CHILDREN'S COGNITIVE REPRESENTATIONS OF EPILEPSY

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THESIS ABSTRACT

Epilepsy is a common paediatric neurological disorder. It has been linked with poor psychosocial outcome, though many children with epilepsy show remarkable resilience. Improved methodologies have outlined the contributions of many factors to variance in psychosocial outcome, but inadequate theoretical frameworks mean these findings are difficult to interpret.

Researchers are increasingly considering cognitive-perceptual factors in relation to adjustment and it is widely agreed that both children and adults organise their illness cognitions along five dimensions – cause, identity/label, cure/control, timeline and consequences.

Based on Leventhal's Self-Regulatory Model, the Illness Perception Questionnaire-Revised (IPQ-R) has helped elucidate the role of adult illness cognitions in adjustment to epilepsy. This thesis describes a study that evaluated the utility of an IPQ-R modified for children (chIPQ-R) with a paediatric epilepsy sample. Fifty children completed the chIPQ-R in a cross-sectional postal questionnaire design.

The chIPQ-R showed good internal consistency. Intra-subscale correlations agreed with predictions, indicating that children organise their illness representations in a similar way to adults. Relationships between chIPQ-R subscales and outcome measures were in hypothesised directions. Hierarchical multiple regressions found that chIPQ-R subscales added significant amounts of explanatory power to models of behavioural disturbance and psychosocial impact after demographic and epilepsy-related variables had been controlled for. Interpretation of these findings was

cautious, because the sample was drawn from a clinic rather than the community, but it was concluded that the chIPQ-R is acceptable to children as young as seven, and is a reliable and meaningful tool for the exploration of adjustment to paediatric epilepsy.

KEYWORDS: Chronic illness; Paediatric epilepsy; Adjustment; Self-regulatory model; Illness representations; Illness Perception Questionnaire

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THE ROLE OF COGNITION IN ADJUSTMENT TO PAEDIATRIC EPILEPSY

Formatting follows guidelines from the Southampton Doctoral Programme in Clinical Psychology and the notes for contributors to Psychology and Health (see appendix one).

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ABSTRACT

This review examines developments in the investigation of psychosocial adjustment to paediatric epilepsy, a common neurological disorder associated with poor psychosocial outcome. Various factors that have been associated with adjustment are described, but interpretation is hampered as there is little evidence about how these factors interact. Without sound theoretical models of adjustment processes, evidence-based interventions for lessening the psychosocial impact of these disorders cannot be developed.

Research into lay cognitions of health and illness in relation to adults and children is then reviewed and it is argued that psychological models of health behaviour based on these illness cognitions may be valuable in guiding research and clinical practice. A self-regulatory model of illness behaviour is described that proposes a mediational relationship between illness cognitions and adjustment to chronic illness. Preliminary evidence that it might be suitable for addressing issues of adjustment to paediatric epilepsy is presented, and further research is suggested.

KEYWORDS: Chronic illness; Paediatric epilepsy; Adjustment; Self-regulatory model; Illness representations; Illness Perception Questionnaire

1. INTRODUCTION

1.1 Background to Review

Epilepsy describes a tendency to experience recurrent, unprovoked seizures (Smith & Wallace, 2001). Seizures can vary hugely in type and frequency, from blank spells or odd sensory sensations to sudden convulsions, and have been described as one of the most dramatic occurrences in medical practice and everyday life (Bergen, 1999). It is predominantly a childhood onset disorder, affecting over 60,000 children in the UK (Hoare & Kerley, 1991).

Epilepsy is a pervasive disorder, and its impact spans a range of clinically important functional and psychosocial domains (Bishop, 1992). Studies continue to document poor adjustment to this disorder, whether indicated by increased psychological sequelae, childhood behavioural difficulties, or poor quality of life (Antonak & Livneh, 1992). A review by Nilsson, Ahlbom, Farahmand, Asberg, & Tomson (2002) showed that estimates of suicide rates among individuals with epilepsy varied from 0-25%, with larger, more controlled studies finding between 5-7% of epilepsy deaths to be suicide, compared with general population rates of 1.4%. The essential conclusions from epilepsy adjustment studies (as with other chronic illnesses) are that there is substantial variability in adjustment even among patients with the same condition of the same severity (Antonak & Livneh, 1992; Mirnics, Bekes, Rozsa, & Halasz, 2001; Suurmeijer, Reuvekamp, & Aldenkamp, 2001; Wallander & Varni, 1998). However, no theoretical framework exists to support researchers or clinicians in their work with this patient group (Couldridge, Kendall, & March, 2001; Kemp, Morley, & Anderson, 1999). Understanding the issues underlying variability in adjustment to epilepsy is an important goal in the medical management of epilepsy (Baker, 2001), and sound

interventions for psychological sequelae will only develop from sound psychological models of the patient experience (Kemp et al., 1999).

Hagger and Orbell (2003) state that adjustment research is increasingly focusing on cognitive-perceptual factors. Cognitive paradigms have been pre-eminent in the last fifty years of psychological research (Weinman & Petrie, 1997), and there is growing support for cognitive models of health behaviour (Williams, 1997). These see a person's emotional adjustment as dependent on their appraisal of an event rather than on objective properties of the event itself (Beck, 1976; Salkovskis & Warwick, 1986). Sensky (1997) states that "adjustment to illness or symptoms is more accurately predicted by cognitive factors than by 'objective' disease-related variables (p565)".

Few studies, however, have considered the role of children's illness cognitions (Hagger & Orbell, 2003), and despite widespread agreement that the impact of chronic paediatric disease varies according to a child's developmental level, very little work has attempted to describe these variations empirically (Eiser, 1993). The clinical implications of building an evidence-base for work with children with chronic illness are clear. For example, if children are actively constructing their own illness cognitions, it may not be adequate to deliver health care advice and information simply to parents, as suggested by some early anecdotal models (Schmidt & Weishaupt, 1990). Swanwick's (1990) anecdotal advice that "caring for sick children ... requires an understanding of child development especially in relation to cognition (p20)" may be intuitively appealing, but it is important to have objective evidence on the nature and strength of apparent relationships between child development, illness cognitions and adjustment outcome before we can produce effective

recommendations about caring for sick children. The aim of this review is to explore the potential contribution of theory and research from clinical and health psychology to our understanding and management of adjustment to paediatric epilepsy.

1.2 Outline of Review

Approaching this question means addressing two separate lines of enquiry – the development of children's knowledge and understanding about health and illness, and the process of adjustment to chronic medical conditions such as epilepsy.

Studies exploring adjustment to epilepsy in adults and children will be reviewed, in order to show how the field has developed and to present the main methodological and theoretical issues arising from these research efforts. This provides a rationale for looking more closely at predominantly academic research into lay models of health and illness and cognitive models of illness perception. Clinical research that has applied cognitive approaches to the exploration of adjustment to chronic medical disorder will then be evaluated, and its suitability for children with epilepsy considered.

2. PSYCHOSOCIAL ADJUSTMENT TO EPILEPSY

2.1 Introduction and Definitions

The adjustment literature specific to epilepsy has followed similar developments to investigations of chronic illnesses generally, and this section will focus largely on epilepsy, drawing occasionally on research into other chronic illnesses where it has a bearing on theoretical or methodological issues. After defining chronic medical conditions, the nature of adjustment is considered. The nature and particular

challenges of epilepsy are then described, and adjustment research outlined, drawing on recent reviews. Theoretical and methodological issues are discussed, and the potential value of cognitive models is introduced. This is not an attempt to comprehensively document the current state of knowledge regarding adjustment to chronic paediatric medical disorders but rather, to introduce the concept of adjustment to epilepsy and show how cognitive approaches may contribute to this field.

2.1.1 Chronic illness

"A chronic physical disorder is one that (1) interferes with daily functioning for more than 3 months in a year; or (2) causes hospitalisation lasting more than one month in a year; or (3) is thought at the time of diagnosis to do either (p29)" (Wallander & Varni, 1998). There is vast heterogeneity, such as between psoriasis and cancer, and not all constitute a threat to life. There is also considerable variation in how much of the time symptoms are present, from conditions which have steady symptom expression to those which are cyclical. The condition may be deteriorating gradually or holding steady, but it is a chronic disorder when the person's knowledge of the existence of disease and the likelihood of symptom recurrence are long-lasting (Radley, 1994).

Most chronic conditions are rare (possibly excepting asthma), but taken together, and including sensory and learning impairments, they affect a surprisingly large number of children, with estimates suggesting that 10-20% of US children (Johnson, 1998) and 10-15% of UK children under sixteen (Eiser, 1993) have a chronic condition. This is significant economically and also for the children and their families, because these children may use ten times more health services than their healthy peers (Johnson, 1998).

2.1.2 Psychosocial Adjustment

It is recognised that major advances in medical treatments have produced 'new' populations – those with a chronic illness who would not previously have survived and who have concerns and difficulties which acute medical services are unprepared for (Trieschmann, 1987; Zarb, Oliver, & Silver, 1990). Treatments for these complex disorders are more biologically aggressive, more stressful and less certain for all patients (Bearison & Mulhern, 1994).

These developments have led to a new view of patients as active providers of their own health care (Horne, 1999). Individuals need to learn to understand and implement their own treatment regime, develop strategies for handling symptoms and cope with the perceived consequences of disease. Unlike those suffering an acute sickness, those with chronic illnesses cannot withdraw for the period of illness (Radley, 1994). Thus having a chronic medical disorder means living with illness amongst the healthy population, and besides managing the medical aspects of their condition, this involves relationships with others, to whom the ill person needs to explain their condition. This process involves parents, siblings, family and friends (Davis, 1993). Issues of identity and communication are therefore important parts of the chronically ill person's active self-management.

The process of managing these diverse tasks in order to live with a chronic condition is loosely termed 'adjustment', and has been defined as "coming to terms with pain or limitations...and an attempt to resolve the dual demands of symptoms and society" (p156: Radley, 1994). Antonak and Livneh (1992) conceptualise adjustment as a process of change in reactions to chronic illness that might be ordered hierarchically

and temporally. In order to measure such a multivariate construct, most researchers make the assumption that well adjusted individuals will show fewer psychosocial difficulties than those who are struggling to adjust. Thus, Wallander and Varni (1998) state that in children, "Good adjustment...is reflected as behaviour that is age-appropriate, normative, and healthy, and that follows a trajectory toward positive adult functioning (p30)". Adjustment is therefore often characterised in terms of the presence or absence of psychological symptomatology, or in judgements of a person's quality of life, as indirect measures of an individual's ability to re-define themself and retain their everyday roles and duties.

2.2 The Nature and Management of Epilepsy

2.2.1 Prevalence and incidence

Epilepsy is the most common neurological disorder after migraine (Scambler, 1997) costing the UK in the region of £2 billion per year (Couldridge et al., 2001), and 10% of the population will have experienced a seizure by their mid-70s (Smith & Wallace, 2001). One in two hundred individuals will develop chronic epilepsy (Scambler, 1997).

2.2.2 Epilepsy and the classification of seizures

Smith and Wallace (2001) define active epilepsy as having an epilepsy diagnosis and having had a seizure within the last five years. Convulsive seizures arise when neuronal conduction within the brain is disrupted (Di Iorio, 1997). Seizure classification is essential for prognosis and choice of treatment (Smith & Wallace, 2001), and has been standardised by the Commission on Classification and Terminology of the International League Against Epilepsy (1989). Seizures take

different forms depending on the site of the abnormal paroxysmal discharge of cerebral neurones (Scambler, 1997) and classification is predominantly clinical rather than electrophysiological (Smith & Wallace, 2001), often relying on witness descriptions of seizures as an important diagnostic aid (Berg, Levy, Testa, & Shinnar, 1999).

Discharges can be confined to one part of the brain ('partial'), or spread to all parts of the brain almost simultaneously ('primary generalised'). Partial seizures tend to be associated with structural cerebral damage (Arts et al., 1999) and involve symptoms relevant to the area of localisation, such as elementary tactile or visual hallucinations or lateralised sensory symptoms such as tingling or pain. About 60% of childhood epilepsies are localisation-related (Smith & Wallace, 2001). Generalised seizure types include absences, involuntary jerking, sudden loss of muscle tone, or whole-body convulsions. Seizures can also be 'simple', with unimpaired consciousness, or 'complex', where consciousness is lost or altered.

The other main axis of classification is based on aetiology. 'Symptomatic' or 'cryptogenic' seizures have been provoked by identified or assumed brain insult, either acute (e.g. metabolic disturbance, encephalitis, drug withdrawal, anoxia) or remote (as in cerebral palsy). 'Idiopathic' seizures are seen as unprovoked, but are assumed to have a genetic origin. It is not known why individual attacks start or finish (Bergen, 1999) and about one third of seizures are unclassifiable (Smith & Wallace, 2001). Childhood epilepsies are generally idiopathic while adult onset is usually symptomatic (Di Iorio, 1997). Interestingly, Derry & McLachlan (1995) found that adults do not limit causal attributions for their seizures to brain injury or heredity, but

include personal behaviour (inadequate sleep or overwork), other people (problems with doctor or with family), a stress response (feeling rundown, tense, angry) or bad luck.

2.2.3 Treatment and prognosis

Treatment predominantly involves the prescription of anti-epileptic drugs (AEDs). Multiple AEDs are usually required for resistant cases (Smith and Wallace, 2001). However, because epilepsy is so pervasive, most authors recommend that clinicians also take into account educational, occupational, psychosocial and emotional needs (Couldridge et al., 2001; Di Iorio, 1997; Mirnics et al., 2001), and recommend that treatment teams should be multiprofessional (Smith & Wallace, 2001). Furthermore, since daily management of the condition (like all chronic illnesses) is not under the total control of a medical team, medical personnel need to work collaboratively on treatment decisions, and patients (and family) must learn about epilepsy and assume responsibility for daily management (Di Iorio, 1997). Despite the fact that the provision of education and counselling is often recommended or mandated, inadequate resources mean these are often not implemented (Couldridge et al., 2001; Department of Health, 2003). This suggests that often the only treatments offered will be medication based, which increases the pressure on individual patients themselves to manage their conditions.

Despite these difficulties, the prognosis for epilepsy has improved greatly with the development of new AEDs. Sander's (2003) study indicates that fewer than 20% of all patients with epilepsy have a poor prognosis, where AEDs are palliative rather than suppressive, 10-20% have an uncertain prognosis, where AEDS are suppressive

but not curative, 30-40% have a good prognosis, with good control by AEDs and remission usually permanent and 20-30% have an excellent prognosis, with no AEDs required and spontaneous remission expected (Sander, 2003).

2.2.4 Epilepsy and cognitive impairment

Epilepsy may nevertheless carry particular risks during childhood. Camfield and Camfield (2002) describe many childhood epilepsies as benign, but state that some interfere catastrophically with the main tasks of childhood, described as the refinement of motor skills and development of complex intellectual and social skills.

Estimates of the prevalence of global or specific cognitive impairment within the epilepsy population range from 25% (Smith & Wallace, 2001) to 40% (Leonard & George, 1999). These might arise from the underlying brain disorder responsible for the seizures, from seizures themselves or from the AEDs prescribed (Smith & Wallace, 2001), any of which may hinder or disrupt normal development (Bergen, 1999; Leonard & George, 1999). Schouten, Oostrom, Pestman, Peters, and Jennekens-Schinkel (2002) have shown that significant underachievement is found even in mainstream school-children with good prognoses and normal intellect. They tested 69 children with idiopathic generalised epilepsy at 48 hours, three months and twelve months post-diagnosis and found significant discrepancies between ability and performance, though these were generally temporary (Schouten et al., 2002). Cognitive impairment appears to be common in this population, ranging from severe learning disability to temporary academic vulnerability among those with otherwise normal IQ.

2.3 Epilepsy and Psychosocial Adjustment

2.3.1 Early developments in adjustment research

Traditional medical research and early health psychology paradigms focused on the psychopathological consequences of illness (Eiser, Eiser, & Hunt, 1986; Wallander & Varni, 1998; Weinman & Petrie, 1997). This 'dispositional' approach (Radley, 1994) involved looking for psychiatric or personality traits associated with chronic illness. In epilepsy, this can be seen in early (1940s) attempts to define the 'epileptic personality', which led to the categorisation of those with epilepsy into the combative and stubborn or the dull-witted and withdrawn (Antonak & Livneh, 1992). Closely tied to the institutionalisation common at the time, this approach has given way to attempts to look at wider psychopathology (Hermann & Whitman, 1984). Di Iorio (1997) describes these attempts as 'medical models' - atheoretical explorations of the relationship between easily quantifiable psychiatric variables and demographic, illness and treatment characteristics.

This research has shown that children and adults with a chronic illness are more vulnerable than the general population to a variety of emotional and behavioural difficulties, including depressive symptoms, low self-esteem, fear, PTSD and suicide (Edwards & Davis, 1997; Eiser, 1990b; Wallander & Varni, 1998), as are those with epilepsy (Antonak & Livneh, 1992; Hermann & Whitman, 1984; Nilsson et al., 2002). Long lists of individual reactions to epilepsy, such as denial, aggression or anxiety were composed in often poorly controlled or anecdotal studies (Antonak & Livneh, 1992; Hermann & Whitman, 1984). However, emotional disturbance is not an inevitable consequence of chronic illness, and such approaches risk pathologising patient groups (Eiser, 1993; Trieschmann, 1987) and have been criticised for being

narrow and atheoretical (Di Iorio, 1997; Weinman & Petrie, 1997). Longitudinal studies have since shown that most children cope very well, after an initial six month to one year upheaval, but that a minority do have problems, and this minority is a larger proportion than expected from comparisons with their healthy peers (Johnson, 1998).

The focus of adjustment research has since been extended to look at resilience and well-being as well as distress and vulnerability (Eiser, 1990b; Petrie, Buick, Weinman, & Booth, 1999) and to draw in other factors that may influence adaptation, such as education, family or social context (Johnson, 1998; Radley, 1994). Such variables are generally classified into biomedical, psychological and social domains (Edwards & Davis, 1997), though epilepsy researchers have tended to follow Hermann and Whitman's (1984) categorisation into neuroepilepsy variables, medication factors and psychosocial factors. Both reflect increasing acceptance of the biopsychosocial framework proposed by Engel (1981). Neuroepilepsy and medication factors associated with adjustment to epilepsy will be presented, followed by studies looking at the role of psychosocial factors in adjustment to epilepsy.

2.3.2 Neuroepilepsy variables and adjustment

With respect to epilepsy, more effort has gone into determining the role of neuroepilepsy and medication variables than psychosocial factors (Scambler, 1997). Scambler (1997) states that there has been a poor return on this effort, and certainly several reviewers have reported inconsistencies and contradictions. Antonak and Livneh's (1992) review shows that adjustment problems have sometimes been shown to increase with frequency of seizures, but that seizure type does not appear to have

been consistently related to adjustment. Chronicity of epilepsy has been found related to well-being but not self-reported adjustment (Antonak & Livneh, 1992). This may reflect the heterogeneity of measures used to assess 'adjustment', from quality of life measures through psychological symptom scales to behavioural measures for children. Age of onset has also produced inconsistent findings, and it is suggested that a curvilinear relationship between adjustment problems and age at onset may obscure some of its effects (Antonak & Livneh, 1992; Heimlich, Westbrook, Austin, Cramer, & Devinsky, 2000; Johnson & Meltzer, 2002). Two consistent findings reported by Antonak and Livneh (1992) are that a) community samples appear to be better adjusted than clinic samples, and b) identifiable neurological abnormality is linked with poor outcome. They conclude that there may be a combination of epilepsy variables that contribute to increased psychological risk.

Arts et al. (1999) agree that the common denominator in research finding links between medical variables and outcome is the presence of neurological disturbance, whether brain abnormality is defined as the presence of partial seizures, remote symptomatic aetiology, a seizure type associated with malignant epilepsy syndromes or an identified neurologic abnormality. It is therefore important that models of adjustment to epilepsy take account of the neurological impact of this disorder on children's physical and cognitive development. This has not always been achieved, and may explain some of the inconsistencies apparent in the research findings to date (Schouten et al., 2002).

Many studies have looked for links between biomedical variables and psychopathology. Piazzini and Canger's (2001) sample of 220 adults with partial

(n=150) or generalised (n=70) epilepsies scored significantly higher on measures of depression and anxiety than a control group matched for age, gender and education (n=70). The group with partial epilepsy had elevated scores compared to the idiopathic generalised group, though the size of this difference is not reported. Gender, lateralisation of epileptic focus, duration of epilepsy, frequency of seizures and medication factors were not related to psychological symptom scores. Hoare and Kerley (1991) prospectively studied a clinic sample of 108 children, finding high rates of behavioural disturbance. Gender, aetiology and seizure type were unrelated to psychiatric disturbance, and only chronicity was consistently related to ratings of behavioural disturbance. Depression is a commonly studied psychiatric variable, and a recent study of 143 consecutive clinic referrals found that about half had intractable epilepsy and about 20% were depressed, but depressive symptoms were unrelated to intractability or seizure frequency (Attarian, Vahle, Carter, Hykes, & Gilliam, 2003). It appears that studies have struggled to show consistent links between biomedical factors and psychopathology.

Adjustment has also been operationalised in terms of 'quality of life', seen as a multidimensional judgement about several areas of a person's life, including physical, psychological, social, educational and occupational aspects. Many such studies have used the 132-item Washington Psychosocial Seizure Inventory (WPSI: Dodrill, Batzel, Quessier, & Temkin, 1980), a theoretically derived epilepsy-specific quality of life measure with subscales covering family background, emotional adjustment, interpersonal adjustment, vocational adjustment, financial status, adjustment to seizures, medicine and medical management and overall functioning. Since these scales include items on medical issues and physical function, one would intuitively

expect to find relationships with objective biomedical variables. Suurmeijer et al.'s (2001) large sample of 210 adults provided an array of socio-demographic, epilepsy-related, psychological and quality of life data. None of the medical variables (including onset age, aetiology, epilepsy type, seizure type, AED use and AED side effects) contributed significantly to the WPSI quality of life scores. All of the explanatory power of the model was provided by psychosocial variables. Suurmeijer et al. (2001) argue that this does not imply that biomedical variables are unimportant, describing a model where quality of life is directly affected by biomedical variables but mainly indirectly affected by psychosocial variables.

It is intuitively attractive to accept Suurmeijer et al's (2001) contention that medical variables are fundamental, but a workable model needs to explain why these physiological variables are often apparently unrelated to psychosocial outcome. A potential explanation is touched on by studies which have included individual perceptions or attributions of their medical disorder. For example, Galletti, Rinna, and Acquafondate (1998) found that perceived severity is more important than objective severity of epilepsy. Peterson, Walker, Runge and Kessler's (1998) prospective study compared 29 individuals with idiopathic generalised epilepsy with nineteen healthy controls. Although the sample was small, they found that quality of life, lower at diagnosis than four weeks later, was inversely correlated with seizure-associated distress and perceived seizure severity. Derry and McLachlan (1995) followed 65 consecutive cases of resistant epilepsy for two years following epilepsy surgery and found good psychosocial outcome was partially predicted by the individual's causal attributions of their seizures - i.e. a sense of personal control over seizures was positively associated with adjustment (Derry & McLachlan, 1995). These findings

concur with authors commenting on chronic illness generally who have suggested that personal perceptions of severity may be more predictive than objective physical criteria (Drotar & Bush, 1985; Edwards & Davis, 1997), but the potential interplay between objective and perceived severity has not been adequately explored.

The role of neuroepilepsy variables in adjustment has not been reliably documented. Some aspects appear to be consistent, however. Clinic samples, which tend to include those with resistant or poorly controlled seizures, are less well adjusted than community samples that are cared for by their paediatrician or GP. Initial onset and diagnosis may produce an upheaval reflected in temporarily lowered adjustment that may last anywhere from four weeks to one year. Identified neurological abnormality may be a risk factor for poor adjustment and quality of life.

2.3.3 Medication variables and adjustment to epilepsy

AEDs are the first-line treatment for seizures, and although newer AEDs appear to have fewer or less adverse side effects than older ones, there are no studies of their side effects in children (Bergen, 1999; Loring & Meador, 2001). The effects of AEDs on the maturing brain is therefore unknown, though animal models suggest they may reduce development of normal neuronal complexity. Their use is not questioned, however, because of the known harm caused by repeated seizures (Bergen, 1999; Loring & Meador, 2001). The main cognitive effects reported are mild to moderate psychomotor slowing, reduced vigilance and memory impairment, and these can be reduced by monotherapy and gradual titration (Aldenkamp & Vermeulen, 1991; Leonard & George, 1999; Loring & Meador, 2001). These issues and the finding that up to 40% of adults discontinue certain AEDs because of neurotoxicity effects

(Mattson, Cramer, & Collins, 1985) suggest that AED use may have an impact on adjustment (Engelberts et al., 2002).

AED side effects and mood have been found to be more strongly related to quality of life than seizure frequency in those patients who are not seizure-free (Loring & Meador, 2001). Miller, Palermo, and Grewe (2003) studied 41 children with epilepsy, and found that only comorbid neurological impairment and number of AEDs were predictive of diminished quality of life - duration of illness, age of onset, seizure severity and treatment type were unrelated. However, these effects have not been reliably reproduced (Hoare & Kerley, 1991; Piazzini & Canger, 2001; Suurmeijer et al., 2001). Again it appears that the intuitive assumption that objective biomedical variables will determine adjustment outcome has not been consistently supported.

2.3.4 Psychosocial factors associated with adjustment

Reviews of research into chronic illnesses generally indicate the potential role of many non-biomedical variables, including personal locus of control, premorbid psychiatric functioning, temperament, developmental level, coping style, self image and social factors including family environment and social support (Wallander & Varni, 1998). Family environment will clearly play an important role in a child's response to chronic illness, and many reviewers have concluded that parental and sibling adjustment is closely related to the adjustment of the chronically ill child (Edwards & Davis, 1997; Johnson, 1998; Wallander & Varni, 1998).

Researchers have also begun looking at positive as well as negative responses to chronic illness. Petrie et al. (1999) reported that 60% of their sample of 195 patients

described some positive effects from their myocardial infarction or breast cancer, with the most common themes being healthy lifestyle or closer relationships with others. Other themes included changed personal priorities, improved empathy or having a second chance. Johnson (1998) reports that chronic illness in children has been associated with greater empathy and emotional responsiveness, and recommends an expanded research focus that considers factors which promote resilience, mastery and pro-social behaviour.

It is therefore important to consider psychosocial as well as biomedical factors when investigating adjustment outcomes.

Before looking specifically at psychosocial factors and adjustment to epilepsy, it is worth considering briefly whether reactions to epilepsy differ significantly from other chronic illnesses. The cognitive impairments common in epilepsy appear to set this population apart. Boekaerts and Roder's (1999) large review of childhood chronic illness found that despite increased school absences, children with a chronic condition do not show poorer academic performance, with the exception of those with epilepsy. Compared to other conditions with CNS involvement, Antonak and Livneh's (1992) review concludes that individuals with epilepsy show better adjustment than those with closed head injuries but are more poorly adjusted than those with general neurological impairments (e.g. multiple sclerosis, myasthenia gravis, muscular dystrophy or poliomyelitis).

Boekaerts and Roder's (1999) review also concluded that diseases with an impact on appearance or social activity such as cancer, epilepsy or asthma had more impact on

social functioning and peer relations than diabetes or cardiac conditions. Austin, Smith, Risinger and Monelis's (1994) longitudinal study of 270 children found that regardless of the severity of illness, children with epilepsy were more vulnerable psychologically, socially and academically than those with asthma. The social stigma of epilepsy appears to be greater than that of other childhood conditions (Levisohn, 2002), and children with epilepsy are more likely than demographically matched children with other chronic disorders or no illness to view life events as beyond their control and to express greater anxiety and lower self-esteem (Antonak & Livneh, 1992; Leonard & George, 1999).

2.3.5 Psychosocial factors and adjustment to epilepsy

Mirnics et al. (2001) state that research using the WPSI shows reported seizure-related psychosocial problems are roughly similar across cultures, and both Couldridge et al. (2001) and Mirnics et al. (2001) argue that these are often seen as more handicapping than seizures themselves. A national study found that 91% of their sample reported their greatest concerns as being fear of seizures and fear of stigma (Chaplin, Yepez Lasso, Shorvon, & Floyd, 1992). In an editorial for a journal issue about stigma, Levisohn (2002) wrote that - "Epilepsy can be seen as a disease whose primary impact is social not physiologic; the burden of the illness is experienced even when the disease is not severe (p489)".

Many studies have investigated psychosocial factors and their relationship with adjustment, and only a few can be described here. A typical adult study is that of Hermann, Whitman, Wyler, Anton, and Vanderzwagg (1990) who collected comprehensive biopsychosocial data from 102 consecutive inpatient referrals. Five

neurological variables (age at onset, chronicity, seizure type, number of seizures and aetiology), eight psychosocial variables (stigma, personal limitations, adjustment to seizures, vocational status, financial status, life event changes, social support and locus of control), four demographic variables (age, gender, educational level and IQ) and two medication variables (barbiturate prescription and mono- versus poly-pharmacy) were entered into a multiple regression equation. The total set of predictors accounted for just 23% of the variance in psychopathology (defined by depression scores). The best predictors were life event changes, adjustment to seizures measured by the WPSI (Dodrill et al., 1980) and financial status. In another study collecting an array of data from different domains, Mirnics et al. (2001) followed 310 outpatients over a one year period in Hungary. They collected neuroepilepsy, medication and demographic data as well as ways of coping, anxiety and depression ratings and the WPSI. Coping was related to psychological symptoms and some WPSI subscales, while age of onset, current seizure frequency and type of epilepsy was unrelated to emotional adjustment. The total number of severe seizures experienced was described as strongly related to adjustment, but no coefficient was provided (Mirnics et al., 2001). These studies indicate that psychosocial factors may be more predictive of adjustment outcome than biomedical variables, but findings are again inconsistent.

Other researchers have investigated the role of the family in childhood epilepsy. Leonard and George (1999) found that parents' education and income were more important determinants of anxiety than seizure patterns. Behavioural problems were found to be independent of seizure type, severity or control, and anxiety continued even after seizure control was obtained. A small study by Long and Moore (1979) showed that parents expected poorer academic and physical functioning, poorer

concentration and less predictable behaviour from the child with epilepsy compared to a healthy sibling. These expectations were linked with being more restrictive and with the child's lower self-esteem and academic achievement (Long & Moore, 1979).

The value of eliciting the individual's perspective is highlighted by Di Iorio (1997), who describes the array of activities that persons with epilepsy might need to undertake in order to manage their condition. She lists common self-management techniques, including following safety precautions concerning driving, bathing alone, or operating machinery, managing medications, dealing with unexpected problems and monitoring seizure frequency. More personalised strategies may be required for using public transport or taking career decisions. Many use seizure avoidance techniques including distraction or stress avoidance. She goes on to include idiosyncrasies based on faulty beliefs, such as believing seizures are caused by temperature imbalance and avoiding extremes of hot and cold (Di Iorio, 1997). Given the range of behavioural variation introduced by these complex and individualised self-management systems, taking individual perspectives seriously is increasingly indicated (Scambler, 1997). Scambler (1997) highlights two individual perspectives which need to be considered: a) 'rationalisation', described as the urge to make sense of what is happening and restore cognitive order, and b) 'action strategy', a need to develop ways of coping with epilepsy and its concomitant psychosocial problems.

Recently, more studies have begun to investigate individual attributions and perceptions, or to include these in their data sets. Cull, Fowler, and Brown (1996) interviewed 79 adolescents with epilepsy about their awareness of seizure precipitants. Despite the mechanics of seizure onset and offset being medically

unknown (Bergen, 1999), over 60% claimed to identify these triggers. 70% claimed to experience warnings and 50% felt they had developed the means to reduce seizure occurrence. This indicates that patient knowledge and beliefs may well be different from their health providers'. Heimlich et al. (2000) sampled 197 children with epilepsy or asthma, and found that negative attitudes towards having a chronic condition were related to increased depression, behavioural problems and decreased academic achievement in both groups.

It appears that the factors related to adjustment in epilepsy are increasingly being explored on a wider, biopsychosocial level, with some success. The large variability in adjustment between children with the same severity of disease (Boekaerts & Roder, 1999) indicates that psychosocial factors play a potentially more salient role than biologic or medication-related factors (Boekaerts & Roder, 1999; Oostrom, Schouten, Kruitwagen, Peters, & Jennekens-Schinkel, 2001). The role of patient perceptions is increasingly being considered (Boekaerts & Roder, 1999; Di Iorio, 1997; Scambler, 1997).

2.4 Treatment Implications

Several authors have discussed the treatment implications of the findings discussed above, particularly the need to address psychosocial factors alongside medical attempts to reduce seizure frequency. In chronic illness generally, treatment is often aimed only at limiting long-term complications and reducing symptom intensity, but not cure (Eiser, 1993). Relapse has been associated with poorer adjustment (Eiser, 1990a), and there is therefore potential scope for interventions that address

psychosocial adjustment, and for cognitive-behavioural treatments that have been found effective in reducing pain and discomfort (Johnson, 1998).

The educational needs of the epilepsy population are discussed by Couldridge et al. (2001). Understanding chronic illness is complex, and it is not enough to know the 'facts' about aetiology and treatment – there is also a need to be able to apply this knowledge and problem-solve in novel situations (Di Iorio, 1997). Yet there are significant deficits evident in disease knowledge, understanding of preventive measures and technical treatment skills, and patients often have little recall of instructions from medics during clinic visits (Couldridge et al., 2001; Johnson, 1998). Couldridge et al. (2001) report on a treatment study that showed a two-day education programme producing a trend towards improved psychosocial functioning and more appropriate self-management. Studies indicate a patient preference for individualised information rather than leaflets, and a need for clinicians to assess existing knowledge, attitudes and perceptions (Couldridge et al., 2001).

Finally, there is preliminary evidence that cognitive-behaviour therapy can improve psychosocial functioning and the impact of epilepsy in those with intractable seizures (Goldstein, McAlpine, Deale, Toone, & Mellers, 2003), but further replication is needed. Understanding the adjustment process may provide a rich evidence base for health psychological treatment programmes.

2.5 Theoretical and Methodological Issues

Certain inconsistent and contradictory results may be due to methodological and design weaknesses. The main difficulties arise from studies of heterogeneous patient

groups using measures of unknown reliability or validity for the sampled population (Hoare & Kerley, 1991; Johnson, 1998). Even where relationships between variables are seen, the nature of these should therefore not be oversimplified (Johnson, 1998). Antonak and Livneh (1992) single out the use of non-specific measures, arguing that many measures of psychopathology are not appropriate for the particular social and psychological concerns of epilepsy populations. The development of measures such as the WPSI (Dodrill et al., 1980) or the 139-item Adolescent Psychosocial Seizure Inventory (APSI: Batzel, Dodrill, & Dubinsky, 1991) reflects this need. As shown earlier, there is now a growing number of longitudinal studies using multidimensional and epilepsy-specific measures of adjustment outcome (Baker, 2001), and these have contributed, for example, to the understanding that adjustment may be a nonlinear construct, subject to changes over time (Antonak & Livneh, 1992; Johnson, 1998).

Despite some improvements in measures and methodology, the field is still focussed on delineating individual factors which relate to adjustment in chronic illness and this approach has been criticised for having narrow implications, as there is little information on the interactions between these factors over time (Edwards & Davis, 1997). The list of factors which have been correlated with adjustment outcomes is growing, patients with epilepsy are no longer pathologised, and clinicians have a more expansive and biopsychosocial understanding of what may constitute risk factors for adjustment problems, but it is questionable whether a list can ever constitute an efficient model of adjustment. Adding one factor after another is not adequate theory-building, as there is no mechanism to guide researchers' choice of which factors to add or when to stop adding them.

It is possible therefore, that some design problems arise from poor theoretical foundations. Generating hypotheses about the interrelationships between biopsychosocial variables would be facilitated by evidence-based models. For example, the effects of age, onset age and disease duration are interdependent (knowing two automatically provides the third) and each can confound the other. The practice of reporting these variables individually does not precisely delineate their respective effects (Johnson & Meltzer, 2002). As another example, illness severity has been measured in several ways – either using objective measures, individual perceptions of severity or by the impact on a person's activities of daily living (Edwards & Davis, 1997), yet these strategies may well be measuring independent constructs. Biomedical variables generally measure medical outcome or medical control - seizure frequency, chronicity, polypharmacy and frequent hospitalisations all objectively indicate poorly controlled or resistant epilepsy. *Medical outcome* could be seen as separate from the *impact* of epilepsy (such as restricted daily functioning), which refers to the changes caused in that person's life by their management of their condition. *Medical outcome* and *impact* may well be different from the individual's *adjustment* in the face of those symptoms and their ongoing impact. *Quality of life* may reflect all three of these domains – outcome, impact and adjustment, but until we have an evidence-based model which describes the inter-relationships between these factors, there will continue to be confusion in our choice of measures and designs.

Of those authors who have offered models explaining adjustment patterns, many have been neuropathological (Arts et al., 1999), and most that offer exogenous explanations base them on stigma effects (Antonak & Livneh, 1992). Stigma models posit an internalisation of rejection and devaluation by society which produces negative and

maladaptive reactions in the individual. While there has been some evidence of widespread stigmatisation and misconceptions (Kale, 1997), this does not help to explain the inter-relationships between adjustment factors. Some authors have attempted to make use of the Health Belief Model (Rosenstock, 1966) and other health behaviour models, but these have been used largely to explain adherence behaviour (Di Iorio, 1997). Suurmeijer et al.'s (2001) model, mentioned earlier, makes an assumption that a person's overall quality of life reflects a judgement directly affected by chronic physical disorder and (perhaps mainly) indirectly affected by psychosocial factors, reflecting stresses and strain induced by a decrease in or loss of social, personal and economic resources. In order to explain these indirect effects, they draw on the concept of 'stress proliferation', where stressors emerge, accumulate and/or expand beyond their initial circumscribed situation. Oostrom et al. (2001) describes a similar model whereby recurring emotional responses induce a 'developing proneness' to react to these emotions. Once developed, proneness can distort cognition and bias perception and action. These social-cognitive theories have a potentially wide range of explanation (Di Iorio, 1997), but have not been adequately tested. There is growing support for cognitive models of health behaviour which see a person's emotional adjustment as dependent on their appraisal of an event rather than on properties of the event itself (Salkovskis & Warwick, 1986; Williams, 1997). People are seen as actively constructing cognitive representations of their illness experiences, and these representations may impact on their adjustment and self-management (Sensky, 1990). The use of such a model may be valuable in enhancing our understanding of the domains involved in adjustment to epilepsy as well as providing some evidence-based direction as to the inter-relationships between these domains.

2.6 Concluding Comments on Adjustment to Chronic Illness and Epilepsy

Antonak and Livneh's (1992) review concludes that most experts agree that a) problems of psychosocial adjustment are prevalent among those with epilepsy, b) they can be more formidable than the medical problems faced by those persons and c) the person's response to rehabilitation opportunities will be limited by poor psychosocial adjustment to this chronic neurological impairment and its treatment.

Research into adjustment to epilepsy has moved from individual psychiatric/personality models, to increasingly sophisticated combinations of biopsychosocial variables, eventually beginning to incorporate individual perceptions of objective biomedical variables. There is still no widely agreed model for drawing together these factors, and therefore there is a need to move from the generation of lists to the development and evaluation of evidence-based theoretical models.

3. INDIVIDUAL PERSPECTIVES ON HEALTH AND ILLNESS

3.1 Introduction

The previous section outlined developments in the field of adjustment to epilepsy, showing a) the potential importance of an individual's perceptions of and attributions about their illness and b) the need for a theoretical model that ties together the inter-dependent factors thought to relate to adjustment. Such developments may contribute to our understanding of psychosocial adjustment processes and our ability to design effective interventions. Cognitive models of health behaviour have been developing over a number of decades and may provide a theoretical framework that can be applied to childhood epilepsy. The next two sections review the background and evidence-base for these models.

In order to describe the starting point from which most patients will be confronting their diagnosis of chronic illness, it is important to consider lay or 'common-sense' models of health and illness. Investigations of how these idiosyncratic models develop in childhood are also considered. Leventhal's Self Regulatory Model (SRM) of illness representations (Leventhal, Nerenz, & Strauss, 1982) applies this basic research to the problem of predicting how people respond to illness, and this model is described. Finally, evidence supporting the SRM is presented.

3.2 Common-sense Models of Health and Illness among Adults

At the time of diagnosis, most chronic diseases have little meaning for adults (Davis, 1993), and most diagnoses allow vast uncertainty about course, symptoms or treatment response. Very little specific knowledge will be held at the time of diagnosis, and new information needs to be assimilated into existing knowledge structures (Edwards & Davis, 1997). It may not be surprising or significant that a person is poorly informed about the cause or physiology of their disease, but some knowledge, at least of the practical aspects of treatment, is necessary, as ignorance can result in an inability to manage aspects of self-care (Eiser, 1990b). Certainly there are clear clinical implications. For example, many adults (and most children) in the 1950s and 1960s were generally not given diagnostic information (Eiser, 1990a). The assumption, based on research from oncology wards, was that the truth can be harmful, raising anxiety and interfering with coping. However, later research indicated that individuals tended instead to make up information and create more anxiety (Eiser, 1990a). Diagnoses are now more often shared with the patient, and this represents an evidence-based change in practice, but there is still little empirical guidance about what form to present information in, how to assess someone's

understanding of their illness, or what risks there may be (Couldridge et al., 2001). Understanding common-sense models of health and illness may help researchers to explore and develop models of the adjustment process as well as helping clinicians to communicate with and educate their patients more effectively.

Adults are not constrained by scientific reasoning when giving medical accounts of illness (Herzlich & Pierret, 1986). Magic, religion and concepts of justice or reward may be brought in by patients to help them explain their symptoms and experiences of ill-health (Bibace, Schmidt, & Walsh, 1998; Siegal & Peterson, 1999). However, when asked to describe what 'being healthy' or 'being sick' means, people generally provide answers which fit certain broad dimensions (Leventhal et al., 1997; Ogden, 1996). These categories cover the nature of the condition (i.e. its symptoms), its causes, likely duration, consequences (such as impact on physical, social and psychological functioning) and its controllability or amenability to treatment or management. When individuals are asked to describe particular illnesses, their answers fit these same dimensions (Lau, 1997). There is a large amount of convergent evidence for these five dimensions, from experimental, qualitative and quantitative studies (Hagger & Orbell, 2003; Lau, 1997; Scharloo et al., 1998) and some preliminary cross-cultural support (Ogden, 1996), and this five-category framework appears to be a good model of how people commonly understand illness. These five dimensions are now widely recognised as the 'basic building blocks' of individuals' constructions of illnesses (Hagger & Orbell, 2003; Heijmans & de Ridder, 1998).

3.3 The Development of Knowledge of Health and Illness in Children

Children are similarly unconstrained by scientific logic, and their explanations of symptoms and illness experiences include notions of disobedience, justice, magic and the power and omniscience of adults (Siegal & Peterson, 1999). However, research into children's understanding of health and illness has evolved differently from adult research, because of a strong basic research foundation in developmental psychology. Bibace, Schmidt, and Walsh (1998) describe several different approaches to this area. Cognitive-developmental models have been used as a basis for theorising about how children might process information about illness. Another approach has focused on predicting health-related behaviour. More recently, qualitative functionalist studies have approached the question of what children actually know about health and illness. These approaches have built up a great deal of evidence about children's knowledge of illness. This section will discuss cognitive-developmental frameworks and some of the functionalist studies which arose from criticisms of these models. Attempts by health behaviour models to draw together some of these findings into an applied clinical model will then be discussed.

3.3.1 Cognitive-developmental models of children's understanding

Piaget's stage model (Piaget, 1929; Piaget & Inhelder, 1969) has been used as a framework for several theoretical or anecdotal attempts to describe children's knowledge of illness (Bibace & Walsh, 1980; Perrin & Gerrity, 1981; Swanwick, 1990; Whitt, Dykstra, & Taylor, 1979). For example, Swanwick's (1990) paper offered nurses a way of understanding children's thought processes that would guide them in giving meaningful explanations of illness to children of different ages. It is based on the Piagetian premise that children's thought processes are qualitatively

different from those of adults, and that the development of these processes follows a sequential series of stages.

According to Piagetian interpretations, as children develop, their ability to use logic in their interactions with the environment increases as their egocentricity decreases. Following a 'pre-operational' stage (age two to seven) dominated by direct perceptual experience, the child enters a 'concrete operational' stage, and begins to separate cause from effect, and to develop logical operations such as generalisation and reversal. 'Formal operational' thought (from age twelve) accompanies adolescent changes in self-concept and allows increasingly abstract reasoning processes (Piaget & Inhelder, 1969). It is proposed that pre-operational ideas about magic and punishment give way to concrete operational contamination or germ theories, and physiological and psychophysiological reasoning appears with formal operational thought during adolescence (Bibace & Walsh, 1980; Swanwick, 1990).

Cognitive-developmental frameworks have been supported by some questionnaire-based research (Bibace & Walsh, 1980; Perrin & Gerrity, 1981), and studies have shown that young children do attribute some symptoms to external magical phenomena, while older children can give physiological explanations with interactive causes (Eiser, 1990a; Paterson, Moss-Morris, & Butler, 1999). There is clearly a relationship between age and sophistication.

Stage models of children's cognitive development have however been heavily criticised for ignoring the context in which this development occurs, particularly the social and cultural influences on a child's knowledge (Edwards & Davis, 1997) and

for being rigid about the sequence in which this knowledge needs to be acquired. There are numerous examples of children with knowledge beyond their years (Eiser, 1993), and evidence that experience with different illnesses produces different conceptualisations (Edwards & Davis, 1997; Schmidt & Weishaupt, 1990).

Methodological weaknesses of cognitive-developmental studies include small samples, absent demographic or illness data, unclear measures and a lack of attention to validity and reliability (Burbach & Peterson, 1986; Paterson et al., 1999). Clinically, stage models have been criticised for their implicit assumption that children's knowledge is qualitatively different from adults', and that children require a different type of explanation and are unable to understand more 'advanced' explanations (Eiser, 1990a). Functionalists have argued that the field should focus more on what the child does actually know, and that qualitative methods would be more appropriate to address this question (Schmidt & Frohling, 2000).

3.3.2 Functionalist models of children's understanding

Functionalist approaches stress the child's role as an active theory-builder (Eiser, 1990a; Schmidt & Frohling, 2000). These accounts acknowledge that the child is less sophisticated than adults, but argue that this difference does not presuppose a stage theory – developmental differences in understanding may result from children being less practically experienced than adults (Eiser, 1990a).

Eiser, Eiser, and Lang (1989) found that groups of both five and eight year olds could give accurate, well-ordered accounts ('scripts') of visiting a doctor. Eight-year-olds provided more detail, but both age groups structured and organised their information

in the same ways. Children as young as three can produce accurate scripts if the activity is familiar to them, such as getting dressed, or baking (Eiser, 1990a). Continued experience appears to lead only to elaboration in terms of detail.

Pidgeon and Olson (1986) examined whether children pass through qualitatively different stages or just become increasingly sophisticated. 152 healthy children were asked to describe aspects of a familiar (common cold) and an unfamiliar illness (diabetes). Their responses were qualitatively categorised in terms of abstraction, differentiation and articulation, then quantitatively analysed. Descriptions were significantly more abstract, differentiated and articulated by older children than younger, and for familiar than unfamiliar illnesses. The latter finding suggests that experience plays a role as well as age, and the authors conclude that this is evidence for a functionalist, increasing-sophistication model. They recommend that health information needs to be more concrete for nine to eleven-year-olds and can become more differentiated and abstract as children mature. While their recommendations are justified, their results clearly showed that knowledge is affected by age as well as experience.

A smaller study asked younger children (aged five to nine) about three familiar illnesses (Schmidt & Weishaupt, 1990). Again, older children were generally more advanced (more elaborate and less concrete), but this age advantage was greater for less familiar illnesses (i.e. measles over cold) and for more sophisticated concepts such as causality over symptoms. Schmidt and Weishaupt (1990) conclude that illness concepts are influenced by cognitive development, by different characteristics of ill-health, and also by experience. Importantly, some children of the younger group held

sophisticated concepts, while some from older group had very concrete and general concepts, suggesting that while development plays an important role, it does not follow the invariant stages proposed by cognitive-developmental models. Other authors have also reported significant variability within age groups (Paterson et al., 1999; Schmidt & Frohling, 2000). Eiser, Havermans and Casas (1993) found that when children aged between three and eight were given information about blood, they were more likely to retain this information if they had had previous experience with blood (e.g. through injury). Eiser et al. (1993) conclude that education about leukaemia should be based on the child's experience rather than on their age.

The debate between cognitive-developmental and functionalist approaches is ongoing, and Bird and Podmore (1990) concluded that findings could be interpreted in terms of developmental level, personal experience and even the cultural influences of changes in children's access to illness information.

One outcome of the functionalist approach has been to generate a richer insight into what children know about health and illness. Whereas Piagetian interpretations appeared to limit researchers to studying children's causal explanations of illness, causation is just one of many themes to emerge from functionalist explorations of children's knowledge. Qualitative approaches have found that children as young as pre-school age use the same five dimensions of symptoms, timeline, consequences, cure/control and cause to organise their explanations of illness that adults do (Goldman, Whitney-Saltiel, Granger, & Rodin, 1991).

Another valuable strand of research has directly examined children's ability to theorise. Kit-fong, Romo, and DeWitt (1999) explored an experimental curriculum ("Think Biology") in which children are taught about germs and their impact in such a way as to encourage thinking. They then tested the children's attempts to theorise about new problems such as the prevention of blood-borne versus skin infections. Children in a comparison group were found to be more likely to talk about observable events than underlying biological phenomena. Kit-fong et al. (1999) argue that children of eight or nine can learn basic concepts, actively fill gaps in their biological belief system and go on to use an understanding of biological causal mechanisms to reason about novel situations and risks. This ability underpins important aspects of disease management (Di Iorio, 1997).

Slaughter, Jaakkola, and Carey (1999) review studies exploring the emergence of concepts of life and death, which appear to develop between the ages of four and seven and become the core of children's reasoning about bodily function. These may not be comprehensive theories, but are present from an early age and are subject to radical change as the child develops. For example, by the age of five, children from several different cultures will attribute properties such as 'grow' or 'wither and die' to living and not inanimate objects (Hatano et al., 1993). Such studies have identified that some children are 'life-theorisers' (Slaughter et al., 1999), making use of these concepts when making judgements about the functions of particular body organs. About a third of four-year-olds appear to be life-theorisers, but by age eight, all children are making use of these concepts to theorise about biological matters.

Siegal and Peterson (1999) propose that early on, children acquire facts such as 'animals are alive', or 'babies come from mothers', in impressive quantities, but do not begin to create a coherent conceptual structure or framework until aged seven, when categories begin to be constructed, such as 'living things' which may include animals, babies and mothers. The validity of these proposals is still under scrutiny, but the important issue is the young age at which children begin to actively construct an understanding of their biological system, and the suggestion that they do not wait passively for the information to be given to them. Siegal and Peterson (1999) go on to argue that children may be constrained into thinking about and constructing models of biology, health and illness, because it is adaptive, in evolutionary terms, to understand our bodies and learn how best to protect them. The implication is that children are driven to draw information from any source available in their need for knowledge of this subject (Siegal & Peterson, 1999).

3.3.3 Conclusions on children's understanding of health and illness

Bibace et al. (1998) conclude that children on a 'normal developmental pathway' will broadly conform to a specifiable trajectory, but that this cannot be seen as invariant. Elements of such a trajectory that may affect children's abilities would include egocentricity and concreteness at early ages, with the development of theorising abilities over time. Perhaps the most important point is that some children are more advanced and some children less so than would be predicted by their chronological age, whether because of natural transitions within their growth (Eiser, 1993), neurological impairments affecting cognitive and emotional development (Leonard & George, 1999), personal experience or cultural context (Bird & Podmore, 1990). Children are active learners who may be innately constrained to build foundational

biological frameworks of health and illness (Edwards & Davis, 1997; Kit-fong et al., 1999; Siegal & Peterson, 1999; Slaughter et al., 1999). These frameworks resemble those of adults, and could have important implications for our understanding of adjustment processes.

3.4 Relating Common-sense Models of Illness to Illness Behaviour and Adjustment

The application of this academic research is limited because few specific links are made between people's understanding of illness and their responses to illness (Schmidt & Weishaupt, 1990). However, people's foundational frameworks are not independent of their explicit responses to illness. Kit-fong et al. (1999) argue that people build foundational theories to seek information about their world and make sense of observations, but also to decide on appropriate courses of action.

A number of health psychological models have attempted to explain the relationship between a person's knowledge and beliefs and their behaviour, including the Health Belief Model (Rosenstock, 1966) and the Theory of Reasoned Action (Fishbein & Ajzen, 1975). Both have been criticised for an overemphasis on rational processes and the omission of emotional content (Ogden, 1996; Radley, 1994), and have been more successfully applied to explanations of individual health behaviours (e.g. screening uptake) than to adjustment processes more generally.

Another approach stresses the role of 'illness cognitions', defined by Croyle and Ditto (1990) as "any mental activity ... undertaken by an individual who believes himself or herself to be ill, regarding the state of his or her health and its possible remedies (p32)". This approach encompasses medical anthropology and medical sociology as

well as health psychology, but despite these diverse backgrounds, different methodologies and populations, there is wide agreement that lay foundational models of illness are organised along the five common dimensions listed earlier – symptoms, timeline, consequences, controllability and cause (Croyle & Barger, 1993; Lau, 1997; Leventhal et al., 1997; Ogden, 1996; Weinman & Petrie, 1997). The importance of these five themes is explained by Lau (1997), when he writes that they provide a cognitive superstructure that aids the individual in information-processing, tells them what to expect and to look for if they believe they might be getting sick and also underpins their potential reactions to such information. This superstructure forms one part of the SRM formulated by Leventhal, Nerenz and Strauss (1982) and Leventhal, Nerenz and Steele (1984).

3.4.1 Leventhal's Self-Regulatory Model of Illness Representations

Leventhal's SRM arose from several decades spent experimentally investigating health behaviour (Leventhal et al., 1997). The data that Leventhal and his colleagues amassed suggested that understanding how people process health-related information was crucial in uncovering their representation of and reaction to health threats (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1982). Experimental investigation of this information processing led to two propositions, namely that a) perceptual events (such as a health threat or a perceived symptom or sign of illness) are processed both cognitively and emotionally, but that these two processes occur in parallel and essentially independently of one another, and b) that the representations of these perceptual events – both emotional and cognitive, are separated from the plan or procedure for protection from the threat that the person chooses (Leventhal et al., 1997; Leventhal et al., 1984).

Leventhal et al. (1980) defined 'illness representations' (IRs) as a person's implicit common sense beliefs about their illness. IRs constitute a central element underlying responses to illness or disease. Leventhal et al.'s (1984) model describes an active and self-regulated problem-solving process (presented in figure one) that is triggered by a somatic or social stimulus (e.g. the perception of a physical symptom) indicating some change in the person's environment or equilibrium. The cognitive and emotional representations of this stimulus independently prompt the planning and implementation of courses of action that aim for a return to the equilibrium state. An appraisal process assesses the success of these actions and if necessary triggers a new interpretation and coping procedure.

- Insert figure one about here -

According to this model, a stimulus such as a symptom triggers a cognitive representation and an emotional reaction, both of which independently produce parallel coping responses. The coping procedures must address both the cognitive and emotional reactions to this threat, which might explain apparently irrational health-related behaviour such as delaying going to the doctor for fear of having cancer. It may also explain the findings of studies that show variable outcomes from individuals with the same condition of the same severity (Antonak & Livneh, 1992; Wallander & Varni, 1998). What one patient sees as time-limited and minor, another may see as lifelong and catastrophic, with significant implications for their coping responses as well as their compliance with medical regimens, psychological distress and illness-related functional disability (Cameron, 1997; Petrie, Moss-Morris, & Weinman, 1995; Petrie, Weinman, Sharpe, & Buckley, 1996).

Leventhal's SRM sees people as active problem-solvers who have a cognitive framework for interpreting social or somatic information about health and illness, and are ready to act on this interpretation. Leventhal et al. (1997) argue that whether an individual's cognitive representations of their illness are explicit or implicit, they cannot be ignored if we are to understand their reaction to that illness.

The structure and dynamic processes described by this model need to be empirically tested. Lau (1997) argues that future research requires a psychometrically competent instrument that makes it easier to measure IRs and is general enough to apply across different types of illnesses, in order to investigate variance in adjustment across larger samples from different illness groups. He also argued that researchers need to look at how these representations develop, rather than just assuming that they develop through experience of illness.

3.5 Concluding Comments on Lay Understanding of Health and Illness

The study of common-sense models of health and illness has shown that there is wide variation in people's IRs, and that these do not always conform to objective biological reasoning. Adults appear to hold varying beliefs about illness that can be understood along a fairly consistent set of dimensions which help them to make sense of their illness and understand and cope with developing symptoms. Despite early controversy about how this understanding develops in childhood, it appears that children from as young as six or seven formulate and use sophisticated theories about health and illness and that their IRs seem to be organised along the same five dimensions as adults. However, the precise contributions of age, experience and intellect are unclear from the research described so far. It has been suggested from an evolutionary perspective

that children are innately constrained to develop a framework from which to theorise and guide their behaviour.

4. ILLNESS REPRESENTATIONS

The final section of this review examines evidence supporting the application of Leventhal's SRM across chronic illnesses for adults and children.

4.1 Methodological Issues

Qualitative methods have been very successful in elucidating the structure of lay IRs (Eiser, 1990a; Leventhal et al., 1980; Ogden, 1996). Leventhal et al. (1980) recommended the use of open-ended interviews to study people's illness cognitions, as these techniques avoid priming participants and do not constrain or limit the field of possible responses as questionnaire methods do. Siegal and Peterson (1999) have argued that questionnaires may have an advantage, particularly for children, by being less socially constraining than interviews, given that there is no need for participants to justify their choices, no need for conversational awareness, a choice of answers rather than a need to invent some and the option of completing them in a familiar environment. More recently, there have been calls for quantitative confirmatory studies (Lau, 1997).

A systematic review of studies up to 1995 showed that most researchers had explored just one or two dimensions (most commonly perceived control) and rarely considered the relationships between dimensions (Scharloo et al., 1998). However, several structured questionnaires now exist, including the Illness Perception Questionnaire (IPQ: Weinman, Petrie, Moss-Morris, & Horne, 1996), as well as illness-specific

measures like the Personal Models of Diabetes Interview (PMDI: Hampson, Glasgow, & Toobert, 1990). Illness-specific tools may provide insights into processes specific to a particular disease but do not meet the criteria of allowing comparisons across patient groups. A recent meta-analytic review of studies testing common sense models of illness indicates that out of 45 quantitative studies, 28 used the IPQ, and no other general measure had been used more than twice (Hagger & Orbell, 2003). This review will therefore focus on the findings of studies that have used the IPQ.

The IPQ items were theoretically derived to assess each of the five IR dimensions (see table one) and tested on a sample of over 800 adult participants with diagnoses of myocardial infarction, rheumatoid arthritis, chronic fatigue, diabetes, pain, asthma or renal disorder, showing good psychometric properties (Weinman et al., 1996). Test-retest reliability over one month was moderate to high but dropped at three and six month retesting, suggesting that people's illness perceptions can be fluid over time. This change is implicit in the appraisal processes and feedback loops described in Leventhal's model (Johnston, Marteau, Partridge, & Gilbert, 1990). Other authors have factor analysed their IPQ data, and found that the factor structure closely reflected the five original IR dimensions (Hagger & Orbell, 2003).

- Insert table one about here -

A recent revision of the IPQ, the IPQ-Revised (IPQ-R: Moss-Morris et al., 2002), has enhanced internal stability by further categorising timeline and cure/control perceptions on the basis of factor analysis, so that the timeline dimension includes acute-chronic and cyclical items separately, and the cure/control dimension separates personal control from perceived treatment efficacy (Moss-Morris et al., 2002).

4.2 Illness Representations Research with Adults

Leventhal's SRM proposes that there is a causal relationship between illness cognitions and coping responses, and that this in turn influences health and psychosocial outcomes (Hagger & Orbell, 2003; Leventhal et al., 1984).

An early prospective study found that patients who saw their hypertension as a chronic condition were more likely to comply with their prescribed regimen and achieve blood pressure reductions than those who saw it as an acute condition, who more often failed to persist with medication and whose blood pressures were more likely to remain uncontrolled (Meyer, Leventhal, & Gutman, 1985). Petrie et al.'s (1996) longitudinal investigation of 143 consecutive myocardial infarction patients showed that those with stronger beliefs in the controllability of their condition were more likely to attend rehabilitation. Those who perceived their condition as being acute and having less serious consequences were more likely to return to work within six weeks, regardless of the severity of their infarction. IRs have also been found to predict disability, coping style and psychological adjustment in chronic fatigue syndrome (Moss-Morris, Petrie, & Weinman, 1996) and return to work and quality of healing following oral surgery (McCarthy, Lyons, Weinman, Talbot, & Purnell, 2003). These studies provide preliminary support for the hypothesised relations between IRs, coping and outcome.

Leventhal et al. (1997) warn that factor analytic studies can give the impression that IRs are independent factors, when they are more accurately seen as being organised and functioning as sets. Essentially, although SRMs can explain how two people with the same illness of the same severity can have widely differing responses (Weinman

& Petrie, 1997), they nevertheless predict that different conditions tend to produce different conceptualisations (Leventhal et al., 1984; Schmidt & Weishaupt, 1990). Thus a runny nose and sore throat may indicate a common cold caused by an infection, which is generally seen as acute and incurable but not very serious, while breathlessness and chest pain may indicate angina, often seen as chronic, with potentially serious consequences for previously enjoyable activities and only partially controllable (Williams, 1997). People tend to have at least three general disease models, fitting acute, cyclic and chronic conditions. Each disorder has their own pattern of identity, causes, timeline, consequences and controllability, and protracted experience may shift a person from one model to another. For example, there is longitudinal evidence that the proportion of patients believing that their cancer is curable and acute drops from the early stages of treatment to six months later (Leventhal et al., 1997). Such a change will not just be restricted to representations of timeline and cure/control, but changes in perceived consequences and perhaps symptom perceptions may follow (Leventhal et al., 1997).

Hagger and Orbell (2003) suggest that these inter-correlations between dimensions provide evidence of the model's validity. Their review identified 103 papers on Leventhal's model, 45 of which were quantitative and allowed meta-analysis. Predictions concerning trends in the organisation of lay beliefs were supported. Meta-analysis showed significant associations between strong illness identity (perceiving illness as highly symptomatic) and views that an illness is uncontrollable, chronic and has serious consequences, and between perceived control and the view that an illness is acute and has less severe consequences.

Hypotheses about the causal relationship between illness cognitions and coping were also supported. Meta-analysis identified moderate to strong correlations between IRs and coping measures (Hagger & Orbell, 2003). High levels of perceived symptoms, perceptions of uncontrollability, chronic timeline and serious consequences were related to denial and avoidant or emotion-focused coping strategies. Hagger and Orbell (2003) argue that this provides support for the a priori assertion of a link between illness cognitions and coping, but causal inference was not possible as most of the studies were cross-sectional.

Hypotheses were also made about the mediational relationship between illness cognitions and outcome (Hagger & Orbell, 2003). As predicted, adaptive outcome was significantly associated with weaker illness identity, less serious perceived consequences and more acute perceived timeline. Correlations between cure/control beliefs and adaptive outcome were also significant, but positive, as predicted. Correlations between illness cognition dimensions and disease state measures were not significant (Hagger & Orbell, 2003).

These meta-analytic findings support specific hypotheses drawn from Leventhal's model about the organisation of IRs and their relationship to coping and psychosocial outcome (Hagger & Orbell, 2003). There is also preliminary randomised controlled trial evidence that interventions targeting patients' IRs can effect significant cognitive-perceptual change and indirectly improve psychosocial and biomedical outcomes (Petrie, Cameron, Ellis, Buick, & Weinman, 2002). However, this is a recent research area, and replication is warranted.

4.2.1 Illness representations research with epilepsy

The IPQ has been used across a wide variety of conditions, but only one study is reported that has examined epilepsy (Kemp & Morley, 2001; Kemp et al., 1999). Kemp et al. (1999) suggest that illness-related coping and adjustment to epilepsy is an ongoing process in which patients actively integrate illness-related information with existing cognitive structures to form an IR. Their study explored differences between patients in the care of their GPs and those under the care of clinics, whose epilepsy is more likely to be poorly controlled. Both these groups had had an epilepsy diagnosis for an average of eighteen years, and Kemp et al. (1999) included a recently diagnosed group (within the last six months on average) to assess the effects of time since onset. They found that the clinic group and the recently diagnosed group were significantly less well adjusted than the GP group. Biomedical variables clearly separated the three groups, with age of onset much earlier for the clinic group (19.6 years) than the recently diagnosed (34.5 years) or GP group (25.3 years) and with seizures better controlled in the GP group (mean days since last seizure = 540) than the recent (34 days) or clinic (fourteen days) groups. However, these epilepsy-related variables did not explain all the variance in psychological adjustment, and coping strategies increased the explanatory power of their model. IRs were associated with coping style, in that a belief in personal control was related to problem-focused coping. After controlling for coping and epilepsy variables, IPQ subscales accounted for a significant proportion of the variance in psychological well-being and distress (Kemp et al., 1999). This study suggests that perceptions of epilepsy, coping procedures and psychosocial outcome are related, though causal inferences cannot be made.

4.3 Illness Representations Research with Children

Many adult health psychological models (e.g. the Health Belief Model) have failed to successfully cross the border to childhood applications (Ogden, 1996), but cognitive models have fared better (Spence, 1994). It was shown earlier that children as young as five or six are actively theorising about health and illness, and use the same five dimensions to organise their illness cognitions as adults. However, few quantitative studies have looked at children's IRs. Of the 45 quantitative studies identified by Hagger and Orbell (2003), only two sampled children specifically (Paterson et al., 1999; Stein, McNicholas, & Collis, 2001). Both of these studies used the IPQ, though Paterson et al. (1999) modified the items to create an interview format.

Paterson et al.'s (1999) study may shed some light on the controversy surrounding the role of personal experience of illness that was discussed earlier. They studied 182 children aged seven to fourteen, who reported having experienced roughly five illnesses each, mostly common ones such as chicken pox, 'flu or measles. 35 had asthma, and three had other chronic illnesses. Demographic information, structured interview (including the IPQ) and a gross measure of intellectual ability were collected. Controlling for demographic and intellectual factors, increasing sophistication was noted with respect to chronological age, but also experience. Experience of an illness produced a more sophisticated conceptualisation of that illness, but this sophistication did not extend to other illnesses. Paterson et al.'s (1999) study suggests that practitioners need to take into account experience of illness as well as cognitive-developmental factors, but realise that children may be greatly sophisticated in respect of one illness while having limited and concrete knowledge of other illnesses. Another clinically important finding of this study was that

understanding of consequences often developed later than knowledge about other dimensions, even in experienced and sophisticated children. Clinicians should be aware that sophistication in certain aspects of illness may not generalise automatically to other aspects of the same illness. Certain IRs may need to receive more emphasis in psychosocial treatment programmes (Paterson et al., 1999).

4.4 Illness Perceptions Approaches: Conclusions and Future Directions

This section has described the application of SRMs to the explanation of adjustment processes as well as of health behaviour. They provide a theoretical framework that is empirically based and more flexible than earlier attempts derived from medical models and health behaviour paradigms. Being based around a framework of five stable dimensions has more face validity than a list-based approach which can theoretically continue growing ad infinitum and without direction. This appears to be an appropriate theoretical model for application to issues of psychosocial adjustment to paediatric epilepsy.

Future research could usefully attempt to develop validated and reliable child measures, for clinical use with chronic illness groups and for academic exploration of the development of illness knowledge in childhood. Measures for very young children could focus on tests of implicit or procedural knowledge (Siegal & Peterson, 1999), but above the age of seven, the IPQ model should be applicable. For disorders that involve significant degrees of learning disability, however, it may be appropriate to adapt or modify adult measures.

Once satisfactory measures have been developed, further research should aim to develop time-lagged hypotheses to test causal assumptions (Hagger, 2003) and to explore the dynamic nature of illness cognition and adjustment over time (Antonak & Livneh, 1992). Exploration of the factors that influence children's IRs could be extended beyond developmental level and disease duration to include family context and socio-cultural variables. Interventional research can provide another testing ground for these models.

It is likely that children adapting to chronic illness need more than just facts about their disease and its management, and the role of emotional representations of illness needs further exploration. Learning how to integrate treatment with social and personal life is important, as is adjusting to changes in self image and dealing with stigma (Eiser, 1990a). However, the illness perceptions approach is an evidence-based, client-focused theoretical model with potential clinical and academic value, and therefore represents a sound development in the investigation of psychosocial adjustment to chronic illness.

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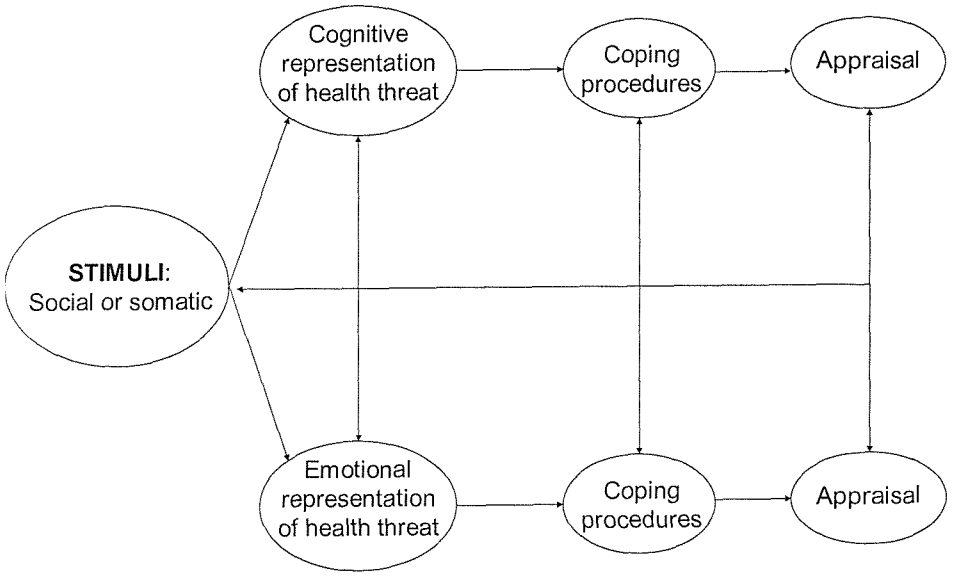
TABLES AND FIGURES:

Table 1: The five subscales of the IPQ

Subscale	Description	Examples for a common illness ('flu)
Illness identity	Patients' ideas about the label and symptoms associated with their condition	Runny nose Fever
Cause	Patients' ideas about the likely cause or causes of their illness	Infection
Timeline	Perceptions of likely duration of illness (acute, chronic or cyclical)	Acute
Consequences	Individuals' beliefs about illness severity and impact on physical, social and psychological functioning	Discomfort
Cure/control	Extent to which patient believes their illness amenable to cure or control	No cure; symptom management possible

Figure 1: Leventhal's parallel response model (from Leventhal et al., 1997).



EVALUATION OF A METHOD FOR ELICITING THE ILLNESS REPRESENTATIONS OF CHILDREN WITH EPILEPSY.

Formatting follows guidelines from the Southampton Doctoral Programme in Clinical Psychology and the notes for contributors to Psychology and Health (see appendix one).

CONTENTS:

ABSTRACT

Objectives. This study aimed to modify the Illness Perception Questionnaire-Revised (IPQ-R) and evaluate its utility for exploring the role of illness cognition in adjustment to paediatric epilepsy.

Design and methods. This cross-sectional postal questionnaire study used a clinic sample comprising a child (aged seven to seventeen) and parent from fifty families.

Results. The modified IPQ-R (chIPQ-R) had good internal stability. Intra-subscale correlations agreed with predictions. Significant relationships between chIPQ-R subscales and outcome measures were in accordance with predictions. Hierarchical multiple regressions found that chIPQ-R subscales added significant amounts of explanatory power to models of behavioural disturbance and psychosocial impact scores (10% and 31% respectively) after demographic and epilepsy-related variables had been controlled for.

Conclusions. The chIPQ-R is acceptable to children from age seven, and may be a reliable and meaningful tool for the exploration of adjustment to paediatric epilepsy.

KEYWORDS: Chronic illness; Paediatric epilepsy; Adjustment; Self-regulatory model; Illness representations; Illness Perception Questionnaire

INTRODUCTION

Epilepsy is a common neurological disorder defined as a tendency to experience recurrent, unprovoked seizures (Scambler, 1997). Onset generally occurs in childhood and adolescence, and epilepsy is considered active if there has been a seizure within the last five years (Smith & Wallace, 2001).

Levisohn (2002) states that epilepsy's primary burden is social, not physiologic, and its impact is pervasive, affecting biomedical, psychological and social domains (Bishop & Allen, 2003; Mirnics, Bekes, Rozsa, & Halasz, 2001). The prevalence of global or specific cognitive impairment in the epilepsy population may be as high as 40% (Leonard & George, 1999). Studies show increased psychopathology (Hermann, Whitman, Wyler, Anton, & Vanderzwagg, 1990; Piazzini & Canger, 2001), higher rates of suicide (Nilsson, Ahlbom, Farahmand, Asberg, & Tomson, 2002), poorer quality of life (Miller, Palermo, & Grewe, 2003; Suurmeijer, Reuvekamp, & Aldenkamp, 2001), increased behavioural disturbance (Dunn, Austin, Caffrey, & Perkins, 2003; Hoare & Kerley, 1991; Oostrom, Schouten, Kruitwagen, Peters, & Jennekens-Schinkel, 2001) and significant academic underachievement (Leonard & George, 1999) when compared to healthy peers or children with other chronic disorders. Medical management is largely based on anti-epileptic drug (AED) prescription, but guidelines increasingly mandate the provision of education and counselling (Couldridge, Kendall, & March, 2001; Department of Health, 2003) and encourage clinicians to take account of psychosocial sequelae (Baker, 2001).

Neuropathological models of adjustment responses have been of limited success, and few exogenous models have been developed to try and explain variability in

adjustment outcome (Antonak & Livneh, 1992; Arts et al., 1999). Most have centred on stigma effects or the consequences of repetitive emotional stress (Levisohn, 2002; Oostrom et al., 2001; Suurmeijer et al., 2001). This creates difficulties for clinicians, because sound interventions for the psychosocial sequelae of epilepsy cannot develop without evidence-based psychological models of the patient experience (Kemp, Morley, & Anderson, 1999).

Increasingly, researchers are turning to cognitive-perceptual factors to try and explain why adjustment patterns vary even among individuals with the same severity of epilepsy (Antonak & Livneh, 1992; Boekaerts & Roder, 1999; Di Iorio, 1997; Hagger & Orbell, 2003). For example, Galletti, Rinna, & Acquafondate (1998) found that children's perceptions of the severity of their epilepsy were more important than objective measures of severity.

Cognitive models have dominated psychological research for several decades, and may provide a theoretical framework for understanding adjustment to chronic illnesses (Weinman & Petrie, 1997; Williams, 1997). The self-regulatory model (SRM: Leventhal, Nerenz, & Steele, 1984) combines two decades of experimental research into people's emotional and behavioural responses to perceived health threats (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Strauss, 1982) with an even longer history of qualitative investigation of lay understanding of health and illness (Croyle & Barger, 1993; Lau, 1997). Leventhal's model proposes that symptoms or indications of illness are processed and interpreted both cognitively and emotionally, in parallel. The resulting cognitive and emotional illness representations (IRs) independently produce coping responses, the consequences of which are then

appraised, resulting either in new interpretations and coping responses (if coping was not successful) or a return to the equilibrium state, which is the goal of the self-regulatory mechanism. People are therefore seen as actively constructing cognitive representations of their illness experiences that may impact on their adjustment through a dynamic process of self-regulation (Leventhal et al., 1997).

There is considerable convergent evidence that lay cognitive representations of illness are organised along five dimensions, concerning the symptoms and label of the illness ('identity'), its likely course ('timeline'), its consequences for social and occupational functioning, its curability or amenability to control ('cure/control') and its likely causes (Croyle & Barger, 1993; Lau, 1997). These five IR dimensions are widely seen as the 'basic building blocks' of individuals' conceptualisations of illness (Hagger & Orbell, 2003; Heijmans & de Ridder, 1998). Quantitative measures of IRs include the widely-used Illness Perception Questionnaire (IPQ: Weinman, Petrie, Moss-Morris, & Horne, 1996), standardised on over 800 participants, and its revision, the Illness Perception Questionnaire – Revised (IPQ-R: Moss-Morris et al., 2002). The IPQ-R has improved internal stability, as the 'timeline' and 'cure/control' subscales have been further categorised on the basis of factor analysis. The timeline dimension now separates chronicity from cyclical items, and the cure dimension separates personal control from perceived treatment efficacy (Moss-Morris et al., 2002). Two further subscales have been added. A meta-cognitive subscale ('illness coherence') allows respondents to indicate how well they feel they understand their condition. The addition of an emotional representations subscale more closely reflects Leventhal's original parallel processing model (Leventhal et al., 1984). This elicits emotional representations specifically of the respondents' condition, and therefore should relate

to but not completely overlap with standard measures of generalised affect (Moss-Morris et al., 2002).

The literature investigating IRs has grown rapidly, and a recent systematic review identified 103 papers testing Leventhal's model, 45 of which were amenable to meta-analysis, confirming many of Leventhal's hypotheses (Hagger & Orbell, 2003). Hagger and Orbell's (2003) meta-analysis confirmed that IRs vary widely, even among those with the same illness of the same severity. Furthermore, predicted trends were identified in the organisation of lay beliefs, such that those with a strong illness identity (perceiving their illness as highly symptomatic) have associated views that their illness is uncontrollable, chronic and has serious consequences. Patients who feel they have control over their illness view their illness as less chronic with less severe consequences. Such evidence supports the validity of the model. Secondly, hypotheses about the mediational relationship between illness cognitions and outcome were confirmed, namely that better adjustment and functioning were related to higher perceived curability, weaker illness identity, less serious perceived consequences and more acute perceived timeline.

Only one study has applied this model to epilepsy. Kemp et al. (1999) sampled 94 adults with epilepsy, covering both recently diagnosed patients, chronic clinic patients and chronic community patients. The clinic patients had more resistant epilepsy, an earlier age of onset, higher seizure frequency and were more likely to be receiving more than one AED (polypharmacy) than the other two groups. The newly diagnosed and the clinic patients were less well adjusted than the community patients. However, epilepsy and medication variables did not explain all the variance in adjustment.

Hierarchical multiple regression indicated that after controlling for demographic, epilepsy-related and coping variables, IPQ subscale scores accounted for a significant proportion of the variance in psychological well-being and distress, suggesting that cognitive representations of epilepsy are related to psychosocial outcome, though no causal inferences can be made (Kemp et al., 1999).

Kemp and Morley (2001) argue that patients construct models based on symptoms and health-related information, drawing on previous experience of illness, medical consultations and the general pool of information current in the culture. Few studies, however, have considered the development of these representations during childhood. Like adults, children also actively theorise about biology and health (Kit-fong, Romo, & DeWitt, 1999; Siegal & Peterson, 1999), from at least the age of seven (Hatano et al., 1993; Slaughter, Jaakkola, & Carey, 1999), and appear to use the same five dimensions as adults to organise their understanding of illness (Goldman, Whitney-Saltiel, Granger, & Rodin, 1991). Hagger and Orbell's (2003) review indicates that only two quantitative studies have investigated children's IRs, both of which used the IPQ (Paterson, Moss-Morris, & Butler, 1999; Stein, McNicholas, & Collis, 2001). These two studies indicate that the IPQ is a potentially valuable measure for eliciting children's IRs, and it would be valuable to investigate the utility of this measure in paediatric epilepsy. As Kemp et al. (1999) argued, evidence-based psychosocial interventions for children with epilepsy depend on the development of empirical models of their cognitive representations of illness.

The aim of this study was to develop and evaluate a method for exploring the IRs of children and adolescents with epilepsy. The primary research question therefore

focused on whether an IPQ-R modified for children and adolescents would elicit meaningful and reliable responses. Reliability will be tested using a measure of internal consistency, and meaningfulness assessed using hypotheses tested in Hagger and Orbell's (2003) systematic review.

Hypotheses

1. Modified IPQ-R subscales completed by children and adolescents will be internally consistent.
2. Modified IPQ-R subscales will show similar intercorrelations to previous research: identity will correlate positively with timeline and consequence dimensions, and negatively with cure/control, which will correlate negatively with timeline and consequence subscales. Previous research largely used the IPQ, before the IPQ-R had split the timeline and cure/control dimensions. The specific relationship of subscales to personal or treatment control and cyclical or chronic timeline is therefore not clear and specific predictions cannot be made.
3. Modified IPQ-R subscales will show similar relationships to outcome measures as previous research: good psychosocial outcome will be associated with higher cure/control scores and lower perceived identity, timeline, and consequence scores. As above, precise relationships within timeline and cure/control dimensions cannot be predicted.
4. Emotional representations will relate to but not completely overlap standard affect measures.

5. Modified IPQ-R subscales will contribute significantly to models explaining the variance in adjustment outcome, over and above the variance explained by demographic and epilepsy-related variables.

METHOD

Participants

Inclusion criteria comprised all children and adolescents seen at epilepsy clinics held by the Paediatric Neurology department of a large teaching hospital (see Appendix two for further information on the database used in this study). Exclusion criteria were age below seven or above eighteen, severe learning disability (SLD) and quadriplegia or significant motor problems that affect writing. Following exclusions, 236 names remained. This was a clinic sample, and likely to include more resistant cases than a standard community sample. The relationships between cognitions and adjustment may be easier to highlight in a clinic group that is likely to experience more difficulties with adjustment.

Design

In order to evaluate the utility of the IPQ-R with children and adolescents, this study planned pilot interviews followed by a cross-sectional postal questionnaire design. Questionnaires were to be completed by the child or adolescent with epilepsy and one parent or guardian. Approval from Hospital data protection, University and Local Research Ethics Committees are documented in Appendices three to five.

Measures and Data Collection

Demographic variables

Details of gender, age and schooling (type of school and level of educational support provided), size of family and external social network were provided by the parent/guardian (see Appendix six for parent/guardian questionnaire). This also indicated whether the parental relationship was intact, and whether the absent parent maintained contact.

Since special educational needs (SEN) are prevalent in this population, and intellectual ability may relate to adjustment outcome, an objective measure of developmental level may be more appropriate than chronological age for delineating cognitive-developmental differences within the sample. The Goodenough-Harris Drawing Test (GHDT: Harris, 1991) is a brief pencil and paper measure of children's mental age, and one of the most widely used psychological assessments (Lezak, 1995). It simply asks participants to draw a man or woman (see Appendix seven for child questionnaire). Children's drawings are known to increase in sophistication at a steady and predictable rate (Goodenough, 1945; Harris, 1963; Lezak, 1995), and this test provides detailed scoring criteria that are independent of drawing ability. Standardised on over 13,000 children, it has good reliability, across time (0.6-0.91) and across raters (0.8-0.96: Scott, 1981). There is some evidence that it may underestimate intelligence (Scott, 1981), and it is not used here as a measure of IQ, but as a reliable measure of the relative maturity of participants. It is valuable in this population because it is child-friendly, non-threatening and its brevity and non-verbal nature means that it is less likely to discriminate against those with learning disabilities (Harris, 1963). It has been reported that children with epilepsy find drawing empowering and enjoyable (Stafstrom & Havlena, 2003).

Epilepsy variables

The parent questionnaire (Appendix six) also elicited age at onset and diagnosis, co-morbidity of other conditions, likely aetiology, seizure frequency, the date of the participant's last seizure and seizure characteristics. Non-professionals can struggle with classifying seizure types, and asking for precise diagnostic detail was deemed unsuitable. Therefore a list of common seizure characteristics were described, based on a list designed by the British Epilepsy Association (see Appendix eight) and the parent/guardian was asked whether their child experienced each characteristic.

Treatment-related data were also collected, including number of AEDs, number of prescription changes and hospital visits in the last year and the presence or absence of side effects.

Cognitive representations of epilepsy

The IPQ-R was developed from the IPQ using principal components analyses of data from 711 respondents (Moss-Morris et al., 2002). It is compared with the IPQ in Table 1. The factorial structure of the new IPQ-R subscales was confirmed through principal components analysis. Internal reliabilities ranged from 0.75 to 0.89 for all subscales except causal attributions. These cover diverse factors, and the authors recommended that causal items should not be used as a single scale. For sample sizes above 90 participants, factor analysis can be used to identify categories of causal beliefs that can then be used as subscales (Moss-Morris et al., 2002).

- Insert Table 1 about here -

The current study modified the IPQ-R for use with children and adolescents. The IPQ-R identity subscale lists generalised symptoms and asks two questions about each - whether the person has experienced them since the start of their illness, and whether they believe the symptom is related to their illness. In the modified IPQ-R (chIPQ-R) participants were asked if they had experienced each listed symptom because of their epilepsy. In order to assess how they identified with their epilepsy diagnosis, an item was included that asked them how often they thought about their epilepsy. This item is not included in the original IPQ or IPQ-R, but was felt to better sample the construct of illness identity or 'self-illness relationship' (Kemp & Morley, 2001) as intended by Leventhal's SRM. The modified chIPQ-R is compared with the original IPQ-R in Appendix nine.

The rest of the IPQ-R asks for responses to statements on a five-point Likert scale from strongly agree to strongly disagree. Since children may find statements hard to disagree with and may not appreciate the differences between 'dis/agree' and 'strongly dis/agree', the chIPQ-R used direct questions with a five-point scale from 'definitely yes' to 'definitely no'. At the start of the scale, an example was given to help participants understand the response format.

The term 'epilepsy' was substituted for the general term 'illness', to focus participants on the relevant medical condition. This also followed advice from local medical practitioners who were attempting to encourage their patients not to see their epilepsy as a disease or illness – this perception was seen as unhelpful for patients who need to learn to live with this condition.

Age-inappropriate items about smoking, aging and drinking alcohol were dropped from the causal attributions subscale and an item about financial impact was dropped from the consequences subscale.

The original wording on some items has been changed to decrease the complexity of the syntax or vocabulary used. For example, the term 'cycles' in items 30 and 32 was omitted, and the phrase 'those who are close to you' in item 11 became 'your parents and friends'. Negative grammatical terms were eliminated, to ensure that comprehension errors did not distort responses, but items remained negatively or positively worded according to the original format, so as not to alter any response set.

The chIPQ-R was then studied by an Epilepsy Nurse Specialist, a paediatric Consultant Clinical Psychologist and a paediatric Neuropsychologist who work with children with epilepsy. All felt that the scale had face validity for the children they work with.

Adjustment

Adjustment has been operationalised as psychopathology (Hermann et al., 1990; Piazzini & Canger, 2001), quality of life (Miller et al., 2003; Suurmeijer et al., 2001) or behavioural disturbance (Dunn et al., 2003; Hoare & Kerley, 1991; Oostrom et al., 2001). Reliable and validated measures of psychopathology in children, such as the Child Behaviour Checklist (CBCL: Achenbach & Edelbrock, 1983) or the Rutter scales (Rutter, 1967), focus on quantifying behavioural disturbance. A more recent and shorter behavioural screen, the Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997), has better psychometric properties and is more sensitive to

inattention/hyperactivity than both the CBCL (Goodman & Scott, 1999) and the Rutter scales (Goodman, 1997). The measure can be completed by parents and comprises five subscales, covering emotional symptoms (a measure of generalised affect), conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behaviour, a structure confirmed by factor analysis of data from 10,438 children aged 3-15 (Goodman, 2001). Subscales had a mean reliability coefficient of 0.73, and showed good re-test stability (Goodman, 1997).

As well as eliciting data on participants's behavioural adjustment, the current study also used an epilepsy-specific measure of psychosocial outcome. The Impact of Paediatric Epilepsy Scale (IPES: Camfield, Breau & Camfield, 2001) consists of 11 items asking parents whether epilepsy has affected various aspects of their child's and family's everyday life, and is scored on a four-point scale from 'not at all' to 'a lot' (see parent questionnaire in Appendix six). It is acceptable to parents and has high internal reliability (0.92). Camfield et al. (2001) divided their sample of 97 children into low impact and high impact groups on the basis of median IPES score, and found that the high impact group had significantly more frequent seizures, took significantly more medications and had had more frequent hospital visits than the low impact group. Camfield et al. (2001) argue that this is evidence of external validity. Measurement of the psychosocial impact of paediatric epilepsy complements the SDQ and both are used to provide a broad index of psychosocial outcome.

Procedure

The chIPQ-R was piloted, to check young children's ability to understand the items and response format, and to observe how much parental help might be requested (see

Appendices ten and eleven for information and consent forms). Unfortunately, only two children from five consecutive clinics met inclusion criteria and only one of these consented to be interviewed. The nine-year-old boy who completed the pilot questionnaire had an intellectual maturity level at the eighth percentile, as estimated by the GHDT, and completed every item on the chIPQ-R, including the additional identity item, without requesting parental help. More pilot data would have been useful, but because of the poor response rate, it was decided that the postal questionnaire should be sent out with the addition of items requesting parents to document how much help they provided (see Appendix twelve for introductory letter). 236 questionnaires were sent. 58 families responded. No follow-up was carried out because of time constraints secondary to having waited longer than planned for pilot data, as mentioned above.

RESULTS

Data were entered into a Microsoft Excel 2002 SP-2 database and analysed using SPSS for windows, release 11.0.1.

Descriptive Data

Demographic variables

Of 58 responses, three indicated the family were no longer known at the address given in the database and one that the named child or adolescent was too busy with exams. Three completed forms indicated that the recipients had SLD, and another that they had had no seizures for over seven years (and therefore could no longer be considered as having active epilepsy) and these four were excluded. Data from the pilot child

(chIPQ-R and GHDT) was included in descriptive statistics and analyses of reliability for these two measures, but not in any inferential analyses.

The eventual sample consisted of a child or adolescent and one parent from 50 families. This response rate (21%) is low, but is hard to interpret because faulty database information makes it impossible to estimate how many intended recipients actually received the questionnaire. The sample is compared with the database population in Table 2. This shows a male to female ratio of 1:1.38, a slight preponderance of females not found in the original database. This may indicate a gender-related response bias. Age and chronicity of epilepsy appears to be roughly similar across datasets. The lower proportion of individuals with special educational needs (SEN) in the study dataset reflects the exclusion of those with SLD, but is still a high proportion. The final sample also included almost twice the proportion of individuals with a co-morbid neurological abnormality than the original dataset.

- Insert Table 2 about here -

Parents also provided information on their child's family network. Respondents generally lived with two (n=20) or three (n=17) adults, sometimes just one (n=11) and occasionally more than three (n=2). Families generally consisted of two (n=22) or three (n=14) children, but sometimes just one (n=8) and occasionally four or more (n=6). The parents of 32 children had an intact marital relationship. Nineteen had divorced or separated, and eleven of these had maintained contact between the child and the absent parent. Forty children had contact with significant others outside the home, generally grandparents, uncles and aunts, but also brothers, sisters or absent

parents. Of this forty, 22 saw one or two contacts regularly, eight had three to four regular contacts, and ten had more than four regular contacts outside the home.

In terms of educational placements, 26 respondents attended mainstream schools without receiving SEN support, twenty received SEN support within mainstream settings, and four attended specialist schools.

Developmental maturity

Cognitive-developmental maturity was assessed using the GHDT. Ten respondents omitted this item. This sample achieved a $mean_{(SD}$[1]$)$ scaled score of $99.87_{(19.07)}$, close to the standardised GHDT $mean_{(SD)}$ of $100_{(15)}$. Scaled scores ranged from 62 to 144 (n=40). To assess discriminant validity, the GHDT scaled scores of respondents in different educational placements were compared. Significant differences were found between respondents in mainstream without SEN support ($mean_{(SD)}=105.05_{(15.01)}$), those with SEN support ($99.65_{(21.27)}$) and those in specialist placements ($75.33_{(8.08)}$), using ANOVA ($F_{2,36}=3.63$, $p<.037$). This test was included to provide an objective means of differentiating developmental level that is more accurate than chronological age, given the extent of intellectual disability within the paediatric epilepsy population and its possible relationship to adjustment. However, given the extent of spoiled responses on this test and the fact that GHDT scores were not significantly related to adjustment as measured by the IPES or the SDQ, GHDT data were not used in further analyses.

[1] SD = standard deviation

Biomedical variables

First seizures were experienced at a $mean_{(SD)}$ age of $5.78_{(4.16)}$ years, range 0-15 years. There was a $mean_{(SD)}$ of $6.99_{(4.22)}$ years since first seizure, range 0-16 years. These parallel the sample's $mean_{(SD)}$ age at diagnosis of $6.81_{(4.13)}$ years (range 0-15) and $mean_{(SD)}$ time since diagnosis of $6.01_{(3.76)}$ years (range 0-16).

Non-neurological co-morbidity was reported by 10 parents (20%), including asthma (n=8), autistic spectrum disorder (n=1) or skin conditions (n=1). Nineteen (38%) reported neurological involvement, including cerebral mass or tumour (n=5), sclerosis (n=3), infection (n=2), head trauma (n=4), pre- or peri-natal growth defect (n=3) or hemiparesis (n=2). Of these neurological conditions, ten (20%) were identified by the parent as the cause of their child's epilepsy.

Parents also reported on the seizure phenomena experienced by their children. 16% of the sample had never had a seizure affecting arms and legs, and only 8% had never lost consciousness. Characteristics of the seizures experienced by this sample are presented in Table 3. The $mean_{(SD)}$ number of seizure characteristics experienced was $5.80_{(2.09)}$, range 1-10. The median seizure frequency was one per month, range 0-140. Eight respondents (18.4%) were having seizures at least daily.

- Insert Table 3 about here -

Four respondents were receiving no medication, nineteen were on one AED and 27 on two or more AEDS. Fifteen reported no changes in medications in the past year, sixteen reported one change and nineteen had had their prescriptions changed two or more times in the past year. The $mean_{(SD)}$ number of hospital/clinic visits in the past

year was $2.47_{(2.65)}$ visits, range 0-15. Forty parents felt that their child had experienced AED side effects, and the $mean_{(SD)}$ number of side effects reported was $2.19_{(1.84)}$ symptoms, range 0-6.

Illness representations

Four chIPQ-R items were omitted, all by different respondents, one each from the timeline (acute-chronic), consequences, illness coherence and emotional representations subscales. In terms of helping their child understand questions, 22 parents gave no help, eighteen a little help and seven a lot of help. 28 parents reported giving their child no help with responses, seventeen a little help and two a lot of help. Whether help was with responses or understanding questions, the respondents tended to be younger and have lower GHDT scaled scores. This indicates that the scale was acceptable to participants between the ages of seven and seventeen, but that younger and developmentally less mature children may need some adult facilitation when completing the questionnaires.

Respondents endorsed between one and ten symptoms on the identity subscale, with a $mean_{(SD)}$ of $4.96_{(2.63)}$. On the additional identity item, which asked how often the respondent thought about epilepsy, the median response was 'a few times a week', ranging from 'hardly ever' (28%) to 'all the time' (10%). As in the adult version, the two components of the identity scale were added to create an identity compound score. In order to describe the IR profile of this sample visually, chIPQ-R scores were standardised so that they shared the same minimum and maximum potential scores, and Figure 1 presents these in a boxplot. Shaded areas represent the proportion of the

sample between the 25th and 75th percentiles, with a horizontal line indicating the sample's median score. Lines outside the shaded area indicate the 10th and 90th percentiles. Higher scores on each subscale indicate a stronger endorsement of the relevant IR, i.e. a higher timeline (acute-chronic) score indicates a more chronic perception of the course of their epilepsy, and a higher illness coherence score indicates a more cohesive understanding of epilepsy.

- Insert Figure 1 about here -

Figure 1 shows that respondents's perceptions of their epilepsy varied widely. The majority of participants expressed a weak to moderate illness identity. Respondents did not see their epilepsy as being very acute nor very long-lasting, and most seemed to see their condition as lasting for the medium term. Participants generally saw their condition as being cyclical, although responses varied widely. Respondents also varied widely in their perception of self-efficacy (personal control), but generally felt they were moderately in control. A higher mean score and lower variance in treatment control responses indicates that respondents generally felt confident in the power of their treatment to cure or control their epilepsy. Participants tended to perceive their epilepsy as having serious consequences, though again there was a lot of variance. Respondents did not indicate that their epilepsy was a complete mystery, but similarly did not tend to feel that they understood their condition well. Emotional representations of epilepsy ranged from very positive to very negative emotions, but indicated largely negative emotional reactions. Causal items were generally not endorsed, indicating that respondents tended not to perceive that their epilepsy had been contributed to by psychological (e.g. stress or personality), immunity-related (e.g. germs), chance or risk factors (e.g. heredity). Participants seemed more likely to

attribute their epilepsy to chance than to other factors. It is difficult to compare these findings with other studies, as none have sampled paediatric epilepsy IRs. The only study to look at adult epilepsy IRs used a modified version of the original IPQ, and their data are not comparable.

Hypothesis 1 – internal stability of chIPQ-R

Unstandardised subscale mean scores and internal reliability coefficients (Cronbach's alpha) are presented in Table 4. All subscales except two of the causal scales showed moderate to good internal stability ($\alpha > 0.6$). The causal subscales elicit perceptions about a wide variety of potential causes – for example, the risk factor scale covers both heredity and behavioural risks, and it is not surprising that such disparate items show low internal consistency. Similar findings have been reported by many authors (Hagger & Orbell, 2003), including the developers of the IPQ-R (Moss-Morris et al., 2002), who recommend that causal items are interpreted only using factor analysis (of samples with over ninety participants). The interpretation of causal data therefore needs to be cautious. The identity compound score shows good internal stability and will therefore be used in further inferential analyses.

- Insert Table 4 about here -

Impact of epilepsy

The $mean_{(SD)}$ IPES score for this sample was $16.48_{(9.5)}$, and scores ranged from 0 to 32. This is higher than the mean score from Camfield et al.'s (2001) normative sample of 6.59, perhaps reflecting the more severe epilepsies found in clinic samples. In contrast to this high impact, parents reported their children's quality of life as good. Rated on an analogue scale from one ('poor') to six ('excellent'), scores ranged from

two to six around a median of 4.5. This scale had high internal stability, with an alpha coefficient of 0.94.

Strengths and difficulties

SDQ scores indicated that a significant proportion of this sample was experiencing emotional and behavioural difficulties. Subscales consist of five items with a possible range of 0 to 10. Table 5 shows the sample's scores, internal reliability coefficients and presents the proportions of respondents scoring within normal, borderline and abnormal clinical ranges. Normative proportions per clinical category expect 80% to be in the normal range, 10% borderline and 10% abnormal. Mean scores from a large UK normative sample are also given (n=10,298: Meltzer, Gatward, Goodman, & Ford, 2000).

- Insert Table 5 about here -

Just over half of the sample scored in the abnormal range on the total SDQ score (which omits the prosocial scale), the peer difficulties and the emotional problems scales, compared to 10% of the normal population. On all except the prosocial subscale, respondents scored higher than the normative group. Three quarters of the sample showed good rates of prosocial behaviour. The inter-item reliability coefficients indicated moderate to high reliability.

Inferential Data

The distributions of all continuous variables were tested for normality using Kolmogorov-Smirnov tests (see Appendix thirteen). Four variables were positively skewed and would require transformation before meeting parametric assumptions: the

number of significant contacts outside the home (n=50, Z=1.72, p<.005), months since last seizure (n=46, Z=2.31, p<.001), number of recent hospital visits (n=50, Z=1.78, p<.004) and seizure frequency (n=44, Z=2.22, p<.001).

Hypothesis 2 – chIPQ-R intra-subscale correlations

Pearson correlation coefficients indicated that as predicted, the identity compound was significantly positively correlated with perceived consequences (r=0.630, p<.001, *n*=50). The predicted relationship between identity and timeline was found in relation to the cyclical dimension (r=0.529, p<.001, *n*=50), but not chronicity (r=0.127, p<.380, *n*=50). Likewise, the predicted relationship with cure/control was found with respect to treatment control (r=-0.465, p<.001, *n*=50), but not personal control (r=.014, p<.913, n=50). It was also predicted that cure/control perceptions will correlate negatively with timeline and consequences dimensions. Personal control correlated negatively with perceived chronicity (r=-0.462, p<.001, *n*=50), but was not significantly related to cyclical perceptions (r=0.196, p<.172, *n*=50) or perceived consequences (r=0.138, p<.341, *n*=50). Treatment control correlated significantly and negatively with both perceived chronicity (r=-0.300, p<.035, *n*=50) and consequences (r=-0.374, p<.008, *n*=50), but not cyclical timeline representations (r=-.265, p<.062, n=50). These relationships were largely as predicted.

Hypothesis 3 – predicted relationships with outcome measures

Links between IR dimensions and outcome were as predicted. Pearson correlation coefficients indicated that lower emotional and behavioural pathology as measured on the SDQ was related to higher perceived treatment control, lower identity compound

scores, a less cyclical but not more acute perceived timeline, and lower perceived consequence scores (see Table 6).

- Insert Table 6 about here -

Increased psychosocial impact was significantly associated with lower treatment control scores, higher identity compound scores, a more cyclical perceived timeline and more severe perceived consequences.

Hypothesis 4 – Emotional representations and affect measures

As predicted, there was a significant but weak positive correlation with the emotional symptoms subscale of the SDQ ($r=0.295$, $p<.040$, $n=49$).

Hypothesis 5 - relationship of demographic, epilepsy-related and illness perception variables with outcome

Two hierarchical multiple regressions assessed the relative influences of demographic, epilepsy-related and IR variables on IPES and SDQ total scores. Total SDQ score was used as a dependent variable instead of individual SDQ subscale scores because total score showed higher internal stability than individual subscales. In preparation for this procedure, continuous and categorical variables were inspected to ensure they met the assumptions of a multiple regression model.

Of the demographic variables, only age was related to outcome, correlating weakly but significantly with SDQ total score ($r=-.280$, $p<0.049$, $n=50$). In the interests of parsimony, gender, social support, family size, parental relationship, developmental

maturity and school type variables were therefore omitted from the multiple regression model.

Several epilepsy variables showed relationships with outcome data. Respondents with co-morbid non-neurological conditions scored on average 0.65sd[2] higher on the SDQ total than those without ($t=2.25$, $df=48$, $p<0.029$). Pearson correlations indicated that age at diagnosis correlated with SDQ total ($r= -.319$, $p<0.035$, $n=44$) and seizure frequency correlated with both SDQ total ($r=.398$, $p<.007$, $n=44$) and IPES ($r=.531$, $p< .001$, $n=44$). IPES scores were related to hospital visits ($r=.386$, $p<.006$, $n=50$), time since last seizure ($r=-.296$, $p<.046$, $n=46$), number of AEDs taken ($r=.361$, $p<.010$, $n=50$) and the number of recent prescription changes ($r=.575$, $p<.001$, $n=50$). The type and the number of seizures experienced, side effects, age of onset, time since diagnosis and onset, the presence of co-morbid neurological abnormality and symptomatic epilepsy were not related to outcome measures and were therefore omitted from further analysis.

Seizure frequency, time since last seizure and number of hospital visits were not normally distributed. Theoretically, time since last seizure and seizure frequency are both measures of seizure control. Further, seizure frequency and number of hospital visits were strongly correlated ($r=.714$, $p<.001$, $n=44$). Strongly intercorrelated variables can cause problems for multiple regression, and therefore partial regressions were carried out to inspect the relative relationships between these three variables and outcome measures. These are presented in Table 7, and show that only seizure

[2] Effect size calculated by dividing the difference between the two groups' mean scores by the standard deviation of the whole sample.

frequency explained variance in outcome measures when the other two variables were partialled out.

- Insert Table 7 about here -

Seizure frequency was so positively skewed that statistical transformations failed to normalise this variable. Over half the sample (52%) experienced one or fewer seizures per month. In order not to lose the power of seizure frequency as a predictor of outcome, this variable was converted into ordinal data expressing ranges of seizure frequency roughly corresponding to monthly (0-3 per month), weekly (4-29 per month), daily (30-59 per month) or more than daily (60+ per month) seizures. The large group not experiencing seizures on a monthly basis were further categorised according to whether they had been seizure-free for six months to two years or more than two years, incorporating some of the information from the time since last seizure item. The new variable consisted of six levels and roughly equated to seizure control. This was used in multiple regression analyses. Ordinal data can complicate multiple regression, but it was felt that this was too significant a variable to omit. The use of an ordinal variable with six levels should not dramatically affect the probability of Type I or II errors (Jaccard & Wan, 1996), but the analyses will need to be interpreted with caution.

Since ordinal variables with just three categories are unsuited to multiple regression, the number of AEDs and AED changes were coded as dichotomies, expressing monopharmacy versus polypharmacy and no recent prescription changes versus one or more prescription changes. Respondents receiving polypharmacy scored an average of 0.71sd higher than those on mono-pharmacy on the IPES ($t=2.58$, $df=46$, $p<.013$),

but did not differ on the SDQ. Those who had had medication changes prescribed recently scored an average 0.82sd higher on the IPES than those whose regimen had remained stable ($t=2.829$, $df=46$, $p<.007$), but did not differ significantly on the SDQ. Therefore these contrasts were entered into IPES but not SDQ regression models.

As shown in Table 6, identity, treatment control, consequences and cyclical timeline were related to both IPES and SDQ scores, and emotional representations and psychological causal attributions were related to IPES scores. These variables were therefore used in the multiple regression models.

- Insert Table 8 about here -

The regression models produced a good fit for both SDQ total scores ($R^2_{adj}=61\%$) and IPES scores ($R^2_{adj}=66\%$), and the relationships were significant in both cases (see Table 8). Epilepsy-related variables explained a significant amount of the variance in IPES (38%) and SDQ (50%) scores, and on both outcome measures, IR variables explained a significant amount of variance over and above these epilepsy variables (11% of SDQ variance and 28% of IPES variance). Table 9 shows the variables entered into the SDQ regression model, and indicates that non-neurological co-morbidity, age at diagnosis, seizure control, illness identity and perceived treatment efficacy had significant independent influence on SDQ totals.

- Insert Table 9 about here -

Table 10 lists the variables entered into the IPES regression model, and indicates that seizure control, illness identity, perceived consequences and emotional representations had significant independent influence on IPES totals.

- Insert Table 10 about here -

DISCUSSION

The chIPQ-R was internally reliable, and acceptable to respondents aged seven to seventeen, though younger children may need a little adult help. Significant intra-subscale correlations were found to be largely in line with predictions, supporting the validity of this modified version of the IPQ-R. Respondents who saw their epilepsy as highly symptomatic were more likely to perceive their condition to be cyclical, have serious consequences and be less amenable to medical control. Those who felt they had some personal control over their condition were more likely to see their condition as acute, and those who felt their epilepsy to be curable tended to see it as less serious and more acute. Interestingly, strong illness identity was not related to perceived chronicity, but to a perceived cyclical course. This may reflect the fact that epilepsy runs a different course from many other chronic illnesses, but it may also be that children and adolescents are less aware of or affected by the likely duration of illness than adults. Further, identity was related to treatment control but not personal control. The relative weakness of personal control may reflect the fact that respondents may share control with their parents. However, participants who saw their condition as chronic tended to feel they had less personal control over their epilepsy, and it may be that this clinic sample was biased towards more chronic cases, obscuring the effects of chronicity. Children and young people's perceptions of timeline and cure/control need further exploration.

The relationships between IRs and psychosocial outcome were also as predicted. Good behavioural adjustment was linked with a belief in treatment efficacy, weaker

illness identity, less serious perceived consequences and a less cyclical perceived course. A weak sense of illness identity and the perceptions that epilepsy is amenable to treatment, not serious and less cyclical were also related to a lower impact on family, peers, school and leisure activities. The hypothesis that the emotional representations subscale would correlate with but not overlap measures of affect was supported by a significant but weak correlation with parental reports of their child's generalised emotional symptoms.

Older respondents were slightly less well adjusted behaviourally, but parental relationship, contact with social support, type of school attended, developmental maturity and gender were unrelated to behavioural or psychosocial outcome. The presence of non-neurological co-morbidity, younger age at diagnosis, higher seizure frequency, more recent seizures, polypharmacy and more recent hospital visits and prescription changes were related to poor behavioural and psychosocial outcome. Chronicity, side effects, the presence of an identified cause, neurological co-morbidity and seizure characteristics were unrelated to either behavioural difficulties or psychosocial impact.

Multiple regression indicated that the combination of chronological age, seizure control, age at diagnosis, the presence of non-neurological co-morbidity, illness identity, perceived consequences, cyclical timeline and treatment efficacy accounted 61% of the variance in emotional and behavioural adjustment. As predicted, IRs contributed a significant amount of this variance (10%) after demographic and epilepsy variables had been controlled for. Combining seizure control, polypharmacy, medication changes, illness identity, consequences, treatment control, cyclical

timeline, emotional representations and psychological causal attributions explained 66% of the variance in psychosocial impact, and in line with hypotheses, IRs again added significant explanatory power to this model (28%), over and above the biomedical variables. The multiple regressions should be interpreted with caution because of the inclusion of an ordinal variable in the models, but they provide preliminary evidence that the IRs of children and adolescents may have similar relationships with adjustment to those of adults.

This study was primarily designed to investigate the utility of an IR component in a model of adjustment to paediatric epilepsy. It has not addressed questions of the accuracy of respondents's IRs by analysing the relationships between IRs and biomedical variables because epilepsy data was acquired from parents and not medical records and therefore cannot be considered to be wholly objective. Given this preliminary evidence that an IR component may be of value, future work would ideally investigate the relationships between IRs and other variables, including biomedical factors.

These findings tie in neatly with previous research. The hypotheses tested by Hagger and Orbell (2003) were supported here, suggesting that the organisation of child and adolescent IRs and their relationship with adjustment may mirror that of adults. The explanatory power of IRs with respect to psychosocial adjustment to epilepsy replicates findings with adults reported by Kemp et al. (1999). It is concluded that the chIPQ-R may be a reliable and meaningful tool for exploring the IRs of children and young people with epilepsy.

Despite the absence of a full pilot stage, further use of the modified IPQ-R with children and adolescents is indicated. However, these findings should not be generalised to the paediatric epilepsy population as a whole. The sample was small and drawn from a hospital clinic and is therefore not representative of the wider population. It is hard to interpret the response rate given that some of the clinical and personal information on the database was out of date, but it is likely that this sample comprises a higher proportion of resistant cases, for whom the impact of epilepsy has been stronger than general population samples reported elsewhere (Camfield et al., 2001). The high rates of emotional and behavioural disturbance in this sample are unrepresentative of young people with epilepsy generally. The IR model may be of value in understanding adjustment to paediatric epilepsy, but these results were drawn from a clinic sample with a high non-response rate, and should not be generalised the paediatric epilepsy population as a whole.

The cross-sectional design of this study makes causal inferences impossible. Further, the exploratory nature of the data analysis meant that many statistical inferences were made, and the lack of a correction to the significance levels set increases the probability of type I error. The conclusions drawn from these findings should therefore reflect hypotheses about the usability and meaningfulness of the chIPQ-R and not specific statements about the relationship between IRs and psychosocial outcome in paediatric epilepsy.

The measures used appeared to be acceptable to most respondents, and no single item on any scale was regularly omitted. The GHDT provided a reliable and valid insight

into relative developmental maturity that could be completed by children with SEN, although this did not turn out to be related to outcome.

Questionnaire studies have been criticised for constraining individuals' responses, and potentially missing important information (Eiser, 1990; Leventhal et al., 1980). However, other authors have called for quantitative studies to confirm the IR structures elucidated by earlier qualitative methods (Lau, 1997). Weinman et al. (1996) found a close fit between interview and IPQ data with more information provided in response to the questionnaire. In fact, questionnaires may be less socially constraining for children than interviews, as there is no need for participants to justify their choices, no need for conversational awareness, a choice of answers rather than a need to invent some and the option of completing them in a familiar environment (Siegal & Peterson, 1999).

Some authors have argued that the epilepsy population is unique (Kemp & Morley, 2001; Kemp et al., 1999; Levisohn, 2002; Suurmeijer et al., 2001) and requires epilepsy-specific measures to properly research the issues relevant to this field. The IPES was a valuable and highly reliable epilepsy-specific outcome measure. However, it is also important to design studies which allow some generalisation between chronic illnesses, both to develop our understanding of IRs and to build a satisfactory theoretical model of adjustment.

Leventhal et al.'s (1984) model stresses the role of coping, which mediates the relationship between IRs and outcome. The aim of the present study was to explore the possibility of using IRs as predictors of paediatric epilepsy outcome, but later

investigations should examine the processes by which they exert this influence, by including measures of coping procedures in their dataset. Larger scale studies (n>90) are required, to be able to make more use of the causal subscales than was possible here, and to verify the measure's factor structure in paediatric samples. If IRs and psychosocial outcome are related independently of biomedical variables, then it will be important to consider the factors that influence IRs – including parents' perceptions of their child's illness (Galletti et al., 1998). Longitudinal research is essential for examination of Leventhal et al.'s (1984) causal hypotheses. A prospective study would also be able to examine the stability of IRs over time, a difficult but important question that would involve separating out and exploring the effects of onset age, disease duration and developmental maturity.

The clinical value of understanding child and adolescent reactions to epilepsy experiences is clear. The prediction of poor responses would enable preventive action at early stages, and an understanding of the processes underlying poor responses will enable clinicians to build evidence-based educational programmes and psychosocial interventions. There is an important role for clinical psychologists in elucidating these relationships and applying academic knowledge from developmental psychology and clinical research from cognitive and health psychology to develop evidence-based interventions for clinical paediatric populations.

Conclusions

This study suggests that the chIPQ-R is a reliable and meaningful tool for the exploration of young people's perceptions of their epilepsy. There is also preliminary evidence that the application of the adult self-regulatory model to children and

adolescents may help to provide insights into the relationship between cognition and psychosocial outcome in paediatric epilepsy.

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TABLES AND FIGURES:

Table 1: IPQ and IPQ-R subscales

IPQ	IPQ-R	Description
Illness identity	Illness identity	Patients' ideas about the label and symptoms associated with their condition
Timeline	Acute-chronic	Perceptions of likely course of illness (short or long term)
	Cyclical	Perceptions of likely course of illness (variable)
Cure/control	Personal control	Extent to which patient believes their illness amenable to personal control
	Treatment control	Extent to which patient believes their illness to be curable
Cause	Causes (psychological attributions)	Patients' attributions of their illness to potential psychological causes (e.g. stress or personality factors)
	Causes (immunity)	Patients' attributions of their illness to potential immune factors (e.g. germs or pollution)
	Causes (risk factors)	Patients' attributions of their illness to potential risk factors (e.g. hereditary or behavioural factors)
	Causes (chance)	Patients' attributions of their illness to chance causes (e.g. bad luck or injury)

IPQ	IPQ-R	Description
Consequences	Consequences	Individuals' beliefs about illness severity and impact on physical, social and psychological functioning
	Illness coherence	Meta-cognitive index of how well the patient feels they understand their illness
	Emotional representations	Assess the specific emotional impact of the illness

Table 2: Description of original dataset:

	Original database	Study dataset, after exclusions[1]	Final sample
	n=413	*n*=236	*n*=50
Proportion of males	52.78%	48.09%	42%
Proportion of females	47.22%	51.91%	58%
Mean$_{(SD)}$ age (years)	11.84$_{(4.63)}$	12.93$_{(2.96)}$	12.95$_{(2.99)}$
Age range (years)	1-22	7-18	7-17
Mean$_{(SD)}$ duration of epilepsy	5.32$_{(4.15)}$ years	5.62$_{(4.37)}$ years	6.01$_{(3.76)}$ years
Duration range	0-16	0-16	0-16
Proportion with SEN (severe, moderate mild or specific learning disability)	64.3%	41.39%	49.10%
Proportion with neurological co-morbidity	Not known	17.75%	38%

[1] Exclusions = age outside 7-18 range (n=87); Severe learning disability (n=84); English as a second language (n=4); Deceased (n=2); Quadriplegia (n=1).

Table 3: Seizure characteristics.

Seizure characteristics:	***n***	**Never**	**Sometimes**	**Always**
Involvement of arms and legs	49	16.3% (8)	42.9% (21)	40.8% (20)
Loss of awareness	48	8.3% (4)	35.4% (17)	56.3% (27)
	n	**No**	**Yes**	**Don't know**
Whole body stiffening	49	30.6% (15)	61.2% (30)	8.2% (4)
Whole body jerking	49	38.8% (19)	59.2% (29)	2% (1)
Losing consciousness	49	38.8% (19)	55.1% (27)	6.1% (3)
Absences	50	8% (4)	90% (45)	2% (1)
Dropping or falling	50	40% (20)	60% (30)	0% (0)
Part of body twitching	50	22% (11)	74% (37)	4% (2)
Going numb	47	29.8% (14)	19.2% (9)	51.1% (24)
Dizziness, sweating, butterflies or nausea	49	20.4% (10)	61.2% (30)	18.4% (9)
Disturbed vision, smell, taste or hearing	49	28.6% (14)	42.9% (21)	28.6% (14)
'Deja vu' or memory flashback	48	35.4% (17)	16.7% (8)	47.9% (23)
Automatisms	49	38.8% (19)	49% (24)	12.3% (6)
Aura	50	34% (17)	52% (26)	14% (7)
Post-ictal confusion	50	8% (4)	90% (45)	2% (1)

Table 4: Mean$_{(SD)}$ chIPQ-R subscale scores and reliability coefficients.

Subscale	*n* items	Possible range	Mean $_{(SD)}$	Range	$\alpha =$
Identity	13	0-13	$4.96_{(2.63)}$	1-10	.68
Identity compound	14	1-19	$7.82_{(3.61)}$	2-16	.64
Timeline (Acute/chronic)	6	6-30	$18.12_{(2.13)}$	14-28	.83
Consequences	5	5-25	$16.92_{(3.45)}$	10-24	.72
Personal control	6	6-30	$18.5_{(4.41)}$	8-27	.75
Treatment control	5	5-25	$20.22_{(3.36)}$	13-25	.65
Illness coherence	5	5-25	$16.6_{(4.02)}$	9-25	.79
Timeline (cyclical)	4	4-20	$13.0_{(3.71)}$	4-18	.61
Emotional representations	6	6-30	$19.16_{(7.88)}$	6-30	.89
Cause (psychological)	6	6-30	$9.48_{(4.07)}$	6-23	.66
Cause (risk factors)	4	4-20	$6.28_{(2.53)}$	4-13	.34
Cause (immunity)	3	3-15	$5.3_{(2.43)}$	3-10	.77
Cause (chance)	2	2-10	$4.74_{(1.85)}$	2-9	.13

Table 5: SDQ profiles and internal reliability coefficients.

Subscale (and mean of norm group)	Mean$_{(SD)}$; range	Frequencies			α=
		Normal	Borderline	Abnormal	
Prosocial	7.49$_{(2.31)}$	76%	12%	12%	.74
8.6$_{(1.6)}$	2-10				
Peer problems	3.77$_{(2.64)}$	40%	8%	52%	.73
1.5$_{(1.7)}$	0-9				
Hyperactivity	5.40$_{(2.79)}$	52%	16%	32%	.73
3.5$_{(2.6)}$	0-10				
Conduct problems	2.16$_{(1.91)}$	58%	26%	16%	.61
1.6$_{(1.7)}$	0-8				
Emotional problems	5.41$_{(2.86)}$	28%	10%	62%	.72
1.9$_{(2.0)}$	0-10				
SDQ Total score	16.73$_{(7.41)}$	30%	16%	54%	.83
8.4$_{(5.8)}$	2-32				

Table 6: Illness perception data and outcome measures.

IPQ subscale	SDQ total score	IPES total score
Identity compound	r = 0.335	r = 0.526
	p < .019*	p < .001**
	n = 49	*n* = 49
Timeline (acute-chronic)	r = 0.191	r = 0.212
	p < .189	p < .144
	n = 9	*n* = 49
Timeline (cyclical)	r = 0.348	r = 0.328
	p < .014*	p < .021*
	n = 49	*n* = 49
Consequences	r = 0.339	r = 0.670
	p < .017*	p < .001**
	n = 49	*n* = 49
Personal control	r = -0.178	r = -0.009
	p < .222	p < .949
	n = 49	*n* = 49
Treatment control	r = -0.306	r = -0.446
	p < .032*	p < .001**
	n = 49	*n* = 49
Illness coherence	r = -0.201	r = -0.215
	p < .167	p < .138
	n = 49	*n* = 49

IPQ subscale	SDQ total score	IPES total score
Emotional representations	r = 0.267	r = 0.429
	p < .063	p < .002**
	n = 49	*n* = 49
Causes (psychological)	r = -0.001	r = 0.300
	p < .994	p < .036*
	n = 49	*n* = 49
Causes (risk)	r = -0.010	r = 0.017
	p < .945	p < .906
	n = 49	*n* = 49
Causes (immunity)	r = 0.049	r = 0.127
	p < .737	p < .385
	n = 49	*n* = 49
Causes (chance)	r = -0.098	r = 0.143
	p < .504	p < .328
	n = 49	*n* = 49

*: $p \leq 0.05$.

**: $p \leq 0.01$.

Table 7: Partial correlations between seizure frequency, hospital visits and time since last seizure, with outcome variables.

Variable	Controlling for	SDQ total	IPES
Seizure frequency	Number of hospital visits	r=.3797	r=.3691
	+	p<0.017*	p<0.021*
	Time since last seizure	n=37	n=37
Number of hospital visits	Seizure frequency	r=-.1301	r=.0035
	+	p<0.430	p<0.983
	Time since last seizure	n=37	n=37
Time since last seizure	Seizure frequency	r=-.1104	r=-.2145
	+	p<0.503	p<0.190
	Number of hospital visits	n=37	n=37

*: $p \leq 0.05$.

**: $p \leq 0.01$.

Table 8: Multiple regression models of influence of demographic, epilepsy-related and illness perception data on outcome measures.

Variables	SDQ total	IPES
Demographic	R^2_{adj}=-.001 F(1,36)=.95, p<.337 [F_{change}(1,36)=.95, p<.337]	None entered
Epilepsy-related	R^2_{adj}=.503 F(4,33)=10.36, p<.001** [F_{change}(3,33)=13.18,p<.001**]	R^2_{adj}=.376 F(3,39)=9.43, p<.001** [F_{change}(5,39)=9.43, p<.001**]
Illness perceptions	R^2_{adj}=.608 F(8,29)=8.16, p<.001** [F_{change}(4,29)=3.19, p<.027*]	R^2_{adj}=.658 F(9,33)=9.97, p<.001** [F_{change}(6,33)=6.36, p<.001**]

*: $p \leq 0.05$.

**: $p \leq 0.01$.

Table 9: Independent contributions of variables to variance in SDQ total scores

Variables	Standardised β weights	t=	df=	p<
Demographic variables				
Child's age	-.038	-.311	29	.758
Epilepsy-related variables				
Non-neurological co-morbidity	.616	4.681	29	.001**
Age at diagnosis	-.391	-3.079	29	.005**
Seizure control	.852	5.635	29	.001**
Illness perception variables				
Identity compound	-.356	-2.231	29	.034*
Consequences	-.036	-.239	29	.813
Treatment control	-.413	-3.377	29	.002**
Timeline (cyclical)	.004	.034	29	.973

*: $p \leq 0.05$.

**: $p \leq 0.01$.

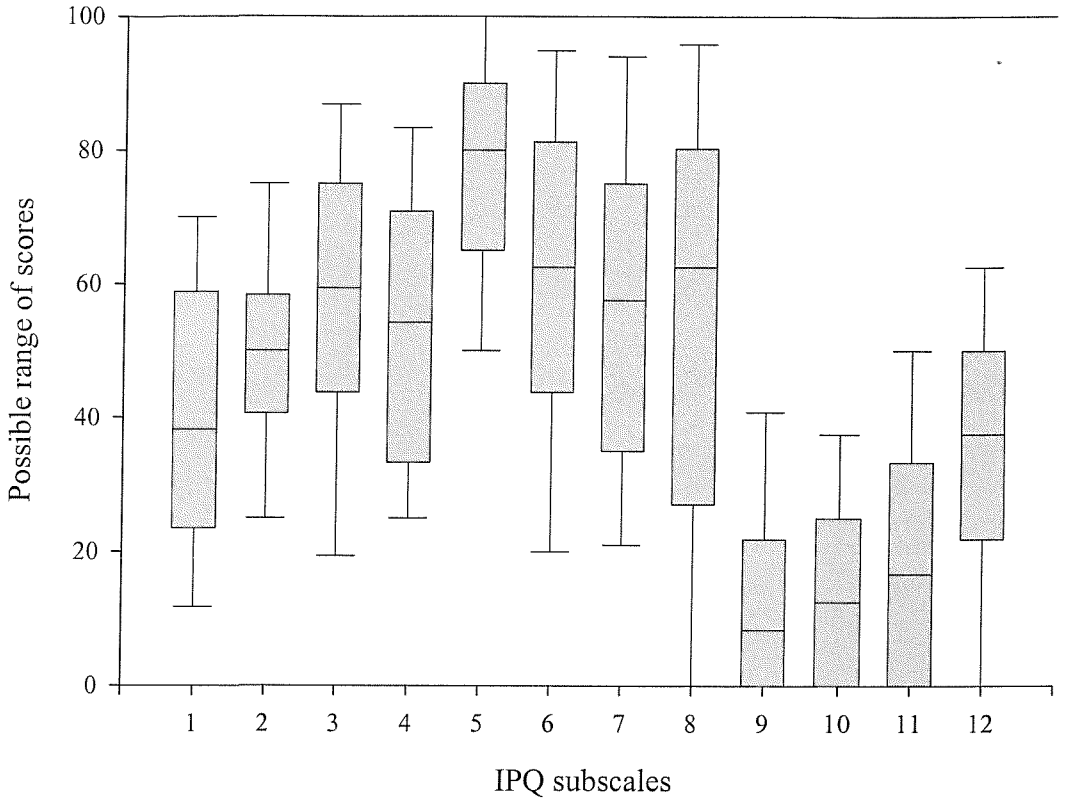
Table 10: Independent contribution of variables to variance in IPES scores

Variables	Standardised β weights	t=	df=	p<
Epilepsy-related variables				
Seizure control	.329	2.811	33	.008**
Mono- versus polypharmacy contrast	.052	.502	33	.619
Prescription changes contrast	-.179	-1.718	33	.095
Illness perception variables				
Identity compound	.364	2.479	33	.018*
Consequences	.435	3.187	33	.003**
Treatment control	-.050	-.432	33	.668
Timeline (cyclical)	.122	1.046	33	.303
Emotional representations	-.482	-3.273	33	.002**
Causes (psychological)	.160	1.688	33	.101

*: $p \leq 0.05$.

**: $p \leq 0.01$.

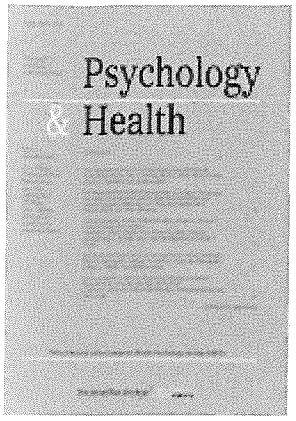
Figure 1: Boxplot showing chIPQ-R profile



1 -	Identity compound
2 -	Timeline (acute-chronic)
3 -	Timeline (cyclical)
4 -	Personal control
5 -	Treatment control
6 -	Consequences
7 -	Illness coherence
8 -	Emotional representations
9 -	Causes (psychological)
10 -	Causes (risk)
11 -	Causes (immunity)
12 -	Causes (chance)

LIST OF APPENDICES:

Appendix 1. Notes for contributors to Psychology and Health:



Instructions for Authors:

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INTRODUCTION

Submission of a paper to *Psychology & Health* will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of editor and publisher. It is a condition of the acceptance by the editor of a typescript for publication that the publisher automatically acquires the copyright of the typescript throughout the world.

SUBMISSION OF MANUSCRIPTS

Three copies of each manuscript should be submitted to Paul Norman, Department of Psychology, University of Sheffield, Sheffield, UK. Each paper will be read by at least two referees.

FORMAT OF MANUSCRIPTS

Manuscripts should be typed according to the guidelines in the Publication Manual of the American Psychological Association (4th edition, 1994); however, please follow the present Instructions for Authors in cases of contradiction with the APA guidelines.

Title page: This should contain the title of the paper, a short running title, the name and full postal address of each author and an indication of which author will be responsible for correspondence, reprints and proofs. Abbreviations in the title should be avoided.

Abstract: This should not exceed 150 words and should be presented on a separate sheet, summarizing the significant coverage and findings.

Key words: Abstracts should be accompanied by up to six key words or phrases that between them characterize the contents of the paper. These will be used for indexing and data retrieval purposes.

TEXT HEADINGS

All headings in the text should be set over to the left-hand margin, and the text should begin on the next line. Type first level (sectional) headings all in capitals. For second and third level headings, only the first letter of the first word should be a capital. Underline third level headings. For example:

FIRST LEVEL TEXT HEADINGS

Second Level Text Headings

Third level text headings

REFERENCES

References should be indicated in the text with the author's name and year of publication in parentheses. If there are two authors, both names should be given. If there are more than two authors, all should be given on the first occasion, and then the first author "et al." should be used subsequently. Use "and" between author names mentioned in the text and an ampersand (&) when mentioned in parentheses and in the reference section. The full list of references should be given in alphabetical order on a separate sheet, with titles of books and journals given in full. Generally, the APA guidelines should be followed for the references. Examples:

1. Johnston, M. (1984) Dimensions of recovery from surgery. *International Review of Applied Psychology*, **33**(4), 505-520.

2. Smith, A.P., Tyrrell, D.A.J., Coyle, K.B., Higgins, P.G. and Willman, J.J. (1990) Individual differences in susceptibility to infection and illness following respiratory virus challenge. *Psychology and Health*, **4**, 201-211.

FIGURES

All figures should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. Figures should be kept separate from the text but an approximate position for each should be indicated in the margin. It is the author's responsibility to obtain permission for any reproduction from other sources.

Preparation: Figures must be of a high enough standard for direct reproduction. They should be prepared in black (india) ink on white card or tracing paper, with all the lettering and symbols included. Axes of graphs should be properly labelled and appropriate units given. Photographs intended for halftone reproduction must be high quality glossy originals of maximum contrast. Redrawing or retouching of unsuitable figures will be charged to authors.

Size: Figures should be planned so that they reduce to 10.5 cm column width. The preferred width of submitted drawings is 16-21 cm, with capital lettering 4 mm high, for reduction by one-half. Photographs for halftone reproduction should be approximately twice the desired size.

Captions: A list of figure captions should be typed on a separate sheet and included in the typescript.

TABLES

Tables should be clearly typed with double spacing. Number tables with consecutive arabic numerals and give each a clear descriptive heading. Avoid the use of vertical rules in tables. Table footnotes should be typed below the table, designated by superior lower-case letters.

PROOFS

Authors will receive proofs (including figures) by air mail for correction, which must be returned within 48 hours of receipt. Authors' alterations in excess of 10% of the original composition cost will be charged to authors.

REPRINTS

Twenty-five reprints per article will be sent to the senior author free of charge. Additional copies may be purchased when returning proofs.

PAGE CHARGES

There are no page charges to individuals or to institutions.

Appendix 2. Further information on epilepsy database:

None of the paediatric neurologists maintained a database that identified children by epilepsy diagnosis. There are ethical, practical and financial difficulties for clinicians attempting to keep databases for research, some of which are touched on by Gauthier, Byrne, and Byrne (1999) in their chapter on managing research within multidisciplinary clinical practice.

The epilepsy specialist nurse for the paediatric neurology team kept a database using a card file system, which I computerised for her. However, without adequate funding and a dedicated person to collect data and keep the database up to date, missing data can be common (Gauthier et al., 1999).

Community paediatricians and school authorities were also approached, but epilepsy diagnosis was not among information routinely collected or held in their information systems either.

When this study had been completed, I presented the data to the neurology team, and discussed issues about information-keeping with the consultants. Although they accepted the research potential that a well-managed database can provide, they did not have the personnel or financial resources at the time, though one consultant has since started looking into acquiring funding for a secretarial post that could include database management.

References:

Gauthier, S., Byrne, J., & Byrne, L. (1999). Research potential. In G. K. Wilcock & R. S. Bucks & K. Rockwood (Eds.), *Diagnosis and management of dementia. A manual for memory disorders teams* (pp. 190-208). Oxford: Oxford University Press.

Appendix 3. Data protection approval letter:

Southampton NHS
University Hospitals NHS Trust

Corporate Information Services Directorate
Data Protection Office
Old Nurses Home, Mailpoint 79
Southampton General Hospital
Tremona Road
Southampton SO16 6YD

Tel: 023 8079 5079
Fax: 023 8079 4741

10 December 2002

DP Ref No: 221/02

K.F. Magnus Cormack
11 Cobden Gardens
Bitterne Park
Southampton
SO18 1LN

Dear Magnus,

Ethics Committee Number: 356/02/w

Thank you for returning the Data Protection Guidance pack duly completed as part of your Ethics Committee submission.

I am pleased to advise you that you comply with the principles of the Data Protection Act 1998 and your response will be held on file within this department. Will you ensure that data is anonymised, secure, password protected and cannot be accessed by any unauthorised person.

If I can be of any further assistance, please do not hesitate to contact me.

Yours sincerely,

Dannie Howe
Data Protection Officer
Corporate Information Services Directorate

Data Protection Notice:
Your response will be held in the Corporate Information Directorate. You have the right to apply for a copy of your information and to have any inaccuracies corrected.

Appendix 4. University ethics committee approval e-mail:

◁ Dissertation: 15 of 49 ▷ Move | Copy this message to:

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Date Tue, 3 Dec 2002 11:49:02 +0000
From KATHRYN SMITH <K.M.Smith@soton.ac.uk>
To kfc200@soton.ac.uk
Reply-To K.M.Smith@soton.ac.uk
Subject Ethical Application
Parts Message Source

Dear Magnus

The application you submitted to the ethical committee has now been approved.

Should you require any further information, please do not hesitate in contacting me. Please quote reference CLIN/2002/38.

Yours sincerely

Kathryn Lucas
Ethical Secretary

Delete | Reply | Reply to all | Forward | Bounce | Resume | Save as | Back to Dissertation

Appendix 5. Local Research Ethics Committee approval letter:

113 Dec

Hampshire and Isle of Wight NHS
Strategic Health Authority

Ref: CPW/HH

11 December 2002

Dr F Kirkham
Consultant Paediatric Neurologist
Child Health
Mp 21, G Level
SGH

SOUTHAMPTON & SOUTH WEST HAMPSHIRE
LOCAL RESEARCH ETHICS COMMITTEES
1ST Floor, Regents Park Surgery
Park Street, Shirley
Southampton
SO16 4 RJ

Tel: 023 8036 2466
023 8036 3462
Fax: 023 8036 4110

General Enquiries: temp1@gp-j82203.nhs.uk
clair.wright@gp-j82203.nhs.uk

Dear Dr Kirkham,

Submission No: 356/02/w – Children's cognitive representations of epilepsy: The relationship between illness perceptions and adjustment to epilepsy.

Following the conditional approval and in response to Mr KFM Cormack's letter dated 26th November 2002, I am pleased to confirm **full approval** having responded satisfactorily to the committees concerns.

The following documents were re-considered:

- Letter from Mr Cormack dated 26th November 2002
- Information Sheet, Version 2 dated 22nd November 2002
- Consent Form, Version 2 dated 22nd November 2002
- Revised Dear Parent/Guardian Letter
- Revised Page 12 of the LREC Application Form
- Revised Protocol

Note: The project title needs to be on everything including the Letter of Invitation.

This approval was granted under Chairman's action by the Chairman Dr Audrey Kemode and will be recorded by the Committee at their meeting in January.

This committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

Yours sincerely

CWright

Mrs Clair Wright
Research Ethics Manager

Chairmen: Dr Audrey Kemode/ Dr David Briggs
Manager: Mrs Clair Wright

Appendix 6. Parent or guardian questionnaire:

Parent Booklet

Guidelines for parents:

Please read the following instructions before you decide whether to ask your child if they want to participate.

1. These questions have been sent to a range of children from age seven to eighteen. We have tried to simplify these questions, but some children may find certain ones hard. Questions that are not understood can be crossed out.
2. The questions do not have to be answered all at once, and children can do them bit by bit if this is easier.
3. It is OK for you to help them if they ask you. Please do not suggest any answers, but *feel free to explain the questions if they ask you. If your child still cannot answer,* then please suggest they cross out the question.
4. If you decide to participate, then this booklet is for you and the other booklet (titled 'Your views about your epilepsy') is for your child. Please discuss this with your child in as much detail as you think best.
5. You and/or your child should feel free not to participate without having to explain why. However, it would be very helpful to us to know some of the reasons why people choose not to participate in this study – it helps us interpret our results more accurately. If you do not want to participate, we would be very grateful if you could write a short note in the space below and return this in the freepost envelope provided.

Thank you very much for your time.

Comments:

1. Background details:

These questions provide important information about your child and their epilepsy. Please answer as many questions as you can either by giving the information requested or by circling the answer.

1. What is your relationship to the child with epilepsy (e.g. natural mother / father / step- or foster parent etc)? .....

2. Please tell us how many adults share the household with you and your child: .....

3. How many children share the household with you and your child: .....

4. Does the child have any close relatives outside the home with whom they have close contact (e.g. parent or grandparent)? **Y / N**

5. If yes, please list: ....

....

6. Gender of child: **M / F** 7. Child's date of birth: ...../...../.....

8. What type of school does your child attend?

Mainstream school without support	**Y / N**
Mainstream school with support (e.g. classroom assistant)	**Y / N**
Special needs department in mainstream school	**Y / N**
Special needs school	**Y / N**

9. At what age did your child have their first seizure? ..... Years old

10. At what age was your child given a diagnosis of epilepsy? ..... Years old

11. Does your child have any other medical conditions? **Y / N**
If yes, please describe: .....

.....

.....

12. Has your child ever had any kind of brain injury (e.g. stroke, tumour, infection, head injury)? **Y / N**
If yes, please describe: .....

.....

.....

13. Is the cause of your child's epilepsy known or not known? **Known / Not known**
If known, please describe: .....

.....

.....

11. When your child has a seizure, does it involve their arms and legs? **Always / Sometimes / Never**

12. Is your child aware of what's happening around them during an attack? **Always / Sometimes / Never**

13. Has your child ever experienced the following during their attacks:

- whole body going stiff **Y / N / don't know**
- whole body jerking **Y / N / don't know**
- losing consciousness **Y / N / don't know**
- 'absences' (staring, blinking or looking vague) **Y / N / don't know**
- dropping or falling to the floor **Y / N / don't know**
- part of the body twitching (e.g. face or arm) **Y / N / don't know**
- going numb **Y / N / don't know**
- dizziness, sweating, butterflies or nausea **Y / N / don't know**
- disturbed vision, smell, taste or hearing **Y / N / don't know**
- 'déjà vu' or a sensation of familiarity or memory flashback **Y / N / don't know**
- 'automatisms', e.g. unwanted repetitive movements such as lipsmacking, scratching, picking or pulling at clothes, swallowing or chewing repeatedly **Y / N / don't know**
- a strange feeling or sensation that an attack is about to happen **Y / N / don't know**
- feeling confused following an attack **Y / N / don't know**

14. When was the last time your child had a seizure: **Month:** ..... **Year:** .....

15. About how many seizures does your child have per month? .....

16. How many epilepsy medications or drugs does your child take? **None / 1 / 2 or more**

17. How many times has their medicine been changed in the last year? **None / Once / Twice or more**

18. Has your child experienced any side effects from their epilepsy medicine? **Y / N**
If yes, please describe: .....
.....
.....

19. How many hospital or clinic visits have you had this year about your child's epilepsy? .....

2. Strengths and Difficulties Questionnaire

For each item, please mark the box for Not true, Somewhat true or Certainly true. It would help me 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 your child's behaviour over the last six months.

	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, downhearted 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	☐	☐	☐

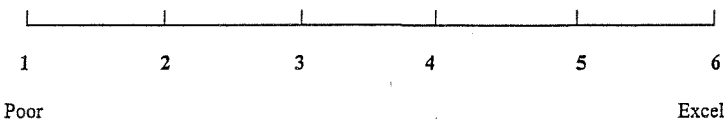
Do you have any other comments or concerns?

3. Impact of Paediatric Epilepsy Scale

I would be interested to know how you feel your child's epilepsy affects your child's and your family's everyday life at the present time and during the past three months. Please indicate with a tick how much impact your child's epilepsy (seizures, treatment, social consequences) had on these aspects of your family's and your child's life.

How much impact has epilepsy had on:	A lot	Some	A little	Not at all	Does not apply
Overall health	☐	☐	☐	☐	☐
Relationships with parents	☐	☐	☐	☐	☐
Relationships with brothers / sisters	☐	☐	☐	☐	☐
Relationships between you and your spouse / partner	☐	☐	☐	☐	☐
Relationships with friends / peers	☐	☐	☐	☐	☐
Social acceptability by others	☐	☐	☐	☐	☐
Number of social activities	☐	☐	☐	☐	☐
School and academic work	☐	☐	☐	☐	☐
Child's self-esteem (self-confidence / feelings about themselves)	☐	☐	☐	☐	☐
Your original hopes for your child	☐	☐	☐	☐	☐
Family activities	☐	☐	☐	☐	☐

Please rate your child's overall 'Quality of life' on the scale below. Choose the number which you feel is best and circle it:



4. Final Items

Please answer these questions last, after the other child and parent questions have been answered:

It would be very helpful if you could give some indication of how much help your child needed answering the questions about their epilepsy.

	none	a *little*	a *lot*
Help with answers:	❑	❑	❑
Help with understanding questions:	❑	❑	❑
Other help (please describe):	❑	❑	❑

Finally, is there anything else you want to say about your child and their epilepsy?

Thank you very much for your time.

Your views about your epilepsy

I am very interested in what you think about your epilepsy. People are very different, so there are no correct answers for these questions. I'd really like to know <u>your own</u> views rather than what other people may have said.

What will you need?

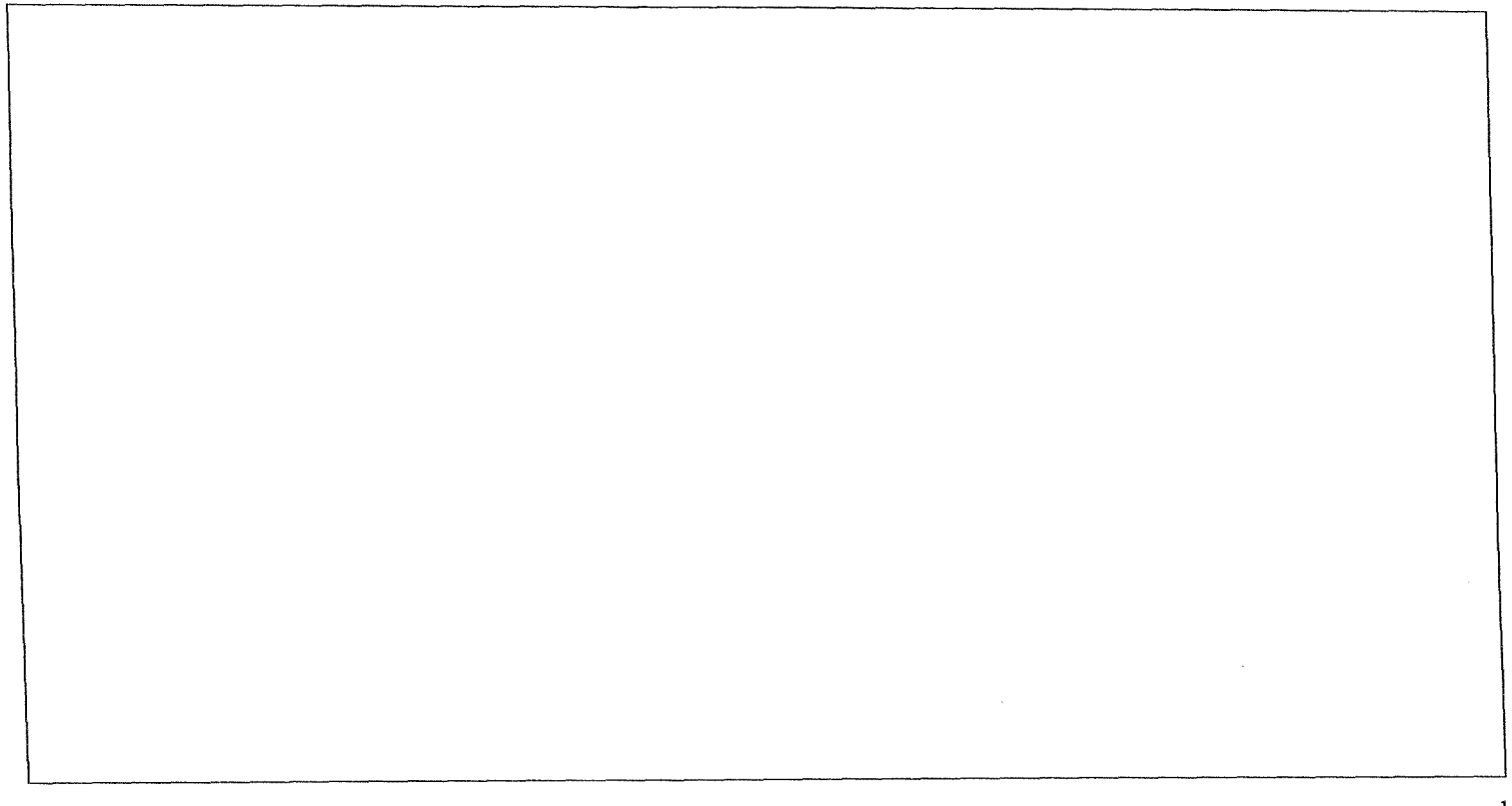
1. A pen or crayon for drawing a picture

2. A pen or pencil for ticking boxes on a questionnaire.

3. Some time (about 20 minutes)

Draw-a-person

First, I would like to see your best drawing of a man or a woman. You can turn the page round if you want to. Make the very best picture you can. Make a big person that fills the page. Draw him carefully. Thank you.



Second, here is a list of some symptoms. Some of them you will have had, and some you won't. It would help me to know if you have had any of these because of your epilepsy. Please circle *yes* or *no* to answer each question.

1	Do you ever get pain because of your epilepsy?	*yes*	*no*
2	Do you ever get a sore throat because of your epilepsy?	*yes*	*no*
3	Do you ever feel out of breath because of your epilepsy?	*yes*	*no*
4	Have you lost any weight recently because of your epilepsy?	*yes*	*no*
5	Do you ever get tired because of your epilepsy?	*yes*	*no*
6	Do you ever feel stiffness in your hips, knees, elbows or wrists because of your epilepsy?	*yes*	*no*
7	Do you get sore eyes because of your epilepsy?	*yes*	*no*
8	Do you ever have trouble breathing because of your epilepsy?	*yes*	*no*
9	Do you get headaches because of your epilepsy?	*yes*	*no*
10	Do you ever get an upset stomach because of your epilepsy?	*yes*	*no*
11	Do you ever have trouble sleeping because of your epilepsy?	*yes*	*no*
12	Do you ever feel dizzy because of your epilepsy?	*yes*	*no*
13	Do you ever feel like your body has got really weak because of your epilepsy?	*yes*	*no*

Now here are some questions about epilepsy. Please read each question and decide if you want to answer *yes* or *no*. If you are not sure, put a tick under *not sure*. If yes, tick one of the *yes* boxes. If no, tick one of the *no* boxes. Here is an example:

		Definitely yes	**Perhaps yes**	**Not sure**	**Perhaps no**	**Definitely no**
1	Do you like ice cream?	Definitely yes ✓	Perhaps yes	Not sure	Perhaps no	Definitely no

Remember, there are no right or wrong answers. I am interested in how you see <u>your</u> illness, not what other people have told you. Please try every question.

		**Definitely yes**	**Perhaps yes**	**Not sure**	**Perhaps no**	**Definitely no**
1	Will your epilepsy go away soon?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
2	Is your epilepsy hard to understand?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
3	Did you get epilepsy because you worried about things?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
4	Is epilepsy serious?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
5	Are there things you can do that make your epilepsy better?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
6	Did you get epilepsy from an accident or injury?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no

		**Definitely yes**	**Perhaps yes**	**Not sure**	**Perhaps no**	**Definitely no**
7	Are there things that make your epilepsy better?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
8	Do your symptoms change a lot from day to day?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
9	Does your epilepsy ever make you feel sad?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
10	Did you get epilepsy from bad air or pollution?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
11	Do you feel like your epilepsy is a mystery?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
12	Will you always have epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
13	Did you get epilepsy because of your personality (because of who you are)?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
14	Do you think your life is different because you have epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
15	Are there things you do that make your epilepsy worse?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
16	Did you get epilepsy because it runs in your family (is it hereditary)?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no

		**Definitely yes**	**Perhaps yes**	**Not sure**	**Perhaps no**	**Definitely no**
17	Will the medicines make your epilepsy go away?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
18	Do your symptoms come and go?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
19	Does your epilepsy ever make you upset?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
20	Did you get epilepsy because of something you did?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
21	Is your epilepsy easy to live with?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
22	Will your epilepsy last for a long time?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
23	Is it up to you whether your epilepsy gets better or worse?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
24	Did you get epilepsy because you felt very sad?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
25	Does taking your epilepsy medicines make it better?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
26	Do you understand your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no

		**Definitely yes**	**Perhaps yes**	**Not sure**	**Perhaps no**	**Definitely no**
27	Did you get epilepsy because your body was not good at fighting off germs and viruses?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
28	Can you tell when your epilepsy is going to be good or bad?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
29	Does your epilepsy ever make you angry?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
30	Did you get epilepsy because of a germ or virus?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
31	Do you think your epilepsy will pass quickly?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
32	Will your epilepsy stay the same whatever you do?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
33	Do other people treat you differently because of your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
34	Can your medicines control your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
35	Does your epilepsy make sense to you?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no

		**Definitely yes**	**Perhaps yes**	**Not sure**	**Perhaps no**	**Definitely no**
36	Is your epilepsy better at some times and worse at others?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
37	Do you ever worry about your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
38	Did you get epilepsy because of problems in your family?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
39	Will you have epilepsy for the rest of your life?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
40	Does your epilepsy make things difficult for your parents or friends?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
41	Can you do anything to change your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
42	Did you get epilepsy because of what you eat?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
43	Is there something that can help your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
44	Do you understand your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
45	Did you get epilepsy because you worked too hard?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no

		**Definitely yes**	**Perhaps yes**	**Not sure**	**Perhaps no**	**Definitely no**
46	Does your epilepsy ever make you scared?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
47	Did you get epilepsy by chance or bad luck?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
48	Do you think your epilepsy will get better?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
49	Do you think that things <u>you</u> do will make a difference to your epilepsy?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
50	Did you get epilepsy because of strong feelings you had?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
51	Does your epilepsy ever make you feel afraid?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no
52	Did you get epilepsy because your doctor did not look after you well?	Definitely yes	Perhaps yes	Not sure	Perhaps no	Definitely no

How often do you think about epilepsy? (Please tick a box):

Hardly ever	Sometimes a week goes by and I haven't thought about epilepsy at all	A few times a week	Every day	More than once a day	All the time

Finally, is there anything else you want to say about your epilepsy?

Thank you very much!

Appendix 8. Seizure type information (from Action Epilepsy, British Epilepsy Association website; URL = http://www.epilepsy.org.uk/info/chartfrm.html):

Type of seizure	What might happen	What to do
Generalised seizures		
Tonic-clonic	The most common sort of generalised seizure - used to be known as 'Grand mal'. You lose consciousness. Tonic phase - The muscles contract, the body stiffens and then - Clonic phase - jerks uncontrollably. You may let out a cry as air is forced out of the lungs and the lips may go blue due to lack of oxygen. When you come round you cannot remember anything. You will need time to recover - from minutes to, in some, hours.	Do not try to restrain the person. Clear away possible risks - sharp edged furniture etc. Cushion the person's head when they fall and, when the limbs stop jerking, put the person in the recovery position. Do not put anything in the person's mouth. Do not try to give the person anything to drink until they have regained consciousness. Be quietly reassuring and stay with them until they have recovered. Do not call for medical help unless the seizure lasts more than 5 minutes or they are injured.
Absence	This generalised seizure is literally an absence - a momentary lapse in awareness - used to be called "Petit Mal'. More common in children and teenagers. You stop what you are doing, stare, blink or look vague for a few seconds before carrying on with what you were doing. Onlookers may think you were just daydreaming or may not notice.	Do not try to 'wake up' the person. Tell them what has happened while their seizure was happening - particularly important for children during lessons.

Type of seizure	What might happen	What to do
Other generalised seizures	These include atonic seizures (drop attacks) and myoclonic seizures which cause brief forceful jerks.	Atonic seizures can cause injury - an increased awareness of safety is vital if this type of seizure occurs regularly. In some instances protective headgear may be appropriate.
Partial seizures		
Simple partial	Occurs in just part of the brain - type of symptoms depend on the area of the brain involved. Symptoms include one or more of the following: twitching, numbness, sweating, dizziness, nausea, disturbances to hearing, vision, smell or taste, strong dŧja vu etc. These symptoms last for several seconds and then go away. You remain fully aware. These seizures often progress to other types of seizure and can therefore act as a warning or 'aura'.	Do not try to restrain the person. Stay with the person and be reassuring until the symptoms go away. Be aware that the person may go on to have a complex partial tonic-clonic seizure - be ready to move any sharp objects, furniture etc, to prevent injury.
Complex partial	This common form of seizure includes temporal lobe epilepsy. You may appear to behave strangely - plucking at your clothes, smacking lips, swallowing repeatedly or wandering around as if drunk - these actions are called automatisms. Other symptoms are similar to simple partial seizures but you will not remember them afterwards. You are not aware of your surroundings or of what you are doing.	Do not try to restrain the person but gently try to steer them away from any unsafe situations. Do not try to 'wake' them. Stay with the person, being gently reassuring, until the person has recovered. The person may need to rest for a while.

Appendix 9. Comparison between the modified chIPQ-R and the IPQ-R:

IPQ-R items		New chIPQ-R items	
Timeline (acute/chronic)			
1*	My illness will last a short time	1*	Will your epilepsy go away soon?
2	My illness is likely to be permanent rather than temporary	2	Will you always have epilepsy?
3	My illness will last for a long time	3	Will your epilepsy last for a long time?
4*	This illness will pass quickly	4*	Do you think your epilepsy will pass quickly?
5	I expect to have this illness for the rest of my life	5	Will you have epilepsy for the rest of your life?
18*	My illness will improve in time	6*	Do you think your epilepsy will get better?
Consequences			
6	My illness is a serious condition	7	Is epilepsy serious?
7	My illness has major consequences on my life	8	Do you think your life is different because you have epilepsy?
8*	My illness does not have much effect on my life	9*	Is your epilepsy easy to live with?
9	My illness strongly affects the way others see me	10	Do other people treat you differently because of your epilepsy?
10	My illness has serious financial consequences		OMITTED
11	My illness causes difficulties for those who are close to me	11	Does your epilepsy make things difficult for your parents or friends?
Personal control			
12	There is a lot which I can do to control my symptoms	12	Are there things you can do that make your epilepsy better?
13	What I do can determine whether my illness gets better or worse	13	Are there things you do that make your epilepsy worse?
14	The course of my illness depends on me	14	Is it up to you whether your epilepsy gets better or worse?
15*	Nothing I do will affect my illness	15*	Will your epilepsy stay the same whatever you do?
16	I have the power to influence my illness	16	Can you do anything to change your epilepsy?
17*	My actions will have no affect on the outcome of my illness	17	Do you think that things <u>you</u> do will make a difference to your epilepsy?
Treatment control			
19*	There is very little that can be done to improve my illness	18	Are there things that make your epilepsy better?

20	My treatment will be effective in curing my illness	19	Will the medicines make your epilepsy go away?
21	The negative effects of my illness can be prevented (avoided) by my treatment	20	Does taking your epilepsy medicines make it better?
22	My treatment can control my illness	21	Can your medicines control your epilepsy?
23*	There is nothing which can help my condition	22	Is there something that can help your epilepsy?
Illness coherence			
24	The symptoms of my condition are puzzling to me	23*	Is your epilepsy hard to understand?
25	My illness is a mystery to me	24*	Do you feel like your epilepsy is a mystery?
26	I don't understand my illness	25	Do you understand your epilepsy?
27	My illness doesn't make any sense to me	26	Does your epilepsy make sense to you?
28*	I have a clear picture or understanding of my condition	27	Do you have a clear understanding of your epilepsy?
Timeline (cyclical)			
29	The symptoms of my illness change a great deal from day to day	28	Do your symptoms change a lot from day to day?
30	My symptoms come and go in cycles	29	Do your symptoms come and go?
31	My illness is very unpredictable	30	Can you tell when your epilepsy is going to be good or bad?
32	I go through cycles in which my illness gets better and worse.	31	Is your epilepsy better at some times and worse at others?
Emotional representations			
33	I get depressed when I think about my illness	32	Does your epilepsy ever make you feel sad?
34	When I think about my illness I get upset	33	Does your epilepsy ever make you upset?
35	My illness makes me feel angry	34	Does your epilepsy ever make you angry?
36*	My illness does not worry me	35	Do you ever worry about your epilepsy?
37	Having this illness makes me feel anxious	36	Does your epilepsy ever make you scared?
38	My illness makes me feel afraid	37	Does your epilepsy ever make you feel afraid?
Causes			
C1	Stress or worry	38	Did you get epilepsy because you worried about things?
C2	Hereditary - it runs in my family	44	Did you get epilepsy because it runs in your family (is it hereditary)?
C3	A Germ or virus	48	Did you get epilepsy because of a germ or virus?

C4	Diet or eating habits	45	Did you get epilepsy because of what you eat?
C5	Chance or bad luck	51	Did you get epilepsy by chance or bad luck?
C6	Poor medical care in my past	46	Did you get epilepsy because your doctor did not look after you well?
C7	Pollution in the environment	49	Did you get epilepsy from bad air or pollution?
C8	My own behaviour	47	Did you get epilepsy because of something you did?
C9	My mental attitude e.g. thinking about life negatively	39	Did you get epilepsy because you felt very sad?
C10	Family problems or worries caused my illness	40	Did you get epilepsy because of problems in your family?
C11	Overwork	41	Did you get epilepsy because you worked too hard?
C12	My emotional state e.g. feeling down, lonely, anxious, empty	42	Did you get epilepsy because of strong feelings you had?
C13	Ageing		OMITTED
C14	Alcohol		OMITTED
C15	Smoking		OMITTED
C16	Accident or injury	52	Did you get epilepsy from an accident or injury?
C17	My personality	43	Did you get epilepsy because of your personality (because of who you are)?
C18	Altered immunity	50	Did you get epilepsy because your body was not good at fighting off germs and viruses?

Appendix 10. Information sheet:

Southampton NHS
University Hospitals NHS Trust
Child Health,
Mailpoint 21, G level,
Southampton General Hospital,
Tremona Road,
Southampton SO16 6YD
(023) 8057 2125
(023) 8079 4765

INFORMATION SHEET
A survey of children's perceptions of epilepsy

You are being asked to take part in a research study. Please read this information carefully before you decide to take part. Please contact me (see below) if there is anything that is not clear. Thank you for reading this.

What is the purpose of the study?
This study is trying to find out what children think about their epilepsy. It is hoped that this information will make it easier for people to help children who find it hard to cope with epilepsy.

Why have I been chosen?
You have been chosen because you have epilepsy.

Do I have to take part?
You do not have to - it is up to you. If you decide to take part, you are still free to stop at any time without giving a reason. Your decision will not affect the care you get, and you do not have to give a reason for not taking part.

If I take part, what do I have to do?
For children, there are some questions and a drawing to do. For parents, there is a different set of questions. This should take about 20 minutes, but may take longer for younger children. Then we would like you to return the booklets in the freepost envelope provided.

Will my taking part in the study be kept confidential?
All information will be kept strictly confidential. The results of this study will have all identifying information removed.

What will happen to the results of this study?
I will write a report. A summary will be available to you if you contact Magnus Cormack on (023) 80572125 or e-mail him at kfc200@soton.ac.uk.

Who is organising and funding the research?
I am a second year clinical trainee at the University of Southampton, Doctoral Programme in Clinical Psychology. This research is part of my training.

Who has reviewed this study?
This study has been reviewed by the Southampton and South West Hampshire Local Research Ethics Committees.

Contact for further information:
If anything is unclear or if you have any questions, please contact Magnus Cormack on (023) 80572125 or e-mail him at kfc200@soton.ac.uk.

Version 2; Date 22-11-2002

Appendix 11. Consent form (pilot stage):

Southampton NHS
University Hospitals NHS Trust

Child Health,
Mailpoint 21, G Level,
Southampton General Hospital,
Southampton
(023) 8079 4765

CONSENT FORM

Title of Project: Children's perceptions of epilepsy.

Name of researcher: Magnus Cormack

		Please initial box
1.	I confirm that I have read and understand the information sheet dated ..... 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 [or my child's] medical care or legal rights being affected.	☐
4.	I agree for my child to take part in the above study.	☐

Name of Child		
Name of Parent or guardian	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Version 2; date 22-11-2002

WTA1504 10/01

Appendix 12. Introductory letter:

Southampton NHS
University Hospitals NHS Trust

Dr F Kirkham,
Consultant Paediatric Neurologist,
Child Health, Mailpoint 21, G Level,
Southampton General Hospital,
Southampton
(023) 8057 2125
(023) 8079 4765

«NoK_title» «NoK_Surname»
«address1»
«address2»
«address3»
«postcode»

Tuesday, 01 July 2003

Dear «NoK_title» «NoK_Surname»,

RE: Research study – Children's perceptions of epilepsy.

We are writing to all families who have had contact with the epilepsy / neurology services at Southampton General Hospital, to introduce you to Magnus Cormack, a Clinical Psychologist in Training, currently based in the Wessex Neurological Centre. We hope that you and «First_name» will consider participating in a research project looking at epilepsy, but you are under no obligation to do so. If «First_name» has not had epilepsy, please ignore this letter and we apologise for taking your time.

Magnus is very interested in how children understand serious medical conditions. There is some evidence that people's understanding is connected to how well they cope with chronic conditions, and Magnus would like to investigate this with children who have epilepsy. This would involve «First_name» and an adult who knows «First_name» well completing questionnaires and returning them in the freepost envelope. The adult questions should take about 20 minutes and the child questions up to half an hour. Younger children may take a bit longer, but do not need to do them all in one go.

We have enclosed an information sheet, some instructions for parents/guardians, the question booklets and a reply paid envelope. If you have any further questions, please feel free to call Magnus Cormack, on (023) 8057 2125, or e-mail him at kfc200@soton.ac.uk.

Yours Sincerely,

Dr Colin Kennedy,
Consultant Paediatric Neurologist

Dr. Fenella Kirkham,
Consultant Paediatric Neurologist

Dr Neil Thomas,
Consultant Paediatric Neurologist

Ann Waggott,
Paediatric Epilepsy Nurse Specialist

Appendix 13. Kolmogorov-Smirnov tests:

Variables	***n* =**	**Z =**	**p ≤** (2-tailed)
Age	51	0.765	0.602
Number of significant contacts	50	1.72	.005**
Age at first seizure	47	0.88	0.425
Age at diagnosis	44	0.98	0.296
Time since first seizure	49	1.07	0.206
Time since diagnosis	49	1.11	0.173
Time since last seizure	46	2.31	0.001**
Seizure frequency	44	2.22	.001**
Number of seizure types	50	1.11	0.169
Number of side effects reported	42	1.10	0.176
Number of hospital visits in last year	50	1.78	0.004**
Draw-a-person test scaled score	40	0.41	0.997
Draw-a-person test adjusted raw score	40	0.60	0.868
IPES total	50	0.98	0.297
IPES quality of life	50	1.31	0.066
Epilepsy intrusiveness item	50	0.16	0.871
SDQ Total score	50	0.55	0.925
SDQ Prosocial subscale	50	1.30	0.069
SDQ Emotional symptoms subscale	50	1.01	0.262
SDQ Conduct problems subscale	50	1.05	0.219
SDQ Hyperactivity subscale	50	1.01	0.259
SDQ Peer problems subscale	50	1.08	0.193
IPQ Identity	50	1.09	0.187
IPQ identity + intrusiveness	50	0.73	0.665
IPQ Illness coherence	50	0.65	0.785
IPQ Timeline (cyclical)	50	1.03	0.243
IPQ Timeline (acute-chronic)	50	1.14	0.150
IPQ Emotional representations	50	0.80	0.555
IPQ Consequences	50	0.70	0.714
IPQ Personal control	50	0.64	0.810
IPQ Treatment control	50	0.93	0.350

*: Significant difference at $p \leq 0.05$.

**: Significant difference at $p \leq 0.01$.