance = .79), for a group of outpatients seeking treatment for stress responses to traumatic life events. In addition, Zilberg *et al.* (1982) completed a factor analytic study that identified items loading correctly on the hypothesised factors of intrusion and avoidance. Discrimination of traumatised versus non-traumatised individuals was also determined.

The omission of IES items tapping criterion D ("persistent symptoms of arousal") was addressed by Weiss and Marmar (1997) who developed the Impact of Event Scale – Revised. The IES-R includes seven new items, six new hyperarousal items and an additional intrusion item to parallel DSM-IV diagnostic criteria. Marmar *et al.* (1996) report high levels of internal consistency, with Cronbach α scores from a number of studies ranging from 0.79 to 0.92. Test-retest reliability was also reported with correlation coefficients ranging from .51 to .94, over different studies. The lower correlation coefficients were thought to be due to the length of time between the two administrations of the IES-R, and the recency of the traumatic event. Overall, the IES-R can be considered a reliable and valid measure of post-traumatic stress symptomatology. In the current study the IES-R is used to investigate the occurrence of trauma symptoms that are distressing to respondents and therefore ratings on the total score are examined, as opposed to sub-scale scores which describe the different aspects of trauma symptomatology.

The IES-R investigates the amount of distress that symptoms cause (rather than the frequency of symptoms) and is rated on a 5-point Likert scale, ranging from 'Not at all' (scored 0) to 'Extremely' (scored 4). The overall score for all items range from zero to eighty-eight. Scores indicating clinical levels of symptomatology are not available for the IES-R. However, scores of 30 or more on the original IES (i.e. intrusion and avoidance sub-scales, scored 0, 1, 3,5 on a four-point Likert scale) are thought to be associated with a high

risk of PTSD and scores of 20 or more are thought to indicate 'cause for concern' (Sclare, 1997). If these scores are scaled down to compare with the 0 to 4 scoring on the IES-R, this would suggest that a score between 16 and 23, on the intrusion and avoidance sub-scales together, indicates moderate levels of trauma, and scores of 24 or more indicate high levels of trauma symptomatology. In addition, examination of DSM IV diagnostic criteria (APA, 1994) would also suggest that these scores indicate at least moderate levels of a number of symptoms, or low levels of all possible symptoms, and could therefore be construed as having an impact on an individual's daily functioning. Clearly, the use of such 'cut-offs' to indicate levels of trauma symptomatology must be approached with caution as they have not been empirically validated. However, they provide an indication of the potential difficulties that the population being studied may be experiencing.

2.7.2 Child Measures

Illness Perceptions Questionnaire – Children's Version

The Illness Perceptions Questionnaire (IPQ; Weinman *et al.*, 1996) is described earlier with the parental measures used in this study. It has been adapted for use with children (Curson, 1998) with internal reliability α scores ranging from 0.54 to 0.70 (with the omission of one item from the control/cure sub-scale).

The IPQ – Children's Version has not previously been published and therefore full details of the scoring system and items in each sub-scale are described in Appendix 5. A total identity score is derived by summing the total number of symptoms that are experienced, resulting in a range of scores for the identity sub-scale of zero to twenty-two. All other items are scored on a 5-point Likert scale ranging from 1 to 5. The time-line sub-scale scores range from 3-

15; the consequences sub-scale scores range from 6-30; the control/cure sub-scale scores range from 5-25.

Spence Children' Anxiety Scale

The Spence Children's Anxiety Scale (SCAS; Spence, 1997) is a 45-item measure of children's anxiety symptoms. Thirty-eight items access anxiety symptoms, with six filler items and an open-ended item that is not scored. The SCAS is comprised of six sub-scales: panic attack and agoraphobia; separation anxiety; physical injury fears; social phobia; obsessive compulsive; and generalized anxiety disorder/overanxious disorder. Scores on the SCAS show a normal distribution, have high internal consistency (coefficient $\alpha = 0.92$) and split-half reliability of 0.90. Internal consistency of the sub-scales was also acceptable with α coefficients ranging from 0.60 to 0.82 (Spence, 1998) . Test-retest reliability was moderate with a correlation coefficient of 0.60 for the total score, with rather lower correlations for sub-scales, ranging from 0.45 to 0.57 (Spence, 1998). Spence's study also demonstrated good concurrent validity with other self-report measures of anxiety in children (correlation coefficient = 0.71). Discrimination between clinically anxious children and a matched control group was also demonstrated .

The SCAS measures levels of anxiety symptomatology, with scores rated on a scale from 0 ('Never') to 3 ('Always'), total scores therefore range from 0 to 114. Spence's (1998) standardisation study included two thousand and fifty two children between the ages of 8 and 12 years in which a mean score of 31.28 (SD = 17.35) was established for total scores on the scale. Discrimination between three groups of children identified mean scores of 18.8 (SD = 9.72) for non-clinical controls; 32.2 (SD = 21.97) for social phobics; and 48.75 (SD = 17.66) for comorbid social phobia and separation anxiety. Norms for sub-scales were also provided, however, in the current study the objective was to examine overall anxiety

symptomatology rather than investigate possible diagnoses, and sub-scales were therefore not analysed.

Birleson Depression Scale

The Birleson Depression Scale (BDS; Birleson, 1981) is an 18-item measure of children's levels of depressive symptomatology. Birleson (1981) reports good levels of internal consistency (coefficient = 0.86) and test retest reliability (coefficient = 0.80). It has also been shown to discriminate between depressed and non-depressed children and shows good concurrent validity, correlating highly with other measures of depression (Birleson *et al.*, 1987). The BDS is not recommended as an instrument for clinical diagnosis but elicits levels of depressive symptomatology (Sclare, 1997).

Items are scored from 0 to 2, with total scores ranging from zero to thirty-six. Non-depressed children have been found to score from 0-11 and scores of 15 and above are considered to provide acceptable levels of specificity and sensitivity for identifying clinical levels of depression (Stallard *et al.*, 1999). Scores between 12-14 could therefore be considered as 'borderline' scores of depressive symptomatology.

Children's Impact of Event Scale

The Children's Impact of Event Scale (IES-8; Sclare, 1997) was derived from the original Impact of Event Scale (IES) described earlier. Yule (e.g. Yule, 1992) and Dyregrov *et al.* (Dyregrov *et al.*, 1996) independently identified a number of questions from the original IES that were prone to being misinterpreted by children. They selected eight items that were thought to reflect the underlying factor structure. As with the original IES there are two sub-scales: Intrusion and Avoidance. The third component of PTSD described above is

hyperarousal, but measures incorporating this component into a child measure of PTSD are not established. The IES-8 has been found to discriminate between groups suffering from PTSD and controls (Sclare, 1997). However, Stallard *et al.* (1999) report an increased rate of misclassifications when comparing the IES and IES-8, but suggest their findings support the validity of the IES-8 while highlighting that it should not be used alone to identify PTSD in children. Internal and test-retest reliabilities have not been reported for this measure. In this study the IES-8 was used as a brief and 'child-friendly' screening tool to indicate reported levels of post-traumatic symptomatology.

The IES-8 investigates the frequency of symptoms rated on a weighted four-point Likert scale: available responses are 'Not at all' (scored 0), 'Rarely' (scored 1), 'Sometimes' (scored 3) and 'Often' (scored 5). A score of 30 on the original IES is thought to be associated with a high risk of having PTSD and the equivalent score on the IES-8 is 17. In addition a score of 20 or more on the original IES is thought to indicate 'cause for concern'. Simple extrapolation would suggest that scores of 11 and above on the IES-8 similarly indicate 'cause for concern'.

2.8 Additional Information Collected

Demographic data was collected from parents, identifying the child's age, responding parent's age, education and occupations of adults at home, age and number of children, time of diagnosis of nephrotic syndrome, family history of chronic illness and the affected child's current medication regime. Additional information relating to the 'severity' of nephrotic syndrome was examined and discussed with medical consultants. However, the complexity of the illness and treatment regimes creates difficulties defining the severity of this highly variable and unpredictable illness. It was therefore considered inappropriate to devise a

severity rating scale and that current treatment was a more reliable and valid indicator of children's health status.

2.9 Statistical Analysis

Data were entered into Excel (version 97 SR-1; © 1985 - 1997 Microsoft Corporation) spreadsheets and then imported into SPSS 8.0 for Windows (© SPSS Inc., 1989 - 1997) for statistical analysis.

Analyses of the data obtained will be carried out to provide descriptions of the sample, responses to open-ended questions and the distribution of scores on the psychological measures (HADS and IES-R for parents, SCAS, BDS and IES-8 for children), parental reports of child behaviour and illness perceptions.

Further analyses required will include confirming the normal distribution of variables and appropriate transformation of skewed variables to permit the use of parametric analysis. Exploration of internal reliability will be carried out using Cronbach's alpha. Further statistical analyses are planned to address the aims and hypotheses presented in Chapter 1: independent t-tests, one-way Analysis of Variance or Pearson's correlations to investigate relationships between demographic/illness-related variables and psychological outcome and illness perceptions; Pearson's correlations to investigate relationships between parent and child psychological symptomatology and between parental reports of child behaviour and parent and child symptomatology; multiple regression analyses to investigate whether illness perceptions and differences between child and parent illness perceptions are predictive of psychological outcome in children and parents.

CHAPTER 3: RESULTS

In this chapter characteristics of the sample are described, including demographic and illness-related variables. This is followed by presentation of participants' responses to the open-ended questions, in order to provide some initial insights into families' experiences of nephrotic syndrome. Distributions of responses on psychological measures and illness perceptions are described to provide a picture of the overall symptomatology of this population and how they perceive this illness. Relationships between demographic and outcome measures are examined to explore potential factors that may influence psychological outcome and illness perceptions. Further analyses examine the relationships between psychological measures and illness perceptions for parent-child dyads i.e. whether parents and children report similar psychological sequelae and illness perceptions. Finally, relationships between illness perceptions and psychological symptoms are examined in two ways: first, to investigate whether child illness perceptions predict child psychological symptomatology and whether parent illness perceptions predict parent psychological symptomatology; second, to investigate whether differences between parent and child illness perceptions predict parent and child psychological symptomatology.

3.1 SAMPLE

Thirty-three families responded to the initial mailing and a further twenty-six families responded to the second mailing, totalling fifty nine families (49%) out of a population of one hundred and twenty-one families. One respondent had received a kidney transplant and was therefore excluded from the analysis, and one respondent omitted several questions from each section and their data was also omitted from the analysis. For two families only parents responded to the questionnaire, and for one family only the child responded to the questionnaire. Therefore fifty-six parents and fifty-five children completed questionnaires.

Information about parent respondents is summarised in Table 2.

Table 2: Parent Respondent Demographics

		Number of respondents	% of respondents
Gender:	Male	6	10.7
	Female	50	89.3
Age:	26 - 35 years	12	21.4
	36 - 45 years	40	71.4
	46 - 55 years	3	5.4
	Missing data	1	1.8
Years of education:	Up to age 16	17	30.4
	Age 16 - 18	14	25.0
	Age 18 and over	19	33.9
	Missing data	6	10.7
Number of adults in household:	1	7	12.5
	2	38	67.9
	3	10	17.9
	4	1	1.8
Number of children in household (including child with nephrotic syndrome):	1	12	21.4
	2	23	41.1
	3	18	32.1
	4	2	3.6
	6	1	1.8
Family history of chronic illness:	Yes	15	26.8
	No	40	71.4
	Missing data	1	1.8

Information about child respondents is provided in Table 3.

Table 3: Child Respondent Demographics and Illness Variables

		Number of respondents	% of respondents
Gender:	Male	30	54.5
	Female	25	45.5
Age:	7 - 8 years	12	21.8
	9 - 10 years	14	25.5
	11 - 12 years	5	9.1
	13 - 14 years	9	16.4
	15 - 16 years	12	21.8
	17 - 18 years	3	5.5
Age at diagnosis:	0 - 2 years	15	27.3
	3 - 5 years	22	40.0
	6 - 8 years	8	14.5
	9 - 11 years	3	5.5
	12 - 13 years	7	12.7
Time since diagnosis:			
	0 - 2 years	6	10.9
	3 - 5 years	19	34.5
	6 - 8 years	14	25.5
	9 - 11 years	8	14.5
	12+ years	8	14.5
Current treatment:	None	18	32.7
	Steroids (with or without other treatment)	24	43.6
	Non-steroid treatment	13	23.6

3.2 OPEN-ENDED QUESTIONS

Open-ended questions derived from the initial interviews were included with the aim of exploring issues which might be missed by tools standardised on other populations. Following the interviews, ten items were included for parents and three for children. Items were selected to elicit a wide range of responses on significant issues raised in the interviews.

A qualitative approach was utilised to organise the data. For each item, sets of categories were derived from analysis of individual responses. All responses were assigned to one or more categories depending on their content. In order to assess the reliability of this coding system, an independent researcher with qualitative research experience was asked to blind code all the responses using the same categories (as presented in Tables 4 to 16 following). Inter-rater reliabilities were calculated for each category using Cohen's Kappa (Robson, 1993). This provides an index of concordance which controls for the effects of chance. Kappa's ranged from 0.80 to 1.0 with the exception of items 1, 3 and 5 for parents and items 2 and 3 for children, which ranged from 0.56 to 1.0. Coding systems for these five items were defined in more detail by inter-rater discussion, and subsequently produced Kappas of between 0.86 and 1.0. In cases where agreement was not reached the author's coding was used.

The experiences elicited by these qualitative items are described using these coding systems, with the number and percentage of respondents in each category. Many responses were quite detailed and contained several components. Each participant's response could therefore receive more than one code. Specific examples used to illustrate the range of responses are provided. Examples are quoted verbatim, in full, from the questionnaires.

3.2.1 Parent Items

Table 4: Parents' Open-ended Question 1a

Has nephrotic syndrome affected your child's physical appearance? If yes, How has this affected your child?		
Categories	Number of responses	% of respondents* (n = 51)
Appearance has not changed	7	13.7%
Weight change, swelling, short stature	42	82.4%
Hair, skin, eye colour changes	17	33.3%
Other changes e.g. joint problems, osteoporosis	4	7.8%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

The effects of nephrotic syndrome on children's physical appearance can be dramatic. The majority of parents involved in this study report changes in their child's physical appearance as a result of the illness and/or its treatment. The main change being in weight, swelling and stature. Typical responses in this category include *"Weight gain and puffiness", "Weight gain dramatic when on steroids", "Put on weight... looks puffy"*. In addition some parents report more subjective reactions to these changes in appearance, e.g. *"The body swells everywhere and makes him look ugly"*.

Changes in hair, skin and eye colour are often reported as being related to treatment (hair loss due to chemotherapy, excessive hair due to steroids and immuno-suppresants). For example, *"Chemotherapy caused skin irritation, nausea and hair thinning", "Side effects of cyclosporin causing hair growth"*.

Other changes were reported by few parents and related to specific difficulties: nausea from chemotherapy, being unable to walk due to swelling, joint problems and osteoporosis as a result of long-term steroid use.

In addition to the categories concerning the physical effects described above, five (9.8%) parents reported effects on the child's mood, for example *"It's made her feel really frightened and scared", "He has become very conscious and moody".*

Table 5: Parents' Open-ended Question 1b

How has it affected the way other people treat your child?

Categories	Number of responses	% of respondents* (n = 50)
It has had no effect	19	38%
Adverse reactions - bullying, teasing, staring etc.	20	40%
Others show concern	9	18%
Others avoid the child or are patronising and pitying	6	12%
Others do not understand what is wrong and don't know how to react	4	8%
Don't know - others are different but not sure in what way	2	4%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

Many families reported that other people do not treat their children differently due to their illness and changes in physical appearance. However, if changes are reported reactions are likely to be adverse. Parents report, for example *"Assume he is lazy, greedy, name calling, bullying, physical abuse"*, *"They often laugh at her, they think she looks strange"*, or different reactions from different people: *"Adults feel sorry for her. Children bully her"*. Some positive responses are also reported, for example, *"Family and friends have been very kind and considerate. School friends and teachers very supportive"*.

Table 6: Parents' Open-ended Question 2

How has nephrotic syndrome and/or its treatment affected your child's activities?

Categories	Number of responses	% of respondents* (n = 53)
No effect or minimal problems	20	37.7%
Activities restricted - hobbies, sports, holidays	31	58.5%
School affected - do different things, miss PE and outings	14	26.4%
Child has become isolated	2	3.8%
Increased aggression affects activities	2	3.8%
Family routine affected	1	1.9%
Diet changed	1	1.9%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

Many parents report few problems in relation to their child's activities, *"It hasn't, we haven't let it"*, *"Not at all. In fact it made her more determined to be active"*. However, the majority describe restrictions in the child's hobbies, sporting activities and holidays. For example,

"Limited physical activity - not able to continue with football", "He can't play like other children because of his weight and difficult to make quick movement", "Unable to do a lot of activities that he loves such as football, running around and games". A number of children are also described as missing a lot of school and PE lessons, *"Unable to join in games lessons properly. Not able to go on school journeys".* One parent reports particularly severe impact of the illness on her child's activities: *"Yes! Couldn't join various sports clubs i.e. Karate, Rugby - as they were contact sports and trainers didn't want responsibility. Also because of steroid treatment, he would be unable to partake in tournaments. He was bullied at various youth clubs, school, holiday venues etc. because he was 'fat'. So he isolated himself or became aggressive".*

Table 7: Parents' Open-ended Question 3

How has nephrotic syndrome and/or its treatment affected the other children in your family?

Categories	Number of responses	% of respondents* (n = 45)
No effect or minimal problems	20	44.4%
Feeling worried, fearful and anxious about ill sibling	12	26.7%
Feeling resentful, jealous and argumentative	11	24.4%
Taking 'second place', and having to put up with ill sibling's moods and behaviour	9	20.0%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

Many parents reported few effects on well siblings in the family. However some parents describe siblings as being left behind or cared for by others and having to put up with the ill child's behaviour. For example, *"Yes because the amount of time we have spent in hospitals and/or having to leave the other boy", "Their sister gets all the attention a lot of the time and I spend a lot of time with their sister".* Some children are described as feeling resentful or jealous, for example, *"They feel left out", "His sister is sometimes jealous of the time he has away from school and when attends hospital and longs to be ill too", "Elder sister was very jealous when he was younger, felt he was getting more attention".* Many children are also reported as being worried, concerned or distressed about their siblings illness: *"Feel frightened (and left out) when she has relapses. Scared - upset", "My older step-daughter has become very protective of her", "Gets upset when she sees the other child sick or upset".*

Table 8: Parents' Open-ended Question 4

How has nephrotic syndrome and/or its treatment affected your child's friendships?

Categories	Number of responses	% of respondents* (n =54)
No effect or minimal problems	33	61.1%
Friendships affected - few friends, isolated, weakened relationships	14	25.9%
Friends supportive	9	16.7%
Restricted contact with friends	6	11.1%
Ill child has problems with aggression which affects friendships	3	5.5%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

The majority of parents report that their child's friendships have not been affected by the illness. However, a substantial proportion felt that their child had difficulties making friends or that established friendships had been weakened. Extreme examples generally include difficulties with being bullied or teased, for example *"Has very few friends - shunned by peers at school - very emotional - isolated"*, *"Some children can be very nasty towards him and won't play with him"*. Mixed reactions were also reported: *"Friends at school tend to pick on him but has a strong friendship with children at home"*. Absence from school and activities was also thought to have an impact in some cases: *"Yes - her best friend found another best friend - due to absence from school - that upset her a lot"*, *"She doesn't see her friends that often out of school and gets upset they're often out playing when she's stuck indoors, especially in the winter cold months"*. In addition, three parents reported difficulties due to the child's moods and behaviour: *"They can become strained due to mood swings, aggression, tearfulness"*.

Table 9: Parents' Open-ended Question 5

How has nephrotic syndrome and/or its treatment affected your child's schooling?

Categories	Number of responses	% of respondents* (n =51)
No effect or minimal problems	9	17.6%
Absence from school and limiting effects of physical problems	39	76.4%
Positive comments - works hard, does well	11	21.6%
Concentration, learning and behaviour affected	8	15.7%
Gets behind and has to catch up	5	9.8%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

Children's schooling was reported as being most affected by absence due to illness and hospital admission. A small number report this as affecting the children in terms of getting behind in their school work but many parents commented positively about their child's determination and achievements: *"As he was always very determined to 'carry on regardless' he coped at school but did not like the interruptions for hospital visits and in-patient care", "she has worked hard to maintain her academic level".* Eight parents reported significant difficulties with learning and behaviour, for example *"He missed a lot at first and also because of behaviour problems always got the blame - teachers not always understanding", "Constant disruption and loss of concentration has resulted in poorer grades than expected".*

Table 10: Parents' Open-ended Question 6

How has your child having nephrotic syndrome affected your work and activities?		
Categories	Number of responses	% of respondents* (n =52)
No effect or minimal problems	17	32.7%
Difficulties with work - time off, not working, restricted opportunities	31	59.6%
Social and leisure activities affected - including family holidays	10	19.2%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

The majority of parents reported difficulties with their work as a result of their child suffering from nephrotic syndrome. Taking annual leave or unpaid leave for hospital visits were reported. Typical comments include: *"I have had to take compassionate time off from*

work when he is admitted to hospital, or take holiday leave", "Both myself and husband have had to take time off work". Others report giving up work: *"I had to give up my work for the time being to look after him and to watch out the progress".* Ten parents also reported restrictions on their lifestyle e.g. *"We have to plan everything around her", "Cut down on social activities to meet with the demands of her treatment", "At one point in my life when she was 2 to 5, I felt sometimes like 'the prisoner of Zenda' - always at home or not doing something for fear that she would get an infection".*

Table 11: Parents' Open-ended Question 7

What have been the worst things about your child having nephrotic syndrome?

Categories	Number of responses	% of respondents* (n =52)
Unpredictability, worry about future	26	50.0%
Effects on the child - appearance, behaviour, emotional effects, loss of activity, schooling, side effects of medications	23	44.2%
Effects on the parents - seeing suffering , being helpless, having to nag and support	17	32.7%
Hospital visits, treatments (not side effects but e.g. having to give pills), child being ill	14	26.9%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

Half of all the parents' responses included comments about the unpredictability of the illness and worries about what will happen. For example, *"Not knowing what the final result will be", "Worrying if disease will lead to chronic renal problems into adult life", "Worrying*

about the long-term effects of medication". Effects on the child, such as changes in appearance, behaviour and mood were also reported by many parents, for example: *"Seeing a normally slim, pretty little girl blow up into a 'baby sumo wrestler', seeing how she suffered when she could not fit into pretty little party dresses", "Her changing appearance and depression and mood swings".* Effects on parents were also reported, often as a result of the effects on the child: *"Seeing him very poorly, watching him suffer physically and mentally and not being able to reassure him",* as well as a result of hospital visits and treatment: *"Seeing her in pain, having horrible treatment, not finding any treatments which worked. Feeling unable to help her".*

Table 12: Parents' Open-ended Question 8

If you were asked to advise other parents on how best to cope with this illness, what would you suggest?

Categories	Number of responses	% of respondents* (n =50)
Suggestions for coping emotionally	30	60.0%
Behaviour with the affected child	21	42.0%
Take doctors' advice and seek information	19	38.0%
Medical advice - checking symptoms, diet etc.	4	8.0%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

The majority of parents offered suggestions for coping 'emotionally' with the day-to-day stresses and talking to others in the same situation, with comments such as *"Try not to worry too much", "Try not to let it take over you life", "Be realistic", "Take one day at a time", "Keep it in perspective", "Seek out other families with the same illness - gain support", "To*

talk and take away the isolation of this disease", "Forming a local support group so that people can share experiences and help each other". Many parents also suggest talking to the child about the illness and treating them as normally as possible: *"Always explain to your child what is happening", "Try not to overprotect the child and let them do normal everyday activities", "Talk to your child a lot, reassure them and to be there for them all the time", "Try not to treat the child any differently".* Parents also suggested taking the doctor's advice, asking them questions and seeking more information: *"Demand full knowledge at outset, not to be shielded from reality", "Ask every question you can think of, do research of your own e.g. via internet, talk to others who have the condition", "Get as much information as possible".* A small number of parents also suggested monitoring symptoms (i.e. checking urine and being careful with the child's diet).

Table 13: Parents' Open-ended Question 9

How have you felt about the medical care that your child has received for nephrotic syndrome?

Categories	Number of responses	% of respondents* (n =52)
Excellent, very good, careful, appropriate, satisfactory	50	96.2%
Initial problems, or a bad incident	9	17.3%
Unhappy	2	3.8%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

Overall, parents were happy with the medical care that their child had received and many praised staff at the hospital where this research was conducted: *"I think she gets all the care*

she could get and I can't praise the doctors and nurses enough for what they do", "I think he could not have had better treatment anywhere in the world". Several parents reported initial problems with local hospitals and GPs: *"Suffered initially by local GP not recognising the condition. Once recognised - no complaints", "We have the best treatment from (current consultants). But I often wonder the 'path' of my son's illness might have been very different from what it is now if he had been diagnosed earlier when he started to show the early symptoms".* Two parents reported being unhappy with medical care: *"Not pleased - never given enough information about drugs - biopsy not done as promised. Local hospital not informed enough to advise on problems and answer questions"* and *"That my child was a learning instrument as in try this and try that. Preventative treatment should be available i.e. in the prevention of osteoporosis due to long-term steroid treatment. With growing children this MUST be standard procedure".*

3.2.2 Child Items

Table 14: Children's Open-ended Question 1

How has nephrotic syndrome made things different for you?		
Categories	Number of responses	% of respondents* (n = 48)
Effects on activities - restricted play, outings, travel, sports, fun	22	45.8%
Going to hospital, taking medications, different diet, having to test urine	18	37.5%

How has nephrotic syndrome made things different for you? (continued)

Categories	Number of responses	% of respondents* (n = 48)
Physical symptoms - pain, tiredness, weakness	9	18.8%
Missing school, doing different things at school	8	16.7%
Nothing is different	5	10.4%
Being depressed, miserable, less confident	4	8.3%
More mature than friends	2	4.2%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

A wide range of responses were given to this general question, with 89% of children reporting at least one thing that is different for them. The most common difference reported was effect on activities: *"I can't have as much fun as I used to"* (9 years), *"It has stopped me doing things I want to do"* (8 years), *"I cannot do things that other children my age (16) do e.g. drink alcohol, play football, stay up very late"* (15 years), *"I was an active boy, but I lost confidence of all the activities"* (9 years), *"Sometimes I can't do what all my friends are doing because I feel too weak. People treat me different from friends"* (12 years). Many children also identified their appearance as making things different: *"I do not like what the illness and drugs have done to my appearance this also makes it harder to blend back in with my friends"*(13 years), *"It has made things different for me because I can't dress like other teenage girls (stretch marks all over legs)"* (14 years), *"I have put on weight and can not run very fast, at all. So I am not always asked by my friends to come to the cinema or to play football with them"* (14 years), *"I am overweight and unfit"* (11 years), *"I don't look so slim as I used to and some kids go around laughing"* (10 years). Children also identified hospital trips and taking medications as being different. Four children also reported being

affected emotionally: *"It gave me a miserable childhood and a start to a miserable teenage life it made me 'beep' overweight and unattractive"* (16 years), *"When I am ill I can't join others play or activities and I feel a little sad"* (7 years). Two sixteen year old children reported having to grow up more quickly.

Table 15: Children's Open-ended Question 2

What is the worst thing about having nephrotic syndrome?		
Categories	Number of responses	% of respondents* (n = 47)
Hospital, taking medications, biopsies, needles, diet	25	53.2%
Changes in physical appearance	20	42.6%
Physical symptoms - pain, diarrhoea, difficulty breathing, feeling poorly	15	31.9%
Restricted activities	11	23.4%
Being different	5	10.6%
Other people teasing and bullying	3	6.4%
Lack of medical knowledge about a cure	1	2.1%
Positive comments - appreciating life more	1	2.1%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

More than half of the children reported hospital visits, medications and other treatments as being one of the worst things about having nephrotic syndrome: *"I hate my nephrotic syndrome because I have to take lots of medicine. Also I have to go to the hospital a lot"* (10 years), *"Nasty tasting medicine, feeling poorly, being in hospital a lot, having big injections"*

(9 years). Many children also reported the changes in their physical appearance as being one of the worst things, *"My worse thing is putting on so much weight"* (13 years), *"Body swells up"* (12 years), *"Being fat"* (10 years), *"Not being able to run even as fast as others jog; because I am a little obese"* (14 years). Two children associated teasing and bullying with weight change: *"When I get fat and other children at school make fun of me"* (15 years), *"When my body swells up because people laugh at me"* (12 years). One child reported *"The lack of medical knowledge about a cure for it"* (16 years) as being the worst thing. One sixteen year old reported appreciating life more.

Table 16: Children's Open-ended Question 3

If you had one wish to make things better for you, what would it be?

Categories	Number of responses	% of respondents* (n = 46)
For the illness to go, to never have had it	28	60.9%
Physical appearance - to be slim and fit	9	19.6%
Have medicines to make it better/control it, to be medically stable	5	10.9%
Not to take medications, have nicer medications	5	10.9%
To be like my friends	2	4.3%
To be more confident, able to control temper	2	4.3%
To identify the trigger and treat that rather than the symptoms	1	2.2%
To have new kidneys	1	2.2%
Other - e.g. a million pounds	3	6.5%

* based on number of respondents completing this item; multiple responses result in the total exceeding 100%

The majority of children wished for their illness to go away, be cured or never to have had the illness: *"My illness to go away"* (9 years), *"My one wish would be to get rid of my nasty illness"* (10 years). Some children wished for the illness to go away and commented on another aspect of the illness. Nine children also commented on their physical appearance: *"To get better and become taller, thinner and faster"* (14 years), *"To wake up one morning and find that it has all gone and I can fit into normal clothes"* (10 years), *"To get back my old weight before I was pumped with steroids and turned into a fat balloon"* (15 years). Some children also focused on not taking medications or finding medications that could control/cure the illness: *"To stop taking so many tablets because it takes up a lot of time in the mornings"* (10 years), *"To find one medicines that would make me all better for good"* (8 years), *"There was a cure or the medicine that I have to take was easier to take and nicer to take"* (16 years). Two children wanted to be like their friends: *"That I never had it in the first place, so I could be like my friends"* (17 years), *"To not have to take tablets to be able to do the things my friends do and to be able to go on an airplain just to be normal because people, friends treat my different they can be so cruel at times"* (8 years). Two children identified behaviours they would like to change: *"I wish I could control my temper"* (8 years), and *"Have more confidence in myself"* (13 years). One child wished that *"They could identify the hidden trigger that causes nephrotic syndrome and therefore treat that instead of the immuno-supressing and treating the symptoms"* (16 years). One seven year old child wished for new kidneys. Three children wished for other things e.g. *"To get better and have 999,999,999 more wishes!"* (8 years).

3.3 PSYCHOLOGICAL MEASURES

For each measure used, the primary focus of analysis is the Total Score rather than individual sub-scales, as the aim of this study was to determine the overall levels of

psychological distress rather than specific diagnoses or different types of symptoms. Sub-scale scores and reliabilities are presented descriptively where appropriate. Several of the measures used produced skewed distributions, and this data was therefore transformed using square root transformations. In all cases, distributions were then reexamined and were no longer significantly skewed, permitting parametric statistical analysis.

3.3.1 Parent Measures

Strengths and Difficulties Questionnaire (SDQ)

Internal reliability for the Total Difficulties Score was high ($\alpha = .86$), and for sub-scales good levels of internal reliability were found, with α co-efficients ranging from .68 to .83.

Parental reports of children's behavioural strengths and difficulties are described in Table 17. Chi-square goodness of fit tests were carried out to compare reported levels of children's behavioural strengths and difficulties with Goodman's predicted norms (1997). Children's Total Difficulties Scores and difficulties sub-scale scores were found to be significantly higher than SDQ norms, while the prosocial sub-scale did not differ significantly from SDQ norms.

The following sub-scales were found to be significantly skewed ($p<0.05$): total difficulties, conduct problems, peer problems and pro-social behaviours. Subsequent analyses have involved square root transformations of these variables in order to allow parametric statistical analysis.

On the SDQ impact supplement 33 parents (58.9%) reported their children as having difficulties. Of these respondents 27 (81.8%) reported these difficulties as having been present for more than a year.

Table 17: Distribution of Scores on the Strengths and Difficulties Questionnaire (n = 56)

	Number of Respondents (Percentage)			χ^2 and p values (d.f. = 2)
	Normal	Borderline	Abnormal	
Total Difficulties Score	33 (58.9%)	7 (12.5%)	16 (28.6%)	$\chi^2 = 22.7$; $p<0.0005$
Sub-scale scores:				
Emotional symptoms	29 (51.8%)	6 (10.7%)	21 (37.5%)	$\chi^2 = 47.95$; $p<0.0005$
Conduct problems	31 (55.4%)	10 (17.9%)	15 (26.8%)	$\chi^2 = 23.49$; $p<0.0005$
Hyperactivity	37 (66.1%)	4 (7.1%)	15 (26.8%)	$\chi^2 = 17.6$; $p<0.0005$
Peer problems	34 (60.7%)	6 (10.7%)	16 (28.6%)	$\chi^2 = 21.94$; $p<0.0005$
Pro-social behaviours	48 (85.7%)	3 (5.4%)	5 (8.9%)	$\chi^2 = 1.5$; p = NS

From the total population, 14 parents (25.0%) reported high levels of perceived difficulties, and 19 (33.9%) reported high impact. Such scores are described as being highly predictive of clinical status (Goodman, 1999). In the population involved in the current study, these scores were found to be significantly correlated with SDQ total difficulties scores: SDQ Perceived Difficulties and Total Difficulties score, Spearman's rho = .723; $p<0.001$; n = 56 SDQ Impact and Total difficulties score, Spearman's rho = .628; $p<0.001$; n = 33. For the purposes of the current study, given the high correlations reported here, the multiple item SDQ Total Difficulties score was used in preference to the single-item perceived difficulties score and the five-item impact score.

Hospital Anxiety and Depression Scale

Internal reliablities for the two sub-scales, anxiety and depression, were high with α co-efficients of .84 and .81 respectively.

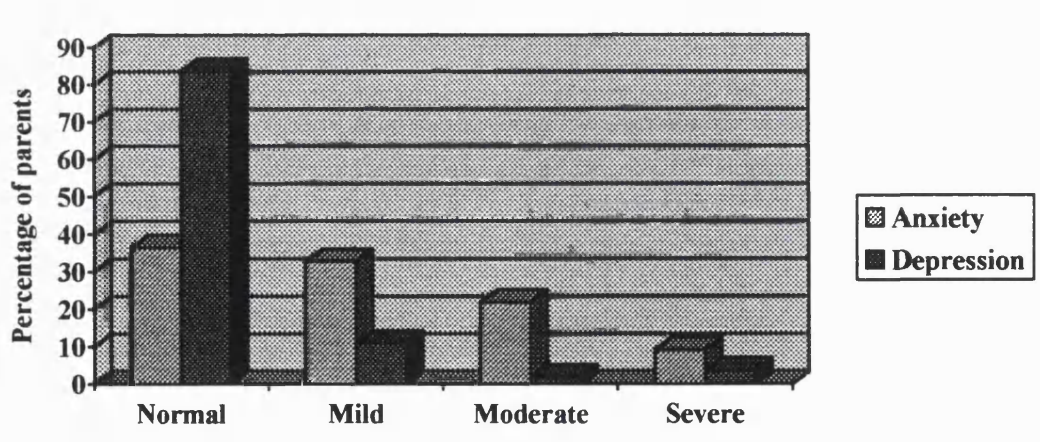
Using clinical cut-off scores, a clear distinction was seen between anxiety and depression symptoms. The majority of parents (54.5%) reported mild to moderate levels of anxiety, while much lower rates of depressive symptomatology were reported. These findings are described in Table 18 and further illustrated in Figure 1.

The depression sub-scale was found to be significantly skewed ($p<0.05$). Subsequent analyses have involved square root transformations of this variable in order to allow parametric statistical analysis.

Table 18: Distribution of Parental Scores on the HADS (n = 55)

	Percentage (Number)			
	Normal (0-7)	Mild (8-10)	Moderate (11-14)	Severe (15-21)
Anxiety symptoms	36.4% (20)	32.7% (18)	21.8% (12)	9.1% (5)
Depression Symptoms	83.6% (46)	10.9% (6)	1.8% (1)	3.6% (2)

Figure 1: Parent Levels of Anxiety and Depression



Impact of Event Scale - Revised

Internal reliabilities for the IES-R were high, with an α coefficient of .93 for the Total score. The sub-scales, intrusion, avoidance and hyperarousal also demonstrated high internal reliabilities with α co-efficients of .87, .82 and .85 respectively.

Forty-nine of the fifty-six parents who returned questionnaires completed the IES-R. Of the remaining seven, three indicated that the illness was in remission and they did not feel that they could answer those questions. It was considered appropriate to assume a score of zero on this measure for parents who did not complete it, given the implication that these parents did not feel it was relevent to them and implying that they do not suffer from trauma symptomatology. This may result in a more conservative estimate of trauma symptomatology in this population. Scores indicating high levels of trauma symptoms (i.e. high risk of PTSD) on the intrusion and avoidance sub-scales were obtained by 16.1% of the sample (9 respondents). A further 23.2% (13 respondents) obtained scores indicating 'cause for concern'. This results in a total of 39.3% of parents showing clinically concerning levels of trauma symptomatology.

The total score and all three sub-scales were found to be significantly skewed ($p<0.05$). Subsequent analyses have involved square root transformations of these variables in order to allow parametric statistical analysis.

3.3.2 Child Measures

Spence Children's Anxiety Scale

Internal reliability for the Total Score on the SCAS was high (α = .91) and for five of the six sub-scales (panic and agoraphobia; separation anxiety; social phobia; obsessive compulsive; GAD/overanxious) with α coefficients ranging from .73 to .80. The physical injury sub-scale demonstrated low levels of internal reliability (α = .37). Norms available for this measure found that a non-clinical control sample obtained a mean score of 18.8 (SD = 9.72), while a clinically anxious group obtained a mean score of 32.2 (SD = 21.97). Eighteen of the children (33%) obtained scores greater than 32. It is also of note that 12 (22%) children scored 39 or more, placing them more than 2 Standard Deviations above the mean of the normative population i.e. scores which only 2.3% of the population would be expected to obtain.

Birleson Depression Scale

Internal reliability for the total depression score was high, with an α coefficient of .83. Fifty-three children completed this section of the questionnaire. Scores within the normal range were obtained by 33 children, 62.3% of the sample, while 14 children (26.4%) scored in the borderline range, and 6 children (11.3%) scored in the range indicating a diagnosis of clinical depression.

Children's Impact of Events Scale

Internal reliability values for the Children's IES were high, with an α coefficient of .85 for the Total Score, and .75 and .80 for the intrusion and avoidance sub-scales respectively.

Four children did not complete this section of the questionnaire pack, and as with parents it was assumed that these children did not feel that the questions were relevant to them and could therefore be considered as not suffering from trauma symptomatology. Their scores were therefore recorded as zero.

Using recommended clinical cut-off scores 16 children (28.1%) obtained scores indicating high levels of trauma symptomatology, while a further 10 children (17.5%) obtained scores indicating 'cause for concern'. Thus 45.6% of this population showed clinically concerning levels of trauma symptomatology.

3.4 ILLNESS PERCEPTIONS

3.4.1 Parents

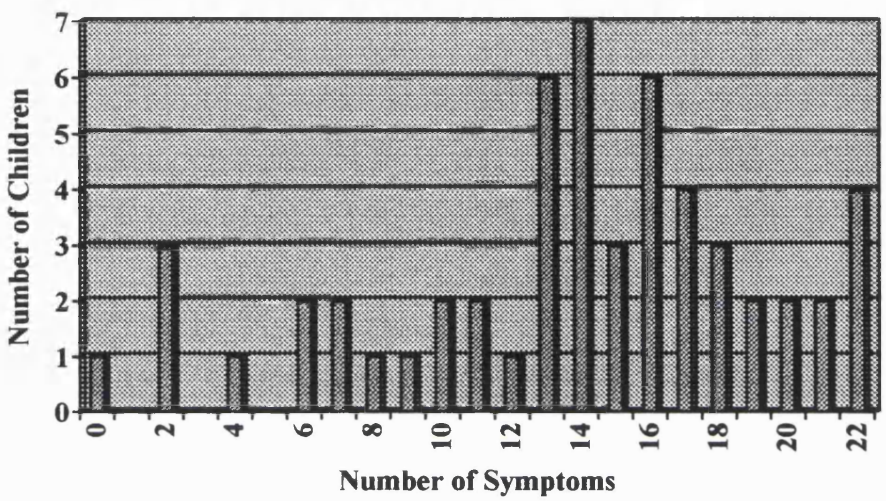
The carer's version of the Illness Perceptions Questionnaire (IPQ) showed high levels of internal reliability for the identity, time-line and consequences sub-scales, with α coefficients of .89, .84 and .71 respectively. The control/cure sub-scale showed low internal reliability with an α of .55. This is similar to the findings of Weinman *et al.* (1996) who report the control/cure sub-scale for the significant other's version of IPQ as having variable internal consistency, possibly as a result of the nature of the illness being studied. Given the low internal reliability for the control/cure sub-scale, findings in relation to this scale must be treated with caution.

Identity Sub-scale

The identity sub-scale identifies the number of symptoms experienced by the ill child. There are twenty-two symptoms included in the IPQ adapted for this study. Parents tended to rate

children as having multiple symptoms with the majority identifying more than half of the symptoms listed (see Figure 2).

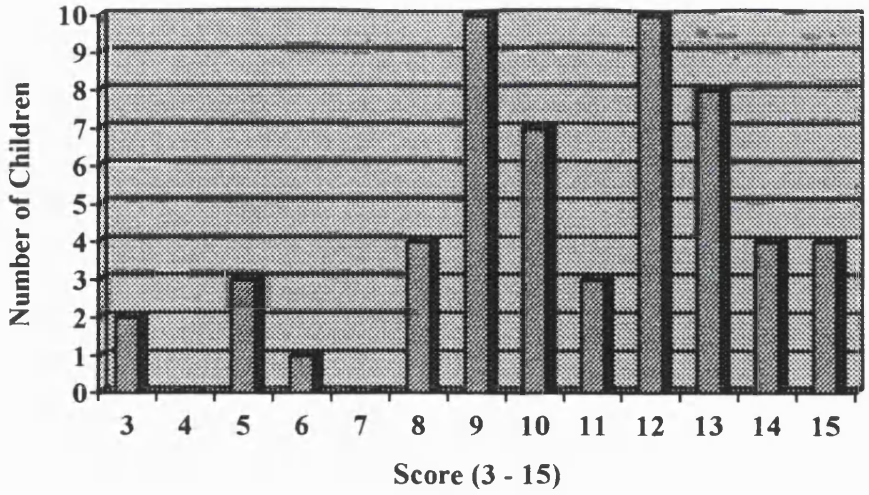
Figure 2: Parent Scores on the IPQ Identity Sub-scale



Time-line Sub-scale

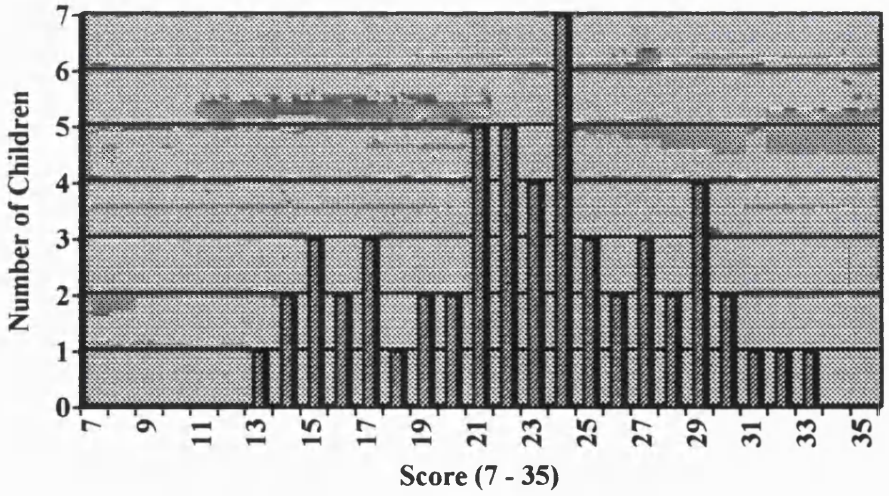
High scores on the time-line sub-scale indicate the belief that the illness will last a long time. Parents tended to report a long duration for the illness (see Figure 3).

Figure 3: Parent Scores on the IPQ Time-line Sub-scale



Consequences Sub-scale

Figure 4: Parent Scores on the IPQ Consequences Sub-scale



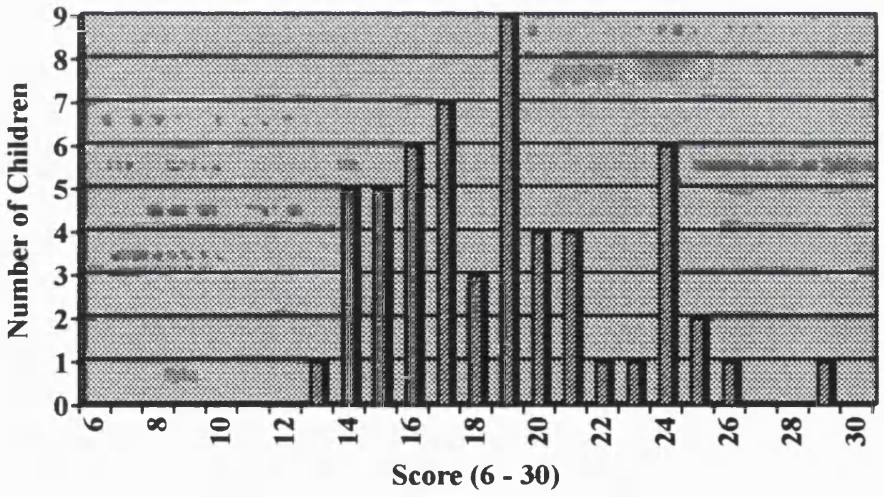
The consequences sub-scale identifies individual's beliefs about the illness severity and likely impact on physical, social and psychological functioning, high scores indicating more

serious consequences. Parents' responses on this sub-scale tended towards high levels of consequences (see Figure 4).

Control/cure Sub-scale

The control/cure sub-scale indicates the extent to which individuals believe the illness is curable or controllable, a high score indicating likelihood of control or cure. Parents' responses were variable, with a slight tendency towards good levels of expected control/cure (see Figure 5).

Figure 5: Parent Scores on the IPQ Control/Cure Sub-scale



The following sub-scales were found to be significantly skewed ($p<0.05$): identity and time-line. Subsequent analyses have involved square root transformations of these variables in order to allow parametric statistical analysis.

Cause Sub-scale

Items on the IPQ Cause sub-scale do not measure just one construct and items are therefore considered individually. Examination of the Cause sub-scale items indicated that two items (the illness was caused by a germ/virus, or happened by chance) were rated as likely causes by 37 (66%) of parents in each case. Other causes of the illness were reported by very few parents: one reported that it could be due to diet, one that it was hereditary, three that it was due to the child being stressed, two that it was due to the child's state of mind, four that it was due to other people and six that it was due to poor medical care. These cause items from the IPQ are not included in further analysis due to the low variance in parent responses

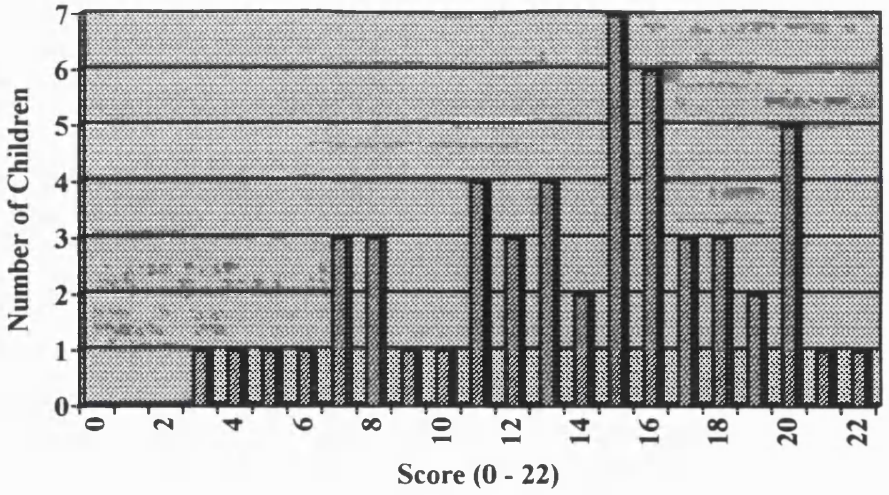
3.4.2 Children

The children's version of the Illness Perceptions Questionnaire showed high levels of internal reliability for the identity ($\alpha = .83$) and consequences ($\alpha = .81$) sub-scales, and satisfactory levels for the time-line sub-scale ($\alpha = .62$). However, internal reliability for the control/cure sub-scale was again rather low with an α coefficient of .47. These levels of internal reliability are consistent with those previously reported (Curson, 1998). However, given the low internal reliability for the control/cure sub-scale, findings in relation to this scale must be treated with caution. The sub-scales represent the same concepts as those described for the carer's version of the IPQ.

Identity Sub-Scale

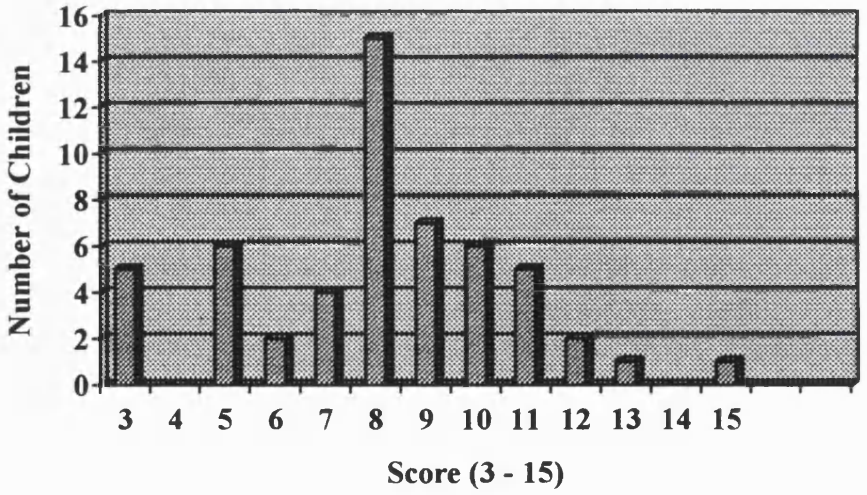
Similar to parents, children also reported experiencing multiple symptoms, with the majority identifying more than half of the symptoms listed (see Figure 6).

Figure 6: Child Scores on the IPQ Identity Sub-scale



Time-line Sub-scale

Figure 7: Child Scores on the IPQ Time-line Sub-scale

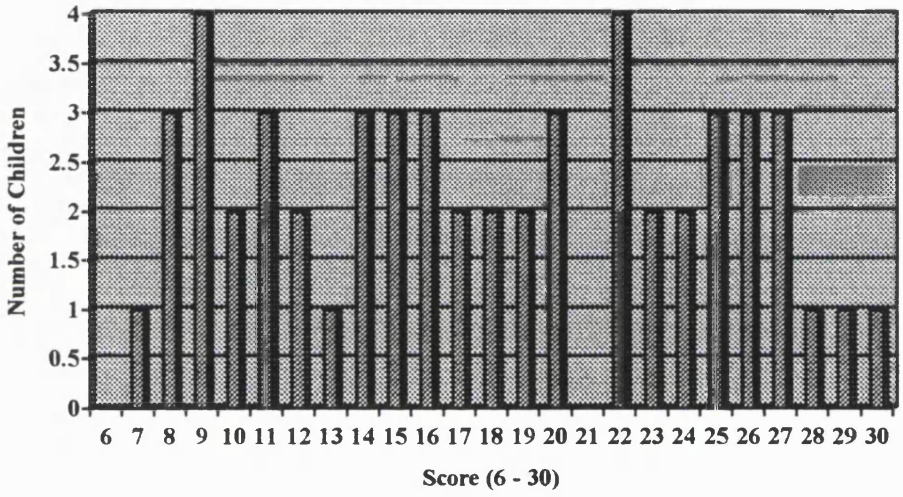


On the time-line sub-scale children tended towards the central point of the scale, indicating that they were 'not sure' as to the likely duration of the illness (see Figure 7).

Consequences Sub-Scale

Children's responses on the consequences sub-scale were very varied with no apparent tendency toward either end of the scale (see Figure 8).

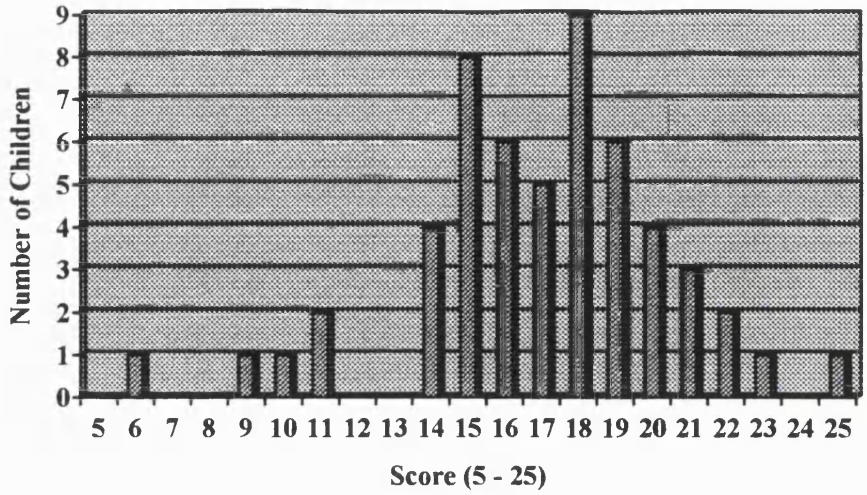
Figure 8: Child Scores on the IPQ Consequences Sub-scale



Control/cure Sub-scale

Children's scores on the control/cure sub-scale indicated a strong tendency towards high levels of likely control and cure (see Figure 9).

Figure 9: Child Scores on the IPQ Control/cure sub-scale



Cause Sub-scale

Items on the IPQ Cause sub-scale do not measure just one construct and items are therefore considered individually. Examination of the Cause sub-scale items indicated that the majority of children did not identify any causes of the illness, although 19 (35%) children thought that the illness had been caused by germs and 13 (24%) that it was due to bad luck. Other causes were identified by up to 9 children as being possible (see Table 19). The slight tendency to attribute the illness to bad luck or germs is similar to responses from parents, although children appear to be less likely to identify a cause for their illness. As with the parent scores, these cause items from the IPQ are not included in further analysis due to the low variance in child responses.

Table 19: Number of Children Identifying Different Causes of their Illness

Cause	Disagree or Don't Know that this was the cause	Agree that this was the cause
Germs	35	19
Bad luck	41	13
Food	45	9
Someone else's fault	48	6
Hereditary	49	5
Being sad	51	3
Doctors	52	2
Didn't look after myself	52	2
Being worried	52	2
Bad air	52	2
Being naughty	54	0

3.5 Demographic and Illness-Related Variables: Differences on Psychological Measures and Illness Perceptions

Independent t-tests, One-way ANOVAs and Pearson's correlations were completed to investigate the potential relationships between demographic or illness variables and parent and child psychological measures and illness perceptions.

Groupings within several of these variables were found to be significantly different on psychological measures and illness perceptions variables for parents, but not for children. Fifty mothers and six fathers completed parental questionnaires, it was therefore not possible

to compare responses on the basis of parent gender. Parents who had received education beyond the age of 18 were less likely to report hyperactivity problems on the SDQ ($F_{(2, 47)}$ = 6.48; p = 0.003) and were more likely to report prosocial behaviours ($F_{(2, 47)}$ = 4.43; p = 0.017) than those educated to the age of 18 and those educated to the age of 16.

Parent scores on the SDQ were greater for boys than girls on total difficulties (t = 3.20; p = 0.003; d.f. = 54) and for the hyperactivity (t = 2.37; p = 0.021; d.f. = 54) and peer problems (t = 3.40; p = 0.001; d.f. = 54) sub-scales. Children's current medical treatment affected parent ratings on the IPQ, with children receiving steroids (with or without other medications) more likely to receive higher carer's identity scores (i.e. more symptoms) than those receiving no treatment, who in turn obtained higher scores than children receiving non-steroid forms of treatment ($F_{(2, 52)}$ = - 4.26; p = 0.019). Parents of children being treated with steroids reported a longer expected duration of the illness than those receiving non-steroid treatments who in turn expected longer duration of the illness than those not receiving treatment ($F_{(2, 53)}$ = 5.45; p = 0.007). Similarly parents of children being treated with steroids reported more consequences of the illness than those receiving non-steroid treatments who reported more consequences than those not receiving treatment ($F_{(2, 53)}$ = 4.03; p = 0.007).

The number of children in the household, familial experience of a chronic illness and age at diagnosis were not found to have a significant relationship with psychological outcome or illness perceptions.

3.6 Relationships Between Psychological Measures and Illness Perceptions Within Parent and Child Dyads

Pearson's correlations were carried out to investigate the relationships between parent and child responses on psychological measures and illness perceptions. The findings of these analyses are described in Table 20.

Table 20: Correlations between Parent and Child Scores on Psychological Measures and Illness Perceptions

	Correlations Between Parent and Child Scores		
	r	p	n
IPQ Identity	.743	.000	51
IPQ Time-line	.198	NS	53
IPQ Consequences*	.657	.000	53
IPQ Control/Cure	.320	.010	53
Anxiety	.467	.000	52
Depression	.468	.000	51
Impact of Events	.402	.001	53

* If one outlier (child scores high on consequences, parent scores low) is removed from the analysis, r = .717; p = 0.000; n = 52.

With the exception of the IPQ time-line sub-scale, all parent and child measures were significantly correlated. High levels of agreement were seen on two of the IPQ sub-scales (Identity and Consequences), and moderate levels of agreement for psychological outcome.

Pearson's correlations were also carried out to investigate the relationships between parental reports of children's difficulties (using the SDQ) and children's reports of their difficulties (on the SCAS and BDS) . Total difficulties scores on the SDQ were positively correlated with children's reports of anxiety ($r = .421$; $p = 0.001$; $n = 53$) and depression ($r = .480$; $p = 0.000$; $n = 52$). In addition the SDQ emotional difficulties sub-scale, which identifies parental reports of depression and anxiety symptoms, was positively correlated with children's reports of anxiety ($r = .475$; $p = 0.000$) and depression ($r = .515$; $p = 0.000$).

Pearson's correlations were completed to investigate the relationships between parental reports of children's difficulties and parental levels of anxiety and depression. Total difficulties scores on the SDQ were positively correlated with parental anxiety ($r = .502$; $p = 0.000$; $n = 55$) and depression ($r = .428$; $p = 0.001$; $n = 55$). Removal of one outlier (obtaining high anxiety and depression scores but a low SDQ score) increased these coefficients to $r = .507$; $p = 0.000$; $n = 54$ for parental anxiety, and $r = .573$; $p = 0.000$; $n = 54$) for parental depression.

3.7 Illness Perceptions and Psychological Measures

Multiple regression analyses were completed to investigate the predictive power of illness perceptions for psychological outcome. Parental illness perceptions were regressed onto parent psychological measures and parental reports of child behaviour (SDQ total difficulties), and child illness perceptions were regressed onto child psychological measures and parental reports of child behaviour (SDQ total difficulties). For each multiple regression, the four sub-scales of the IPQ that each yield a total score were used (identity, time-line, consequences and control/cure). As noted earlier, the internal reliability rating for the control/cure sub-scale was low for both parent and child versions of the IPQ, and therefore the findings in relation to this sub-scale must be considered with caution.

However, it was considered worthwhile to include this sub-scale in the current analysis to explore its potential value in combination with the other IPQ sub-scales as a predictor of psychological distress. Clearly, further development of this measure would be recommended to establish its value as part of an illness perceptions model and predictive factor for psychological sequelae in childhood illness and nephrotic syndrome.

The IPQ was found to be significantly predictive for all child and parent psychological outcome measures. These analyses are detailed below with the independent effects of each IPQ sub-scale tabulated. In addition, analyses were completed to confirm that single sub-scales alone did not account for similar levels of variance as the whole IPQ model. In each case the IPQ model accounted for substantially more of the variance than individual sub-scales.

3.7.1 Parent Illness Perceptions and Psychological Measures

Parent Illness Perceptions and Anxiety Scores

The model accounted for 35% of the variance in the HADS anxiety scores, and the overall regression was significant ($F_{(4, 49)} = 6.52$, $p<0.001$). Parent IPQ identity and consequences sub-scales were significantly associated with parental anxiety (see Table 21).

Table 21: Parent IPQ and HADS Anxiety Scores

Predictor Variable	Beta	t	p
Identity	.408	3.12	.003
Time-line	-.175	-1.30	.200
Consequences	.321	2.27	.028
Control/cure	-.029	-.231	.818

Parent Illness Perceptions and Depression Scores

The model accounted for 27% of variance in the HADS depression scores, and the overall regression was significant ($F_{(4, 49)} = 4.48$, $p<0.005$). The Parent IPQ consequences sub-scale was significantly associated with parental depression (see Table 22).

Table 22: Parent IPQ and HADS Depression Scores

Predictor Variable	Beta	t	p
Identity	.144	1.043	.302
Time-line	-.179	-1.251	.217
Consequences	.482	3.223	.002
Control/cure	-.010	-.078	.938

Parent Illness Perceptions and Trauma Symptomatology Scores

The model accounted for 17% of the variance in the IES-R scores, and the overall regression was significant ($F_{(4, 50)} = 2.62$, $p<0.05$). The Parent IPQ consequences sub-scale was significantly associated with parental trauma symptomatology (see Table 23).

Table 23: Parent IPQ and IES-R Trauma Symptomatology Scores

Predictor Variable	Beta	t	p
Identity	.183	1.258	.214
Time-line	-.106	-.703	.485
Consequences	.329	2.093	.041
Control/cure	-.014	-.098	.922

Parent Illness Perceptions and Reports of Child Behaviour

The multiple regression analysis examining parent IPQ scores and parental reports of child behaviour (SDQ total difficulties scores) also included child gender as an independent variable, as it was noted earlier that child gender is significantly associated with total difficulties scores on the IPQ. The model accounted for 31% of the variance in the SDQ total difficulties scores, and the overall regression was significant ($F_{(5, 49)} = 4.47$, $p<0.005$). Child gender was significantly associated with parental reports of child behaviour (see Table 24). This model accounted for more variance than child gender alone, which when regressed on SDQ total difficulties scores accounted for only 17% of the variance.

Table 24: Parent IPQ with Child Gender and SDQ Total Difficulties Scores

Predictor Variable	Beta	t	p
Identity	.138	1.018	.314
Time-line	.066	.471	.640
Consequences	.199	1.375	.175
Control/cure	-.138	-1.083	.284
Child gender	-.389	-3.240	.002

3.7.2 Child Illness Perceptions and Psychological Measures

Child Illness Perceptions and Anxiety Scores

The model accounted for 23% of the variance in child anxiety scores, and the overall regression was significant ($F_{(4, 48)} = 3.58$, $p<0.05$). IPQ sub-scales were not significantly associated with child anxiety ratings (see Table 25).

Table 25: Child IPQ and SCAS Scores

Predictor Variable	Beta	t	p
Identity	.281	1.896	.064
Time-line	-.178	-1.213	.231
Consequences	.235	1.564	.124
Control/cure	-.164	-1.111	.272

Child Illness Perceptions and Depression Scores

The model accounted for 32% of the variance in child depression scores, and the overall regression was significant ($F_{(4, 48)} = 5.665$, $p<0.005$). The child IPQ identity sub-scales was significantly associated with child depression scores (see Table 26).

Table 26: Child IPQ and BDS Scores

Predictor Variable	Beta	t	p
Identity	.406	2.912	.005
Time-line	-.098	-.715	.478
Consequences	.170	1.202	.235
Control/cure	-.259	-1.868	.068

Child Illness Perceptions and Trauma Symptomatology Scores

The model accounted for 43% of the variance in child IES-8 scores, and the overall regression was significant ($F_{(4, 48)} = 8.95$, $p<0.001$). Child IPQ time-line, consequences and control/cure sub-scales were significantly associated with child levels of trauma symptomatology (see Table 27).

Table 27: Child IPQ and IES-8 Scores

Predictor Variable	Beta	t	p
Identity	.201	1.571	.123
Time-line	-.380	-3.009	.004
Consequences	.436	3.365	.002
Control/cure	-.272	-2.135	.038

Child Illness Perceptions and Parental Reports of Child Behaviour

The model accounted for 22% of the variance in SDQ total difficulties scores, and the overall regression was significant ($F_{(4, 47)} = 3.24$, $p<0.05$). The child IPQ identity sub-scale was significantly associated with parental reports of child behaviour (see Table 28).

Table 28: Child IPQ and SDQ Total Difficulties Scores

Predictor Variable	Beta	t	p
Identity	.481	3.135	.003
Time-line	.147	.985	.330
Consequences	-.123	-.789	.434
Control/cure	-.069	-.457	.650

3.8 Differences Between Parent and Child IPQ Scores

Parent and child IPQ scores on the time-line and control/cure sub-scales were not highly correlated, and these scores were therefore examined to investigate how parents and children perceived these aspects of the child's illness differently. On the time-line sub-scale 75.5% of parents obtained higher scores than their children, 11.3% obtained identical scores and 13.2% of parents obtained lower scores than their children. This indicates that the majority of parents expect the illness to last longer than the children do. On the control/cure sub-scale mean scores were obtained due to different numbers of items on the parent and child versions of the IPQ. The majority of parents perceived lower levels of control and curability for the illness than their children did, with 60.4% of parents obtaining lower mean scores than their children and 39.6% obtaining higher mean scores.

Dissimilarity scores were computed for each parent-child dyad by subtracting the parent's score from the child's score, as described by Heijmans (1999), for the time-line and control/cure sub-scales of the IPQ. Multiple regression analyses were then completed using these variables to investigate whether they may be predictive of psychological outcome. None of these regression models were significant, indicating that dissimilarity on these IPQ sub-scales does not predict psychological outcome for either parents or children.

CHAPTER 4: DISCUSSION

The aim of the current study was to explore families' experiences of childhood nephrotic syndrome, perceptions of the illness and the psychological impact of the illness on affected children and their parents. This discussion will present a summary of the findings of the current study. These findings will then be discussed in relation to the literature presented in the first chapter. Advantages and disadvantages of the theoretical and methodological approaches employed in this study will be addressed. Research and clinical implications of this study and recommendations for the development of this work will be suggested. Finally, conclusions will be made as to the impact of childhood nephrotic syndrome on children and their parents.

4.1 Summary of the Findings

4.1.1 Demographic and Illness-Related Factors: Relationships with Psychological Symptomatology and Illness Perceptions

Several demographic and illness-related variables were found to be significantly associated with parental illness perceptions and parental reports of child behaviour. Parents who received higher education (i.e. beyond the age of eighteen years) were less likely to report hyperactivity problems in their children, and were more likely to report pro-social behaviours. Boys were also more likely to be reported by parents as having more total behavioural difficulties, hyperactivity and peer problems. This is perhaps associated with the increased prevalence among boys for difficulties such as attention-deficit/hyperactivity disorder (e.g. Shelton and Barkley, 1995).

Children's treatment for nephrotic syndrome was found to be significantly related to parental illness perceptions. Parents whose children were currently taking steroids reported more symptoms than children not receiving any treatment who in turn reported more symptoms than children receiving non-steroid treatments. Parents whose children were currently taking steroids also reported a longer perceived duration and more consequences as a result of the illness. These variables were higher than for those on non-steroid treatments which in turn were greater than for those currently not receiving treatment. These findings suggest that the type of treatment that children receive has a significant impact on how parents perceive the illness, with steroids having the most severe effects in terms of increased symptoms, duration and consequences of the illness. Interestingly, receiving steroid treatment does not necessarily correspond with the actual severity of nephrotic syndrome in terms of, for example, likelihood of renal failure, which is more likely to occur in steroid resistant forms of the illness.

4.1.2 Open-ended Questions

Open-ended questions revealed a number of areas which may be particularly relevant in attempts to understand the experience of childhood nephrotic syndrome. Changes in their child's physical appearance were reported by the majority of parents, in particular weight changes as the result of steroid treatment. Many children were reported as suffering from teasing and bullying as a result of these changes. In addition children's activities and schooling were described as being restricted as a result of this illness. Children were described as missing a lot of school due to hospital admissions, clinic visits and being too poorly to attend. Many children were also seen as not being able to join in social activities to the same extent as their peers for the same reasons, as well as being restricted by the physical changes they experience (being overweight and unfit). Changes in children's mood, behaviour and concentration were also described, with a minority showing increased levels

of aggression. A significant number of parents felt that their children's friendships were affected of as a result of one or more of these factors. Parents also reported that some siblings were affected by having a brother or sister with nephrotic syndrome, describing difficulties with feeling jealous or resentful or having to take second place. Some siblings were also thought to worry about their ill brother or sister.

The majority of parents reported difficulties with their work, having to take time off to care for their children, or being unable to work as a result of their child's illness. Fifty percent of the parents described the worst thing about their child having nephrotic syndrome as being the worry about the progress of the illness, the long-term effects and the unpredictability of it. Other effects, such as the difficulties experienced by the child, and the distress of seeing their child suffering and being helpless were also reported. These findings suggest that the difficulties experienced by parents can be wide-ranging, with practical implications for their work, and emotional implications with reports of worrying about their child's experiences and future.

Parents generally did have suggestions for other parents in terms of coping with the illness. Many suggested ways of coping emotionally, for example, 'taking it one day at a time', not letting the illness take over, but also finding other families with similar experiences to be able to discuss relevant issues and seek support. Other parents recommended ways of helping the affected child, talking to their child about what was happening while also treating them as normal. Some families also felt it was important to learn as much about the illness as possible and to discuss the diagnosis, treatment and prognosis in detail with the doctors. Given the unpredictability and complexity of nephrotic syndrome from a medical perspective, it is perhaps difficult for families to feel satisfied with the information that they receive. However, almost all parents thought the medical care that their children received was excellent or good, with only two parents being unhappy with the medical care. Some

parents reported initial difficulties in the diagnosis of the illness and with local hospitals and GPs.

Open-ended questions for the children involved in this study were very general. Children reported being different to their peers mainly due to being restricted in their activities, having to attend hospital or take medication, and looking different as a result of changes in their physical appearance. Similarly, these were reported as the worst things about the illness, along with feeling poorly. These findings again suggest that changes in physical appearance have a large impact on these children.

4.1.3 Psychological Outcome

The first hypothesis of this study predicted that children experiencing nephrotic syndrome and their parents would show higher levels of anxiety, depression and trauma symptoms than the general population. These hypotheses were supported, with the current study indicating higher levels of these psychological symptoms for both parents and children, compared to norms. Mild to moderate levels of anxiety were reported for the majority of parents involved in this study. The HADS is a measure of an adult's general level of anxiety, not in relation to a specific stressor, and the current findings suggest that having a child with nephrotic syndrome increases the likelihood of parents becoming clinically anxious. Parental scores on the IES-R, a measure which does not diagnose post-traumatic stress disorder but identifies levels of trauma symptomatology, were also high with a substantial proportion of this group showing clinically concerning levels of trauma symptomatology. In contrast to this, levels of depression, as measured on the HADS were much lower. A slightly increased vulnerability to depressive symptoms was seen but to a much lesser degree than anxiety and trauma symptomatology. These findings indicate that parents of children with nephrotic syndrome are at increased risk of developing clinically significant levels of

anxiety and trauma-related symptoms. This is a clinically interesting finding given parents' qualitative reports about the unpredictability of the illness, the lack of information and potential isolation.

Children also showed increased levels of anxiety, depression and trauma symptomatology, compared to norms. Fewer children in this study appeared to be anxious compared to their parents, although a substantial number of children reported levels of anxiety symptoms higher than the normal population. In contrast, children were more likely than their parents to describe depressive symptoms, again with substantially more children reporting higher levels of depressive symptoms than would be expected in the normal population (Fleming and Offord, 1990), or for children with other chronic medical conditions (Bennett, 1994). High levels of trauma symptomatology were also reported by many children, with almost half of the sample showing clinically concerning levels of trauma. These findings indicate that children suffering from nephrotic syndrome are at increased risk of developing clinically significant levels of anxiety, depression and trauma-related symptomatology.

Parental reports of children's strengths and difficulties were also obtained. Total difficulties scores indicated that children with nephrotic syndrome are reported by parents to suffer from significantly more difficulties than the normal population. In particular, emotional symptoms were reported by almost half of all parents, as well as significantly higher levels of conduct problems, hyperactivity and peer problems. These findings fit well with children's own reports of difficulties as described above. It is of interest to note that parents reported their children as showing good pro-social behaviours, slightly better than would be expected in the general population. This suggests that the experience of nephrotic syndrome has not affected children's ability to learn how to interact and behave appropriately with other people.

The second hypothesis predicted that child levels of anxiety, depression and trauma symptoms would be correlated with parental levels of the same symptoms. Again this hypothesis was supported with moderate positive correlations for anxiety, depression and trauma symptoms ranging. The moderate strength of these relationships is likely to reflect differences in the frequencies of high levels of these symptoms (i.e. parents tended to show high rates of anxiety, while children showed higher levels of depression). However, they do indicate that there are significant relationships between parental psychological symptoms and child psychological symptoms. If parents are showing high levels of symptomatology then children are also likely to show increased levels of psychological symptoms, and vice versa.

The third hypothesis predicted that parental reports of their child's difficulties would be correlated with children's own reports of psychological symptomatology. Parental reports of children's overall difficulties, and specifically emotional problems, were moderately correlated with children's anxiety and depression ratings. This suggests that parents' reports of children's emotional difficulties are a reasonable indicator of their child' psychological symptoms as measured by self-report inventories. In addition, parental reports of child difficulties are correlated with parental levels of anxiety and depression. This suggests that parents' perceptions of their child's difficulties are associated with their own psychological state, so that parents who report their children as having difficulties are more likely to be suffering from higher levels of anxiety and depression themselves.

4.1.4 Illness Perceptions

Parents and children both tended to report high levels of symptoms (IPQ Identity), with the majority identifying with more than half of the symptoms included on the IPQ. A strong relationship was seen between parent and child scores on this measure. Parents and children

also tended to agree on the most likely cause of the illness (i.e. a germ or virus, or chance). However it was noted that fewer children identified a cause for the illness than parents did. Parents tended to report high perceived levels of consequences for their child as a result of the illness, and this was significantly correlated with children's perceptions of the consequences of the illness. However, examination of the raw data indicated that children's responses were more varied on this measure of perceived consequences, than parents' responses. In terms of control and curability of the illness, children tended to perceive that they had high levels of control and/or were likely to be cured. Parents also showed a slight trend in this direction but showed more variability in their responses. Parent and child responses on the control/cure sub-scale of the IPQ were significantly correlated although the comparatively low value of this correlation highlights the variability in these responses. Parents and children differed in terms of their perceptions of the duration of the illness. Parents tended to anticipate a long duration, while children appeared to be unsure with a slight tendency to perceive a short duration to their illness.

On the two sub-scales (time-line and control/cure) with low correlations between parent and child ratings, dissimilarity scores were calculated. These indicated that parents were more likely to perceive a longer duration of the illness and lower controllability or curability of the illness. It may be that this difference in illness perceptions increases the likelihood of anxiety symptoms in parents compared to children.

In summary, parents tended to report high levels of symptoms, felt that the illness was either due to chance or a germ or virus, felt that the child suffered from a high degree of consequences, were unsure or were slightly positive about the controllability or curability of the illness, and expected the illness to last for a long time. Children tended to report high levels of symptoms, were unlikely to identify a cause of the illness, reported varying levels

of consequences, felt that the illness was likely to be controllable or curable, and were not sure whether the illness would be of short or long duration.

4.1.5 Illness Perceptions and Psychological Outcome

It was hypothesised that illness perceptions would predict levels of psychological symptomatology. Firstly children's illness perceptions were hypothesised to predict child levels of psychological symptomatology. Multiple regression analyses confirmed this hypothesis. A model incorporating children's scores on the identity (symptoms), time-line, consequences and control/cure sub-scales was found to be predictive of child anxiety, depression and trauma symptomatology. For each of these variables high levels of symptoms and consequences, low levels of control/cure and a short duration of the illness were predictive of poorer psychological outcome. It would seem intuitive that feeling very poorly, having impaired functioning (in terms of daily activities being affected) and feeling helpless in terms of the illness improving, would increase the risk of psychological symptomatology. However, perceiving a short duration of the illness is not so readily interpreted, but may perhaps reflect increases in levels of unpredictability i.e. children are not adjusting to this illness as a chronic or life-long situation to which they must adapt, with the relapsing-remitting nature of the illness resulting in children experiencing nephrotic syndrome as a series of illnesses rather than a chronic condition.

A high score on the identity sub-scale was independently predictive of children's depression scores, and low scores on the time-line and control/cure sub-scales and a high score on the consequences sub-scale were each independently predictive of children's ratings of trauma symptomatology. However, in each of these cases the overall model described above accounted for more of the variance than these independent predictors alone.

Additionally, parental reports of child behaviour were predicted by their children's illness perceptions. High levels of symptoms and consequences, low levels of control cure and a long duration of the illness being predictive of parental reports of high levels of behavioural difficulties. In contrast to the multiple regression model describing children's illness perceptions and psychological symptomatology, this model relies on a long perceived illness duration in its explanation of increased behavioural difficulties. The reason for this is not clear, but it suggests that different mechanisms may underlie the psychological difficulties and the behavioural problems experienced by these children, and that their perception of how chronic their illness is has some bearing on these mechanisms. A high score on the children's identity sub-scale of the IPQ was independently predictive of a high score for parental reports of total difficulties with child behaviour, suggesting that levels of physical symptoms are relevant to children's development of behavioural problems. This finding is relevant to one of the primary issues raised by the open-ended questions, with reports of children experiencing difficulties when their physical appearance changes and they gain weight.

Parents' illness perceptions were also hypothesised to predict parental levels of psychological symptomatology. Multiple regression analyses also confirmed this hypothesis. A model incorporating parents' scores on the identity (symptoms), time-line, consequences and control/cure sub-scales was found to be predictive of higher levels of parent anxiety, depression and trauma symptomatology. Again, high levels of symptoms and consequences, low levels of control/cure and a short duration of the illness were predictive of psychological outcome.

Independently, high levels of symptoms and consequences were each predictive of high anxiety levels for parents. High scores on the consequences sub-scale were also independently predictive of high levels of parental depression and trauma. However, in each

of these cases the overall model described above accounted for more of the variance than these independent predictors alone.

Parental reports of child behaviour were also considered within this model of parents' illness perceptions. Since child gender was previously found to affect parental reports of behaviour difficulties this variable was also included in the model. High levels of symptoms and consequences, low levels of control cure, a long duration of the illness and the child being a boy were predictive of parental reports of difficulties with children's behaviour. Independently, the child being male was predictive of high ratings of behavioural difficulties and suggests that boys with nephrotic syndrome are more vulnerable than girls to developing behaviour problems. However, the multiple regression model incorporating illness perceptions and child gender explained more of the variance in behaviour difficulties scores than child gender alone.

Overall, it was found that illness perceptions were predictive of psychological symptomatology in both parents and children. High levels of perceived symptoms and/or consequences and low levels of perceived controllability or cure were associated with increased levels of anxiety, depression and trauma symptomatology.

Dissimilarity between parent and child dyad illness perception ratings were hypothesised to predict parent and child levels of psychological symptomatology. However, strong correlations between parent and child perceptions of identity (symptoms) and consequences resulted in these two sub-scales being omitted from this part of the analysis. Therefore multiple regression analyses included only the time-line and control/cure sub-scales. This model did not predict either parent or child levels of psychological symptomatology.

4.2 FINDINGS IN RELATION TO THE LITERATURE

4.2.1 Children

The literature relating to childhood chronic illness indicates that children suffering from such an illness are more likely to suffer from psychological and adjustment problems (e.g. Eiser *et al.*, 1995). The findings from the current study support this indication, with children suffering from nephrotic syndrome showing higher levels of anxiety, depression and trauma symptoms than would be expected in the normal population. As noted by Wallander (1998) this does not necessarily represent the majority of the population studied (i.e. less than 50%) but the number of children suffering such difficulties is much greater than would be found amongst healthy children. Eiser (1990) describes a study which identified children with chronic illness as being twice as likely as healthy children to develop psychiatric disorder but no more likely to become socially maladjusted. This finding is supported in the current study in which parental reports of children's behaviour identified emotional and behavioural difficulties, but no difficulties with pro-social behaviour.

The high rates of trauma symptomatology found in the current study are very similar to those reported in childhood cancer patients (Stuber *et al.*, 1994a). Stuber et. al. (1994a) report mild to moderate levels of trauma symptoms in almost half of the children in their study, while the current study identified a very similar proportion of children showing either clinically diagnostic levels of symptoms or levels indicating 'cause for concern'. This area of traumatic stress in childhood chronic illness appears to have been one that has been largely neglected, although recognition of post-traumatic stress disorder (PTSD) in children (e.g. Di Gallo *et al.*, 1997; Yule, 1992) and medical patients (Jones, 1998) is increasingly being recognised. However, the current study used a simple screening measure that is not recommended as a diagnostic tool, and this suggests that further research to clarify the

experience and theoretical concept of 'post-traumatic stress' in an ongoing chronic illness would be essential to fully understand this finding. The fact that children with nephrotic syndrome will continue to have relapses and invasive treatments that could be considered cumulatively traumatic, does not fit well with a definition of PTSD that requires experience of a specific past event or events that are outside the realms of an individual's normal experience and which cannot realistically be expected to recur. These children in contrast, may be experiencing post-traumatic symptoms and realistically expecting the trauma to be repeated in the future.

The literature examining childhood chronic illness identifies a number of potential factors that may influence children's psychological symptomatology, for example, the severity of the illness. In the current study, an objective rating of severity was not utilised, as childhood nephrotic syndrome does not conform to such a linear concept. As described earlier, nephrotic syndrome sub-types follow an unpredictable relapsing-remitting course with highly individual presentations related to systemic disease progression, and treatment patterns and side-effects. The type of treatment currently being received could be considered as one indicator of the current severity of the illness, and parents of children receiving steroids were found to perceive the illness as having more symptoms, a longer duration and more serious consequences. However, type of treatment did not have a direct, significant impact on psychological outcome for either children or parents. The type of treatment in the case of childhood nephrotic syndrome could be considered as having a direct effect on other influential factors. In particular, steroids affect children's physical appearance and can restrict their ability to participate in activities.

Research focusing on children with cancer indicates that visible and serious effects of treatment (Greenberg *et al.*, 1989) are likely to increase children's vulnerability to depressive symptoms. Eiser *et al* (1995) also included physical appearance, interference with activity,

peer rejection, integration in school, family relationships, anxiety about symptoms, recurrence of disease and impact of treatment as variables that contributed to children's experience of the illness. Interestingly, these variables were mentioned relatively frequently in the open-ended questions of the current study. It seems possible that the high frequency of negatively perceived physical appearance changes, restricted activities, relationship difficulties, the frequent relapses typical of nephrotic syndrome and the high impact treatment of steroids significantly increases the psychological risk of childhood nephrotic syndrome.

As suggested by Wallander and Varni (1998) it may be disease-specific perceived stress, rather than aspects of the disease or treatment itself, that is associated with psychological and behavioural difficulties. This suggestion fits well with the current findings which indicate that illness perceptions are highly predictive of psychological outcome, with high levels of symptoms and consequences, and low levels of controllability that predict poor outcome in both children and their parents. The relationships between severity of the illness, treatment per se, treatment side-effects and psychosocial variables are very complex, and it is likely that they all impact on one another. The culmination of all these factors may determine both child and parent illness perceptions, which in turn appear to be useful predictors of psychological vulnerability.

4.2.2 Parents

The research evidence described earlier suggests that parents may also be vulnerable to psychological difficulties as a result of their child suffering from a chronic illness (e.g. Cadman *et al.*, 1991). The current study indicates that parents of children with nephrotic syndrome are more likely than the general population to suffer from anxiety and trauma symptoms. Significant relationships were identified between parent and child reports of

psychological symptoms, and highlight the importance of considering family responses to childhood illness. Stuber (1996a) suggests that parents may be more severely affected as they are more likely to be aware of the dangers posed by the illness and treatment. However, the current study found similarly high levels of trauma symptomatology for both children and parents. In contrast to Stuber's work the current study also found that parent and child levels of post-traumatic stress symptoms were correlated. This suggests that the difficulties experienced by parents and children in the current population may have been very similar.

Factors influencing parental and family psychological adjustment are not well understood or clearly documented. However, similar to Wallander and Noojin (1995) the open-ended questions included in the current study identified parents as finding the effects on the child and the child's experiences and situation (e.g. restricted activities and effects on schooling) particularly difficult and stressful. Practicalities such as hospital admissions, clinic visits and administering medications were also described, but not so often. In addition, half of the parents involved in this study described the worst thing about the illness as being the unpredictability of it and worries about the future.

Something that is rarely mentioned in the literature is how the unpredictability of an illness may impact on parent and child psychological functioning. With childhood nephrotic syndrome it is particularly difficult to predict the course of the illness and treatments used. Although the majority of children will not suffer from kidney failure, this 'worst case scenario' cannot be ruled out in most cases. As mentioned above, many parents commented in the open-ended questions that it was very difficult to cope with "not knowing" what would happen in the long-term. However, children did not seem to mention this aspect of their illness. Quantitative analysis of these comments was not completed in the current

study, but it may be that this strong feeling of unpredictability in parents is somehow related to the increased prevalence of anxiety among parents compared to their children.

4.2.3 The Illness Perceptions Model

The illness perceptions model was utilised in the current study to investigate whether parents' and children's illness perceptions were related to psychological outcome. It was found that parent illness perceptions were predictive of parent psychological outcome and child illness perceptions were predictive of child psychological outcome. These findings support Weinman and Petrie's (1997) suggestion that illness perceptions will affect coping responses, adaptation and adjustment to illness. Given the scarcity of literature relating to whether children's illness perceptions have an effect on their emotional and behavioural responses to chronic illness, the current study provides new information suggesting that this may be the case. Similar to Moss-Morris *et al.*'s (1997) study involving adults with chronic fatigue syndrome, a strong illness identity (i.e. high levels of symptoms), lack of control and serious consequences were predictive of poor psychological adjustment in children with nephrotic syndrome and their parents.

Similar to Heijmans (1999) comparisons for patients and carers, the current study found that parent and child scores on the time-line sub-scale were not correlated. However, Weinman (1996) found that the identity sub-scale, and Heijmans (1999) found that the consequences sub-scale were not correlated for patient and carer scores, whereas the current study found a low correlation on the control/cure sub-scale. It was hypothesised that similar to Heijmans (1999) study with patients and spouses, differences on illness perception sub-scales would predict psychological outcome for children and parents. However, this was not the case in the current study. The reasons for this were not clear from the current study, but it may be that children's understanding and perceptions of the illness are determined by their

developmental level and they may not be in any conflict with their parents as to how they perceive the illness. In addition, parents may feel that it is beneficial for their children to perceive the illness differently to how they themselves perceive it.

4.2.4 Comparison with Previous Research on Childhood Nephrotic Syndrome

The current study provides evidence that is in contrast to that of Vance and colleagues (1983;1980), who concluded that the impact of nephrotic syndrome was less serious than they had anticipated. The current study suggests that the psychological impact of childhood nephrotic syndrome can be very serious, and affects a large number of children suffering from the illness as well as their parents. The reasons for this discrepancy may be related to the areas addressed by the studies. The current study focused on psychological symptomatology in terms of anxiety, depression and trauma in parents and children. Vance and Pless (1983) investigated children's 'self-perceptions', and relationships with peers, home, teachers and school. In addition, Vance *et al.* (1980) found that compared to a control group, families with a child suffering from nephrotic syndrome experienced significantly limited travel. This was an area that was mentioned in responses to the open-ended questions of the current study, but far less frequently than for example, impacts on parents' working experience, such as, taking time off, using annual leave for hospital admissions and general worry and anxiety for family members. These areas were not directly assessed by Vance *et al.* (1980), and highlights the value of the qualitative information elicited from this population. The open-ended questions for parents in the current study also focused on siblings' experiences and identified that the majority did not suffer from difficulties, although there were concerns about siblings feeling jealous or resentful as well as worrying about their brother's or sister's health and well-being. This supports the suggestions made by Vance *et al.* (1980) that siblings of children with nephrotic syndrome may be a population that are vulnerable to increased psychological difficulties.

4.3 ADVANTAGES AND DISADVANTAGES OF THE CURRENT STUDY

The current study focused on a total population of families in which a child between the ages of seven and eighteen years attends a national clinic for childhood nephrotic syndrome. A good return rate of questionnaires resulted in forty-seven percent of this total population being included in the statistical analysis. It is worth noting, however, that a number of families known clinically to the medical and psychology services at this clinic did not respond to requests to be involved in this study. It was considered that these families, who are known to be having clinically significant difficulties coping with this illness, may have found it too difficult (both in terms of describing their difficulties and finding the time to complete the questionnaire) to be involved in the study. For other families it was known that the child suffering from nephrotic syndrome had been in remission for more than a year, and these non-responders may not have wanted to consider their past experiences of the illness. Alternatively they may have felt that it was no longer relevant to consider the possible difficulties that they experienced, as the child is currently well. This suggests that those families that did respond may represent a 'middle group' who are neither extremely well nor extremely ill. Therefore the respondents in this study could be considered as representative for the majority of families with a child suffering from nephrotic syndrome. However, there may be families who are suffering from greater difficulties than those described here, as well as families who are experiencing no difficulties at all as a result of this illness.

There was a strong bias towards mothers completing the parental questionnaires, with only six fathers responding, perhaps due to mothers being the main carer of the affected child. Few single parents returned questionnaires, whether this is typical of the current population is not known, although it may be that the practical difficulties of completing a questionnaire restricted the number of single parents who felt able to respond. Children of all ages completed the questionnaires, although fewer older adolescents (aged seventeen and

eighteen years) responded. Possible explanations for this include the nature of the questions being inappropriate for this older age group, or adolescents of this age being unwilling to discuss their difficulties. The age at which children received a diagnosis of nephrotic syndrome was most likely to be before five years. This would be expected given that the highest incidence of childhood nephrotic syndrome is within the age range of two to five years (Haycock, 1994).

The current study was designed as an exploratory investigation into a rare illness that has received very little research attention. The sample size was relatively small, restricting analyses, for example, of age effects and illness-type. However, the current sample represents a large proportion of a small population. In addition, it could be argued that the use of questionnaires is not as valid as, say, objective observations or detailed interviews, but the focus of the current study was to obtain subjective self-report information from as many families as possible. This provided a broad perspective on the experiences of families in which a child has nephrotic syndrome. Clearly, responding to a postal questionnaire results in a self-selected sample, but the fact that nearly half of all the families at the clinic responded to the questionnaire, suggests a relatively representative sample, even though as noted earlier the most severely affected families are known not to have responded. The amount of information collected through the questionnaires was also substantial, providing information about anxiety, depression, trauma, illness perceptions, physical effects of the illness and other psychosocial factors. Therefore this methodological approach provided a great deal of information from a substantial proportion of the childhood nephrotic syndrome population registered at a national clinic. It should be noted that given the large number of statistical analyses that were completed there is an increased risk of Type I errors and therefore the results of this study should be considered with caution.

The current study could be criticised for not including a control or comparison group. However, given that there is virtually no information concerning the psychological outcome for children with nephrotic syndrome and their parents it was considered important to establish areas that required investigation. In addition, the use of standardised tools allowed for some comparison with levels of psychological symptomatology in the general population. Clearly, future research in this area would best include suitable comparison groups, ideally including comparison with healthy controls and children with other chronic illnesses.

An advantage of the current study is that it incorporated open-ended questions that yielded information about families' own descriptions of the difficulties that they faced. This approach identified the need to consider a variety of factors when considering the psychological sequelae of this illness.

The cross-sectional nature of this study could also be argued to be a less than ideal methodological approach. It may be that the children and parents responded to the questionnaires when the child was particularly ill or when they were having particular difficulties. It may also be that the symptoms reported are temporary and will not result in long-term difficulties. However, the nature of childhood nephrotic syndrome is that it is a relapsing/remitting illness that commonly lasts for many years and 90% of the children in the current study were identified as having had the illness for more than two years. Longitudinal information would be of value to identify whether there are changes in children and parents' illness perceptions and psychological difficulties as the illness progresses through recurrent phases of relapse and remission.

The standardised measures utilised in the current study were of value in providing clinical cut-offs and norms for the general population. However, the IES-R and IES-8 are known to

be very simple measures of reports of trauma symptoms and do not directly assess post-traumatic stress disorder. Therefore, further investigation is required to clarify the implications of the current findings. The illness perceptions questionnaire could be considered a useful tool in the context of the current study, providing valuable information about how parents and children perceive a chronic childhood illness, and acting as predictor of psychological outcome in both children and parents. For both parents and children the Illness Perceptions Questionnaire showed low levels of internal reliability for the control/cure sub-scale. This has been reported in a previous study involving children (Curson, 1998) and suggests the need to further validate the children's version of the IPQ. However, this low level of internal reliability has not been reported in previous studies with adults and suggests that this scale may need to adapted for the current population. Within the current study the low internal reliabilities for this sub-scale may be due to the wide range of issues that the items address, in the context of nephrotic syndrome. The unpredictable nature of the illness itself may result in parents and children responding inconsistently to this group of items. For example, parents may expect the illness to improve in time (medically, this is reported as likely in the majority of cases) and gain a high score for this control/cure item. However, they may also feel that treatment will not be effective in curing their child's illness (as it is made clear by medics that treatment is to control symptoms not to cure the illness) and gain a low score for this control/cure item. It is perhaps for this reason that items within the control/cure sub-scale do not correlate highly. Further development of this sub-scale, would therefore be highly recommended for use with families experiencing childhood nephrotic syndrome.

Despite the difficulties with the IPQ control/cure sub-scale described above, the illness perceptions model was found to be of value in the current study. It provided information about how parents and children experience and perceive the child's illness and treatment, and how this might relate to psychological symptomatology. Development of a theoretical

approach for working with children with nephrotic syndrome would appear to be enhanced by using this illness perceptions approach to consider the cognitive dimensions of the illness experience for both children and parents. Further, the impact of these cognitions being predictive of psychological sequelae could be usefully explored within the context of this model. Overall, the illness perceptions model appears to be useful with good explanatory power that needs further research, but with adjustment to the research tools it could be a versatile and relatively powerful model.

4.4 Research and Clinical Implications of the Current Study

The research implications of the current study include the need to expand and adapt current methods for investigating childhood chronic illness to fully understand childhood nephrotic syndrome, an illness which follows an unpredictable and idiosyncratic course. The use of qualitative methods to consider the range of difficulties faced by the families appears to be a valuable approach which could in turn be utilised to develop shorter quantitative approaches for working with a large proportion of this population. The use of open-ended questions in the current study indicated that factors such as changes in physical appearance, school attendance and restricted activities must be taken into account when considering the experiences of children with nephrotic syndrome.

The prevalence data derived from this study suggests that children with nephrotic syndrome, and their parents, show increased vulnerability to psychological symptomatology. However, it must be stressed that less than half of the population studied reported clinically significant levels of difficulties i.e. experiencing nephrotic syndrome does not necessarily lead to psychological sequelae, but appears to increase the risk. The clinical significance of the statistical relationships between parent and child illness perceptions and psychological symptoms and the predictive power of illness perceptions is less clear, but is suggestive of

the need to explore further the interactions betweeen cognitions about illness and psychological adaptation.

The increased levels of psychological symptoms that were identified in the current study have clinical implications for developing treatment strategies and service provision. Children appeared to show normal levels of pro-social skills, but generally internalised their difficulties showing anxiety and depression, becoming isolated and occasionally showing 'out of character' problems such as sporadic aggression (attributed to medication side-effects). The qualitative data suggests that changes in appearance, missing school and being unable to participate fully in activities are major factors affecting most of the population. These factors may contribute to such difficulties as children being teased and bullied, and children's self-confidence and relationships with peers and family being affected. For parents, who showed high levels of anxiety, the qualitative data also highlighted the unpredictability of the illness and the associated worries regarding the course of the illness and prognosis. The open-ended questions identified many parents as wanting more information about the illness and support groups where families could share their experiences. Such information suggests that it would be of great value to provide detailed educational information, in the form of written or video presentations and to provide opportunities for support groups to be established. In addition, the availability of psychological support to target anxiety, depression and trauma symptoms, in both children and parents, could be considered essential, as would the development of preventative strategies for new and returning patients.

4.5 FURTHER RESEARCH

This exploratory study has provided evidence of significant psychological difficulties amongst children with nephrotic syndrome, and their parents. Given its exploratory nature

many areas requiring further research have been identified. The development of appropriate methods and tools for this population is required to confirm the findings of this study and establish the full implications of these findings. The clinical implications discussed above also require further research. Families requested further information about the illness, and availability of support groups. It would be of great value to provide these facilities and monitor their impact on the current population and future populations, in terms of their psychological adjustment to the illness. The high levels of trauma symptomatology identified in the current study suggest the urgent need for research to establish the nature of these symptoms and to consider treatment and prevention issues. In addition, prevention and treatment strategies for children and parents developing anxiety and depression symptoms need to be implemented and researched to establish their efficacy.

4.6 CONCLUSIONS

This study suggests that childhood nephrotic syndrome increases children's risk of developing anxiety, depression and trauma symptomatology, and increases parents' risk of developing anxiety and trauma symptomatology. Factors such as changes in the child's physical appearance, restricted activities, absence from school and difficulties coping with the unpredictability of the illness were identified as problems faced by a large proportion of the population. The development of psychological sequelae was found to be predicted by child and parent illness perceptions.

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APPENDIX 1

The Guy's, King's College and St Thomas' Hospitals' Medical and Dental School

Guy's Campus
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London SE1 9RT

Guy's Research Ethics Committee
Chairman: Professor Steven Sacks
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Tel: 0171 955 5000 Ext. 5181
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KING'S College LONDON
Founded 1829
University of London

07 December 1999
99/11/05

Dr Melinda Edwards
Paediatric Psychology Department
Newcomen Centre
Guy's Hospital

Dear Dr Edwards

Re: 99/11/05 A pilot study investigating children's and parents' perceptions of childhood nephrotic syndrome and associated psychological distress
Information Sheet for Families and young people for interview and postal questionnaire use, and Consent form, *including consent form for young people aged 16-18 years*
Experiences of Nephrotic Syndrome Questionnaire for parents and for children
I.P.Q. Parents' Version, Strengths & Difficulties Questionnaire, HADS, Impact of Events Scale - Revised
I.P.Q. Child & Adolescents' Version, SCAS, Birleson Depression Scale Questionnaire, IES
JENNIFER LIMOND

Thank you for the letter dated 2 December 1999 from yourself and Jenny Limond in response to my letter of 26 November 1999, and for sending a consent form for young people aged 16-18 years. Your letter answers the Committee's concerns and the study has Guy's Research Ethics Committee approval.

All consent forms in this study need to carry the Ethics Committee reference number and version number/date.

Permission is granted on the understanding that:

i) Any ethical problem arising in the course of the project will be reported to the Committee;

ii) Any change in the protocol or subsequent protocol amendments will be forwarded to the Committee using the enclosed form. The principal investigator should see and approve any such changes and this needs to be indicated in the forwarding letter to the Committee.

iii) All serious adverse events must be reported within 1 week to the Ethics Committee, at the same time indicating that the principal investigator has seen the report and whether or not they feel it poses any new ethical or safety issues.

iv) A brief report will be submitted one year after commencement, thereafter annually, and after completion of the study. Continuing approval is dependent upon this report.

v) Approval is given for research to start within 12 months of the date of application. If the start is delayed beyond this time, applicants are required to consult the Chairman of the Committee. **Please notify the Committee of the date of commencement for record purposes.**

A list of members in attendance at the 24 November 1999 meeting is enclosed.

Yours sincerely

Steven H Sacks
Chairman of the Guy's Hospital Research Ethics Committee

Please reply to: **Guy's Research Ethics Committee**
Department of Nephrology & Transplantation
Floor 5 Thomas Guy House, Guy's Hospital, London SE1 9RT

APPENDIX 2

NEWCOMEN CENTRE

Tel No: 0171 955 5000 Ext: 5672
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GUY'S & ST THOMAS' HOSPITAL TRUST

GUY'S HOSPITAL
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LONDON SE1 9RT

INFORMATION SHEET FOR FAMILIES TAKING PART IN A STUDY TO EXPLORE CHILDREN'S AND PARENTS' EXPERIENCES OF CHILDHOOD NEPHROTIC SYNDROME (INTERVIEWS)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

We are interested to learn as much as we can about families' experiences of childhood nephrotic syndrome and its treatment. We hope to use this information to help us develop our clinical practice and provide the best quality of care and information for all children and families who experience this illness.

We would be grateful if you, and your child, could spare some time to talk to us and answer some questions, our interview should last between 30 minutes and one hour. We are interested to find out how nephrotic syndrome has affected you and your child and how you have coped with this. Your family has been chosen to participate in this part of the study as your child has experienced steroid resistant nephrotic syndrome and multiple treatments and is therefore likely to have a great deal of experience and information which would be helpful to our research. After interviews have been completed this research will use the information gathered to ask other families to complete a number of questionnaires relating to their experiences of nephrotic syndrome and how they feel about this.

We hope to be able to arrange a time which is convenient for you to meet us first, and then if you agree, for us to talk with you and your child. Our interview will be treated with complete confidentiality. If you consent to take part in the research your child's medical records may be inspected by the researchers for purposes of analysing the results. Your name, however, will not be disclosed outside the hospital.

We respect that coping with this illness can be very difficult and that some children and families prefer not to talk about it and we would certainly not place any pressure on you or your child to do so. If you prefer not to take part in the study or if you agree and then wish to withdraw you are, of course, completely free to do so. If you choose not to take part this will not affect your child's care either now or in the future. If you agree to help us with the study we will explain it and discuss it with you in person before we start the interview.

This study is being carried out with the full approval of your Consultant Paediatric Nephrologist, and the results of this research are likely to be published early in the year 2001. Results will also be presented to staff working with children with nephrotic syndrome in order to contribute to the care of children with this illness. Families participating in this study will not be identified in any report or publication.

If you require any further information please contact **Melinda Edwards, Consultant Clinical Psychologist**, or **Jenny Limond, Psychologist in Clinical Training,** at Guy's Hospital on 0171-955 5000 ext.5672.

This information sheet is for you to keep. Thank you very much for your help.

APPENDIX 2

EXPERIENCES OF NEPHROTIC SYNDROME: STAFF INTERVIEW

Illness Perceptions and Experiences

1. What is the experience of having a child with nephrotic syndrome like for families?

2. What symptoms do children with nephrotic syndrome suffer from?

3. What do parents and children think has caused, or contributed to, the illness?

4. How long do families appear to think the child's illness will last? (Acute/Chronic/Cyclic)

5. Do parents appear to think there is anything they or their child can do to help them recover? If so, what?

6. When a child has high levels of protein in their urine, what do families think are the reasons for this?

7. How serious (i.e. severe/dangerous) do families generally think their child's illness is?

8. How does nephrotic syndrome appear to affect children's ways of life (everyday activities, general health, independence and family)?

    8a. How does it appear to affect how they feel about themselves?

    8b. Do you think there are there any other consequences?

9. Do you think it affects children's mood? If yes, how?

    9a. In what way do you think other people see the children differently as a result of this illness, if at all?

    9b. In what way do you think other people treat the children differently because of this illness, if at all?

    9c. In what way do you think the children would act differently if they did not have this illness, if at all?

10. Does having nephrotic syndrome appear to affect children's schooling?

11. Does having nephrotic syndrome appear to affect children's friendships (including siblings)?

12. Does having nephrotic syndrome appear to affect parents' ways of life?

13. Do you think that children having nephrotic syndrome changes the way parents feel about things? If so, how?

APPENDIX 2

13a. Does it appear to affect how much parents worry about things in general?

13b. Does it appear to affect parents' mood? If yes, how?

13c. Do parents appear to think about their child's illness a lot?

13d. Do parents appear to still enjoy things in life?

13e. In what way do you think parents are seen differently by other people because of their child's illness, if at all?

13f. In what way do you think other people treat parents differently because of their child's illness, if at all?

13g. In what way do you think parents would be different if their child did not have this illness, if at all?

14. What do you think parents would say have been the worst things about having a child with nephrotic syndrome?

15. If parents were asked to advise other parents on how best to cope with this illness, what do you think they would you suggest?

16. How do you think parents feel about the medical care that their children have received for nephrotic syndrome?

17. Do you have any other comments you would like to add?

APPENDIX 2

EXPERIENCES OF NEPHROTIC SYNDROME: PARENTS' INTERVIEW

Background Information

1. Name of child
2. Age of child
3. Age of parents/guardians
4. Occupations of parents/guardians
5. Number and ages of brothers and sisters
6. When was your child first diagnosed with nephrotic syndrome?
7. How many times has your child been hospitalised as a result of nephrotic syndrome?
8. What medications is your child currently taking for nephrotic syndrome?
9. Has anyone else in your family ever suffered from nephrotic syndrome? If yes, who

Illness Perceptions and Experiences

10. What has the experience of having a child with nephrotic syndrome been like for your family?
11. What symptoms of nephrotic syndrome does your child suffer from?
12. In your opinion what has caused, or contributed to, your child's illness?
13. How long do you think your child's illness will last? (Acute/Chronic/Cyclic)
14. Do you think there is anything you or your child can do to help him/her recover? If so, what?
    - 14a. Do you think there is anything else that can happen to help him/her recover? If so, what?
15. When your child has high levels of protein in their urine, what do you think are the reasons for this?
16. How serious (i.e. severe/dangerous) do you think your child's illness is now?
17. How has nephrotic syndrome affected your child's way of life (everyday activities, general health, independence and family)?
    - 17a. How has it affected how they feel about themselves?
    - 17b. Are there any other consequences?

APPENDIX 2

18. Do you think it has affected their mood? If yes, how?

    18a. In what way do you think other people see your child differently as a result of this illness, if at all?

    18b. In what way do you think other people treat your child differently because of this illness, if at all?

    18c. In what way do you think your child would act differently if they did not have this illness, if at all?

19. How has having nephrotic syndrome affected your child's schooling?

20. How has having nephrotic syndrome affected your child's friendships (including siblings)?

21. How has nephrotic syndrome affected your way of life?

22. Do you think that your child having nephrotic syndrome has changed the way you feel about things? If so, how?

    22a. Has it affected how much you worry about things in general?

    22b. Has it affected your mood? If yes, how

    22c. Do you think about your child's illness a lot?

    22d. Do you still enjoy things in life as much as you used to?

    22e. In what way do you think other people see you differently because of your child's illness, if at all?

    22f. In what way do other people treat you differently because of your child's illness, if at all?

    22g. In what way do you think you would be different if your child did not have this illness, if at all?

23. What do you think have been the worst things about your child having nephrotic syndrome?

24. If you were asked to advise other parents on how best to cope with this illness, what would you suggest?

25. How have you felt about the medical care that your child has received for nephrotic syndrome?

26. How would you describe your child?

27. Do you have any other comments you would like to add?

APPENDIX 2

EXPERIENCES OF NEPHROTIC SYNDROME: CHILDREN'S INTERVIEW

1. What has it been like having nephrotic syndrome?

2. What has it been like for your family?

3. What sort of symptoms do you get? (what does nephrotic syndrome do to you?)

4. What do you think made you get nephrotic syndrome?

5. How long do you think your illness will last? (acute/chronic/cyclic)

6. Do you think there is anything you can do to make yourself better?

    6a. Do you think there is anything else that can happen to help you get better?

7. When you have high levels of protein in your urine, what do you think might have made this happen?

8. How serious (bad) do you think your illness is?

9. Has being ill affected your mood, how happy or sad you are?

    9a. What sort of things do you feel sad about? (including things other than your illness)

    9b. What sort of things do you worry about? (including things other than your illness)

    9c. Do you think about your illness a lot?

    9d. What sort of things do you enjoy?

    9e. What would things be like if you did not have nephrotic syndrome?

    9f. Do you think other people think you are different because of your illness?

    9g. Do you think that other people treat you differently because of your illness?

    9h. Do you think you would do things differently if you did not have this illness?

10. What do you think have been the worst things about having nephrotic syndrome?

11. How has having nephrotic syndrome affected being at school?

12. How has having nephrotic syndrome affected your friendships (including with brothers and sisters)?

13. If you were asked to tell other children with nephrotic syndrome what they could do to feel better, what would you say?

APPENDIX 3

NEWCOMEN CENTRE

GUY'S & ST THOMAS' HOSPITAL TRUST

Tel No: 0171 955 5000 Ext: 5672
Fax No: 0171 955 4950

GUY'S HOSPITAL
ST THOMAS STREET
LONDON SE1 9RT

ME/JL/jc
Date as postmarked

Dear Parent

We are carrying out a study to help us find out more about nephrotic syndrome and how it affects children and their families. We hope to use this information to provide better care and support for families who have a child with nephrotic syndrome. We are therefore asking families who have a child who has or has had this illness to participate in this study. We would be extremely grateful if you would complete the enclosed questionnaires and return them to us in the envelope provided.

There is a questionnaire for your child with nephrotic syndrome to complete. These questions are widely used and have been designed for children of all ages. However, some younger children may need a little help with some of the questions. If any question is too difficult for your child it is fine if they leave it blank, or if you want to help them with that particular question.

There is also a questionnaire for one parent to complete. If there are any other adults in the family who would be willing to complete this questionnaire, we would be very interested to hear their views. If this is the case please write to Melinda Edwards or Jenny Limond at the Newcomen Centre or call on 0171 955 5000 ext: 5672 and we will send another copy of the questionnaire.

Please do not hesitate to contact us if you have any concerns or queries about this research.

Many thanks for your help.

Yours sincerely

Melinda Edwards
Consultant Clinical Psychologist

Jenny Limond
Psychologist in Clinical Training

enc

APPENDIX 3

NEWCOMEN CENTRE

Tel No: 0171 955 5000 Ext: 5672
Fax No: 0171 955 4950

GUY'S & ST THOMAS' HOSPITAL TRUST

GUY'S HOSPITAL
ST THOMAS STREET
LONDON SE1 9RT

INFORMATION SHEET FOR FAMILIES TAKING PART IN A STUDY TO EXPLORE CHILDREN'S AND PARENTS' EXPERIENCES OF CHILDHOOD NEPHROTIC SYNDROME

POSTAL QUESTIONNAIRES

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

We are interested to learn as much as we can about families' experiences of childhood nephrotic syndrome and its treatment. We hope to use this information to help us develop our clinical practice and provide the best quality of care and information for all children and families who experience this illness.

We would be grateful if you, and your child, could spare some time to complete the questionnaires enclosed. One set of questionnaires is for your child to complete and two copies of questionnaires for parents/guardians to complete are also enclosed. We are interested to find out how nephrotic syndrome has affected you and your child and how you feel about this.

All the information collected will be treated with complete confidentiality. If you consent to take part in the research your child's medical records may be inspected by the researchers for the purposes of analysing the results. Your name, however, will not be disclosed outside the hospital.

We respect that coping with this illness can be very difficult and that some children and families prefer not to talk about it and we would certainly not place any pressure on you or your child to do so. If you choose not to take part this will not affect your child's care either now or in the future. However, we would be grateful if you would return the blank questionnaires in the envelope provided.

This study is being carried out with the full approval of your Consultant Paediatric Nephrologist and the results of this research are likely to be published early in the year 2001. Results will also be presented to staff working with children with nephrotic syndrome in order to contribute to the care of children with this illness. Families participating in this study will not be identified in any report or publication.

If you require any further information please contact **Melinda Edwards, Consultant Clinical Psychologist**, or **Jenny Limond, Psychologist in Clinical Training,** at Guy's Hospital on 0171-955 5000 ext.5672.

This information sheet is for you to keep.

Thank you very much for your help.

Version 2.3 (99/11/05)

APPENDIX 3

I.P.Q.
PARENTS' VERSION

Please indicate how much you feel that the following *symptoms are part of your child's illness and its treatment.*

SYMPTOM	ALL THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Pain				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Sore Eyes				
Headaches				
Upset Stomach				
Sleep Difficulties				
Dizziness				
Loss of Strength				
Aggression				
Hunger				
Weight gain				
Skin complaints				
Getting hot				
Muscle cramp				
Swelling / puffiness				
Not urinating				
Restlessness				
Poor concentration				

We are interested in your own personal views of how you see your child's illness. Please indicate how much you agree or disagree with the following statements about your child's illness by ticking the appropriate box for <u>each item</u>.

	VIEWS ABOUT YOUR CHILD'S ILLNESS	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP1	A germ or virus caused my child's illness					
IP2	Diet played a major role in causing my child's illness					
IP3	Pollution of the environment caused my child's illness					
IP4	My child's illness is hereditary - it runs in his/her family					

APPENDIX 3

I.P.Q
VIEWS ABOUT YOUR CHILD'S ILLNESS (Continued)

	VIEWS ABOUT YOUR CHILD'S ILLNESS	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP5	It was just by chance that my child became ill					
IP6	Stress was a major factor in causing my child's illness					
IP7	My child's illness is largely due to his/her own behaviour					
IP8	Other people played a large role in causing my child's illness					
IP9	My child's illness was caused by poor medical care in the past					
IP10	My child's state of mind played a major part in causing his/her illness					
IP11	My child's illness will last a short time					
IP12	My child's illness is likely to be permanent rather than temporary					
IP13	My child's illness will last for a long time					
IP14	My child's illness is a serious condition					
IP15	My child's illness has had major consequences on his/her life					
IP16	My child's illness has become easier to live with					
IP17	My child's illness has not had much effect on his/her life					
IP18	My child's illness has strongly affected the way others see him/her					
IP19	My child's illness has serious economic and financial consequences					
IP20	My child's illness has strongly affected the way I see him/her as a person					
IP21	My child's illness will improve in time					
IP22	There is a lot which my child can do to control his/her symptoms					
IP23	There is very little that can be done to improve my child's illness					
IP24	Treatment will be effective in curing my child's illness					
IP25	My child's recovery from his/her illness is largely dependent on chance or fate					
IP26	What my child does can determine whether his/her illness gets better or worse					

APPENDIX 3

Has nephrotic syndrome and/or its treatment affected your child's physical appearance? **Yes / No**

If yes: How has this affected your child?

. . . . . .

How has it affected the way other people treat your child?

. . . . . .

How has nephrotic syndrome and/or its treatment affected your child's activities?

. . . . . .

. . . . . .

How has nephrotic syndrome and/or its treatment affected the other children in your family?

. . . . . .

. . . . . .

How has nephrotic syndrome and/or its treatment affected your child's friendships?

. . . . . .

. . . . . .

How has nephrotic syndrome and/or its treatment affected your child's schooling?

. . . . . .

. . . . . .

How has your child having nephrotic syndrome affected your work and activities?

. . . . . .

. . . . . .

What have been the worst things about your child having nephrotic syndrome?

. . . . . .

. . . . . .

If you were asked to advise other parents on how best to cope with this illness, what would you suggest?

. . . . . .

How have you felt about the medical care that your child has received for nephrotic syndrome?

. . . . . .

APPENDIX 3

YOUR CHILD'S STRENGTHS AND DIFFICULTIES

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
Often has temper tantrums or hot tempers	☐	☐	☐
Rather solitary, tends to play alone	☐	☐	☐
Generally obedient, usually does what adults request	☐	☐	☐
Many worries, often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, down-hearted or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets on better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

APPENDIX 3

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes - minor difficulties	Yes - definite difficulties	Yes - severe difficulties
❑	❑	❑	❑

If you have answered "Yes", please answer the following questions about these difficulties:

How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
❑	❑	❑	❑

Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
❑	❑	❑	❑

Do the difficulties interfere with your child's everday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	❑	❑	❑	❑
FRIENDSHIPS	❑	❑	❑	❑
LEARNING	❑	❑	❑	❑
LEISURE ACTIVITIES	❑	❑	❑	❑

Do the difficulties put a burden on your family as a whole?

Not at all	Only a little	Quite a lot	A great deal
❑	❑	❑	❑

Thank you very much for your help

APPENDIX 3

YOUR EMOTIONAL WELL-BEING

Please read each item and tick the box next to the reply that comes closest to how you have been feeling in the past week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. I feel tense or 'wound up':

- ❑ Most of the time.
- ❑ A lot of the time.
- ❑ From time to time, occasionally.
- ❑ Not at all

2. I still enjoy the things I used to enjoy:

- ❑ Definitely as much.
- ❑ Not quite so much.
- ❑ Only a little.
- ❑ Hardly at all.

3. I get a sort of frightened feeling as if something awful is about to happen:

- ❑ Very definitely and quite badly.
- ❑ Yes, but not too badly.
- ❑ A little, but it doesn't worry me.
- ❑ Not at all.

4. I can laugh and see the funny side of things:

- ❑ As much as I always could
- ❑ Not quite so much now
- ❑ Definitely not so much now
- ❑ Not at all

5. Worrying thoughts go through my mind:

- ❑ A great deal of the time
- ❑ A lot of the time
- ❑ From time to time but not too often
- ❑ Only occasionally

6. I feel cheerful:

- ❑ Not at all
- ❑ Not often
- ❑ Sometimes
- ❑ Most of the time

7. I can sit at ease and feel relaxed:

- ❑ Definitely
- ❑ Usually
- ❑ Not often
- ❑ Not at all

8. I feel as if I am slowed down:

- ❑ Nearly all the time
- ❑ Very often
- ❑ Sometimes
- ❑ Not at all

9. I get a sort of frightened feeling like 'butterflies' in the stomach:

- ❑ Not at all
- ❑ Occasionally
- ❑ Quite often
- ❑ Very often

10. I have lost interest in my appearance:

- ❑ Definitely
- ❑ I don't take so much care as I should
- ❑ I may not take quite as much care
- ❑ I take just as much care as ever

11. I feel restless as if I have to be on the move:

- ❑ Very much indeed
- ❑ Quite a lot
- ❑ Not very much
- ❑ Not at all

12. I look forward with enjoyment to things:

- ❑ As much as I ever did
- ❑ Rather less than I used to
- ❑ Definitely less than I used to
- ❑ Hardly at all

13. I get sudden feelings of panic

- ❑ Very often indeed
- ❑ Quite often
- ❑ Not very often
- ❑ Not at all

14. I can enjoy a good book or radio or TV programme:

- ❑ Often
- ❑ Sometimes
- ❑ Not often
- ❑ Very seldom

APPENDIX 3

How Has Your Child's Illness and its Treatment Affected You

The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you ***during the past 7 days*** with respect to your child's illness and treatment. How much were you distressed or bothered by these difficulties?

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I felt irritable and angry	0	1	2	3	4
5. I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
6. I thought about it when I didn't mean to	0	1	2	3	4
7. I felt as if it hadn't happened or wasn't real	0	1	2	3	4
8. I stayed away from reminders about it	0	1	2	3	4
9. Pictures about it popped into my mind	0	1	2	3	4
10. I was jumpy and easily startled	0	1	2	3	4
11. I tried not to think about it	0	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	2	3	4
13. My feelings about it were kind of numb	0	1	2	3	4
14. I found myself acting or feeling like I was back at that time	0	1	2	3	4
15. I had trouble falling asleep	0	1	2	3	4
16. I had waves of strong feelings about it	0	1	2	3	4
17. I tried to remove it from my memory	0	1	2	3	4
18. I had trouble concentrating	0	1	2	3	4
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart	0	1	2	3	4
20. I had dreams about it	0	1	2	3	4
21. I felt watchful and on guard	0	1	2	3	4
22. I tried not to talk about it	0	1	2	3	4

APPENDIX 3

NEWCOMEN CENTRE

Tel No: 0171 955 5000 Ext: 5672
Fax No: 0171 955 4950

GUY'S & ST THOMAS' HOSPITAL TRUST

GUY'S HOSPITAL
ST THOMAS STREET
LONDON SE1 9RT

INFORMATION SHEET FOR YOUNG PEOPLE TAKING PART IN A STUDY TO EXPLORE CHILDREN'S AND PARENTS' EXPERIENCES OF CHILDHOOD NEPHROTIC SYNDROME

POSTAL QUESTIONNAIRES

You are being invited to take part in a research study. Before you decide it is important for you to read this letter and talk to your family and friends about it if you want to. Ask us if there is anything you do not understand or would like to talk about with us. We are carrying out the study to look at how children feel about having nephrotic syndrome. We would like to ask you to fill in some questionnaires about what it has been like for you and how you are feeling now. We hope the information that young people give us will help us to give the best care possible to all children who have nephrotic syndrome. We would be very grateful if you could spare us some time and take part but you do not have to help us if you do not want to. It is really up to you. All of the information is treated as confidential, no one else will know what you have said to us.

If you would like to talk more about this study, please speak to
Melinda Edwards or **Jenny Limond** at Guy's Hospital on 0171-955 5000 ext 5672.

This information sheet is for you to keep.

Thank you for your help.

Version 1.4 (99/11/05)

APPENDIX 3

Centre Number:
LREC Study Number:
Patient Identification Number for this trial:

CONSENT FORM
FOR YOUNG PEOPLE AGED 16 - 18 YEARS

Title of Project: A Pilot investigating children's and parents' perceptions of childhood nephrotic syndrome and associated psychological distress.

Name of Researchers: Melinda Edwards, Consultant Clinical Psychologist
Jennifer Limond, Psychologist in Clinical Training

Please initial box

1. I confirm that I have read and understand the information sheet dated ..... (version.....) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that sections of any of my medical notes may be looked at by the researchers. I give permission for these individuals to have access to my records. ☐

4. I agree to take part in the above study. ☐

_____
Name of Child

_____ _____ _____
Name of Parent/Guardian Date Signature

1 for family; 1 for researcher

APPENDIX 3

Please try and answer all questions. It doesn't matter if you don't know an answer or don't want to give an answer, just tick the answer you think is closest to how you feel, or leave it blank.

I.P.Q.
CHILD AND ADOLESCENTS' VERSION

Please tick how often you have the following ***symptoms as part of your illness and treatment.***

SYMPTOM	ALWAYS	QUITE A LOT	A LITTLE BIT	NEVER
I am in pain				
I feel sick				
I find it difficult to breathe				
I lose weight				
I feel tired				
I ache				
I get sore eyes				
I get headaches				
I get an upset stomach				
I find it difficult to sleep				
I feel dizzy				
I feel weak				
I lose my temper				
I feel hungry				
I put on weight				
I get bad skin				
I get hot				
I get muscle cramps				
My body swells up / gets puffy				
I stop urinating				
I can't sit still				
I can't concentrate				

We are interested in your own personal views of how you now see your illness. Please indicate how much you agree or disagree with the following statements about your illness.

	VIEWS ABOUT YOUR ILLNESS	DEFINITELY YES	PERHAPS YES	NOT SURE	PERHAPS NO	DEFINITELY NO
IP1	Do you think that bad air caused your illness?					
IP2	Does your illness stop you doing the things your friends do?					

APPENDIX 3

How has nephrotic syndrome made things different for you?

. . . . . .

. . . . . .

. . . . . .

. . . . . .

. . . . . .

What is the worst thing about having nephrotic syndrome?

. . . . . .

. . . . . .

. . . . . .

. . . . . .

. . . . . .

If you had one wish to make things better for you, what would it be?

. . . . . .

. . . . . .

. . . . . .

. . . . . .

. . . . . .

APPENDIX 3

HOW HAVE YOU FELT ABOUT YOUR ILLNESS AND ITS TREATMENT

Below is a list of comments made by people after stressful life events. Please check each item, indicating how often these comments were true for you about your illness and its treatment, during the past seven days. If they did not occur during that time, please tick the 'not at all' box.

	Not at all	Rarely	Some times	Often
1. I thought about it when I didn't mean to	❑	❑	❑	❑
2. I tried to remove it from memory	❑	❑	❑	❑
3. I had waves of strong feeling about it	❑	❑	❑	❑
4. I stayed away from reminders about it	❑	❑	❑	❑
5. I tried not to talk about it	❑	❑	❑	❑
6. Pictures about it popped into my mind	❑	❑	❑	❑
7. Other things kept making me think about it	❑	❑	❑	❑
8. I tried not to think about it	❑	❑	❑	❑

APPENDIX 3

HOW HAVE YOU FELT ABOUT OTHER THINGS (PART 1)

Please tick the box under the word that shows how often each of these things happen to you. There are no right or wrong answers.

	Never	Some times	Often	Always
1. I worry about things	❑	❑	❑	❑
2. I am scared of the dark	❑	❑	❑	❑
3. When I have a problem, I get a funny feeling in my stomach	❑	❑	❑	❑
4. I feel afraid	❑	❑	❑	❑
5. I would feel afraid of being on my own at home	❑	❑	❑	❑
6. I feel scared when I have to take a test	❑	❑	❑	❑
7. I feel afraid if I have to use public toilets or bathrooms	❑	❑	❑	❑
8. I worry about being away from my parents	❑	❑	❑	❑
9. I feel afraid that I will make a fool of myself in front of people	❑	❑	❑	❑
10. I worry that I will do badly at my school work	❑	❑	❑	❑
11. I am popular amongst other kids of my own age	❑	❑	❑	❑
12. I worry that something awful will happen to someone in my family	❑	❑	❑	❑
13. I suddenly feel as if I can't breathe when there is no reason for this	❑	❑	❑	❑
14. I have to keep checking that I have done things right (like the switch is off, or the door is locked)	❑	❑	❑	❑
15. I feel scared if I have to sleep on my own	❑	❑	❑	❑
16. I have trouble going to school in the mornings because I feel nervous or afraid	❑	❑	❑	❑
17. I am good at sports	❑	❑	❑	❑
18. I am scared of dogs	❑	❑	❑	❑
19. I can't seem to get bad or silly thoughts out of my head	❑	❑	❑	❑
20. When I have a problem, my heart beats really fast	❑	❑	❑	❑
21. I suddenly start to tremble or shake when there is no reason for this	❑	❑	❑	❑
22. I worry that something bad will happen to me	❑	❑	❑	❑
23. I am scared of going to the doctor or dentist	❑	❑	❑	❑
24. When I have a problem, I feel shaky	❑	❑	❑	❑

APPENDIX 3

	Never	Some times	Often	Always
25. I am scared of being in high places or lifts	❑	❑	❑	❑
26. I am a good person	❑	❑	❑	❑
27. I have to think of special thoughts (like numbers of words) to stop bad things from happening	❑	❑	❑	❑
28. I feel scared if I have to travel in the car, or on a bus or train	❑	❑	❑	❑
29. I worry what other people think of me	❑	❑	❑	❑
30. I am afraid of being in crowded places (like shopping centres, the movies, buses, busy playgrounds)	❑	❑	❑	❑
31. I feel happy	❑	❑	❑	❑
32. All of a sudden I feel really scared for no reason at all	❑	❑	❑	❑
33. I am scared of insects or spiders	❑	❑	❑	❑
34. I suddenly become dizzy or faint when there is no reason for this	❑	❑	❑	❑
35. I feel afraid if I have to talk in front of my class	❑	❑	❑	❑
36. My heart suddenly starts to beat too quickly for no reason	❑	❑	❑	❑
37. I worry that I will suddenly get a scared feeling when there is nothing to be afraid of	❑	❑	❑	❑
38. I like myself	❑	❑	❑	❑
39. I am afraid of being in small closed places, like tunnels or small rooms	❑	❑	❑	❑
40. I have to do some things over and over again (like washing my hands, cleaning or putting things in a certain order)	❑	❑	❑	❑
41.I get bothered by bad or silly thoughts or pictures in my mind	❑	❑	❑	❑
42. I have to do some things in just the right way to stop bad things happening	❑	❑	❑	❑
43. I am proud of my school work	❑	❑	❑	❑
44. I would feel scared if I had to stay away from home overnight	❑	❑	❑	❑
45. Is there something else that you are really afraid of ?	Yes	❑	No	❑

Please write down what it is

_____

APPENDIX 3

HOW HAVE YOU FELT ABOUT OTHER THINGS (PART 2)

The statements below refer to how you have felt over the past week. There are no right answers but it is important to say how you have felt. Please answer as honestly as you can. Put a tick in the appropriate box. Thank you.

	Most	Sometimes	Never
1. I look forward to things as much as I used to	☐	☐	☐
2. I sleep very well	☐	☐	☐
3. I feel like crying	☐	☐	☐
4. I like to go out to play	☐	☐	☐
5. I feel like running away	☐	☐	☐
6. I get tummy aches	☐	☐	☐
7. I have lots of energy	☐	☐	☐
8. I enjoy my food	☐	☐	☐
9. I can stick up for myself	☐	☐	☐
10. I think life isn't worth living	☐	☐	☐
11. I am good at things I do	☐	☐	☐
12. I enjoy the things I do as much as I used to	☐	☐	☐
13. I like talking with my family	☐	☐	☐
14. I have horrible dreams	☐	☐	☐
15. I feel very lonely	☐	☐	☐
16. I am easily cheered up	☐	☐	☐
17. I feel so sad I can hardly stand it	☐	☐	☐
18. I feel very bored	☐	☐	☐

APPENDIX 4

NEWCOMEN CENTRE

GUY'S & ST THOMAS' HOSPITAL TRUST

Tel No: 0171 955 5000 Ext: 5672
Fax No: 0171 955 4950

GUY'S HOSPITAL
ST THOMAS STREET
LONDON SE1 9RT

ME/JL/jc
Date as postmarked

Dear Parent

We have been carrying out a study to help us find out more about nephrotic syndrome and how it affects children and their families. Many families have already completed forms for us and it is clear that there is a lot we need to learn about the experience of nephrotic syndrome. The information that we have received so far has led us to believe that we could make some important recommendations with regard to the provision of services and resources for families and children. However, because it is such a rare condition, we need to hear from as many families as possible, and so we are sending out our questions a second time.

Some families contacted us to ask if they should complete questionnaires if the child in question has been in remission for a long period. We are interested to hear from all families who have experienced nephrotic syndrome. Possible long-term effects and successful recovery are important for us to understand. If your child is in remission, please answer the questions from the point of view of how you feel about things now.

Other families have contacted us to say that there are other reasons why they do not want to complete the questionnaires. That is absolutely fine and we certainly do not want to cause you or your child any distress. If this is the case we would be very pleased if you could return the blank questionnaires, and if you have any comments you would like to make we would be very interested to hear them.

If you have any queries or concerns about this research please do not hesitate to contact Melinda Edwards or Jenny Limond at the Newcomen Centre, telephone number: 0171 955 5000 ext: 5672.

Many thanks for your help.

Yours sincerely

Melinda Edwards
Consultant Clinical Psychologist

Jenny Limond
Psychologist in Clinical Training
enc

APPENDIX 5

ILLNESS PERCEPTIONS QUESTIONNAIRE – CHILDREN'S VERSION: SCORING SYSTEM

Illness Identity

This sub-scale is scored in the same way as the original IPQ with a score of 1 allocated to each item identified as being experienced by the respondent, irrespective of the frequency at which it is experienced.

Cause, Time-line, Consequences and Control/Cure Sub-scales – Allocation of items and Scoring

Sub-scale	Number of items	Item numbers on IPQ - Children's Version
Cause	11	1 7 8 10 12 16 17 18 21 22 24
Time-line	3	5 ® 14 19 ®
Consequences	6	2 4 6 9 13 ® 25
Control/cure	5	3 ® 11 15 20 23 ®

® = Reversed scoring

All items are scored on a 5-point Likert scale ranging from 1 'Definitely No' to 5 'Definitely Yes', with the exception of those identified as reversed scoring (Items 3, 5, 13, 19 and 23).

As with the original IPQ items comprising the Cause sub-scale are considered to reflect specific causal beliefs and therefore scores cannot be summed to give an overall score.