

**AN INVESTIGATION INTO HOW
OLDER ADOLESCENTS WITH
EPILEPSY COPE WITH MAKING
THE TRANSITION TO ADULTHOOD**

**A thesis submitted to the Faculty of Medicine of the
University of Leicester for the degree of Doctor of Clinical
Psychology**

by

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An Investigation into How Older Adolescents with Epilepsy Cope with Making the Transition to Adulthood

Dawn K. Reeve

Abstract

Chronic illnesses such as epilepsy, have been shown to have detrimental effects on both psychological adjustment and coping behaviour. Using the process model of coping, these effects were investigated in a patient group of 36, 16-21 year olds with epilepsy. The patient group were compared with a control group of 31 of their peers with regard to both their psychological adjustment and how they coped with making the transition to adulthood. In order to further test the process theory, a comparison was made between how the patient group coped with making the transition to adulthood and how they coped with epilepsy. The relative importance of the perception of illness and condition characteristics to psychological adjustment and coping was also considered in the patient group. Participants completed a postal questionnaire which contained measures of psychological adjustment (self esteem, affect, self efficacy) and an adolescent coping questionnaire. Results showed that the patient group exhibited significantly more non productive coping than the control group. The control group exhibited significantly more problem solving coping and displayed a significantly more problem solving bias than the patient group. No differences were found between the patient and control group on measures of psychological adjustment. However, psychological adjustment was found to be associated with coping response in the patient and not the control group. Some differences were found in the cross-situational coping response within the patient group. Perception of illness, in particular, acceptance of illness, had more influence on the psychological adjustment and coping behaviour of the patient group than condition characteristics. The clinical and theoretical implications of these findings are discussed and the limitations of the study acknowledged.

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1 Introduction

1.1 Introduction

There is in existence, a large body of literature concerned with how individuals cope with a variety of stresses, including those of chronic illness (e.g. Maes, Leventhal & De Ridder, 1996, Morse & Johnson, 1991, Devins & Binik 1996). However, there has been little research into the specific issue of how older adolescents with epilepsy cope not only with their illness, but with the developmental task of making the transition to adulthood. The importance of making a successful transition to adulthood for the future psychological well being of people with epilepsy warrants research into how individuals cope with this issue and is considered in the present study. A person's degree of psychological adjustment can be related to coping with such a potentially stressful challenge as the transition to adulthood and is also examined. How well individuals cope with the experience of epilepsy will be included, as it has an impact on psychological well being and coping resources.

The following review considers literature relevant to a number of areas. Firstly, a brief history of coping theory is given with the emphasis on the process approach to coping. A definition of coping and its measurement are given from the process standpoint. The experience of chronic illness in general, and epilepsy in particular is presented as a challenge to coping resources. Studies of coping are described to illustrate adaptive and non adaptive coping strategies. These studies also offer an insight into the type of methodology used in the study of coping. The relationship between coping and psychological factors of self esteem, self efficacy and mood will be examined briefly as will the relationship between coping and the perceived impact of illness.

As there has been little research into how older adolescents cope with epilepsy or the transition to adulthood, literature is included from the following related areas: the challenge of chronic illnesses other than epilepsy to coping resources, the process of coping in the adolescent population and the challenge of the transition to adulthood. Where possible, studies of adolescent populations will be included, where no such studies could be found, evidence from adult studies will be used to inform the discussion.

1.2 Coping theory

Coping theory can be divided into the style and the process approaches. The style approach holds that certain stable personality traits determine the coping strategy used regardless of the situation facing the individual. The process approach emphasises the interaction between particular elements of the situation and the individual's perception of it, this determines the choice of coping strategy.

1.2.1 The coping style approach

The roots of coping theory stem from the psychoanalytical school of thought which forms the basis of the coping style or trait approach. According to authors such as Vaillant (1977), coping refers to unconscious, mature defence mechanisms which act as buffers against psychological distress. The concept that these defence mechanisms are unconscious led to the use of observation or projective techniques to study coping.

A more modern version of the coping style approach is seen in the work of authors such as Miller (1987) who believe that individuals are more or less likely to use a certain coping strategy dependent on their personality traits. Miller found that individuals two main styles of 'monitor' or 'blunter', i.e. they sought or did not seek information to help them cope with the stressful situation. Miller (1987) developed the Miller Behavioural Scale which asks individuals to consciously reflect on their degree of information seeking across a number of situations.

1.2.2 The coping process approach

Lazarus (1966, 1993), Lazarus et al (1974) and Lazarus and Folkman (1984) have been the most influential proponents of coping theory over the last two decades and developed the process approach to coping. Lazarus and Folkman (1984) criticised both the psychoanalytic concept of defence and the methods used to measure it as a coping mechanism. They argued particularly against the concept of coping as unconscious and instead developed a model where it was considered to be a conscious process. The frustration expressed at the methodology of the style approach was that it did not give a detailed description of the specific strategies of coping in particular stress contexts. This led Lazarus and Folkman

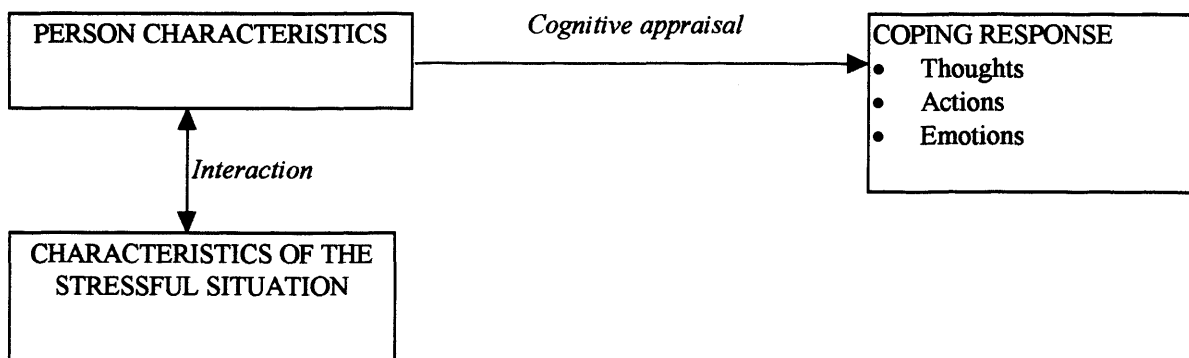
(1984) to develop a methodology which asked individuals to reflect on their conscious efforts to cope with stressful situations.

Lazarus and Folkman's (1984) definition of coping describes a dynamic process where coping changes over time and in response to the situation in which it occurs. Coping is defined as:

'constantly changing cognitive and behavioural efforts to manage the specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman 1984, p114).

Lazarus (1993) simplifies this definition to, 'coping consists of cognitive and behavioural efforts to manage psychological stress'. (Lazarus 1993, p237). Thus coping is concerned with the thoughts and actions a person makes in response to a taxing situation. The individual's response to the situation is governed by their cognitive appraisal of that situation. The concept of appraisal as a mediating force between a person's environment and their coping behaviour is central to the concept of coping as a process. The process theory is represented in Fig. 1 below.

Figure 1.1: The process model of coping based on Lazarus and Folkman (1984)



Lazarus (1993) states that the personal meaning of a situation, such as what an individual perceives as threatening is, 'the most important aspect of psychological stress with which the person must cope, and [it directs] the choice of coping strategy'. (Lazarus 1993, p244). This transaction between the person and the environment has led to the process approach

also being known as a transactional theory. The terms transactional theory and process theory are used interchangeably in this account.

1.3 Coping and issues of measurement

Principles guiding the measurement of coping as a process, according to Lazarus (1993) and Lazarus et al (1974) will be outlined and illustrated with relevant studies.

Broadly speaking , in order to make a study of coping, it is necessary to take three variables into account, the nature of the stressful situation, the coping response made to that situation and the characteristics of the individual who is in that situation. It is the interaction of the variables of situation and person which determine the coping response via the person's appraisal of an event. For example, threatening situations may elicit vigilant forms of defence, whilst other situations may elicit an avoidant response. Lazarus (1993) emphasises the importance of specifying the particular threats of a situation to the individual.

Coping strategies can be inferred from a variety of coping response data including self reports, physiological changes, expressive reactions and observable behaviour. However, the most commonly used method is self report, in the form of a questionnaire. Folkman and Lazarus (1988) constructed the Ways of Coping Questionnaire which was designed to provide a description of what an individual thinks or does in an effort to cope with a stressful encounter. This questionnaire consists of eight factors, for example, Positive Reappraisal and Planful Problem Solving, with each factor being elicited from several questions relevant to that factor. Individuals are asked to endorse any of the thoughts or actions listed on the questionnaire employed by them to cope with a particular stressful encounter. The Ways of Coping Questionnaire has formed the blueprint for the majority of process coping scales in use today.

Lazarus (1993) calls for the repeated use of process coping scales across both time and different stressful encounters within the same population. Thus making research designs both intraindividual and interindividual. This would allow the researcher to assess both coping as a process and as a style, with consistency across situations supporting the style approach and inconsistency the process approach.

The dynamic nature of coping can be assessed at different stages within the same stressful event. To illustrate the value of repeated testing, Folkman and Lazarus (1985) studied emotion and coping in 108 undergraduate students at three stages of an examination, anticipating the test, waiting for results and following results. A stress questionnaire including 15 different emotions was used to assess the emotions felt at each stage and the Ways of Coping Questionnaire was used to assess coping. The results of the study showed that problem focused coping and emphasising the positive were more salient during the anticipatory stage and distancing was more prominent during waiting for results. The study also showed individual differences across situations with each individual coping differently at each stage. These results support the view that coping is a process as it changes in response to different events and individuals did not show trait coping styles.

In order to ascertain the relative 'adaptiveness' or 'maladaptiveness' (Lazarus 1993, p235) of coping thoughts and actions, they need to be studied independently from their outcomes. Outcomes are often measured in the form of psychological or social well being. Lazarus stresses the danger of declaring some coping strategies as universally adaptive or maladaptive. Whether a coping process is good or bad depends on the individual and the kind of stressful encounter. Thus the term 'coping' is employed regardless of whether the process is successful or unsuccessful.

The adaptiveness of certain coping strategies of 2300 adults was examined by Pearlin and Schooler (1978) who provide evidence for both the style and the process approach. Individuals were interviewed to identify the stresses they experienced in the social role areas of marriage, parenting, household economics and occupation and the coping responses made in each area, examples of which were, selective ignoring and optimistic action. Pearlin and Schooler (1978) interpreted their findings as showing that in general, attempts to cope with stress were more successful in the areas of interpersonal relationships such as marriage and child rearing than in the area of occupation. An optimistic outlook and reflecting on the problem were examples of strategies considered effective in ameliorating stress, whereas selective ignoring was considered to be a counterproductive strategy. The use of particular strategies in the interpersonal domain supports the process view that some strategies are more suited to certain situations. However, it was felt that coping with impersonal situations such as those of occupation, was more reliant on, 'possessing the

‘right’ personality characteristics’ (Pearlin and Schooler 1978, p13), such as high self esteem, thus supporting the style approach.

1.3.1 Contemporary debate regarding coping theory and it’s application in health settings

Coping has engendered heated critical debate in recent years from both theoretical and applied perspectives. De Ridder (1997) maintains that coping theory is in need of conceptual clarification and believes that this will in turn rectify the methodological shortcomings she observes in its assessment. Most notably, she points out that the process approach infers that coping is ‘an inherently variable concept’ (DeRidder, 1997, p 418) and that therefore measuring coping using psychometric tests is inappropriate. Her reasoning is that psychometric validation processes such as factor analysis are designed to evaluate stable, rather than variable constructs. Also, she believes that the process theory has not been tested adequately by investigating the response of the same participants across different situations or by testing the response of participants to the same situation over time.

Maes, Leventhal and De Ridder (1996) have criticised the application of the process model of coping to research into chronic illness. These authors state that the ‘situation’ dimension of the ‘person-situation interaction’ is poorly defined and needs to be examined more specifically in terms of what exactly the ‘situation’ of chronic illness presents the individual with, such as it’s current ‘valence’ for that individual. Somerfield (1997) sparked a recent debate over the application of process theory to applied health psychology research. His conclusion was that the systems model presented by Lazarus and Folkman (1984) was too cumbersome and too generalised to test in applied settings. His conclusion was to design a ‘microanalytic’ method of investigation constituting a ‘problem specific systems model’ (Somerfield, 1997, p133) centring on the specific demands of a health related problem. Somerfield (1997) used this method to investigate treatment induced sterility in bone marrow transplantation survivors.

Somerfield (1997) believes that concentrating on illness specific problems is the most effective way to inform clinical practice, he also believes that it will progress basic coping research. In a reply to his article however, Folkman (1997), disagrees with this latter point stating that basic coping research needs to be at a more macro level with larger numbers of participants and a more generic approach to sources of stress. The present study follows

Somerfield (1997) to a greater extent, in an attempt to test coping theory in relation to specific situations in both healthy and patient populations.

1.3.2 Coping terminology

To ensure clarity regarding the aspects of coping being measured, it is important to use consistent terminology. For the purpose of the present study, Compas's (1987) differentiation of terminology will be used. Compas (1987) distinguishes between coping strategies, styles and resources.). Coping strategies are defined as the cognitive, emotional or behavioural actions engaged in by an individual. The term coping style can be used in the contexts of both the style and process theories. Coping style refers to the consistent use of a certain type of coping strategy either in response to one situation (process approach) or across different situations (style approach). Coping resources stem from within the self (internal resources) or the environment (external resources) and affect coping ability.

As the situation the individual has to cope with is assumed to be 'stressful' a definition of stress is included. Lazarus (1995) states that stress refers to 'emotions that are distress related, such as anger, anxiety, guilt, shame, envy, jealousy, disgust' (Lazarus 1995, p183).

1.4 Dimensions of coping

Attempts have been made by Lazarus and others to classify different dimensions or functions of coping, with the main distinction being drawn between problem focused and emotion focused coping. Problem focused coping describes efforts to alter the stress provoking relationship between the environment and the individual. This is done by acting directly to alter the environment or oneself. Emotion focused coping functions in two ways. Firstly, by altering one's attendance, by being vigilant to or avoiding the stressful relationship to the environment. Alternatively, stress can be mitigated by reappraising the situation in such a way that it is no longer perceived as stressful, despite remaining unchanged in other ways. For example, a child who disobeys a parent may present a less stressful challenge if their parent reappraises the situation from perceiving the child as 'naughty' to 'overtired'. The parent can then view the child sympathetically rather than angrily and may experience less stress as a result.

Whether problem focused or emotion focused coping is employed has been shown to depend on both the type of stressful situation and whether the individual feels that they can achieve a degree of control over the situation. Folkman and Lazarus (1980) used the Ways of Coping Checklist to study the way in which 100 adults coped with stressful encounters during the course of a year. Stressful encounters were dealt with more often in a problem focused manner using problem solving if they were experienced in the context of the workplace. Alternatively, stressful encounters concerning people's health tended to be dealt with in an emotion focused way. It was also found that if an individual felt they could gain control over the situation by taking constructive action, they took a problem focused approach. If however, the situation could not be changed, individuals tended to cope with it by using an emotion focused approach to reappraise and accept the situation. With respect to control, it is possible to make generalisations regarding these results. It is more often possible to take action to improve a work situation than to effect a health related problem. However, it is important not to oversimplify these results, as in the majority of cases individuals used both problem and emotion focused strategies in an attempt to cope with a situation and it is only the trend towards problem or emotion focused coping which is emphasised in the results.

Another important distinction has been made between approach and avoidant ways of coping, also perceived as the difference between active and passive coping. The use of strategies of approach and avoidance have been considered by authors such as Krohne (1993) in work regarding the difference between vigilance and cognitive avoidance as coping strategies.

A criticism which can be made of attempts to classify and measure coping responses, is that the differences between dimensions may not refer to real, conceptual differences. There have however, been attempts to validate the construct validity of instruments such as the Ways of Coping Checklist by Edwards and Baglioni (1993).

That the stability of certain individual coping strategies appears to vary and the fact that this may be due in some respect to stable personality traits is acknowledged by Lazarus (1993). Folkman et al (1986) conducted a study of a monthly stressful encounter over a six month period in the same individuals. It was found that the strategy of seeking social support was inconsistent across stressful situations but that using positive appraisal was moderately

consistent. This indicates that the use of some coping strategies are situation dependent and others may depend on the characteristics of the individual.

1.5 Correlates of coping

Relationships have been found between a number of variables and coping responses. Examples of these correlates of coping are age, mood and self concept including self efficacy. The nature of these relationships will be described in brief below, making reference to coping with chronic illness in adolescence where possible.

1.5.1 Coping and age

The following discussion will address the differences in coping during adolescence only and will highlight the finding that use of coping strategies differs between younger and older adolescents. However, Frydenberg's (1997) point that older adolescents differ in turn from adults is also noteworthy but will not be discussed further. Generally speaking, the use of functional coping i.e. taking a problem solving approach tends to decrease and emotional coping, such as wishful thinking increases with age during adolescence. This development in use of coping strategy was supported by Frydenberg and Lewis (1993a) in their comparison of adolescents in terms of age, gender and ethnicity. Using the Adolescent Coping Scale (Frydenberg & Lewis 1993b), older adolescents were found to use more of the 18 possible strategies listed under the emotion focused dimension than younger adolescents. In the same study, Frydenberg and Lewis (1993a) also using the Adolescent Coping Scale, evaluated the age related response of 673 Australian students aged 12-17 years. The younger part of the sample used more work related and less tension releasing strategies than any other age group. The oldest students reported using the 'Work hard and achieve' strategy the least and the 'Tension reduction' and 'Self blame' strategies more than any other group. These results are explained by the authors as being partly due to the stage of education of the students. It is hypothesised that the transition from primary to secondary school is characterised by optimism and the desire to work hard. In contrast, older adolescents face more pressure both to achieve in examinations and from their peers, and may feel they have already exhausted the utility of the 'Work hard' strategy.

1.5.2 Coping and mood

The relationship between mood and coping can be seen as reciprocal. An inability to cope with stressful events can lead to depression and/or anxiety, equally, the existence of these disorders of mood can affect the individual's ability to cope. For example, if an individual is depressed and lacks motivation, they are less likely to use active, problem solving strategies. Also, the existence of negative automatic thoughts and dysfunctional assumptions in depressed individuals as identified by Beck (1976), could prevent coping via the cognitive reappraisal of a situation.

The effects of stressful situations, including chronic illness on mood have been studied more often than the effects of mood on coping. In their study, 'Partners in adversity: mood and coping', Surtees and Miller (1994) found relationships between mood and degree of successful coping in three groups of married women, with each group having experienced a different category of traumatic event. Coping was measured using an adapted version of the Mental Adjustment to Cancer Scale (Greer and Watson 1987). Mood was measured using the General Health Questionnaire (Goldberg 1978). Individuals were classified as 'exceptional', 'good' or 'limited/poor' copers and levels of anxiety and depression were recorded. Significant relationships were found between high levels of depression and anxiety and 'limited/poor' coping. However, the direction of the relationship between mood and coping was unclear. Also, the results are interpreted in very general terms with no indication as to whether anxiety or depression have different effects on coping. With regard to the population with epilepsy, the incidence of depression and anxiety are 15 per cent and 30 per cent respectively.

1.5.3 Coping and self related resources, self esteem and self efficacy

1.5.3.1 Coping and self esteem

Self esteem is the judgement the individual makes of themselves and their behaviour. The study of it's relationship to coping has been quite recent. Seiffge-Krenke (1990) found an association between dominant coping style and levels of self esteem in a study of adolescents. 'Active copers' were found to report high self esteem, in contrast to 'problem avoiders'. Jerusalem and Schwarzer (1989) studied 467 male, Berlin apprentices aged 17-

22. Results indicated a positive relationship between instrumental coping and self esteem and a negative correlation between emotional coping and self esteem. The authors judged use of instrumental coping to be more effective than emotional coping and therefore stated that individuals with high self esteem cope better than those whose self esteem is low.

The relationship between self esteem and coping needs to be considered to be bi-directional. The reciprocal nature of the relationship leads to the question of whether it is more therapeutically effective to focus on enhancing self esteem or increase an individuals' repertoire of coping strategies. Seligman (1995) argues that developing coping strategies will in turn enhance self esteem.

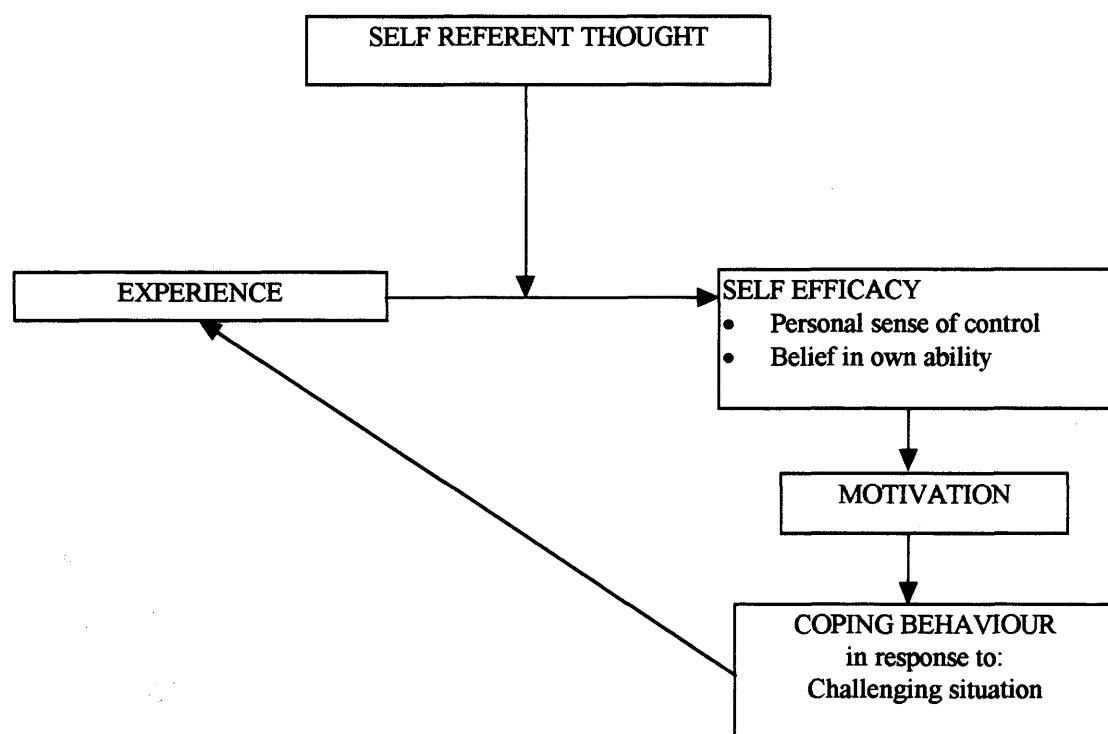
1.5.3.2 Coping and self efficacy

Bandura (1977, 1982) introduced the concept of self efficacy with respect to behaviour modification. Self efficacy relates to both having a personal sense of control and belief in one's ability to perform an action to achieve a desired outcome. Bandura states, 'Perceived self efficacy is concerned with judgements of how well one can execute courses of action required to deal with prospective situations.' (Bandura 1982, p122). Individuals' belief in their abilities is based on past experience and is a form of self referent thought which mediates between knowledge and action i.e. people may not act in the way they believe to be most effective because they judge themselves to be incapable of so doing. Therefore, motivation and behaviour are influenced by perceptions of self efficacy. The concept of self efficacy as self referent thought distinguishes self efficacy theory as strongly cognitive in nature.

The relationship between self efficacy and coping is alluded to by Bandura in the statement, 'People's judgements of their capabilities additionally influence their thought patterns during anticipatory and actual transactions with the environment' (Bandura 1982, p123). In this statement, Bandura appears to take the process approach to coping by speaking in terms of interactions between the person and the environment. The relationship between coping and self efficacy is represented in Fig. 2 Bandura also believes that perceived self efficacy should be studied in as situation specific a way as possible, believing self efficacy to be tied to particular task demands and characteristics of a situation. A belief in being able to master challenge by adaptive action may be related to an ability to cope successfully with stressful

events. A strong sense of self efficacy increases motivation and encourages individuals to persist. The resulting high degree of confidence allows individuals to attempt more challenging tasks. It is likely that a strong sense of self efficacy or agency, would lead to the use of active coping strategies and also some cognitive reappraisal of situations using evidence from past success.

Figure 1.2: The relationship between self efficacy and coping, based on Bandura (1982)



Self efficacy is related to other correlates of coping such as affect. Schwarzer and Fuchs (1996) point out the association of a low sense of self efficacy with anxiety, depression and helplessness. They also emphasise that a strong sense of self efficacy is based on a realistic appraisal of one's abilities and is not simply a case of wishful thinking or positive illusion. However, they do acknowledge that self belief has more influence on coping behaviour if it is a slight overestimation of perceived coping abilities.

Schwarzer and Fuchs (1996) discuss ways of operationalising the self efficacy model into a way of measuring it as a concept. They advise that self efficacy items should consist of confidence statements such as, 'I am confident that I can (perform something), even if (barrier)' (Schwarzer and Fuchs 1996 p180).

In a study of perceived self efficacy in 52 adults with epilepsy, Tedman, Thornton and Baker (1995) began from the premise that epilepsy presents a unique challenge to the individual due to its unpredictability and social stigma. The experience of epilepsy is then proposed to lead to the development of certain negative core beliefs which in turn reduce the perceived self efficacy of individuals. Perceived self efficacy and core beliefs were measured during a semi structured interview. The Hospital Anxiety and Depression Scale and an adjustment to epilepsy scale were also administered. A comparison of individuals with epilepsy with a control group revealed lower levels of perceived self efficacy and higher levels of depression and anxiety in the group with epilepsy. Tedman et al (1995) point out the relationship between low self efficacy and depression found in their study and propose that the passive coping strategies found in studies of depression may also be used by individuals with low self efficacy.

1.5.4 The influence of the perceived impact of the stressful situation.

Emphasis has already been placed on the specific characteristics of each particular stressful situation, however, the individual's perception of the magnitude of the situation and the challenge it presents, is of equal importance. Ireys et al (1994) measured the self esteem of young adults with the Rosenberg Self Esteem Scale and the perceived impact of chronic illness on their social relationships with a series of questions, the condition characteristics of each individual such as age at onset were also noted. A significant relationship was found between self esteem and the perceived impact of the condition, but not its condition characteristics. The only characteristics which were associated with low self esteem were, unpredictability and visibility. Ireys et al (1994) explain their results in terms of a cognitive appraisal model where imagined limitations are just as influential as the real limitations of illness.

The influence of the individual's perception of their illness on coping strategies used was addressed in a study of 205 adults with chronic illness by Schussler (1992). Schussler used Lipowski's (1970) concepts of disease to categorise participants' perception of their illness, for example, disease as challenge, enemy or relief. Individual perception of control over illness was also assessed. Coping was measured by The Ways of Coping Checklist, (Lazarus and Folkman 1984). Results showed that perception of control over the illness

and an acceptance of it led to active, problem solving coping. Alternatively, persons used emotional coping if they did not accept their illness or consider it to be controllable.

1.6 The challenge of epilepsy to coping resources

Coping research can contribute to the understanding of the impact of stressors on health, a chronic health condition such as epilepsy, in and of itself can constitute a stressor and a challenge to coping resources. The following section seeks to establish epilepsy as a stressor. Literature specific to adolescents with epilepsy will be drawn on where possible, otherwise, reference will be made to literature relevant to other chronic illnesses.

1.6.1 Chronic illness as a stressor

Controversy exists over whether the experience of chronic illness constitutes a stressor. Cassileth et al (1984) showed that adults with chronic illness did not report higher stress levels or lower levels of well being than similar healthy participants. This was not the case however, if the participants were in the initial or end stages of a disease which indicates that the results were affected by fluctuating condition characteristics. Similarly, Westbrook, Silver, Coupey and Shinnar (1991, p87) quote opposing studies which support the 'psychosocial integrity' and the 'psychosocial vulnerability' of adolescents with chronic illnesses. Additionally, Wolman et al (1994) found that although adolescents with chronic health conditions scored less well on measures of psychological adjustment, family connectedness was a more important contributory factor than chronic illness. However, it is arguable that this finding could be explained by the effect of chronic illness on family connectedness.

The value of studying a population with one particular chronic illness rather than the whole population of people with varying chronic illnesses has also been the subject of debate. Proponents of the 'general factors' model (Stein and Jessop 1982) believe that chronic illness increases the risk for problems of psychological adjustment in the same way for all illnesses. This view is in opposition to the stance taken by the 'illness dependent or specifist' model that specific illnesses have specific psychological consequences on the individual.

It is possible that both of the above viewpoints are legitimate. The broad applicability of illness factors such as those outlined below points to the fact that individuals are affected similarly regardless of illness type, with the proviso that each factor is not equally applicable to every chronic illness. Alternatively, it can be argued that individual chronic illnesses have specific features in addition to these general factors and therefore have some unique consequences for the sufferer. For example epilepsy can be differentiated from other chronic illnesses where unpredictable losses of control do not occur, or where treatment and monitoring of the condition is effective.

There are few studies comparing adolescents with epilepsy to those with other chronic diseases. Howe et al (1993) make a more crude comparison of the social, psychological and academic adjustment of adolescents aged 12-20 years with neurological and non neurological conditions with a healthy control group. Their results showed that adolescents with brain based conditions reported more psychological symptoms, had more behavioural problems, functioned less autonomously and achieved less well at school than controls. Those with non neurological conditions only differed from their healthy peers in terms of poorer maths scores and less work experience. Howes et al's (1993) finding that the adjustment of adolescents depends on the nature of the condition provides evidence for the specifist model. However, this evidence could have been strengthened by the direct comparison of individual illnesses rather than the comparison of neurological and non neurological conditions.

1.6.2 A definition of epilepsy

Epilepsy affects 1 in every 200 people and there are around 300,000 people in the United Kingdom with the condition according to British Epilepsy Association (1993) figures. Epilepsy has a prevalence of 0.5 per cent and a lifetime incidence of 3 per cent (Baker 1992). Most individuals with epilepsy develop the condition before the age of 20 years. Epilepsy is medically defined as the tendency to have recurrent seizures which may take a variety of forms, some resulting in loss of consciousness. Seizures occur as a result of a chemical state within the brain caused by irregular electrical activity. Seizures can be as diverse as a brief alteration of sensation or a sudden loss of consciousness accompanied by convulsions. Seizure frequency varies according to the individual. A list of the different

classifications of seizure types including a description of each type is given below according to Jeavons & Aspinall (1985):

1 Primary generalised seizures which involve both sides of the brain from the onset of the seizure and include *tonic-clonic* seizures (characterised by unconsciousness, the body becoming stiff with all limbs jerking and frothing at the mouth) ; *myoclonic* seizures (characterised by bilateral muscle jerks) and *absence* seizures (characterised by a brief episode of blankness without falling which may involve flickering of the eyelids).

2 Partial seizures which arise from only part of the brain these include *simple partial* seizures (involving motor and/or sensory seizures) and *complex partial seizures* (characterised by complicated sensations or automatic actions such as lip smacking, gesturing or fidgeting, and also including psychomotor seizures which involve emotional and behavioural changes).

1.6.3 The effects of chronic illness

Maes et al (1996) assert that the way an individual experiences a disease is paramount, and often correlates little with its medically defined characteristics. Morse and Johnson (1991) describe the psychological effects of chronic illness on the individual as they move towards an acceptance of illness, in the 'illness constellation' model. This is a staged model, where the individual passes from: struggling to understand the meaning of their symptoms; to experiencing the disruption of the disease and becoming dependent on others; to striving to recover their identity by using coping strategies to gain control over the illness and finally to the restoration of well being due to the acceptance of the illness and its consequences.

There are certain factors related to the experience of chronic illness which may be equally applicable to the chronically ill population as a whole, in terms of affecting their quality of life. Devins and Binik (1996) list five such factors: diagnostic uncertainty; disability; dependency; illness intrusiveness and biases and stigma. Each factor is outlined below and discussed in terms of its relevance to epilepsy.

a) Diagnostic uncertainties

Uncertainties regarding both making a definite diagnosis of an illness and its prognosis are considered to elicit anxiety and distress due to the lack of control that accompanies uncertainty. This is applicable to epilepsy, diagnostic tests such as the electroencephalogram (EEG), computerised tomography (CT) and magnetic resonance imaging (MRI) tests cannot detect epilepsy reliably in every case. Diagnosis often relies upon the detailed description of an individual's seizures by an observer. Prognosis can also be unsure and in most cases depends upon finding the correct dose of the right anti-epileptic medication by a process of trial and error. According to Baker (1992), between 20 per cent and 40 per cent of people with epilepsy never achieve remission from seizures for a significant length of time. The most common treatment for epilepsy is medication such as Sodium Valproate, although in extreme cases surgery may be undertaken to remove the part of the brain which has been identified as the epileptic focus. Even if an individual's epilepsy is well controlled at one point in time, there is no guarantee that this will continue.

b) Disability

Disability is a common feature of chronic illness and can be the result of functional limitation, cognitive impairment or pain. A number of functional limitations are placed on the life of the individual with epilepsy to accommodate the possibility of having a seizure. On medical advice, individuals are encouraged to ensure that certain activities are supervised. The law also creates statutory barriers for people with epilepsy in the areas of driving and choice of career.

c) Dependency

The lifetime dependency of the individual on professional expertise and medication can lead to the individual feeling disempowered. As a consequence of epilepsy, individuals are dependent on anti-epileptic medication which can produce a variety of side effects including cognitive impairment. They are also dependent on others for supervision of activities, some of them highly personal such as bathing, or for transport.

d) Illness Intrusiveness

Devins and Binik (1996) define illness intrusiveness as:

‘illness-induced disruptions to valued activities and interests’ (Devins and Binik (1996), p642).

They suggest that illness intrusiveness influences psychosocial well being and quality of life in two related ways. The first is the reduction of positively reinforcing experiences due to decreased involvement in valued activities. The second constitutes a reduced perception of personal control or self efficacy, which further reduces the individual’s ability to obtain positively valued outcomes and avoid negative ones.

It is probable that the illness intrusiveness of epilepsy depends on the severity of the individual’s illness and also their perception of its impact on their life. It is likely that individual levels of illness intrusiveness alter during the course of the illness. In cognitive terms, it is conceivable that individuals with epilepsy have an ‘epilepsy schema’ or ‘special view of the world’ according to Stebbins (1970). The epilepsy schema contains representations of past experiences related to epilepsy which guide the response to new epilepsy related experiences. Thus, illness intrusiveness varies simultaneously with the activation of an ‘epilepsy schema’.

e) Biases and stigma

Devins and Binik (1996) state that people with chronic conditions are often the subject of negative biases and stigma, with negative stereotypes leading the physically healthy to avoid them, or employers to deny them jobs. Negative attitudes may deter the individual with epilepsy from social interaction and limit their opportunities for positive interpersonal exchange.

An important link has been made between the experience of epilepsy and the concept of stigma. In general terms, ‘stigma’ is the result of deviating from cultural norms dictated by social order, such norms include the qualities people should possess and how they should act. Stigma is associated with feelings of shame. Simply by having epilepsy, the individual

fails to conform to the cultural norm of how a person should be i.e. 'healthy'. In a review of the effect of chronic illness on social relationships in young people, Stein (1989 p140) uses the term 'violation of expectations' to describe deviation from the cultural norm.

Scambler (1984) applies the social construction of stigma described above to the experience of illness in general and epilepsy in particular. He uses Goffman's (1968) classification of individuals who transgress societal norms to describe people with epilepsy as potentially 'discreditable' if their illness is not known about and being 'discredited', i.e. stigmatised if their illness is revealed.

Scambler (1983) interviewed 94 adults with epilepsy in London in an attempt to answer the question, of how living with a stigmatising condition alters one's ideas of self and self worth. In drawing on other people's attitude to them following diagnosis, Scambler (1983) found that 84 per cent of the sample saw the lay community as,

'typically ignorant, intolerant and predisposed to discriminatory practices against epileptics'.

In an earlier paper reporting results from the same study, Scambler and Hopkins (1980) reported that when asked, 90 per cent of the sample felt that having epilepsy was stigmatising, but only 30 per cent could cite one or more example of discrimination solely on the grounds of their perceived social unacceptability or inferiority. This demonstrates the difference between what Scambler (1984) calls 'felt' and 'enacted' stigma, with felt stigma referring to the shame felt in association with having epilepsy and enacted stigma referring to discrimination on the grounds of perceived social unacceptability of epilepsy. It is significant that such a high proportion of the sample report feelings of stigma, despite a lack of confirmatory experiences.

A further consequence of felt stigma is demonstrated in Scambler's (1983) study where he found high levels of non disclosure of in individuals with epilepsy. where individuals did not disclose their epilepsy to their partners or children. In a study which compared 13-19 year olds with epilepsy to groups with and without other chronic illnesses, Westbrook, Silver, Coupey and Shinnar (1991) found that adolescents with epilepsy were significantly less likely to disclose their illness to a friend or teacher.

A degree of caution must be applied to the consideration of felt and enacted stigma as independent concepts. The nondisclosure which results from felt stigma can serve to protect the individual from enacted stigma which could in turn fuel the person's perception of the world as hostile and increase the degree of felt stigma. Nevertheless, the much higher rates of felt stigma reported by Scambler and Hopkins (1980) study indicate that it is a source of more personal unhappiness than enacted stigma.

It is arguable that stigma may be linked with levels of self esteem in people with epilepsy, the evidence for which is mixed. Arnston et al (1986) found a relationship between felt stigma and self esteem in adults with epilepsy, whilst Hills and Baker (1992) found no such relationship. Westbrook, Bauman and Shinnar (1992) attempted to apply Goffman's (1968) model of stigma to investigate the experience of epilepsy in adolescents. Their results were mixed, over half of the sample did not express felt stigma, but those that did had correspondingly low self esteem scores.

1.6.4 The long term effects of chronic illness

Long term detrimental effects of chronic illness would provide a convincing argument for clinical intervention to enhance coping at an earlier stage, such as adolescence. There are very few longitudinal population studies which examine the relationship between the presence of a chronic illness during childhood and negative psychosocial consequences in adult life. Wadsworth, Peckham and Taylor (1984) conducted a secondary analyses of two British cohorts from 1946 and 1958, data was collected from the cohorts at regular intervals through childhood and adulthood. The preliminary findings of this study are reported by Pless and Wadsworth (1989). Individuals were identified as having been chronically ill in childhood or adolescence if they had had a physical illness which lasted longer than three months. During adolescence, significant differences were found on the Eysenck Personality Inventory between those who had been chronically ill and those who had not. Poorer educational attainment was also found in those with chronic illness at ages 15 and 26 years. At age 36 years, differences were found in terms of marriage rates, separations and divorce, with greater numbers of the chronically ill group experiencing relationship difficulties. Findings regarding emotional state using the Present State Examination are as yet unclear. However, the chronically ill group were not considered severely disadvantaged compared to the healthy group overall.

The lack of a strong relationship between chronic health and subsequent negative outcomes from large, longitudinal studies may be due to the fact that their explanatory power is reduced by the number of questions which are asked of the data and the number of variables measured. Asking more specific questions of a group with one chronic illness, such as whether a certain characteristic of an illness relates to a specific outcome measure, may increase the statistical power of the study.

The increased risk of suicide and depression in adults with epilepsy is an alarming long term psychological effect of the illness. Barraclough (1981) found that individuals with epilepsy are up to five times more likely to commit suicide than the general population. Kim (1991) states that there are no similar figures available for adolescents, but that evidence exists of an overrepresentation of young people with epilepsy who attempt suicide.

1.6.5 A summary of the effects of epilepsy

As was shown above, individuals with epilepsy suffer illness related variables of, diagnostic uncertainty, disability, dependency, illness intrusiveness, bias and stigma to a greater or lesser extent than individuals with other chronic illnesses. The experience of stigma and concomitant low self esteem as well as lack of control appear particularly salient features of epilepsy. The unpredictability of seizures mirrors this lack of control and therefore may be responsible for it. In addition, a wide range of effects of epilepsy are highlighted by writers such as Hermann and Whitman (1991) regarding adults, and Kim (1991) regarding children and adolescents. In a review of the literature regarding the psychosocial effects of epilepsy, Levin, Banks and Berg (1988) list the following areas as being negatively affected by the experience of epilepsy, family background and adjustment, emotional adjustment, interpersonal adjustment, vocational adjustment, financial status, adjustment to seizures and medicine and medical management. It is not possible to go into these areas in detail. Upton and Thompson (1992) state that evidence exists to suggest that people with chronic epilepsy are at higher risk of emotional problems, depression, anxiety and social phobia than their healthy peers. They describe the rather overwhelming number of areas of life affected as 'a potential myriad of psychosocial sequelae' (Upton and Thompson 1992, p 4). Some evidence exists to suggest that mood is also affected in individuals with epilepsy, particularly those with temporal lobe epilepsy with a left sided focus. Altshuler, Devinsky,

Post and Theodore (1990) observed a significant number of participants who scored above the cut-off score of the Beck Depression Inventory indicating low levels of positive affect.

In his review of the literature on children and adolescents with epilepsy, Kim (1991) describes a similarly long list of difficulties associated with the illness. Kim (1991) quotes studies which describe children and adolescents with epilepsy as dependent, withdrawn, anxious, socially isolated and having low self esteem. Developmental problems such as regressive behaviour are described, along with increased incidence of conduct disorder and other behavioural disorders. The impact of the child's epilepsy on parents is discussed, including the experience of loss and mourning for the healthy child and the tendency to overprotect and indulge the child. Regarding adolescence, Kim (1991) comments that adolescents with epilepsy may have to forego some of the 'exciting' adolescent activities due to the functional limitations of the illness. He also states that 'common teenage activities,' such as exercise, dieting, irregular eating and sleep deprivation may lead to psychophysiological excitement that disrupts central nervous system homeostasis and precipitates seizures. Kim (1991) believes that adolescents require particularly close medical monitoring and advice.

The above effects of chronic illness in general and epilepsy in particular, justify coping research with individuals with epilepsy. The clinical value of such research may fulfil some of the recommendations in recent green and white papers. Enhanced coping may both improve the quality of life of the individual (Government green paper, 'Our Healthier Nation', 1998) and reduce suicide levels (Government white paper, 'The Health of the Nation, 1992).

1.7 Coping with epilepsy at a time of transition in late adolescence

In order to address the specific issue of coping with epilepsy at a transitional time in adolescence the following related issues will be included: the challenging nature of adolescence; how adolescents cope with chronic illness; how adults cope with epilepsy; how adolescents with chronic illnesses cope with the transition to adulthood.

1.7.1 Adolescence, a time of transition

The origins of the word 'adolescence' stem from the Latin word 'adolescere' which translates, 'to grow up' or 'to grow into maturity'. It is difficult to specify clear boundaries regarding when adolescence begins and ends, due to individual and cultural differences. One view is that the start of adolescence corresponds primarily to an individual's biological age and biological changes of puberty and that the end of adolescence depends more on the person's 'social age' or emotional maturity. For the purposes of research however, it is necessary to define cut-off points. The present study is concerned with 16-21 year olds who are classed as 'older adolescents'.

The concept of adolescence held by authors such as Freud (1958) as a time of disturbance and crisis, where the individual remains passive as they are bombarded by change has been replaced by the notion of transition. The concept of transition refers to a period of change between one relatively stable point and another relatively stable but different point. The stable points being in this case childhood and adulthood. Thus adolescence is the period of transition between social, physical and sexual immaturity and maturity as experienced by children and adults.

The passage through adolescence is marked by the accomplishment of a number of developmental tasks. Developmental tasks can be considered normative, that is they are applicable to most adolescents, tend to be achieved at approximately the same age and are anticipated and expected by the individual. Havighurst (1972) lists the following developmental tasks as those of older adolescence: preparing for marriage and family life; preparing for an economic career; acquiring a set of values and an ethical system or ideology to guide behaviour; desiring and achieving socially responsible behaviour. However, one should be cautious in being overprescriptive regarding whether these developmental tasks are the only or most important ones of late adolescence.

The nature of identity formation has been addressed by Erikson (1963, 1968, 1985) who perceived the main developmental task of adolescence as the formation of a comfortable set of self perceptions and goals with which to face adulthood. The concept of identity comprises a number of dimensions. Identity consists of adopting definite ideological, occupational and interpersonal stances. Identity is influenced by cultural factors such as

societal norms. Identity formation is an active process where adolescents adopt and reject a number of career possibilities, potential partners and ideologies.

Erikson (1968) applied the term 'identity confusion' to the case of adolescents who struggle to forge an identity which fits their personality and environment. Identity confusion can lead to low self esteem, anxiety and depression as well as feelings of uncertainty about oneself and one's possibilities in life and can prevent individuals reaching the full potential of their abilities in occupational and interpersonal matters. Alternatively, a clear sense of identity leads individuals to work towards well defined, achievable goals, develop close relationships with others and possess high self esteem and low levels of anxiety and depression.

It is possible to imagine that adolescents with epilepsy may find it harder to cope with the challenges of exams and employment prospects as well as resolve issues associated with their identity, sexuality and relationships.

1.7.2 Coping in adolescence

The notion of adolescence as a period of transition, rather than a time of disturbance and upheaval incorporates the view that the adolescent is able to influence the course of their development. This influence can be exerted by the thoughts and actions i.e. coping strategies adopted by young people to deal with the challenge of making the transition to adulthood.

Due to the varied nature of the process of transition to adulthood and the complexity of the developmental tasks required, adolescence has been deemed an ideal stage in the life span to study coping responses by authors such as Peterson, who has studied the adolescent coping response to normative developmental challenges. According to Peterson and Ebata (1987), the majority of adolescents manage to cope successfully with the demands of adolescence. However, Seiffge-Krenke (1993) found that clinical populations appraised situations as more threatening and responded by withdrawing, in contrast to normal populations who tended to use active coping strategies such as problem solving. Members of the clinical

population were defined as individuals who were undergoing treatment for emotional difficulties.

Studies of coping in adolescence vary in terms of the nature of the stressful situation examined. Some studies consider coping responses to normative or non normative life events or 'daily hassles'. Different methodologies can be observed, some studies examine both normative and clinical samples and may study longitudinal or situation specific stress. An example of both a situation specific and a longitudinal study will be given to illustrate different methodologies in the study of coping in the normative adolescent population. These studies also highlight the influence of age and gender on the coping response.

Phelps and Jarvis (1994) asked 484, 14-18 year olds to describe a specific important problem that they had dealt with in the last two months and indicate the degree to which they used 60 coping measures to deal with it. The specific stressors cited were categorised from most to least common as parental conflicts, academic grades and concerns, boy/girl friend issues, peer conflicts and extracurricular activities. Factor analysis revealed that coping responses fell into the following four categories, active, avoidant, emotion focused and acceptance. Significant differences were found in the use of coping strategies by each gender. Females made more use than males of the 'accept' and 'emotion focused' strategies and males used 'avoidant' strategies more.

In a longitudinal study of coping, Groer et al (1992) collected data from 167 participants, aged 13-18 years, at two points in time separated by three years. Degree of stress experienced was measured by the Adolescent Life Change Event Scale which measures the occurrence of specified developmentally appropriate life events experienced over the past year. A measure of coping strategies used in response to life events was also used. Groer et al's (1992) findings revealed gender and age differences which emerged by comparing the results of the same individuals over time. Levels of stress as measured by life events were higher at the second point of testing, with females reporting more stress at both testings than males. Females reported more life events associated with interpersonal relationships. The most commonly reported methods of coping were active distraction techniques such as exercise. However, females use of active distraction decreased with age and their use of passive distraction increased, whilst self destructive and aggressive coping behaviour increased for males. As in this study, older adolescents have generally been shown to use

less productive coping strategies and to use tension releasing coping strategies such as using alcohol or drugs or acting out as well as more avoidance strategies. In general, the use of such coping strategies is considered less productive than a problem solving approach.

Thus, the examples of longitudinal and situation specific studies revealed that adolescents contend with stressful experiences and use a range of coping strategies to do so. Gender differences were also highlighted in each study. However, neither study attempted to assess the adaptive nature of coping strategies by the use of outcome measures such as psychological well being. The wide variety of life events and specific situations reported in each study prevents the emergence of a clear relationship between type of situation and coping strategies employed. A method which defined a specific situation and measured related coping responses would reveal how adolescents cope with specific challenges. Reducing the number of potential stressors would also increase the impact of any statistical relationship between situation and coping response.

1.7.3 Coping with chronic illness in adolescence

Hauser and Bowlds (1990) highlight the existence of non normative stressors such as the death of a parent, which add to the normative challenges of adolescence. Non normative stressors are perceived as risk factors which increase the likelihood of psychological disturbance both during adolescence and in later life. As a non normative stressor, chronic illness may act in addition to normative stressors to make the experience of adolescence more difficult to cope with. The effects of illness on self related resources such as self esteem may decrease the chronically ill young person's ability to cope with the usual stresses of adolescence, as well as confronting them with one more stressful challenge to cope with. The effects of chronic illness on the adolescent have been more extensively researched than their ability to adapt to normative stresses.

The experience of chronic illness may make the achievement of developmental tasks more difficult. Developing a sense of identity which is not dominated by being a sufferer of a certain illness may be problematic. Aspects of identity such as accepting one's body, may be more difficult for adolescents with health problems. Achieving emotional and functional independence from parents may also be more difficult. For example, adolescents may be dependent on their parents for more of their everyday needs than their peers, such as

transport. Also, parents may have fostered a relationship of dependence between the child and themselves due to the perception that their child is in need of special protection and monitoring and thus make it more difficult for adolescents to separate from them. This may halt their development and lead to the 'immaturity' noted by Ingram (1964, p.93) in adolescents with cerebral palsy.

In a study of 135 adolescents with insulin dependent diabetes, Hanson et al (1989) found that older adolescents used more tension releasing, 'ventilation' and avoidance activities to cope with stress in contrast to younger adolescents. An explanation for these results was that being older correlated with negative factors, such as the greater stress of a longer duration of illness and also a lack of family cohesiveness. A study by Milousheva et al (1996) comparing the coping strategies of children and older adolescents with insulin dependent diabetes in Japan found age and gender differences akin to those in the normative adolescent population. Females were found to use strategies of seeking social support, mostly by talking to friends and behavioural distraction with equal frequency, whilst males used the behavioural avoidance tactic of 'sleep' as well as cognitive and behavioural distractions. Age specific problems were reported by the older group and included, finding a job, marriage and having children. Milousheva et al (1996) can be criticised for comparing the results of the two different age groups which were gained by using different methods of investigation, i.e. a projective drawing technique and a questionnaire.

Olson et al (1993) compared the use of cognitive coping strategies in individuals aged 8-18 years who had asthma, diabetes or rheumatoid arthritis with a healthy control group. A cognitive questionnaire was used to measure coping responses to the situations of receiving an injection, giving a talk and a stressful event personal to the participant. Cognitive coping strategies such as positive self talk, were used with equal frequency in both the healthy group and the group with chronic illness across all situations. Some within group differences existed in the group with chronic health problems, individuals with rheumatoid arthritis exhibited higher levels of cognitive coping and offered more complex coping responses. The influence of the higher level of coping in this group may have masked poorer coping in the illness subgroups of asthma or diabetes. Therefore, a study comparing a group of individuals with one illness with healthy peers may reveal patterns of illness specific coping responses to stressful situations. Similarly, in a study of coping with everyday concerns, Woodgate (1993 in Frydenberg 1997) compared the coping responses

of 40 hospital patients with 60 healthy peers, aged 14-20 years. In general, it was found that similar coping responses were employed by each group, with non productive coping being the most frequent response.

The fact that adolescents with chronic illness exhibit similar coping strategies to their peers may indicate that the experience of chronic illness stimulates the growth of coping strategies. However, the nature of these strategies may not always be helpful. Cowen et al (1984) found that adolescents with cystic fibrosis aged 16 and above, employed strategies of denial, anger, guilt, sadness, shock or worry. In a study of young people in hospital due to chronic illness, Bullard (1987) described the use of strategies of intellectualisation, over identification with medical staff, denial and obsessive rituals.

1.7.4 Studies of coping with epilepsy

Due to the general scarcity of studies dealing with how individuals cope with epilepsy, particularly in adolescence, two studies concerning adults will be given in detail.

Schneider and Conrad (1981) published an important study which differentiated between adults with epilepsy based on how they coped with the illness. The study is unusual in its use of a qualitative method. Some 80 adults with epilepsy were interviewed using 50 open questions regarding the experience of having and coping with epilepsy. A grounded analysis of the data led to the emergence of a number of 'typologies' of people, classified according to the way in which they coped with epilepsy. The two main typologies were either 'adjusted adaptation' or 'unadjusted adaptation', each typology then breaks down further into several subtypes.

Adjusted adaptation was seen in individuals who were able to neutralise the actual or perceived negative impact of epilepsy by cultivating successful strategies for gaining some control over seizures and the side-effects of medication and for dealing with stigma and discrimination. Epilepsy was perceived as minimally disruptive to life by this group.

The three subtypes of the adjusted group are 'pragmatic', 'quasi-liberated' and 'secret'. The pragmatic group minimised the impact of epilepsy to themselves and others, but did not conceal it in situations where information about it was expected. This group tended to

cultivate 'healthy habits' with regard to their treatment regime and were compliant with medication and limits on alcohol intake. The secret group perceived epilepsy as stigmatising and like the individuals in Scambler's (1983) study, did not disclose their illness in any situation. The secret group perceived themselves as passing as 'normal' socially until the medical diagnosis was revealed, by for example a public seizure which led to feelings of shame. The behaviour demonstrated by the secret group included planning a daily schedule which avoided situations where they were at risk of having a seizure. The quasi liberated group, sought to educate others about epilepsy and free themselves from any need for secrecy by addressing the root of stigma i.e. the ignorance of society.

Unadjusted adaptation was seen in individuals who felt overwhelmed by the experience of epilepsy and believed it to have a great negative impact on their lives. This group had not developed strategies for managing the impact of epilepsy. An extreme subtype of unadjusted adaptation was seen in a subgroup labelled 'debilitated'. People's response to epilepsy tended to be to withdraw into it and away from social contact. Schneider and Conrad (1981) gave examples of individuals in this group who felt 'incarcerated' by the negative aspect of epilepsy, who perceived it as an 'an unclean spirit', one woman's response to epilepsy was as follows:

'My only way of dealing with it was to close it up inside me. I didn't know how to handle it. It was very destructive, it overwhelmed me. My mind was so blocked up with epilepsy and its horrors that I couldn't really relate. It was overpowering.' Schneider and Conrad (1981 p217).

The main difference between the adjusted and unadjusted typologies was a sense of agency or control over epilepsy and its impact on life. It appeared that taking control, whether this was achieved by taking medication or choosing whether to disclose the diagnosis of epilepsy minimised its impact epilepsy on the life of the individual.

Important and interesting as Schneider and Conrad's (1981) findings are, criticisms can be made of their methodology. Their method of analysis is not specified beyond the fact that it is 'grounded'. It is also unclear as to whether there were differences other than ways of coping between the members of the emergent typologies. For example, differences in condition characteristics could provide an alternative explanation of their findings.

A more recent study by Upton and Thompson (1992) examined the relationship between the type of coping strategy used to cope with epilepsy and the psychological adjustment of individuals as measured by acceptance of illness, self esteem, anxiety, depression and social avoidance questionnaires. Participants were 139 adults with chronic and severe epilepsy. Coping was measured using the Ways of Coping Checklist which measures six coping strategies.

Upton and Thompson (1992) found that certain coping variables were found to correlate significantly with greater emotional problems. Importantly, it was found that individuals achieved better scores on psychological outcome measures if they used a 'cognitive restructuring' rather than a 'wish fulfilment' strategy. Cognitive restructuring correlated with better acceptance of illness and less depression, social avoidance and anxiety. This strategy involved reframing the experience of epilepsy as having positive elements, such as giving the individual more scope for inner growth. Conversely, use of a 'wish fulfilment' strategy correlated with higher levels of depression and anxiety, lower self esteem and less acceptance of illness. Wish fulfilment involved wishing that the illness would disappear and provided an escape into an illness free fantasy. Other findings were that use of a 'self blame' strategy correlated with lower levels of self esteem and acceptance of illness and that the 'emotional expression' strategy correlated with lower levels of acceptance of illness. It is important to note that women were found to have lower levels of psychological adjustment, reporting higher levels of anxiety, lower levels of self esteem and less acceptance of illness compared to men.

Interestingly, Upton and Thompson (1992) did not find significant correlations between outcome measures of adjustment and condition characteristics such as seizure type or frequency, duration of epilepsy or site of epileptic foci. Only age at onset correlated with adjustment with those whose epilepsy began in their teenage years showing greater levels of depression. An explanation of these findings could be that the type of coping strategy used is more important to psychological adjustment than the actual characteristics of the illness. Alternatively, as most of the sample were considered to have severe epilepsy, it could be the case that there was insufficient variation in certain condition characteristics such as seizure frequency to allow relationships with outcome variables to emerge.

The above two studies demonstrate the fact that individuals cope with having epilepsy in a variety of ways, some of which are associated with better psychological outcomes than others. The work of Schneider and Conrad (1981) highlighted the importance of a sense of control which was linked to adaptive coping above (Pearlin and Schooler 1978). Upton and Thompson (1992) identified cognitive reframing as the most adaptive strategy for coping with epilepsy which illustrates the importance of cognitive reframing emphasised by Lazarus and Folkman (1984) above.

1.7.5 Coping with chronic illness at a time of transition,

Only one recent study was found regarding the transition to adulthood in young people with chronic health conditions, none were found specific to epilepsy. Gortmaker et al (1993) used data from the American National Survey of Youth to consider the relationship between having a chronic health problem from the age of 14 to 21 years and the transition to adulthood. A sample of 10,485 individuals, 1.9 per cent of whom reported a chronic health problem, were followed from 1979 to 1986. Gortmaker et al (1993) hypothesised that although the majority of individuals with chronic health problems would make the transition to adulthood smoothly, a significant number would experience difficulty due to education being interrupted by illness, cognitive ability being impaired by medication, lack of opportunities for socialisation and difficulties in psychological adjustment. Each year, a questionnaire was answered by the cohort. The Rosenberg Self Esteem (Rosenberg 1967) scale was administered in 1980 and 1987. The main outcome variable of the study was the occupational status of the individual. Compared to healthy peers, a smaller percentage of individuals with a chronic health condition were working, a higher percentage were working in the home or were unable to work and more were receiving state benefits. However, none of the other expected significant differences were found between the two groups in terms of educational attainment or self esteem. It was concluded that young adults are at a slightly higher risk of problems in early adult life, but this may be better explained by social, economic and demographic characteristics variables than the experience of illness.

The above study can be criticised on several counts which provides a good argument for further research into this topic area. Over half of the individuals with a chronic illness had asthma, other illnesses were very poorly represented. Also, the cohort data from 1979-1986 may not reflect current issues which affect the transition of adolescents to adulthood,

as changes in related areas such as education and social policy have been made. The definition of 'success' used in the study regarding the transition to adulthood was also somewhat short-sighted, with 'house-keeping' being less valued than other forms of work. Only one measure was made of psychological well being i.e. self esteem, using other measures may have given a clearer idea of the psychological adjustment of this group.

1.8 Summary

The process and style approaches to coping have been compared. Coping has been defined as cognitive and behavioural attempts to deal with situations which challenge coping resources. The process approach that coping is a dynamic transaction between person and environment has been favoured, an emphasis has been placed on the view that coping changes in response to the particular stressful situation. Dimensions of coping such as problem or emotion focused have been described. Whether coping can be considered as adaptive or non adaptive is also believed to depend on the situation. However, strategies of active problem solving or cognitive reappraisal appear to be more adaptive than wish-fulfilling, acting out or other such non productive strategies.

Variables such as self esteem, self efficacy, and mood have been identified both as correlates of coping and indicators of psychological adjustment. Links were identified between feelings of control, expressed as self efficacy and self esteem and more adaptive coping. The perceived impact of the situation by the individual has also been highlighted as being as important as the characteristics of the situation. The challenge of chronic illness to coping resources was discussed and the unique challenge of epilepsy was established in terms of the particular elements of social stigma and lack of control. The value of studying individuals with a particular chronic illness rather than a mixed group was emphasised.

Studies of coping with chronic illness were described. Studies showed that coping with epilepsy depended on the degree of perceived control and was more successful if cognitive reframing rather than wish fulfilment was used. Coping with a chronic illness such as epilepsy during late adolescence was introduced by a discussion of adolescence as an ideal time to study coping. The extra non normative stress of chronic illness at this time was identified as influencing tasks such as developing an identity and independence.

Longitudinal studies of transition to adulthood showed weak links between negative psychological well being and occupational success, but were criticised for a paucity of psychological measures and neglecting to study disorders of low prevalence.

The long term effects of chronic illness were discussed in order to highlight the clinical importance of enabling young people to cope with not only their illness, but with the challenge of becoming an adult. It was hoped that well timed psychological intervention could have a role in preventing psychosocial difficulties in the long term.

1.9 Description of the study

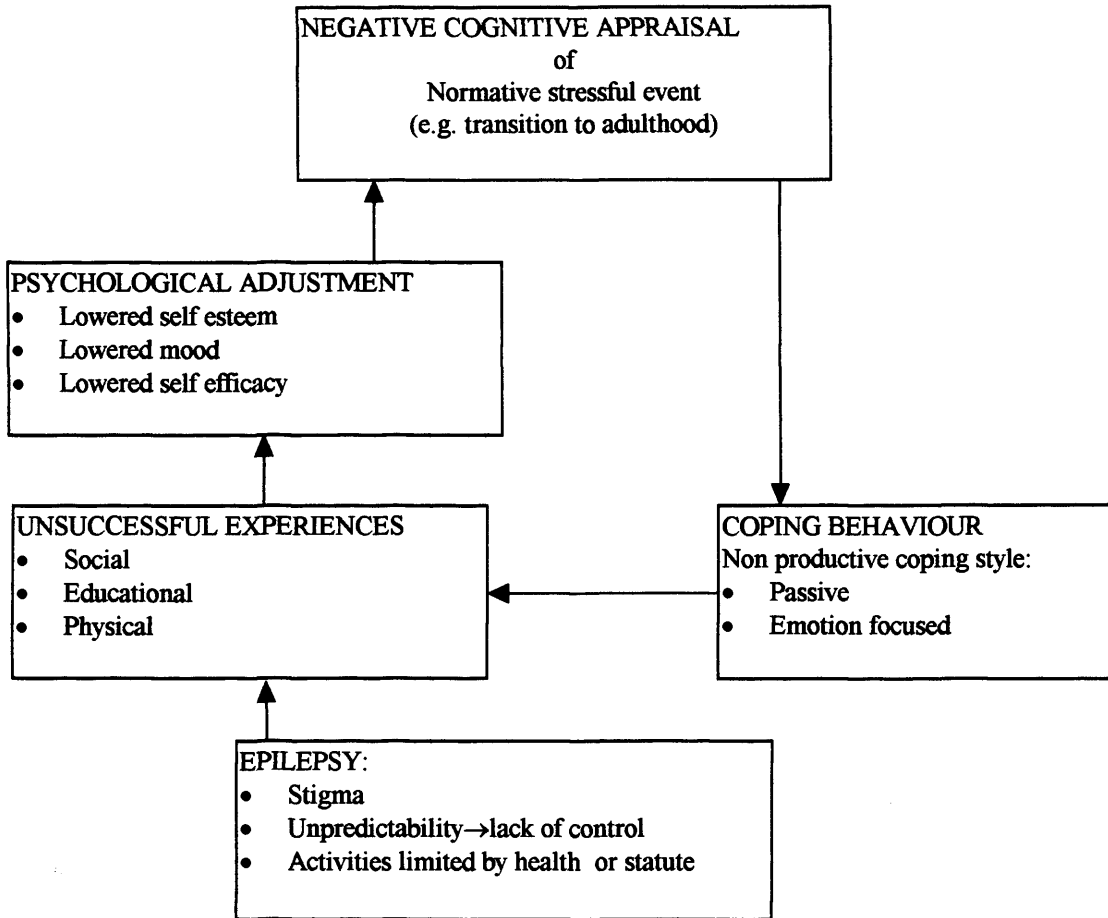
The study reported below aims to make a comparison between older adolescents with and without epilepsy with regard to their psychological adjustment and their method of coping with a transitional issue. Within group comparisons will also be made in the group with epilepsy to compare whether older adolescents cope differently with different stressors, i.e. illness and transitional issues. The influence of condition characteristics on psychological adjustment and coping will also be examined.

Psychological adjustment will be ascertained by measuring self esteem, mood, self efficacy and acceptance of illness. Coping strategy will be measured by the specific version of the Adolescent Coping Scale which can be adapted to the issue of coping with epilepsy or with a transitional issue. Condition characteristics of individuals with epilepsy such as seizure severity will also be measured, as well as a measure of the degree of perceived control individuals have over their epilepsy.

1.10 Underlying assumptions and hypotheses

In view of the literature review above, several assumptions can be made which form the theoretical basis of the present study, this is represented in Fig.1.3. Each assumption in the following text is outlined and followed by a specific hypothesis (in bold) and presented in order of the most relevant first. Hypotheses 1 and 2 relate to expected between group differences and 3 and 4 relate to findings expected within the epilepsy group.

Figure 1.3: Proposed model of the effect of epilepsy on coping with normative stressful event



Hypothesis 1

The experience of epilepsy constitutes a significant stressor to the older adolescent and results in poorer psychological adjustment when compared to their peers.

Adolescents with epilepsy will demonstrate poorer psychological adjustment than their peers. They will achieve lower self esteem, lower self efficacy and lower positive affect and higher negative affect scores than their peers due to the experience of epilepsy.

Hypothesis 2

Psychological adjustment is related to ability to cope with stressors such as illness or transitional issues.

Due to poorer psychological adjustment, adolescents with epilepsy will cope less well than their peers with the transitional issue of deciding what to do with their future. This will be seen in the patient group's use of less problem solving coping strategies and more non productive coping strategies compared to their peers.

Hypothesis 3

Coping response varies in response to different situations.

Adolescents with epilepsy will use different ways of coping with their illness compared to coping with the transitional issue of deciding what to do with their future.

It is not possible to predict the nature of these differences with confidence, individuals may cope better with the transitional issue because they have more control over what they decided to do with their life. Individuals may show more problem solving strategies regarding issues of the future compared to more non productive strategies with regard to epilepsy. Self efficacy ratings may be higher with regard to transitional issues than epilepsy.

Hypothesis 4

Coping response is more closely associated with perceived impact of illness than condition characteristics.

Relationships will exist between coping response and scores of acceptance of illness and perceived control over seizures rather than condition characteristics of epilepsy.

2 Method

2.1 Participants

Participants were recruited via the six Consultant Adult and Paediatric Neurologists at the Queen's Medical Centre in Nottingham. Permission was gained for the study from the hospital Ethics Committee. Participants were selected from these consultants' current patients if they had a diagnosis of epilepsy, were aged between 16 and 21 years of age and had no known learning difficulties according to their medical notes. One hundred and nineteen individuals were identified as satisfying the selection criteria. Each individual was sent a request to take part in the study (see Appendix 1).

Of the 119 participants identified, six (5%) indicated that they did not wish to be sent further information. The remaining 113 participants were sent a questionnaire together with a covering letter, they were asked to complete and return the questionnaire and written consent form within two months from it's receipt. Further details regarding the contents of the questionnaire are given below. Additional selection criteria were included in the questionnaire in the form of health screening questions (see Appendix 7, p. 11). Potential participants were not included in the study if they had a chronic illness in addition to epilepsy, if they had suffered a stroke or a head injury requiring hospitalisation.

Thirty eight of the remaining participants returned completed questionnaires and written consent forms. Two of the 38 participants were not included in the study as screening questions revealed that one individual had asthma and the other had had a head injury requiring hospitalisation. Thus 36, (30%) of the original population formed the sample of individuals with epilepsy in the present study. Available information showed that individuals who did not respond did not differ significantly in terms of age, diagnosis or medication. However, nonresponders did differ in terms of gender, with almost twice as many women responding from the original population of approximately equal numbers of males and females (56 males, 53 females).

A control group was recruited by asking participants with epilepsy to ask a friend or relative aged between 16 to 21 years who did not have epilepsy to fill in a separate questionnaire. By using this method of recruitment, it was hoped that factors such as social class and

education would be controlled for. Control participants were required to answer the same health screening questions as the patient group. Thirty four control participants were recruited in this way, three of whom were excluded from the study due to asthma (2 individuals) and head injury (1 individual). Therefore, the control group consisted of 31 individuals.

2.2 Procedure

Based on the selection criteria described above, patients were contacted by letter. The letter briefly outlined the aims of the study and gave participants the opportunity to decline any further correspondence concerning the study. This was followed by a second collection of correspondence including the following items which can be found in the appendices.

- covering letter including a request to recruit a control participant (see Appendix 2)
- information sheet giving the participant detailed briefing information regarding the study and assuring participant confidentiality and anonymity (see Appendix 3)
- patient consent form (see Appendix 4)
- stamp addressed envelope
- separate package of correspondence for the control participant, marked 'friend or relative' (containing information sheet, consent form (see Appendices 5 and 6), questionnaire¹ and stamp addressed envelope)
- postal questionnaire containing the measures described below, plus health screening questions and questions asking for further details regarding their epilepsy (see Appendix 7)

Written instructions for completing the measures were included in the questionnaire and it is assumed that participants completed questionnaires without assistance. Participants were requested to return the questionnaire in the stamp addressed envelope by a certain date and a maximum of two reminder letters were sent if they had not done so. Participants were given the opportunity for debriefing by telephone or offered information regarding the outcome of the study following its completion. In both cases, participants were required to contact the author, six of whom did so.

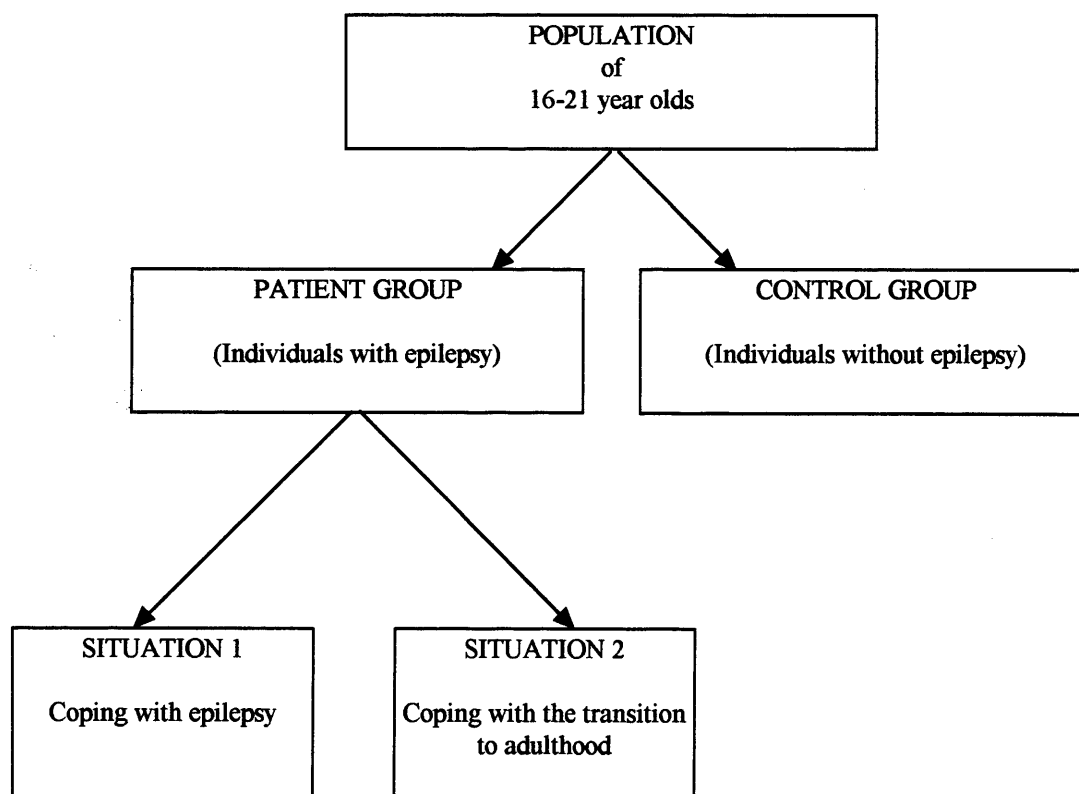
¹ The control questionnaire is not included as a separate appendix since it is identical to the patient questionnaire, but with some sections removed. Table 1a and 1b list which measures were completed by the patient and control groups.

Letters were sent to the General Practitioners and Consultant Neurologists of the patient group to inform them that patients under their care had agreed to take part in the study. This was done to satisfy the requirements of the hospital Ethics Committee.

2.3 Design

The design of the study was structured to facilitate both between group and within group comparisons and is illustrated in Fig. 2.1. Two separate groups were included, the group with epilepsy, labelled the 'patient group' and the group without epilepsy, labelled the 'control group'. Attempts were made to match the participants in terms of age and other demographic variables.

Figure 2.1: Study design



The primary design of the study was a between groups analysis (epilepsy and non epilepsy) of a range of dependent measures (self esteem, negative affect, positive affect, self efficacy, use of coping style and strategy related to transition to adulthood). Within the epilepsy group a further between group analysis was undertaken with situation serving as the independent variable (epilepsy and transition to adulthood) and coping strategy and style as the dependent variables. Relationships between dependent variables and condition characteristics were investigated within the patient group. Variables measured in the patient group only were: acceptance of illness; seizure severity; perception of control over seizures; use of coping style and strategy related to epilepsy.

2.4 Measures

Tables 1a and 1b below summarise the use of standardised and non standardised measures used in the study and give details of the constructs measured and the authors where applicable. All measures were completed by both the patient and control group unless indicated otherwise.

Table 1a: Standardised measures used in the study

Measure	Construct (s) measured	Authors
Adolescent Coping Scale (Short Form, Specific Version)	Coping with the transition to adulthood	Frydenberg & Lewis (1993b)
Rosenberg Self Esteem Scale	Self esteem	Rosenberg (1967)
Positive and Negative Affect Scale	Mood: <ul style="list-style-type: none"> • Positive affect • Negative affect 	Watson, Clark & Tellegen (1988)
*Acceptance of Illness Scale	Acceptance of illness	Felton, Revenson & Hinrichson (1984)
*Seizure Severity Scale	<ul style="list-style-type: none"> • Seizure severity • Perception of control over seizures 	Baker, Smith, Dewey, Morrow, Crawford & Chadwick, (1991)
*Adolescent Coping Scale (Short Form, Specific Version)	Coping with epilepsy	Frydenberg & Lewis (1993b)

* Indicates completed by patient group only

Table 1b: Non standardised measures used in the study

Measure	Construct (s) measured
Self Efficacy Rating 1	Self efficacy re ability to influence own future
Open Questions 1	Coping with making decisions re own future, self efficacy re own future
*Self Efficacy Rating 2	Self efficacy re ability to influence own epilepsy
*Open Questions 2	Coping with epilepsy, degree of influence over epilepsy

* Indicates completed by patient group only

The order in which measures and other questions was presented in Table 2 for each group.

Table 2.2: Order of presentation of standardised measures and other questions

Patient Group	Control Group
Acceptance of Illness Scale	Rosenberg Self Esteem Scale
Rosenberg Self Esteem Scale	Adolescent Coping Scale re. the Future
Adolescent Coping Scale re Epilepsy	Positive & Negative Affect Scale
Adolescent Coping Scale re. the Future	Open questions
Positive & Negative Affect Scale	Demographic questions
Open questions	Screening questions re health
Demographic questions	
Screening questions re health and information re epilepsy	
Seizure Severity Scale	

2.4.1 Standardised measures

The above standardised assessments were included in the patient and control questionnaires. Three measures were completed by both patient and control groups in order to make between group comparisons possible. Additional measures were completed by the patient group to gain information specific to their experience of epilepsy and to permit a within group comparison of coping across situations, i.e. epilepsy and transitional issues. Measures which were completed by both groups are described, followed by a description of those completed by the patient group alone.

2.4.1.1 Standardised measures completed by patient and control groups

a) Self esteem

The Rosenberg Self Esteem Scale (RSE), was used to measure self esteem, it is a widely used measure and was developed for use with adolescents in the first instance. The RSE is a ten item scale consisting of equal numbers of positive and negative expressions of self esteem. For each item, participants are required to agree or disagree with each statement on a four point scale, with a score of one on each item indicating high self esteem. Scores range from 10 to 40 with higher scores indicating low self esteem. The mean score for a mixed sample of 2,294 participants aged 18-65 was 34.73 (standard deviation, 4.86) (Rosenberg 1989). Johnston, Wright & Weinman (1995) comment that this sample's scores on the RSE are negatively skewed towards low self esteem, with over 20 per cent of participants scoring the maximum of 40. Johnston et al (1995) also highlight two other facts important in the evaluation of the RSE, firstly, that despite its popularity, little data exists on which to judge its psychometric status and secondly, that it is difficult to identify other tests of self esteem in health psychology to compare with the RSE to establish its external validity.

The RSE was self administered with standard instructions according to Rosenberg included above the ten items on the form, it was titled 'How you feel about yourself' (see Appendix 7, p. 2).

b) Affect

Affect or mood was measured using the Positive and Negative Affect Schedule (PANAS). In the construction of this scale, positive and negative affect are considered as independent dimensions with positive affect (PA) reflecting 'the extent to which a person feels enthusiastic, active and alert' and negative affect (NA) reflecting the degree of 'subjective distress and unpleasurable engagement that subsumes a variety of aversive mood states' (Watson et al 1988, p.1063).

The PANAS was an attractive measure of affect because high levels of NA are related to poor coping and health complaints and high PA is associated with physical and social

activity which can be construed as positive coping strategies. It is also a brief scale, taking only around five minutes to complete.

The PANAS comprises two 10 item mood scales, one negative and one positive. The negative affect scale includes adjectives which refer to negative mood states and the positive affect scale to positive moods. Participants indicate to what extent these adjectives describe their feelings and emotions on a 5 point scale from 'very slightly or not at all' to 'extremely'.

The PANAS was self administered using standard instructions which are included on the form and was titled 'How you are feeling at the moment' (see Appendix 7, p. 7). It is possible to use a variety of different time periods in the instructions to the PANAS. The time frame 'during the past few days' was chosen in preference to 'the present moment' or 'today' in case the participant had recently had a seizure which may unduly influence their mood.

The PANAS was scored to give separate NA and PA scores. Item scores range from one to five and were summed for each scale giving a possible range of scores from 10 to 50. Watson et al (1988) quote the results from a study of 1002 undergraduates based on completion of the PANAS including the instruction 'the past few days' of 33.3 (mean) and 7.2 (standard deviation) for the PA Scale and 17.4 (mean) and 6.2 (standard deviation) for the NA Scale. No significant sex differences were found.

For the time frame 'the past few days', Watson et al (1988) report internal consistency figures (Cronbach's coefficient) of 0.88 (PA) and 0.85 (NA) and test-retest reliability over an eight week period of 0.48 (PA) and 0.42 (NA). Correlation between the PA and NA scales was -0.22 which supports the stance that the scales measure independent dimensions where a NA score does not predict PA scores. The external validity of the PANAS has been investigated by exploring its relationship to other measures of distress and psychopathology. The best correlation (0.74) has been found between the NA scale and the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth & Covi 1974) which is a measure of general distress and dysfunction. The validity of The PANAS was further validated by Watson and Pennebaker (1989) who used it in six studies to establish a relationship between negative affect and poor health status.

c) Coping with the transition to adulthood

How participants coped with the transition to adulthood was measured using the Adolescent Coping Scale (ACS) which was chosen from relatively few measures specifically designed for adolescents. The ACS follows the multivariate approach for exploring and interpreting coping responses pioneered by Folkman and Lazarus (1988) in the Ways of Coping Questionnaire. One reason for choosing the ACS was the association between coping and self esteem found by Frydenberg and Lewis (1993b) using this measure.

The ACS is a self report inventory of which there are four different formats, an 80 item long form and an 18 item short form both of which are available in specific and general versions. The specific version of the short form was used for its brevity (it takes around three minutes to complete) and its situation-specificity, as it allows the measurement of responses to a particular 'administrator-nominated' concern (Frydenberg & Lewis 1993b, p.6). All versions of the ACS measure '18 conceptually and empirically distinct coping strategies' (Frydenberg & Lewis 1993b, p.6) with each item in the short form representing one type of coping strategy. The scale is designed for use with 12 to 18 year olds, however, the authors state that it is consistently perceived as relevant by older participants in their experience. It was therefore chosen as a measure which would be relevant to the 16 to 21 year old age group studied.

The standard instructions for use of the short form of the specific ACS were modified to elicit how participants coped with deciding what to do with their future as the administrator nominated concern. Examples were included of the kind of decisions young people have to make during the transition to adulthood. Coping with making decisions regarding the future was chosen as a representative issue of the transition to adulthood as it was assumed that all participants would have had to make such decisions.

Participants were encouraged to consider current decisions or decisions made in the last few years. Full details of the modified instructions can be found in Appendix 7, p. 5, the standard instructions for the short form of the ACS are included in Appendix 8. The ACS was self administered and participants were required to rate their use of each strategy on a five point Likert scale (1- doesn't apply or don't do it, 2 - used very little, 3 - used

sometimes, 4 - used often, 5 - used a great deal). The ACS was self administered and was titled 'How you cope with the future'.

The short form of the ACS requires no scoring to produce individual coping profiles, as each participant's scale represents the extent to which they use each of the eighteen coping strategies. Total and adjusted scores were calculated according to Frydenberg and Lewis (1993b p.42&43) regarding the extent to which participants used three coping styles identified as underlying the 18 coping strategies using factor analysis. Participants' use of each coping style was categorised as 'Not used at all, Used very little, Used sometimes, Used frequently or Used a great deal' according to their adjusted scores (p.44). The coping styles were conceptualised as problem focused coping (items 2,3,6,15,17,18), coping by reference to others (items 1,10,14,16) and non-productive coping (items 4,5,6,7,8,9,11,12,13). Frydenberg and Lewis (1993b) describe 'Solve the Problem' in the most positive terms as 'working at solving the problem while remaining optimistic, fit, relaxed and socially connected' (Frydenberg and Lewis 1993b p.42). In contrast, 'Non Productive Coping' refers to strategies such as avoidance which are associated with an inability to cope. 'Reference to Others' is characterised by turning to peers, deities or professionals to cope with the concern. Frydenberg and Lewis (1993b) recommend that these coping styles are interpreted tentatively as they have not been fully researched.

Regarding the psychometric properties of the ACS, Frydenberg (1997) believes that concepts such as reliability are of limited use to coping measures because the nature of coping is dynamic. However, in the development of the ACS, its statistical properties were examined in a study of 673 participants aged between 12 and 18, which produced test-retest reliability ranging from 0.49 to 0.82 and internal consistency coefficients ranging from 0.62 to 0.87 for the Specific Form. In terms of validity, the content of the ACS was generated by 643 adolescents aged 15 to 18 in response to open questions regarding their strategies for coping with their concerns and refined into its current form by factor analysis.

Frydenberg (1997) claims that the ACS has demonstrated predictive validity in several studies, such as Fallon et al (1993) where adolescents of more religious families scored more highly on the 'Seek Spiritual Support' scale of the ACS and those in families with high levels of conflict scored highly on the 'Tension Reduction' scale.

2.4.1.2 Standardised measures completed by the patient group only

a) Coping with epilepsy

How participants coped with having epilepsy was measured using the Adolescent Coping Scale (ACS), please refer to the section above for a description of the test, its psychometric properties and the method of scoring. The administration of the ACS in this instance differed only in the instructions which were modified to elicit how participants coped with having epilepsy as the administrator nominated concern. The scale was titled 'How you cope with having epilepsy'. The modified instructions included examples of the kind of challenges epilepsy can present to an individual's coping resources and can be found in Appendix 7, p. 3.

Participants were encouraged to consider how they deal with epilepsy or how they have dealt with it in the past even if they are currently seizure free.

b) Acceptance of illness

Participant's acceptance of or adjustment to having epilepsy was measured using the Acceptance of Illness Scale (AIS).

The AIS is an eight item scale of statements about having an illness, such as 'I have a hard time adjusting to the limitations of my illness'. It takes under five minutes to complete. The scale was self administered and used standard instructions (see Appendix 7, p. 1). The scale was titled 'How you feel about having epilepsy'. The seven items including the word 'illness' were modified with 'epilepsy' replacing 'illness' to make it easier for participants to relate to the statements. Respondents were required to indicate the extent to which they agreed with each statement on a five point scale, where 1 indicates 'strongly agree' and 5 indicates 'strongly disagree'.

All but item 6 are scored in a negative direction i.e. the statement attributes a negative value to having an illness. Scoring is reversed for item 6. Overall scores range from 8 indicating extremely low acceptance of illness to 40 indicating extremely high acceptance of illness.

Felton et al (1984) give means and standard deviations for overall scores and individual items for a sample of 151 participants with a variety of chronic illnesses. Participants completed the AIS twice, with means for each item of 3.51 and 3.56 and standard deviations of 0.7 and 0.74 respectively. Multiplying these figures by the number of items in the scale gives corresponding overall mean scores of 28.08 and 28.48. The test-retest reliability over a seven month period was 0.69 and the internal consistency ranged from 0.81 to 0.83. Felton et al (1984) have established some construct validity as a result of their finding that low acceptance of illness correlates with use of wish fulfilment as a coping strategy.

c) Seizure severity and perception of control over seizures

The Seizure Severity Scale (SSS) was used to measure both the severity of seizures in terms of their ictal and post ictal effects and the perceived degree of control participants felt they had over their seizures.

The SSS is comprised of two subscales, one measuring perception of control over seizures (items 1-8) and one measuring ictal and post ictal effects (items 9-20). Perception of control over seizures is measured by items concerning the timing of seizures, whether patients experience an aura and whether individuals can predict the onset of a seizure. Ictal and post ictal effects are measured by items regarding loss of consciousness, post ictal confusion, incontinence, falls, tongue biting and other injury, perceived overall severity and the degree to which seizures interfere with normal activities.

The SSS was originally developed as a 16 item questionnaire which individuals were asked to complete as part of an interview with reference to seizures experienced in the past four weeks. A more recent version of the questionnaire was obtained from the author and used with permission. This self report version comprises 20 items and includes instructions which refer to seizures which have occurred during the past year (see Appendix 7, p. 11-14). The scale was referred to as 'Now some more questions about the attacks you have'. Individuals were only required to complete the SSS if they had had a seizure in the past year. Items are phrased as questions to which respondents are required to respond by circling a number indicating one of four or five responses. For example, 'When your

attacks have happened, how often have you been able to tell when you will have them?

a) Always 1; b) Usually 2, c) Sometimes 3, d) Never 4.

Responses are scored on a four point scale, scoring is reversed for ten of the items and scores are then summed. Where a choice of five responses are given, choice of the fifth response is scored as zero. The possible range of scores for the percept scale is 8-32 and 10-48 for the ictal/post ictal scale, with higher ictal/post ictal scores indicating more severe seizures and higher percept scores indicating perception of less control over seizures. Mean scores for each subscale are available only for the 16 item scale and are given for four different types of seizure, simple partial, complex partial, secondary generalised tonic clonic seizure and primary generalised tonic clonic seizure. These figures were used to calculate the original means for each subscale for the total number of participants comprising the seizure subgroups. According to this calculation, the percept subscale mean was 17.4 and the post ictal subscale mean was 15.4. In order to make comparisons between the 16 and the 20 item scales, the scores obtained for each participant were multiplied by 0.8 when calculating mean scores to obtain pro rating scores.

Psychometric properties are available for the original 16 item scale only which was standardised on a group of 159 patients aged 15 to 79 years. Test-retest correlations were 0.79 for the perception of control subscale and 0.80 for the ictal/post ictal subscale, with the Cronbach alpha being 0.69 and 0.85 respectively. Internal consistency reliability was 0.69 and 0.85 for the perception and ictal/post ictal subscales respectively. Inter-rater reliability correlations ranged from 0.64 to 0.73. Construct validity was explored by correlating the patients responses with those of their relatives and carers to four items, correlations ranged from 0.64 to 0.77. The ictal/post ictal subscale proved sensitive to type of seizure. Smith et al (1991) also found that seizure severity was related to low self esteem and external locus of control in a sample of 100 patients.

2.4.2 Use of non standardised measures

Several open questions were constructed specifically for the study to investigate the following variables.

a) Self efficacy

Participants' self efficacy was measured in the form of confidence statements following Schwarzer and Fuch's (1996) method of operationalising the self efficacy model outlined above. The following two confidence statements were constructed, regarding the sense of personal control participants had over their future and over the effect of epilepsy on their life respectively:

I am confident that I can influence my future.

I am confident that I can influence the effect that epilepsy has on my life.

All participants completed the former statement, only the patient group completed the latter. Participants were required to indicate their level of agreement with the statement on a seven point scale, with 1 indicating low confidence and 7 high confidence (see Appendix 7, p. 8, Ques. 3 and 4. The questions were included in the section titled 'Your personal opinions').

b) Coping

Open questions were formulated to further investigate coping and self efficacy in order to give participants the opportunity to express their view more freely than the more structured, standardised instruments allowed (see Appendix 7, p. 8, Ques. 1 and 2). The questions were included in the section titled 'Your personal opinions'. It was also hoped that the results obtained from the standardised coping measure instrument (the Adolescent Coping Scale) and self efficacy ratings using a Likert scale would be validated by the use of a different methodology. Participants were invited to respond in writing to the following:

1. *Please write about how you deal with having epilepsy*
2. *Please write about how you deal with making decisions about the future*
3. *Please write about how much influence you feel you have over what happens to you in the future*

4. Please write about how much influence you feel you have over your epilepsy

All participants were invited to respond to items 2 and 3, only the patient group were invited to respond to items 1 and 4.

Participants' written responses were analysed as recommended by Patton (1987), for each question. Specific or paraphrased quotes were taken from the responses and identified as raw data themes. These were then organised into meaningful categories or 'first order themes', which were further organised into higher order categories, labelled general dimensions which represented common themes of the greatest abstraction.

In summary, following recruitment, participants completed the above self report measures as part of a single questionnaire and returned them by post

2.5 Pilot study

A pilot study was conducted with the help of a local sixth form college to test the face validity and the completion time of the questionnaire. Eight individuals aged 16-19 completed the questionnaire, four of whom had epilepsy and four did not. Participants were asked to give feedback on the questionnaire (see Appendix 9) the majority of whom said it was reasonably easy to complete and understand, took around 30 minutes to complete and would recommend filling in this questionnaire to a friend. Based on feedback, some minor changes were made to the wording of the open questions.

3 Results

3.1 Description of analysis

Parametric statistics were used to analyse the data collected in the study, as the measures used possessed interval properties and visual inspection of histograms showed the majority of the data was normally distributed. The difference of five in sample size between the patient and control groups was judged insufficient to warrant the use of non parametric statistics. In order to verify that parametric statistics were not being used inappropriately, comparisons were made of results from parametric and non parametric tests of between group differences following advice from Bryman & Cramer (1997). No differences were found between results using t tests or Mann Whitney U tests in terms of whether a between group difference was significant or not, therefore the decision was made to proceed with parametric statistics.

Between group analysis involved using independent sample t tests at one tailed significance levels to examine between group differences on coping and adjustment measures. Pearson's Product Moment Correlation Coefficient (Pearson's r) was used to investigate the existence of relationships between coping and measures of adjustment. A two tailed level of significance was chosen as the direction of any relationship was not predicted. A series of multiple regression equations were calculated to identify the relative contribution of each outcome variable to coping performance and were also used to explain self efficacy ratings.

Within group analysis of data from the patient group involved using paired sample t tests using two tailed significance levels to investigate differences in cross situation coping. Pearson's r using a two tailed level of significance was used to explore relationships between coping, adjustment and condition characteristics. Multiple regression was used to identify the contribution of outcome variables and condition characteristics to coping performance.

A brief content analysis was done to analyse the open questions regarding coping and self efficacy for both groups. This is used to make both between and within subject comparisons aswell as to further explore participants' perception of coping and self efficacy.

The results are divided into four sections, the first of which describes sample characteristics. The second section includes between subject comparisons in the areas of self esteem, mood, self efficacy and coping in order to test the major hypotheses stated above. A third section tests hypotheses relevant to within subject comparisons; this relates to cross situation coping and the relative impact of condition characteristics and perception of illness on psychological adjustment and coping. A fourth section describes the analysis of open questions in brief.

3.2 Sample characteristics

Relevant demographic information for both the patient and control group was elicited in response to questions included in both the patient and control questionnaires (see Appendix 7, p. 9). A selection of demographic data is summarised in Table 3.1. In order to gain an idea of participants' socioeconomic class, participants' fathers' occupations were classified according to the Office of Population Censuses and Surveys Standard Occupational Classification System, an extra category of 'unemployed' was added to the classification system (see Appendix 10). Five of the patient group and one control participant failed to provide information regarding their father's occupation. It was decided to use the occupation of the father rather than the participant, as a significant proportion of both groups were in some form of education making the classification of their occupation problematic. Details of both participants' and their fathers' occupations can be found in Appendix 11. It was not possible to use the occupation of the participants' mother as this information was not provided in the majority of cases.

Age at leaving school and number of General Certificates of Secondary Education (GCSEs) obtained at grade C or above were included as an indication of intellectual status and educational achievement. Data was not available regarding school leaving age or number of GCSEs obtained for four of the patient and 7 of the control group which can be explained by the fact that these participants had not yet left school.

Table 3.1: Patient and control group demographic data

	Patient group N36		Control group N31	
Age (years)	Mean	18.5	Mean	18.4
	Range	16-21	Range	16-21
Gender	Female	23	Female	19
	Male	13	Male	12
	Total	36	Total	31
Ethnic origin	White	35	White	30
	Black	1	Black	1
Marital status	Single	29	Single	25
	Married	1	Married	3
	Living with partner	6	Living with partner	3
Age left school	Mean	16.2	Mean	16.3
GCSEs grade C or above	Mean	3.9	Mean	4.6

Using chi-square tests, no significant differences were found between the patient and control groups with regard to gender, ethnic origin or marital status. Similarly, two tailed independent t tests revealed no significant differences between the two groups with regard to age, participant occupation or father's occupation.

3.2.1 Medical information relevant to the patient group

Medical information elicited from the patient group in response to a series of questions in the patient questionnaire (see Appendix 7, p. 10) is represented in Tables 3.2a, 3.2b and 3.2c below. The median age at diagnosis of epilepsy was 14 years (range 1-19 years). Duration of epilepsy was calculated by subtracting age at diagnosis from the current age of each participant giving a median figure of four and a half years duration (range 1-20 years). These figures are included in Table 3.2a.

Participants were asked to give the date of their last seizure and this is represented in Table 3.2a. Number of months since last seizure was calculated by subtracting this date from the month the completed questionnaire was received, calculations were made to the nearest month. The median number of months since last seizure was four (range 0-21 months), however, the modal figure was 0 indicating that the majority of participants experienced seizures on at least a monthly basis. This finding was supported by information gained regarding the frequency of seizures experienced, represented in Table 3.2b. Individuals were asked to categorise the frequency of their seizures according to the options listed in

Table 3.2b. The majority of participants (17) experienced seizures at the rate of greater than one per month with a significant proportion also experiencing less than one seizure per month.

Table 3.2a: Medical information relevant to epilepsy in the patient group *N*36

	Mean	Median	Mode	Range
Age of diagnosis (years)	12	14	16	1-19
Duration of epilepsy (years)	7	4.5	1	1-20
Number of months since last seizure	6	4	0	0-21

Table 3.2b: Frequency of seizures in the patient group in the last year *N*36

Frequency of seizures	Number of patient participants
None in the last year	5
Less than one per month	14
More than one per month	17
Total	36

In order to establish the type of seizure experienced by the patient group, participants were given a list of five different seizures and asked to indicate which they had experienced (see Appendix 7, p. 11). Each seizure was given a label as indicated in Table 3.2c followed by a short description of the characteristics of each. This list was used in research into living with epilepsy at the Department of Neurosciences, Walton Hospital, Liverpool and is used with permission. Nineteen participants reported experiencing one type of seizure only, whilst 17 listed two or more. Grand mal and petit mal seizure were experienced most commonly with 67 per cent and 51 per cent of the patient group respectively, listing these kind of seizure.

Table 3.2c: Frequency of type of seizure experienced by the patient group *N*36

Seizure type	Frequency
Grand mal attack	25
Petit mal attack	19
Attacks with a trance like state	8
Attacks of falling	7
Brief jerks of the arms and body	5
Some other kind of attack	3

Participants were asked to list the anti-epileptic medication they were taking, 29 of whom were prescribed one type of medication. Only one participant was not currently taking any

anti-epileptic medication. A full list of the type of medication taken by each participant is given in Appendix 12.

Key to abbreviations used in results

RSE	Rosenberg Self Esteem Scale
NA	Negative Affect Scale from the Positive and Negative Affect Scale
PA	Positive Affect Scale from the Positive and Negative Affect Scale
SER	Self Efficacy Rating regarding influencing the future
ACS	Adolescent Coping Scale
NP	Use of 'non productive' Coping Style re coping with the future from the ACS
SP	Use of 'solve the problem' Coping Style re coping with the future from the ACS
AIS	Acceptance of Illness Scale
SSS	Seizure Severity Scale

3.3 Overall influence of age and sex on outcome variables

Due to the fact that no significant difference was found regarding demographic variables between the patient and control group, demographic data was not included in the analysis of between group differences. However, the influence of sex and age in the sample as a whole was investigated using two tailed independent t tests. The difference in the outcome variables, use of 'non productive' coping style, use of 'solve the problem' coping style, negative affect, positive affect, self esteem and self efficacy regarding transition was assessed separately for the sample on the grounds of age and sex. The sample divided into 25 male and 42 female participants, significant differences were found for the variables of self esteem and self efficacy. Females had significantly lower self esteem and self efficacy than males and the relevant mean, t and significance values are given in the Table 3.3a below. No significant differences were found regarding the other outcome variables.

Table 3.3a: Differences in outcome variables between male and female participants for the entire sample

Outcome variable	Mean (SD)		t	sig level
	Male (N25)	Female (N42)		
RSE	18.3 (SD 5.00)	21.2 (SD 5.69)	-2.14	0.037 ^a
SER	5.6 (SD 1.78)	4.6 (SD 1.58)	2.31	0.024 ^a

^ap < 0.05; ^bp < 0.01; ^cp < 0.001; ^dp < 0.0001

Regarding age, participants were divided into two groups, aged 16-18 and 19-21 years. A significant difference was found regarding negative affect with the younger group expressing more negative affect than the older group, the relevant mean, t and significance values are given in the Table 3.3b below. No other significant differences were found on the following: use of ‘non productive’ coping style; use of ‘solve the problem’ coping style; positive affect; self esteem and self efficacy regarding transition.

Table 3.3b: Differences in negative affect between older and younger members of the sample N67

Outcome variable	Mean (SD)		t	sig level
	16-18 yrs (N34)	19-21 yrs (N33)		
NA	24.6 (SD 8.83)	19.8 (SD 9.01)	2.17	0.033 ^a

^ap < 0.05; ^bp < 0.01; ^cp < 0.001; ^dp < 0.0001

3.4 Between group analyses

Analyses were conducted using data from measures of self esteem, self efficacy, affect and coping. Summary statistics for scores obtained on these measures are given in the Tables 3.4a to 3.4d below. Scores are given separately for each group, please refer to the key to abbreviations above.

Table 3.4a: Summary statistics for the Rosenberg Self Esteem Scale

	Patient Group N36			Control Group N31		
	Mean	SD	Range	Mean	SD	Range
RSE	20.9	6.43	10-34	19.2	4.33	11-30

The scores of both groups fell below the total possible score of 40, which indicates extremely low self esteem. The scores of all participants were below the mean of 34.7 quoted above, indicating that both groups possessed higher self esteem than the participants in the Rosenberg (1989) study.

Table 3.4b: Summary statistics for the Positive and Negative Affect Scale

	Patient Group N36			Control Group N31		
	Mean	SD	Range	Mean	SD	Range
NA	22.8	9.98	9-49	21.6	8.23	10-38
PA	30.5	8.95	14-46	31.8	4.16	23-41

Scores can range from 10-50 on both NA and PA with higher scores indicating a greater degree of negative and positive affect respectively. Scores in the patient group spanned a wider range than the control group.

Compared to the mean NA scores quoted above, (Watson et al 1988, mean 17.4, SD 6.2), 25 per cent of the patient group and 16.13 per cent of the control group had scores two or more standard deviations above the mean. This result indicates a higher degree of negative affect compared to Watson et al (1988), which is particularly pronounced in the patient group.

Regarding PA, compared to the study quoted above, (Watson et al 1988, mean 33.3 SD 7.2) 30.56 per cent of the patient group scored at or below one standard deviation below the mean, compared to 3.22 per cent of the control group. This result indicates that the patient group expressed less positive affect than both the control group or the participants in Watson et al (1988).

Table 3.4c: Summary statistics for self efficacy rating re. transition

	Patient Group N36			Control Group N31		
	Mean	SD	Range	Mean	SD	Range
SER	4.8	1.88	1-7	5.1	1.50	2-7

A mean self efficacy rating of 4.8 in the patient group indicates that they are moderately confident in their ability to influence their future. This rating falls just over midway between ratings indicating no confidence and extreme confidence. A mean rating of 5.1 in the control group indicates a moderate to strong degree of confidence in ability to influence the future.

Table 3.4d: Summary statistics for the use of coping styles from the ACS

Coping style	Patient Group N36			Control Group N31		
	Mean	SD	Range	Mean	SD	Range
NP	2.6	0.87	1-4	2.2	0.87	1-3
SP	2.9	0.84	1-4	3.3	0.58	2-4

Although it was possible to categorise the coping strategies on the ACS into three coping styles, only ‘non productive’ and ‘solve the problem’ were included in the analysis. This was due to the fact that unlike NP and SP, the third coping style ‘reference to others’ was not the subject of the hypotheses. Also, ‘reference to others’ was found to be used very little by both groups at the level of both coping strategy and coping style.

The mean figures are calculated from scores which range from 1-5, with scores of between 2 and 3 indicating a style is used ‘very little or sometimes’ and scores between 3 and 4 indicating a style is used ‘sometimes or frequently’. It is apparent from Table 3.4d that the patient group exhibit a greater use of ‘non productive’ coping compared to the control group. However, both patient and control groups used ‘solve the problem’ coping style more frequently than ‘non productive’ coping. However, a t test revealed that there was no statistically significant difference between the patient group’s use of ‘non productive’ and ‘solve the problem’ coping style ($t = -1.4$, $p = 0.169$). The control group used ‘solve the problem’ significantly more than ‘non productive’ coping ($t = -7.23$, $p=0.00$).

3.4.1 Tests of statistical difference between groups

Based on the premise that the experience of epilepsy constitutes a significant stressor, the following four constituents of Hypothesis One were stated above, that when compared with controls, the patient group would:

- a) Use more ‘non productive’ and less problem solving coping strategies or styles
- b) Exhibit lower self esteem
- c) Express greater negative and less positive affect
- d) Make lower self efficacy ratings regarding their future

Independent sample t tests were used to test the above. One tailed tests were conducted, using 65 degrees of freedom, the results are reported below.

Hypothesis 'a'

Significant differences were found regarding use of coping style and hypothesis 'a' was confirmed. The patient group used the 'non productive' coping style significantly more than the control group ($t = 2.11$, $p=0.019$). The control group used the 'solve the problem' coping style significantly more than the patient group ($t = -1.91$, $p=0.03$). However, both the patient and the control groups used the 'solve the problem' coping style more than the 'non productive' coping style. Only the control group used the 'solve the problem' coping style significantly more than the 'non productive' coping style.

Differences in coping style were analysed further in order to establish whether the patient group used the 'non productive' coping style more frequently than the 'solve the problem' style relative to the control group. Each participant's use of 'solve the problem' (possible range 1-5) was subtracted from their use of 'non productive' coping (possible range 1-5). A one tailed independent samples t test was conducted on the results. The results confirmed that the patient group were significantly less likely to make a problem solving coping response to a situation than the control group ($t = 2.70$, $p=0.004$). Thus, the control group showed a significantly more problem solving bias than the patient group.

Two tailed independent sample t tests were conducted at the level of coping strategy on each of the 18 strategies of the ACS. Significant differences were found regarding the two following strategies (items 10 and 16):

- The control group used the strategy, '*Join with other people who have the same concern*' significantly more than the patient group ($t = -2.62$, $p=0.011$).
- The patient group used the strategy, '*Ask a professional person for help*' ($t = 2.17$, $p=0.033$) significantly more than the control group.

Hypotheses 'b', 'c' & 'd'

No significant differences between the groups were found regarding self esteem, self efficacy or affect. Thus hypotheses 'b', 'c' and 'd' regarding predicted differences in self esteem, affect and self efficacy were not confirmed.

3.4.2 Relationships between variables in the control and patient groups

Relationships between coping and psychological adjustment were investigated to address Hypothesis Two. Pearsons Product Moment Correlation Coefficient (Pearson's r) was calculated to establish the strength of any relationships between coping and self esteem, self efficacy and affect. Visual inspection of scattergrams revealed that they were homoscedastic (i.e. that the pattern of scatter of data points about the line of best fit is even) for the majority of variables making calculation of correlation coefficients appropriate. However, the presence of two outliers was noted in the scores on the NA scale for the patient group. To ensure that these outliers did not influence the value of r unduly, an analysis of the residuals was done for this variable and removal of the outliers was not found to alter the significance of the correlations found. Therefore, the decision was made to include the two outlying scores in the analysis.

All tests of significance were two tailed due to the difficulty of predicting the direction of the relationship between coping and measures of psychological adjustment. Correlations between coping and psychological adjustment were calculated at both the level of coping strategy and coping style (considering only 'non productive' and 'solve the problem' coping styles). Tests were conducted for the patient and the control groups separately.

3.4.2.1 Relationship between use of coping strategy and psychological adjustment

Pearson's r was used to correlate each of the 18 coping strategies with NA, PA, SER and RSE. This analysis revealed 20 significant relationships in the patient group compared to 11 in the control group. As the vast majority of these relationships were with coping strategies classified as 'non productive', no further analysis of individual items was done, as these results are consistent with the above findings regarding 'non productive' coping style.

It is of note that one coping strategy, 'Don't let others know how I'm feeling' correlated with all four measures of adjustment in the patient group only. The direction of these relationships was the same as is quoted above for the use of 'non productive' coping style.

3.4.2.2 Relationship between use of coping style and psychological adjustment

At the level of coping style, significant relationships were found between the patient group's use of the 'non productive' coping style and all four measures of psychological adjustment. These results are presented in Table 3.5. It can be seen that higher negative affect and lower self esteem correlated positively with increased use of 'non productive' coping. High levels of positive affect and perceived self efficacy correlated negatively with less use of the 'non productive' coping style.

No significant relationships were found between 'solve the problem' coping style and measures of psychological adjustment in either group.

Table 3.5: Significant relationships between use of 'non productive' coping style and adjustment variables found in the patient group *N*36

	NA		PA		RSE		SER	
	<i>r</i>	sig level	<i>r</i>	sig level	<i>r</i>	sig level	<i>r</i>	sig level
NP	0.53	0.001 ^c	-0.37	0.027 ^c	0.48	0.003 ^b	-0.50	0.002 ^b

^a*p* < 0.05; ^b*p* < 0.01; ^c*p* < 0.001; ^d*p* < 0.0001

Relationships between coping style and the other outcome variables were analysed further using multiple linear regression. The relevant literature was drawn upon to determine which outcome variables (independent variables) were most likely to explain the use of coping style (dependent variable). Multiple regression equations were calculated for the entire sample, the patient group and the control group respectively. Demographic variables of age and sex were included in calculations for the entire sample only. They accounted for very little of the variance in the dependent variables concerned and were therefore omitted from the patient and control group calculations in order to preserve the statistical power of the equations.

To calculate the multiple coefficient of determination (r^2), all of the independent variables were entered simultaneously using the enter method. The equation was then repeated, each time omitting a single independent variable in order to calculate the additional amount of variance explained by each variable when the others were held constant, the unadjusted r^2 value was used for this calculation. The results are given in Tables 3.6a-3.6f below. The multiple coefficient of determination is given separately for each dependent variable with the adjusted r^2 value in brackets. The standardised regression coefficient beta is given for each independent variable. The significance value for beta is given under 'beta sig level', which indicates the statistical significance of each individual regression coefficient. The additional amount of variance explained by each variable when the others are held constant is included under ' r^{2+} '.

Table 3.6a: Multiple regression equation to explain the use of 'non productive' coping in relation to the transition to adulthood in the entire sample N67

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.346 (0.293)	-	-	-
NA	-	0.061	0.285	0.020 ^a
SER	-	0.035	-0.239	ns
RSE	-	0.020	0.183	ns
Age	-	0.003	-0.059	ns
Sex	-	0.002	0.049	ns

^a $p < 0.05$; ^b $p < 0.01$; ^c $p < 0.001$; ^d $p < 0.0001$

Table 3.6b: Multiple regression equation to explain the use of 'solve the problem' coping in relation to the transition to adulthood in the entire sample N67

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.124 (0.053)	-	-	-
PA	-	0.055	-0.190	ns
SER	-	0.000	-0.096	ns
RSE	-	0.020	-0.035	ns
Age	-	0.008	0.261	ns
Sex	-	0.000	-0.001	ns

Table 3.6c: Multiple regression equation to explain the use of ‘non productive’ coping in relation to the transition to adulthood in the patient group *N*36

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.386 (0.329)	-	-	-
NA	-	0.088	0.344	0.040 ^a
SER	-	0.040	-0.259	ns
RSE	-	0.107	0.156	ns

^a $p < 0.05$; ^b $p < 0.01$; ^c $p < 0.001$; ^d $p < 0.0001$

Table 3.6d: Multiple regression equation to explain the use of ‘solve the problem’ coping in relation to the transition to adulthood in the patient group *N*36

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.137 (0.056)	-	-	-
PA	-	0.035	0.214	ns
SER	-	0.001	-0.030	ns
RSE	-	0.027	-0.230	ns

Table 3.6e: Multiple regression equation to explain the use of ‘non productive’ coping in relation to the transition to adulthood in the control group *N*31

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.218 (0.131)	-	-	-
NA	-	0.069	0.271	ns
SER	-	0.029	-0.191	ns
RSE	-	0.028	0.190	ns

Table 3.6f: Multiple regression equation to explain the use of ‘solve the problem’ coping in relation to the transition to adulthood in the control group *N*31

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.055 (0.050)	-	-	-
PA	-	0.053	-0.022	ns
SER	-	0.000	0.239	ns
RSE	-	0.000	-0.001	ns

Explanation of use of coping style:

‘Non productive’ coping style

Collectively, SER, RSE, age, sex (age and sex were only included for the entire group) and negative affect explained 34.6 per cent, 38.6 per cent and 21.8 per cent of the variance for the use of ‘non productive’ coping style in the entire, patient and control groups respectively. Relative to the other variables, negative affect explained more of the variance and was the only variable significantly associated with use of ‘non productive’ coping in the entire and the patient group. Higher levels of negative affect were associated with increased use of the ‘non productive’ coping style. However, this did not hold true for the control group where a non significant relationship existed between the dependent and independent variables collectively.

‘Solve the problem’ coping style

Use of the ‘solve the problem’ coping style was not well explained by the chosen variables of RSE, PA or SER in the entire, patient or control group. No significant relationships were found between use of ‘solve the problem’ and the above variables collectively.

3.5 Analysis within the patient group

Summary statistics for those measures completed by the patient group only are given in Tables 3.7a to 3.7e below.

Table 3.7a: Self Efficacy Rating: Perceived influence over epilepsy in the patient group
N36

	Mean	SD	Range
SER	4.2	1.96	1-7

A mean self efficacy rating of 4.2 falls almost exactly in-between the two extremes of the rating scale (not at all confident to extremely confident). This rating indicates that the patient group are moderately confident that they can influence the effect that epilepsy has on their life.

Table 3.7b: Patient scores on the Acceptance of Illness Scale *N*36

	Mean	SD	Range
AIS	26.6	8.37	11-40

Scores can range from 8-40 with higher scores indicating higher acceptance of illness. The mean score of 26.6 in the patient group is similar to that of 28.1 in a sample of individuals with chronic illness mentioned above (Felton et al 1984) and indicates only a slightly lower acceptance of illness. The wide range of the sample indicates the variation in the level of acceptance of epilepsy in the patient group.

The results presented in Tables 3.7c and 3.7d represent 32 of the 36 patient participants, 4 individuals had not experienced a seizure within the last twelve months and were therefore not required to complete the SSS.

Table 3.7c: Unadjusted patient scores on the Seizure Severity Scale *N*32

SSS	Mean	SD	Range
Percept scale	23.6	4.00	16-30
Ictal scale	26.8	7.79	11-40

As outlined above, participants' scores on the SSS were adjusted pro rating so that a comparison with means for the 16 item scale could be made. These results are presented in Table 3.7d below.

Table 3.7d: Patient scores on the Seizure Severity Scale adjusted pro rating *N*32

SSS	Mean	SD	Range
Percept scale	18.8	3.20	16-30
Ictal scale	21.5	6.23	11-40

Scores can range from 8-32 for the Percept Scale and 10-48 for the Ictal Scale, higher scores indicate less perception of control over seizures and greater severity of seizures respectively. When compared to overall mean scores for all types of seizure quoted above, (Percept subscale mean = 17.4, Ictal subscale mean = 15.7) the patient group perceived a similar degree of control over their seizures but appear to experience seizures of greater severity. The range of results represented in Tables 3.7c and 3.7d indicates a wide variation

in both perception of control over seizures and degree of severity of seizure experienced. The range is particularly large with regard to seizure severity.

Table 3.7e: Patient use of coping style when coping with epilepsy *N*36

Coping style	Mean	SD	Range
NP	2.4	0.90	1-4
SP	2.9	0.83	1-4

Only ‘non productive’ and ‘solve the problem’ were included in the analysis. Use of each coping style ranged from ‘Not used at all’ (categorised as 1) to ‘Used frequently’ (categorised as 4), the highest rating of ‘Used a great deal’ (categorised as 5) was not used. Figures in Table 3.7d indicate that each coping style is used ‘Very little or sometimes’ on average, with ‘solve the problem’ being used slightly more than the ‘non productive’ Coping Style.

3.5.1 Tests of statistical difference in coping across situations

Using coping process theory, it was hypothesised above (Hypothesis Three) that the patient group would cope differently in response to the transition to adulthood compared to epilepsy. Within group comparisons of use of coping strategy and style were conducted using two tailed, paired sample t tests at 35 degrees of freedom at the $p < 0.05$ level.

Cross situation use of coping style

No significant difference was found in the extent to which the patient group used either ‘non productive’ or ‘solve the problem’ coping styles across the two situations.

Cross situation use of coping strategy

Significant differences were found in the extent to which the patient group used 3 out of the 18 coping strategies on the ACS. Each of these strategies were used more frequently in response to coping with the future than with epilepsy. Each coping strategy is listed in Table 3.8 below, together with t and significance values.

Table 3.8: Significant differences in use of coping strategy across situations in the patient group *N*36

Item No	Strategy	t	Sig level
3	Work hard	-2.82	0.008 ^b
6	Improve my relationship with others	2.13	0.040 ^a
16	Ask a professional person for help	2.06	0.047 ^a

^a*p* < 0.05; ^b*p* < 0.01; ^c*p* < 0.001; ^d*p* < 0.0001

Cross situation ratings of self efficacy

It was hypothesised (Hypothesis three) that the patient group would make higher self efficacy ratings in response to coping with the future as opposed to coping with epilepsy. This was tested using a one tailed paired sample t using 35 degrees of freedom at the *p*<0.05 level. This hypothesis was confirmed, participants indicated that they were more confident in their ability to influence their future than to influence the effect that epilepsy had on their life (*t* = 2.31, *p*=0.013).

3.5.2 The influence of condition characteristics and the perception of illness

It was hypothesised above that the individual's perception of their experience of epilepsy would have more of an effect on outcome variables than characteristics of the illness. Multiple regression equations were calculated to determine the relative contribution of condition characteristics and perception of illness to the outcome variables. Due to the sample size, the number of variables entered in the equation had to be very limited. Perception of illness was represented by the independent variables of the acceptance of illness and perception of control over seizures as measured by the Acceptance of Illness Scale and the Percept Subscale from the Seizure Severity Scale. Condition characteristics were represented by the independent variables of duration of illness since diagnosis and seizure severity, as measured by the Ictal/Post Ictal scale of the Seizure Severity Scale. Use of variables from the Seizure Severity Scale meant that data from the four individuals who did not complete this measure were excluded for all of the multiple regression equations. The results are presented in Tables 3.9a-3.9i below.

Explanation of coping style

Table 3.9a: Multiple regression equation to explain the use of ‘non productive’ coping in relation to transition to adulthood in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.374 (0.281)	-	-	-
AIS	-	0.186	-0.482	0.009 ^b
Percept	-	0.044	0.224	ns
Ictal	-	0.014	0.131	ns
Duration	-	0.002	0.043	ns

^ap < 0.05; ^bp < 0.01; ^cp < 0.001; ^dp < 0.0001

Table 3.9b: Multiple regression equation to explain the use of ‘non productive’ coping in relation to epilepsy in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.514 (0.442)	-	-	-
AIS	-	0.242	-0.551	0.001 ^c
Percept	-	0.000	0.027	ns
Ictal	-	0.063	0.277	ns
Duration	-	0.053	-0.256	ns

^ap < 0.05; ^bp < 0.01; ^cp = 0.001; ^dp < 0.0001

Table 3.9c: Multiple regression equation to explain the use of ‘solve the problem’ coping in relation to epilepsy in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.031 (-0.112)	-	-	-
AIS	-	0.025	0.177	ns
Percept	-	0.003	-0.064	ns
Ictal	-	0.003	0.065	ns
Duration	-	0.001	0.039	ns

Table 3.9d: Multiple regression equation to explain the use of ‘solve the problem’ coping in relation to transition to adulthood in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.073 (0.064)	-	-	-
AIS	-	0.023	0.172	ns
Percept	-	0.001	0.033	ns
Ictal	-	0.007	0.093	ns
Duration	-	0.020	-0.157	ns

Relative to the other independent variables, acceptance of illness explained more of the variance regarding the use of ‘non productive’ coping with both epilepsy and transition accounting for 24.2 per cent and 18.6 per cent of the variance respectively when the other variables were held constant. Greater acceptance of illness was associated with less use of ‘non productive’ coping.

‘Solve the problem’ coping style was not well explained by the independent variables entered. The F ratio indicated a non significant relationship between the dependent and independent variables collectively.

Explanation of affect

Table 3.9e: Multiple regression equation to explain negative affect in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.321 (0.220)	-	-	-
AIS	-	0.203	-0.503	0.009 ^b
Percept	-	0.002	0.043	ns
Ictal	-	0.001	-0.100	ns
Duration	-	0.118	-0.380	0.040 ^a

^ap < 0.05; ^bp < 0.01; ^cp < 0.001; ^dp < 0.0001

Table 3.9f: Multiple regression equation to explain positive affect in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.374 (0.281)	-	-	-
AIS	-	0.291	0.604	0.001 ^c
Percept	-	0.033	-0.194	ns
Ictal	-	0.039	0.217	ns
Duration	-	0.059	0.269	ns

^ap < 0.05; ^bp < 0.01; ^cp = 0.001; ^dp < 0.0001

Again, acceptance of illness explained more of the variance regarding both positive and negative affect. When the other variables were held constant, acceptance of illness explained an additional 20.8 per cent and 14.5 per cent of the variance respectively. Greater acceptance of illness was associated with greater positive affect and less acceptance with more negative affect. However, with regard to negative affect, duration of illness contributed an additional 11.8 per cent to the variance, which also represented a statistically significant relationship with negative affect (beta = -0.380, p<0.04). The relationship was negative, indicating an association between increased negative affect and shorter duration of illness.

Explanation of self efficacy ratings

Table 3.9g: Multiple regression equation to explain self efficacy in relation to epilepsy in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.321 (0.220)	-	-	-
AIS	-	0.099	0.352	ns
Percept	-	0.089	-0.319	ns
Ictal	-	0.009	-0.105	ns
Duration	-	0.016	0.141	ns

Table 3.9h: Multiple regression equation to explain self efficacy in relation to the transition to adulthood in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.373 (0.280)	-	-	-
AIS	-	0.237	0.545	0.004 ^b
Percept	-	0.000	0.002	ns
Ictal	-	0.020	-0.158	ns
Duration	-	0.001	0.042	ns

^ap < 0.05; ^bp < 0.01; ^cp < 0.001; ^dp < 0.0001

Self efficacy with relation to transition to adulthood was best explained by acceptance of illness and contributed an additional 23.7 per cent when the other variables were held constant. Self efficacy with relation to epilepsy was best explained by acceptance of illness and perception of control over illness, which contributed additional 9.9 per cent and 8.9 per cent to the variance respectively. However, the relationship of these variables to self efficacy ratings regarding epilepsy were non significant. Greater acceptance of illness was associated with increased feelings of self efficacy.

Explanation of self esteem

Table 3.9i: Multiple regression equation to explain self esteem in the patient group N32

Independent Variables	Multiple r^2 (Adjusted r^2)	r^{2+}	Beta	Beta Sig level
All variables	0.455 (0.375)	-	-	-
AIS	-	0.331	-0.644	0.000 ^d
Percept	-	0.000	-0.008	ns
Ictal	-	0.011	0.108	ns
Duration	-	0.009	-0.107	ns

^ap < 0.05; ^bp < 0.01; ^cp < 0.001; ^dp < 0.0001

Again, acceptance of illness explained more of the variance regarding self esteem and contributed an additional 33.1 per cent of the variance when the other variables were held constant. Greater acceptance of illness was associated with increased self esteem.

3.6 Analysis of open questions

A brief content analysis of the open questions was conducted which aimed to identify common themes running through the participants' answers. Common themes were identified separately for the patient and the control group regarding coping with making decisions about the future and the degree of influence (or self efficacy) they felt that they had over the future. Further analyses was conducted relevant to the patient group only, regarding coping with epilepsy and the influence (or self efficacy) they felt that they had over epilepsy.

For each content analysis, bar charts are displayed (Fig. 3.1a-3.1f) which present the common themes identified, the percentage of raw data themes accounted for by each theme and the percentage of participants citing each theme. As this method comprises a secondary analysis of coping and self efficacy to those already described above, comments on the data will be limited to major findings only.

3.6.1 A comparison of the patient and control group regarding coping with making decisions about the future

Figure 3.1a: Situation - 'Coping with the future'. Common themes in the patient group
N36

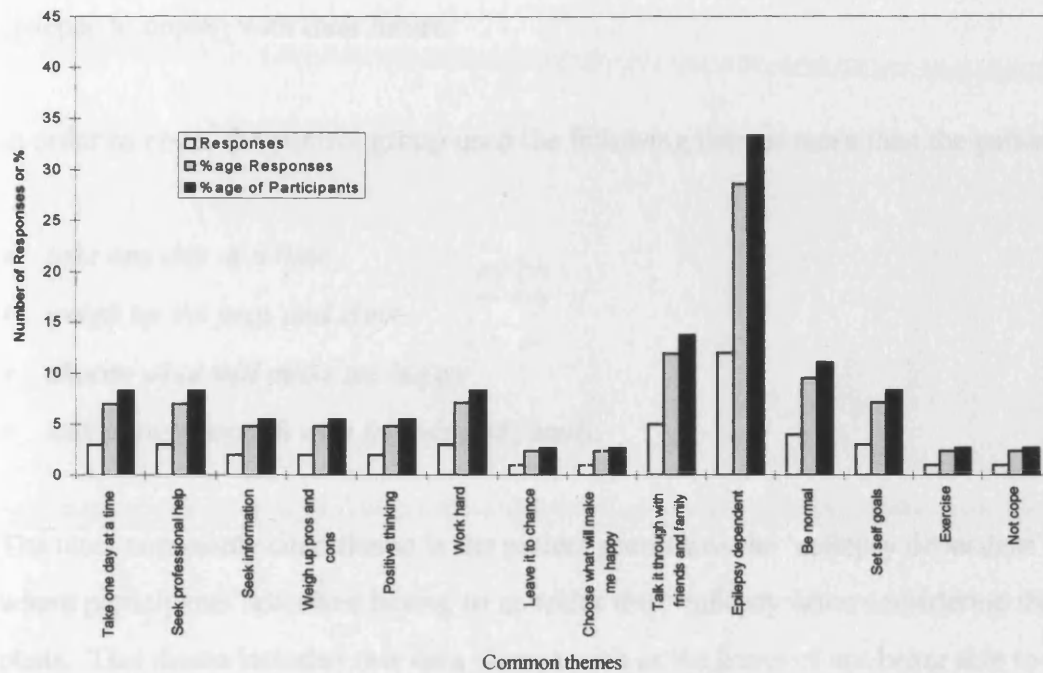
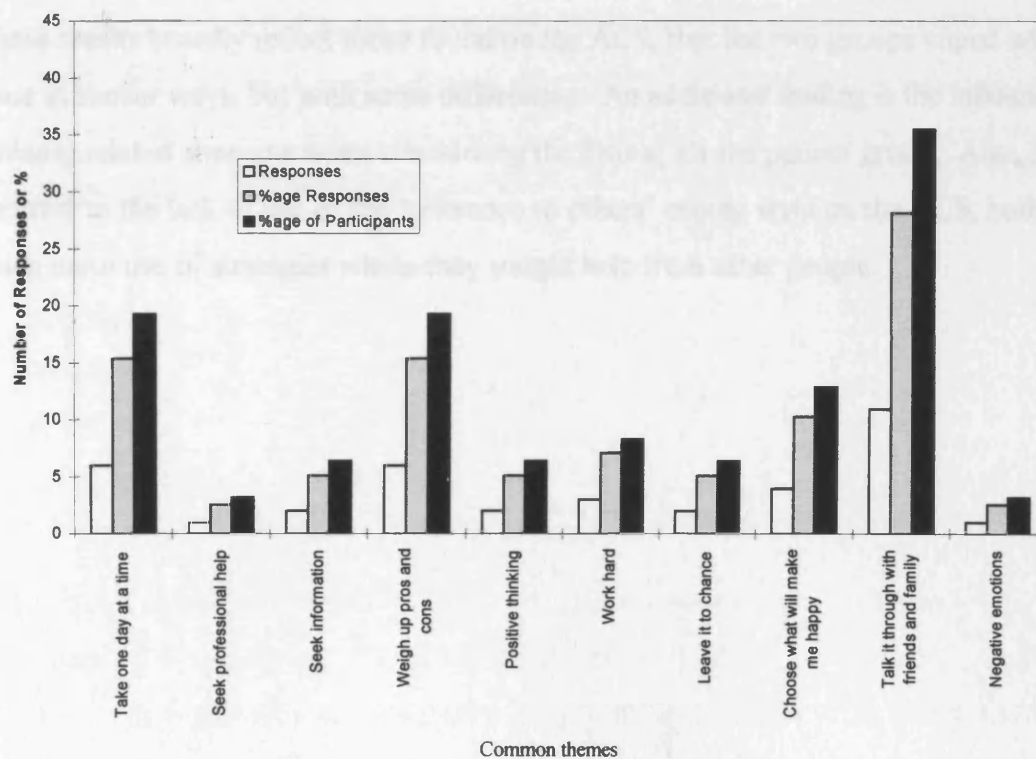


Figure 3.1b: Situation - 'Coping with the future'. Common themes in the control group
N31



It can be seen that many of the same themes emerged regarding coping with the future in both the patient and the control groups. The groups could be distinguished however, regarding the percentage of participants citing some of the themes. Also, a number of additional themes emerged from the patient group, most of which related their experience of epilepsy to coping with their future.

In order to cope, the control group used the following themes more than the patient group:

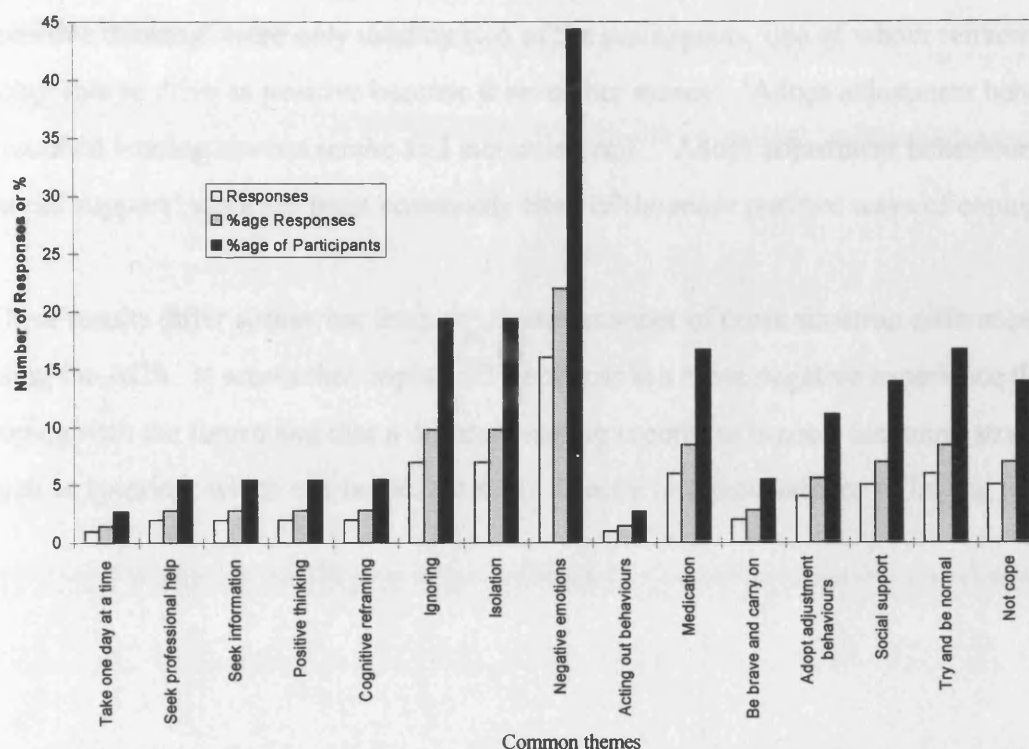
- *take one day at a time*
- *weigh up the pros and cons*
- *choose what will make me happy*
- *talk things through with friends and family.*

The most commonly cited theme in the patient group was the ‘epilepsy dependent’ theme, where participants described having to consider their epilepsy when considering their future plans. This theme included raw data themes such as the limits of not being able to drive, do certain jobs or use certain contraception, as well as issues of whether to disclose epilepsy to prospective employers or romantic partners.

These results broadly reflect those found on the ACS, that the two groups coped with this issue in similar ways, but with some differences. An additional finding is the influence of epilepsy related concerns when considering the future, for the patient group. Also, in contrast to the lack of use of the ‘reference to others’ coping style on the ACS, both groups made more use of strategies where they sought help from other people.

3.6.2 A comparison of coping with the future and coping with epilepsy in the patient group

Figure 3.1c: Situation - 'Coping with epilepsy'. Common themes in the patient group *N*36



A comparison of Fig. 3.1a. and Fig. 3.1c reveals that the vast majority of the themes which emerged regarding coping with epilepsy in the patient group were different from those cited regarding coping with the future. The most commonly cited theme was 'negative emotions'. Almost half the patient group expressed negative emotions with regard to their epilepsy, including frustration, anger, depression and fear. Other commonly used themes described reactions to epilepsy such as:

- *ignoring*
- *isolation,*
- *medication*
- *try and be normal*

'Ignoring' included raw data themes describing attempts to deny the existence of epilepsy and refusal to think about it. 'Isolation' described feeling different from the peer group, unable to join in activities, non disclosure of epilepsy and confabulation to disguise seizures. Taking medication was listed commonly as a way of coping with epilepsy. 'Ignoring' and

'isolation' describe negative ways of dealing with epilepsy, more positive ways of coping were less commonly cited. Those that were, include 'social support', 'cognitive reframing', 'positive thinking' and 'adopt adjustment behaviours'. 'Social support' involved friends and family giving emotional support or helping if a seizure occurred. 'Cognitive reframing' and 'positive thinking' were only used by two of the participants, one of whom reframed not being able to drive as positive because it saved her money. 'Adopt adjustment behaviours' described limiting alcohol intake and increasing rest. 'Adopt adjustment behaviours' and 'social support' were the most commonly cited of the more positive ways of coping.

These results differ somewhat from the limited number of cross situation differences found using the ACS. It seems that coping with epilepsy is a more negative experience than coping with the future and that a different coping repertoire is used, including strategies such as ignoring, which can be related more directly to the experience of having epilepsy.

3.6.3 A comparison of the patient and control groups' perceived influence over their future

Figure 3.1d: Common themes relating to self efficacy in the patient group - influence over personal futures N36

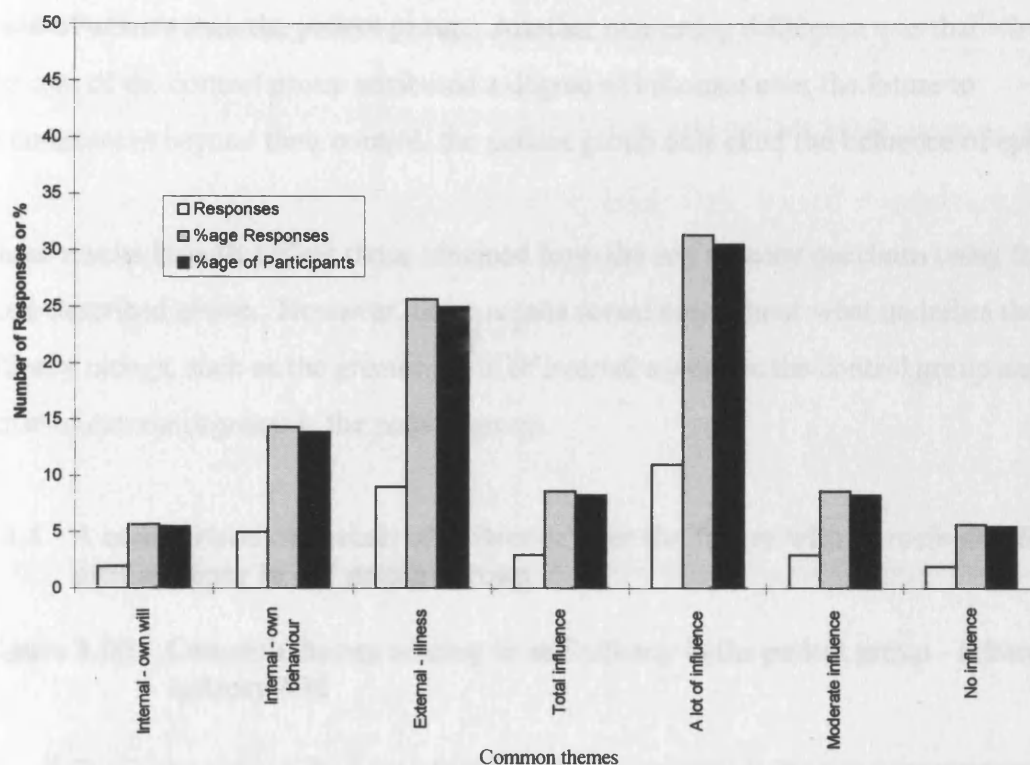
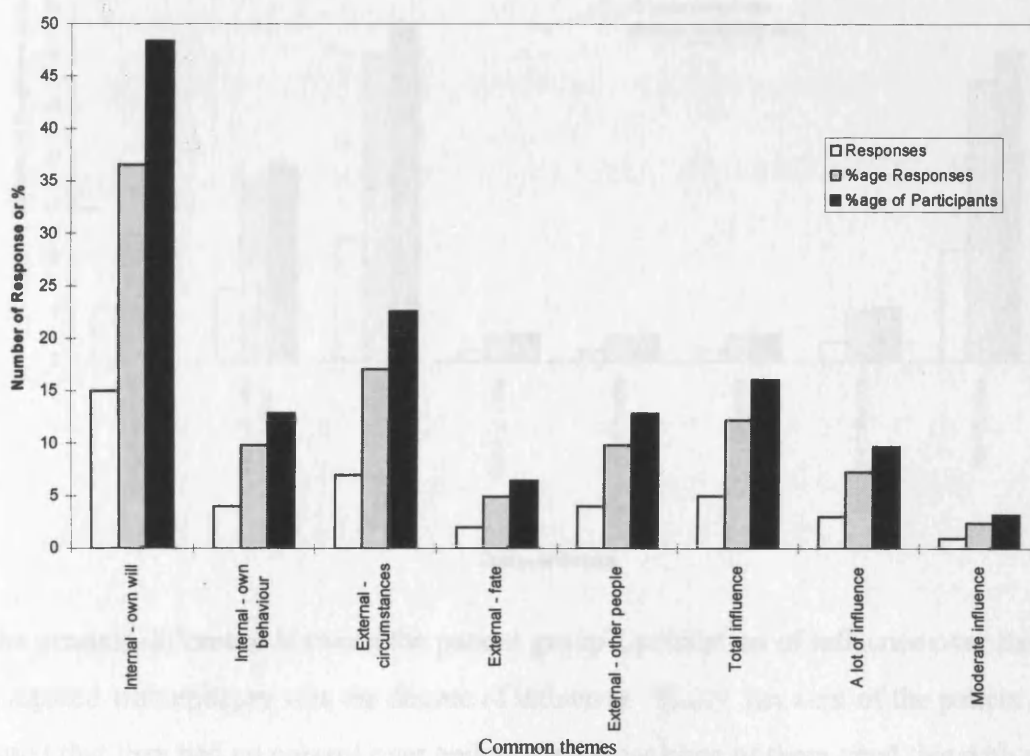


Figure 3.1e: Common themes relating to self efficacy in the control group - influence over personal futures N31

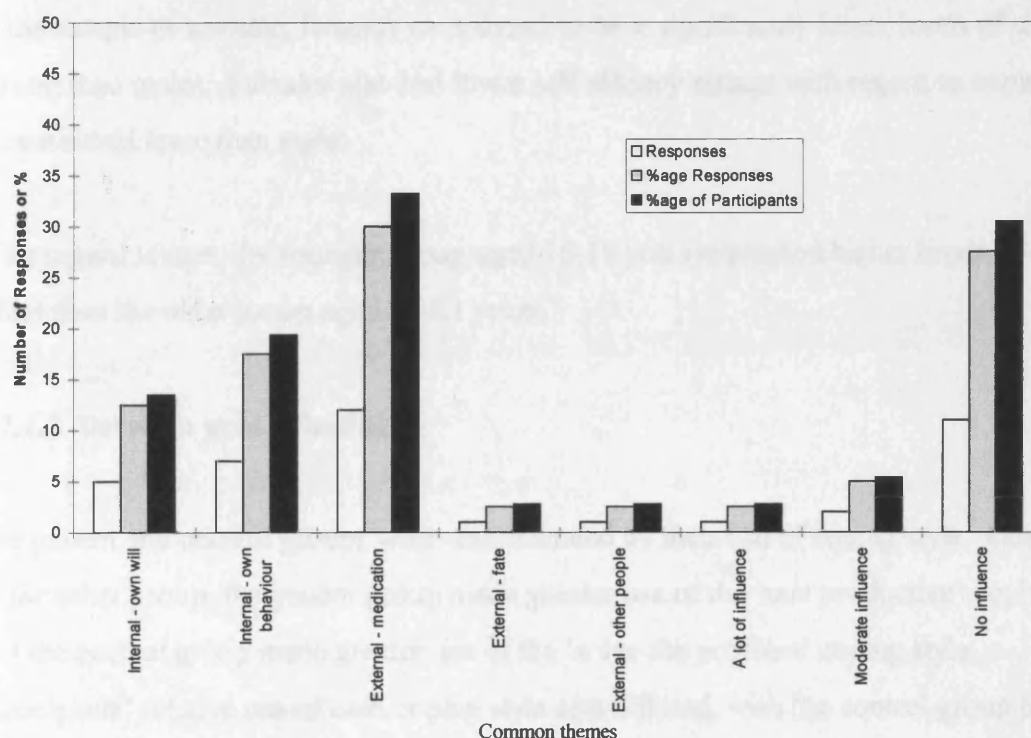


Similar themes emerged from both groups regarding the perceived influence they had over their future. However, once more, the groups were distinguished with regard to how frequently each theme was cited. The most notable difference related to citing the self as the internal agent of control over the future, the control group expressed more personal sense of agency than the patient group. Another interesting difference was that where 22.6 per cent of the control group attributed a degree of influence over the future to circumstances beyond their control, the patient group only cited the influence of epilepsy.

These results broadly reflect those obtained from the self efficacy questions using the Likert scale described above. However, these results reveal more about what underlies the self efficacy ratings, such as the greater sense of internal agency in the control group and the sense of external agency in the patient group.

3.6.4 A comparison of perceived influence over the future with perceived influence over epilepsy in the patient group

Figure 3.1f: Common themes relating to self efficacy in the patient group - influence over epilepsy N36



The greatest difference between the patient group's perception of influence over the future compared with epilepsy was the degree of influence. Thirty per cent of the patient group stated that they had no control over epilepsy, whereas none of them cited this with regard to

their future. Thirty per cent of participants stated that they had a lot of influence over their future, compared to 2.7 per cent with regard to epilepsy. This reflects the results of the self efficacy questions using a Likert scale reported above.

The patient group attributed more influence to external factors for both epilepsy and the future. The most commonly cited raw data theme regarding epilepsy was the attribution of control to medication. A similar amount of influence was attributed to the behaviour of the participant in both situations. Actions such as working hard were cited as influencing one's future, whereas avoiding alcohol, getting enough rest and monitoring one's body were cited as influencing epilepsy.

3.7 Summary of results

3.7.1 Summary of results of statistical tests

3.7.1.1 Demographic influence in the sample as a whole

In the sample as a whole, females were found to have significantly lower levels of self esteem than males. Females also had lower self efficacy ratings with regard to coping with a transitional issue than males.

With regard to age, the younger group aged 16-18 years expressed higher levels of negative affect than the older group aged 19-21 years.

3.7.1.2 Between group findings

The patient and control groups were discriminated by their use of coping style. Compared to the other group, the patient group made greater use of the 'non productive' coping style and the control group made greater use of the 'solve the problem' coping style.

Participants' relative use of each coping style also differed, with the control group being more likely to choose a problem solving approach than the patient group. Thus, the control group displayed a more problem solving bias than the patient group. The reference to others coping style was used very little by either group.

The groups were also distinguished by their use of the following 2 out of 18 coping strategies.

- *Join with people who have the same concern* - used more by the control group
- *Ask a professional person for help* - used more by the patient group

No statistical difference was found between the two groups in the following areas: self esteem; self efficacy with regard to ability to influence one's future; negative affect and positive affect.

There was more evidence of relationships between coping and the other outcome variables in the patient than the control group. Variables were most commonly associated with 'non productive' coping in the patient group. The coping strategy, 'Don't let others know how I'm feeling' correlated with all of the measures (self esteem, self efficacy, negative affect and positive affect) in the patient group.

Higher levels of negative affect best explained the increased use of 'non productive' coping strategies in the sample as a whole, as well as in the patient group, but this did not hold true for the control group. Use of the 'solve the problem' coping style was not well explained by any of the variables chosen.

Increased ratings of self efficacy were best explained by higher levels of self esteem in the sample as a whole, the patient and the control group. This association was strongest in the patient group.

3.7.1.3 Findings within the patient group

Within the patient group, no significant differences were found regarding use of either 'non productive' or 'solve the problem' coping styles in relation to coping with a transitional issue or coping with epilepsy. However, the patient group used the following three coping strategies significantly more in relation to coping with their future compared to coping with epilepsy:

- *Work hard*
- *Improve my relationship with others*
- *Ask a professional person for help*

Significant differences in self efficacy ratings showed that the patient group were more confident in their ability to influence their future than their epilepsy.

Within the patient group, the perception of epilepsy as measured by acceptance of illness explained the results of the outcome measures better than condition characteristics.

Decreased use of 'non productive' coping was best explained by increased acceptance of illness, in relation to both coping with epilepsy and with a transitional issue. The analysis failed to identify a variable which best explained use of 'solve the problem' coping style.

With regard to affect, increased positive affect was best explained by increased acceptance of illness, whilst increased negative affect was best explained by less acceptance of illness. However, increased negative affect was also predicted by a shorter duration of illness.

Increased acceptance of illness best explained ratings of self efficacy in relation to both epilepsy and a transitional issue.

Higher levels of self esteem were also best predicted by increased acceptance of illness.

3.7.2 Summary of content analysis findings

Both the patient and control group cited using similar ways of coping with their future, but to different degrees. The coping response of the patient group regarding their future was influenced by issues related to epilepsy.

The patient group used a broadly different coping repertoire when coping with epilepsy in contrast to coping with making decisions regarding their future. Coping responses were centred around reacting to epilepsy in a more negative than positive way.

Regarding feelings of self efficacy or influence over the future, the control group made more internal attributions of control and the patient group made more external attributions, mostly to their illness.

4 Discussion

4.1 Introduction

The results of the present study will be interpreted within the context of the hypotheses posed and relevant theoretical and research implications will be discussed. The clinical implications and limitations of the study will then be considered.

4.2 The effect of epilepsy on psychological adjustment (Hypothesis 1)

Based on the premise that the experience of epilepsy constitutes a significant stressor, it was hypothesised that psychological adjustment would be detrimentally affected in the patient group. Specifically, it was expected that the patient group would exhibit lower self esteem, higher negative affect, lower positive affect and lower self efficacy (with regard to their future) than the control group. No statistically significant differences were found between the control and the patient group on these measures. Limited evidence of differences between the two groups emerged from the distribution of scores on the Positive and Negative Affect Scale. The range of scores in the patient group was notably wider for both positive and negative affect, indicating more of a tendency to the extremities of mood. Most notably, more of the patient group had scores indicating significantly higher negative affect and lower positive affect than in the control group. Although these findings do not represent a statistical difference, they do seem to indicate a trend towards less positive and more negative affect in the patient group.

Apart from the trends described in relation to mood, it would appear that having epilepsy did not have a detrimental effect on the global psychological adjustment of older adolescents in the present study. This finding is contrary to the argument that chronic illness, in this case epilepsy, has adverse psychological effects. This raises the controversial debate described above (Cassileth 1984, Wolman 1994) over whether in fact chronic illness is actually a stressful, psychologically damaging experience.

The notion that the experience of chronic illness has no potentially damaging effect on the psychological adjustment of the individual is one of several explanation of these findings. It is possible that psychosocial factors not measured in the present study were in operation and

acted as buffers to protect the individual from the potentially damaging effects of epilepsy. For example, Wolman et al (1994) found that family connectedness predicted emotional well being. Other factors such as social support may have acted similarly as a buffer to promote the 'psychosocial integrity' and reduce 'psychosocial vulnerability' (Westbrook et al 1991) of the adolescents in the present study. It is conceivable that the experience of epilepsy did constitute a psychological challenge and actually stimulated personal growth and development in the young person. Such development may have been more possible in a supportive environment at home and school.

It may be possible to explain these mostly negative results in terms of illness intrusiveness, Cassileth (1984) found that reported levels of well being and stress were higher when individuals were at the end stage of a disease. It may be that levels of illness intrusiveness were low for those individuals in the present study whose epilepsy was well controlled and was not limiting their activities. Thus, their 'epilepsy schema' (Stebbins 1970) was not activated and they suffered little from the experience of epilepsy. It is possible that in the future, illness intrusiveness will activate the epilepsy schema and this group will experience more pronounced psychological effects of epilepsy. It may have been more revealing to investigate differences regarding psychological adjustment within the patient group by comparing participants on the grounds of condition characteristics such as seizure type which affect illness intrusiveness.

A significant number of the patient group were diagnosed during their teenage years, which could have limited the influence of epilepsy on aspects of their psychological development. For example, individuals may have already developed a strong sense of their own identity and established their independence from their parents prior to diagnosis. These psychological developments may have proved robust to the challenge of chronic illness later in life. It may have been useful to compare the psychological adjustment of individuals who effectively 'grew up' with epilepsy with those diagnosed later in life.

Another explanation for these mainly negative results is that the issues of adolescence were the most salient issues for both the control and the patient group. It is possible that the effects of being an adolescent were more powerful than the effects of epilepsy at this stage of the patient participants' lives and that adolescence was the most powerful factor in

explaining the results. It is not possible to determine the accuracy of this explanation without conducting a similar study with people with epilepsy of different age groups.

4.3 The effect of epilepsy on coping with normative stress at the time of transition to adulthood (Hypothesis 2)

It was hypothesised that adolescents with epilepsy would cope less well with the transition to adulthood than their healthy peers and that this would be demonstrated in the greater use of non productive as opposed to problem solving strategies. Support was found for this hypothesis regarding the use of coping style. On the whole, the control group used problem solving strategies more than the patient group and the patient group used non productive coping strategies more than the control group. The control group exhibited a significantly greater bias towards using problem solving, rather than non productive coping strategies compared to the patient group. Within the control group, problem solving strategies were used significantly more than non productive coping strategies. Within the patient group there was no significant difference in the use of coping style. A reasonable interpretation of these findings is that the control group exhibited a more problem solving bias than the patient group and that compared to the control group the patient group made use of more non productive coping strategies. Little difference was observed between the two groups' use of individual coping strategies, only 2 out of 18 strategies were used significantly differently by each group. Findings at the level of coping strategy may be less reliable than those at the level of coping style and may be prone to Type I errors, as some significant differences could be the result of using a relatively large number of strategies. It may therefore be better to focus on the findings at the level of coping style.

An explanation of a reduced problem solving bias in the patient group could be that their past attempts to cope with epilepsy by active problem solving failed because it is an illness which is mostly out of the person's control. As a result of this experience, the patient group learnt not to use a problem solving approach but to respond in a more emotional, less productive way by using strategies such as worrying or acting out behaviours. This tendency to use less problem solving strategies may have generalised to coping with stressful situations other than epilepsy, or the influence of epilepsy may have pervaded the issue of transition to adulthood, resulting in a similar response.

The content analysis revealed that the patient and control groups used broadly similar ways of coping. The main difference between the groups was the inclusion of epilepsy dependent approaches to coping by the patient group. Also, the control group made more use of four of the common themes of coping than the patient group. These results indicate that the impact of epilepsy complicates the task of coping with normative stress, such as making the transition to adulthood. It also appears that the patient group were making less use of some positive coping strategies, such as 'weigh up the pros and cons' of a decision.

Earlier studies of coping in older adolescents with chronic illness cited above (Hanson 1989, Olson 1993 and Woodgate 1993) found an overall trend towards the use of non productive strategies such as tension releasing or avoidance in both healthy and chronically ill groups. The current findings are inconsistent with these results, as the healthy group tended to use problem solving strategies and there was no difference in the use of non productive or problem solving strategies in the group with epilepsy. The reason for this inconsistency may be that it is not possible to make comparisons between these and the present study. None of the above studies included adolescents with epilepsy and measured coping in response to different sources of stress compared to the present study. The current findings support Gortmaker et al's (1993) conclusion that most adolescents with chronic illness cope reasonably well with the transition to adulthood but are somewhat vulnerable to problems in early adult life.

Theoretical divisions have been drawn between different dimensions of coping, as described above. The distinction between problem and emotion focused coping is the most applicable to the results of the present study. 'Solve the problem' coping style is taken to represent problem focused coping and 'non productive' coping to represent emotion focused coping. Thus, according to the process theory, the control group exhibit more efforts to alter the relationship between the environment represented by the challenge of making the transition to adulthood than the patient group who respond in a more emotional way. Whether the difference between 'non productive' and 'solve the problem' coping styles represents a true conceptual difference with regard to dimensions of coping is a matter of debate. Further research needs to be done to validate the construct validity of the different coping styles on the Adolescent Coping Scale.

The relative adaptive qualities of 'solve the problem' and 'non productive' coping styles is also a matter for debate. Folkman and Lazarus (1980) found that whether different dimensions of coping were more or less adaptive was dependent on the situation encountered. Folkman and Lazarus (1980) observed that if a situation had the potential to be resolved by constructive action, then a problem solving approach was most adaptive. In contrast, they found that if the situation could not be altered, an emotion focused approach of reappraising and accepting the situation was more adaptive. In the context of the present study, it is reasonable to argue that a problem solving approach is the most adaptive way of coping with making decisions about the future, as individuals can take a variety of action such as seek career information, talk to peers and relatives and consider a wide range of alternatives. Therefore, it can be said that the control group are coping in a more adaptive way with the challenge of the transition to adulthood than the patient group.

Although statistically significant, the differences in use of coping style between the patient and control groups represent a relatively minor difference between whether a style is used 'very little or sometimes' or 'sometimes or frequently'. In general, participants did not indicate very frequent use of the coping strategies on the ACS. This has two implications, the first being that the difference in use of coping style between the two groups is not dramatic but represents a definite trend towards a more problem solving bias in the control group. The limited use of coping strategies in general may be due to the fact that participants make little effort to respond to stressful situations, that the situation was not stressful enough to warrant a coping response or that the ACS did not provide an adequate repertoire of strategies to which the young people could relate. It would be interesting to repeat the present study and using the longer, 80 item version of the ACS to give the participants more strategies to choose from and see whether the results differ. This finding highlights the usefulness of the open questions which placed less restriction on the response of the individual.

4.4 The relationship between coping and psychological adjustment (Hypothesis 2)

The expected difference in coping response predicted by hypothesis 2 was based on the assumption that ability to cope is related to psychological adjustment. Convincing evidence was found for this assumption in the patient group with regard to non productive coping. Bivariate correlations revealed significant relationships between the 'non productive' coping

style and all four measures of psychological adjustment (self esteem, positive affect, negative affect and self efficacy). Also, almost twice as many significant correlations existed between non productive coping strategies and measures of psychological adjustment in the patient group compared to the control group. It is acknowledged that the relatively large number of bivariate correlations undertaken may increase the likelihood of a Type I error, however, these results can be interpreted as representing the general trend of a relationship between psychological adjustment and non productive coping in the patient group.

Further evidence for the relationship between non productive coping and psychological adjustment in the patient group emerged from the results of multiple regression equations. Collectively, the four adjustment measures were significantly associated with the use of non productive coping in the patient group, with negative affect being the strongest explanatory factor for the use of non productive coping. By contrast, no evidence was found to explain the use of non productive coping in the control group in terms of the psychological adjustment.

The above findings indicate that in the older adolescent with epilepsy, psychological adjustment interacts with the challenge of a stressful situation to exert a negative influence on coping response. This interpretation is consistent with the process theory of coping, it exemplifies the 'transaction' between the specific characteristics of a situation with the characteristics of the individual which influences the individual's coping response. Despite the lack of between group differences regarding psychological adjustment in isolation, it appears that factors such as self esteem, self efficacy and affect distinguish the two groups when they are faced with a challenge. The fact that the negative dimensions of psychological adjustment explained the increased use of non productive coping adds weight to the argument that this is a non adaptive coping style.

The reason for the distinguishing interaction between psychological adjustment and coping in the patient group is an interesting topic for discussion. It is possible that people with epilepsy need to be more robust psychologically than their peers to cope with normative stress such as the transition to adulthood in addition to the difficulties they experience as a result of epilepsy. This could result in the increased sensitivity of their coping response to relatively small reductions in factors of psychological adjustment. The healthy peers may

have had other resources upon which to draw, which were not measured in the present study and exerted a more positive effect on their coping response. For example, the control group may have made use of additional self related resources such as a stronger sense of identity, an aspect of psychological adjustment which may be particularly vulnerable in adolescents with epilepsy.

Closer investigation of the precise nature of the interaction between person and situation characteristics in young people with epilepsy would seem to be an important area for future research. It would be useful to make explicit, exactly which aspects of the situation of coping with the future pose a challenge to the patient rather than the control group. The relationship of these aspects to the personal characteristics of the individual could then be investigated with regression analysis.

The above findings are consistent with the evidence that self esteem, mood and self efficacy are indeed correlates of coping. Levels of these factors which indicate that individuals are well adjusted psychologically are associated with more adaptive ways of coping, as the literature suggests (Seiffge-Krenke 1990, Bandura 1982, Miller 1984). The analysis in the current study was organised in such a way as to reveal the effects of self esteem, affect and self efficacy on coping, which it did successfully in the patient group. However, evidence of relationships cannot reveal the direction of the association between coping and the above factors. Further analysis may have shown that use of coping style was equally influential in explaining levels of psychological adjustment. For this aspect of coping theory to be clarified, future research needs to establish whether coping behaviour determines psychological adjustment or vice versa, or, what is more probable, that the relationship is bi-directional.

4.5 Cross situational consistency in coping response (Hypothesis 3)

Using the process theory of coping according to Lazarus (1966, 1974, 1993) and Lazarus and Folkman (1984), it was hypothesised that the patient group would cope differently across the situations of transition to adulthood and epilepsy. Based on evidence from authors such as Upton and Thompson (1992), use of more non productive coping such as wish fulfilment was expected with regard to epilepsy. Limited evidence was found for this prediction. No evidence was found to support the prediction that individuals would cope

differently across situations at the level of coping style, i.e. there was no difference in the degree to which the patient group tended to use a non productive or problem solving approach. A limited amount of evidence was found to support this prediction at the level of coping strategy.

The patient group used 3 out of 18 coping strategies less often in response to coping with epilepsy compared with coping with the transition to adulthood. Participants with epilepsy used the coping strategies, 'work hard', 'improve my relationship with others' and 'ask a professional person for help' less in response to epilepsy compared to transition to adulthood. For at least 2 out of the 3 strategies, this difference in use of coping strategy can be attributed to the different challenges presented by the two situations. It is hard to imagine how working hard with regard to epilepsy could be considered a constructive coping response, whereas working hard in relation to achieving career goals for example, would be understandable. Participants may have sought to improve their social relationships less in response to epilepsy because they believe it is a stigmatising condition and do not want to disclose it to their peers. Also, perhaps participants felt that their acquaintances would not be able to relate to, or help them with their difficulties with epilepsy, in contrast to transitional issues which are experienced universally. This interpretation is consistent with the theory that choice of coping strategy is determined by the transactional process of an individual response to the specific demands of a situation.

The importance of the findings at the level of coping strategy cannot be overemphasised, due to the small proportion of the total number of coping strategies in which significant differences were found and the lack of evidence at the level of coping style, which could have given a more reliable indicator of cross situation difference.

The observed preference to use professional advice with regard to making decisions regarding the future rather than with regard to epilepsy is surprising. It would be reasonable to expect individuals with epilepsy to seek advice from medical and related professions to at least the same degree as they seek professional advice regarding transitional issues. This finding could be explained by the fact that the participants were offered more help with transitional issues by professionals such as teachers and career advisors than by the medical profession. Alternatively, participants may have found medical advice unhelpful or may feel that nothing can be done to improve the situation of their

illness and seek less help as a result. This interpretation is also consistent with the theory that different situations elicit different coping responses, in this case, the degree to which participants seek professional help.

Lazarus et al's (1986) interpretation of the results from a study of cross situational coping could be used to accommodate the lack of difference found between coping across situations in the present study. Lazarus et al (1986) interpreted their results as indicating that some strategies were used across situations more consistently than others. Most notably, use of social support was found to vary across situations, a finding which is replicated in the present study in the varying use of improving social relationships as a coping strategy. However, it would seem an unsatisfactory explanation that 15 out of 18 coping strategies are simply used more consistently than the other 3. The power of the process theory in predicting coping response is lessened by the incorporation of concepts such as the consistent use of coping strategy which are better explained by the style theory.

The lack of difference in the broader measure of coping style or in the majority of individual coping strategies could be interpreted as evidence for the theory that coping response is governed by a personality trait of the individual, as hypothesised by authors such as Miller (1987). Therefore, it would be expected that the individual tendencies of the participants would cause them to react similarly to coping with the future and coping with epilepsy. According to this theory, significant individual differences in coping response would have been expected within the patient group, regardless of situation. Differences in coping response could be expected to correlate with different personality types, such as Miller's (1987) 'monitors' and 'blunters'. In order to investigate this theory further, variations in coping response within the patient group could be studied more closely and classification of personality traits could be made, with the expectation that these factors would be related. In summary, evidence regarding whether coping is consistent across situations is inconclusive from the present study and warrants further investigation.

It should be noted that the content analysis provided more evidence to indicate that participants coped differently across the two situations than was found using the ACS. This was demonstrated in the very different repertoire of coping strategies which emerged. Coping with epilepsy appeared to be a more negative experience than coping with transitional issues and elicited coping reactions such as ignoring the illness and hiding it

away from others. Several of the coping responses were similar to those demonstrated by the unadjusted and adjusted typologies of individuals with epilepsy as classified by Schneider and Conrad (1981). Like the 'pragmatic' group, some participants in the present study tried to minimise the effect epilepsy had on their life by 'cognitive reframing' and 'positive thinking' and adopted the same kind of 'healthy habits' such as being compliant with medication and limiting alcohol intake. In the same way as the 'secret' group, some participants did not disclose their illness and attempted to fit in with their peers, seen in the themes of 'isolation' and 'try and be normal'. As with the 'debilitated' group, a number of participants seemed similarly overwhelmed by epilepsy by their use of 'not cope' with the illness. Unlike Schneider and Conrad (1981), it is not possible to state whether the users of these ways of coping were 'adjusted' or 'unadjusted' individuals psychologically, although the common theme of 'negative affect' implies that a number were not. Results from the standardised measures of psychological adjustment were not correlated with the results from the content analysis as it did not form the main coping measure and a decision was made not to mix qualitative and quantitative methodologies. In order to establish the adaptive nature of the emergent coping themes, it may be necessary to investigate the psychological adjustment of participants using a similarly qualitative methodology and establish which coping themes relate to better psychological adjustment.

4.5.1 Perception of greater self efficacy regarding transitional issues versus epilepsy within the patient group (Hypothesis 3)

A secondary part of hypothesis three was that the patient group would make higher self efficacy ratings with regard to coping with transition to adulthood, compared to coping with epilepsy. This hypothesis was confirmed by the use of both a Likert scale and the content analysis of an open question. Analysis of results using the Likert scale revealed a statistical difference in the degree of confidence participants had in their ability to influence their future or the effect of epilepsy. Analysis of the open questions revealed that similar patterns of external locus of control regarding perceived influence existed across situations. However, as with the Likert scale, the open question reflected a marked difference in the degree of influence felt, 'a lot of influence' was a common theme with regard to the future, whereas this was almost absent with regard to epilepsy and 'no influence' was the second most common theme. Using Bandura's (1977,1982) model of self efficacy, these results can be interpreted as indicating that the patient group had less of a sense of personal control or belief in their ability to achieve a desired outcome with regard to epilepsy, compared to

making the transition to adulthood. It is interesting to note the much reduced self efficacy ratings with regard to epilepsy, despite increased attributions of control to the influence of their own will and actions. This may indicate that the impact of epilepsy is overwhelming and attempts to deal with it are perceived as pointless.

Some evidence of a link was found between low self efficacy and non productive coping with regard to transitional issues. This finding goes some way to validating the link between self efficacy and coping proposed by Bandura (1982) and Tedman, Thornton and Baker (1995). Further analysis of the relationships between self efficacy and both negative affect and non productive coping is warranted.

4.6 The primacy of the psychological impact of epilepsy (Hypothesis 4)

The hypothesis that the individual's perception of epilepsy would affect outcome measures of coping and psychological adjustment more so than the actual condition characteristics of the illness was confirmed. Acceptance of illness explained the results of the majority of outcome measures significantly better than the condition characteristics of illness duration or seizure severity. Acceptance of illness correlated positively with successful outcomes and negatively with unsuccessful outcomes. Therefore, it would seem that acceptance of illness is a more powerful indicator of how individuals cope with both normative and epilepsy related stressful events. This result validates the findings of Ireys et al (1994) regarding the relationship between self esteem and the perceived social impact of chronic illness and can be interpreted similarly in terms of cognitive appraisal. Thus it can be said that simply having a diagnosis of epilepsy is sufficient to lead to non productive coping, lower levels of self esteem and self efficacy and affect, due to the individual's personal interpretation of their illness experience, regardless of the severity of the epilepsy.

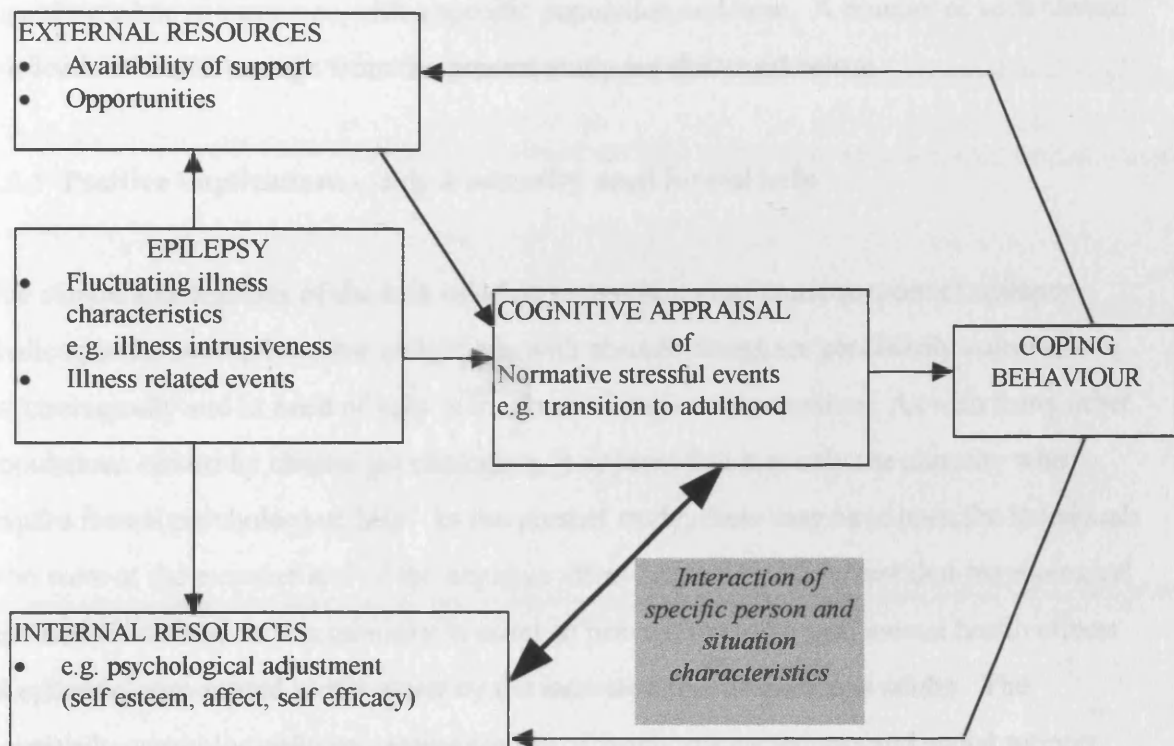
Condition characteristics only explained part of the variance within one variable, negative affect. Shorter duration of epilepsy was associated with increased negative affect. Although it may have been expected that longer duration of illness would engender more negative feelings, this finding could be explained by the fact that the modal duration of illness was one year and the modal age at diagnosis was 16 years. Upton and Thompson (1992) found that onset of epilepsy in the teenage years correlated with increased depression and it can be assumed that as the highest number of individuals in the present

study were diagnosed around one year ago, that they were teenagers at diagnosis. One year may have been insufficient time for individuals to make psychological adjustments to the illness and they may still have been experiencing emotions such as shock, anger or disbelief in response to the diagnosis.

Perception of control over seizures was the second variable chosen to represent the individual's perception of their illness. This variable only explained part of the variance with regard to self efficacy ratings pertaining to influence over epilepsy. However, this relationship between perception of control over seizures and self efficacy was non significant. The greater influence of acceptance of illness may be due to the fact that the Acceptance of Illness Scale measures a broad spectrum of illness related factors which could affect the individual psychologically, such as the social impact of epilepsy. In contrast, the Percept Scale is limited to the perception of control over seizures and although the finding that this is related to perceived influence over epilepsy is clearly logical and consistent, it demonstrates the limited influence of the perception of this aspect of epilepsy on psychological outcome measures.

The above discussion of the findings of the present study lead to the proposal of an extended model of coping with normative stress by the individual with epilepsy, see Fig. 4.1. This model places more of an emphasis on the interaction of the specific characteristics of the person and the situation. It incorporates both the past experience of illness and the fluctuating nature of illness characteristics as influences on external and internal resources and coping response. It also highlights the bi-directional nature of coping and the individual's internal (psychological adjustment) and external resources. The theoretical implications which have emerged from the present study would seem to contradict Folkman's (1997) point that applied research cannot further basic coping theory.

Figure 4.1: Extended model of coping with normative stress by the individual with epilepsy



4.7 The effects of age and gender within the entire sample

Although not a specific part of the hypotheses, the overall effects of age and gender within the entire sample are worth noting. The fact that females exhibited lower self esteem and self efficacy compared to males may reflect a general lack of self confidence in older female adolescents.

The finding that younger members of the sample expressed more negative affect than the older members runs contrary to earlier research findings that adolescents express more negative affect as they get older. This finding may be explained by the fact that the highest frequency of the patient group were diagnosed at age 16, which implies that some of the youngest members of the sample had been recently diagnosed. The experience of diagnosis can lead to negative feelings. Therefore, the recent diagnosis of some of the younger members of the patient group may have exerted undue influence on the overall levels of negative affect in the sample.

4.8 Clinical implications

The value of applied research into a specific illness is that it guides clinical practice regarding when to intervene with a specific population and how. A number of such clinical implications which emerge from the present study are discussed below.

4.8.1 Positive implications - only a minority need formal help

The clinical implications of the lack of adverse psychological consequences of epilepsy challenges the assumption that individuals with chronic illness are necessarily vulnerable psychologically and in need of help in the form of clinical intervention. As with many other populations served by clinical psychologists, it appears that it is only the minority who require formal psychological help. In the present study, these may have been the individuals who were at the extreme end of the negative affect scale. It is important that psychological services are offered to this minority in order to prevent the long term mental health effects of epilepsy, represented at it's worst by the increased risk of suicide in adults. The potentially psychologically protective factors of family connectedness and social support should alert the clinician to considering the system in which the young person with epilepsy is placed, rather than simply treating them individually. The evidence that some older adolescents with epilepsy are psychologically well adjusted may be used by clinicians to motivate those who do need psychological help as role models.

4.8.2 The importance of intervening at the right time in the most effective way

Evidence that psychological adjustment interacts with a stressful situation to produce a non adaptive coping response has important clinical implications. It highlights both the vulnerability of adolescents with epilepsy during the transition to adulthood and the vital importance of factors affecting their psychological adjustment. Due to the probable bi-directional relationship between coping and psychological adjustment, it would seem that the clinical psychologist has the option of intervening at both the level of improving the young person's coping skills and enhancing their level of psychological adjustment. The coping repertoire of the individual could be broadened by encouraging them to develop further cognitive or behavioural ways of coping. Enhancement of psychological adjustment could be addressed in a number of ways, for example by improving level of self esteem or

self efficacy by altering patterns of self referent thought and cognitively reframing the individuals view of themselves compared to others.

The finding that older adolescents with epilepsy exhibit a less problem solving style, could imply that this group need encouragement to adopt a more problem solving approach in response to making decisions about their future. Currently, their peers appear to have an advantage, in that they are using a more adaptive approach to this universally important aspect of making the transition to adulthood. If the reason for less use of problem solving is due to past experience, then cognitive reframing of this experience may increase the motivation of the adolescent with epilepsy to attempt to alter the stressful situation to their advantage. The trend away from a problem solving bias may represent the existence of a significant number of individuals who do have difficulty making the transition to adulthood. Therefore, clinical services should take particular care to monitor the progress of young people with epilepsy at this time in their life. Services should be made available and acceptable to adolescents, perhaps by the adoption of a 'drop in', self referral model to a multidisciplinary 'teenage clinic'.

The finding that young people with epilepsy are reluctant to seek professional help in relation to their epilepsy has important implications for healthcare professionals. It may be necessary for the Health Service to offer a better service to older adolescents, perhaps acknowledging their particular frustrations with their illness pertaining to issues such as contraception, alcohol and driving. As pointed out by Kim (1991), young people with epilepsy have to forgo some of the usual adolescent activities due to the limitations of their illness and require close monitoring and advice. This point carries with it implications for service provision, all too often it seems that the transition from child to adult health care services is not smooth and there can be an unacceptable delay in treatment provision. Adolescents may find that their particular needs are not met by child or adult services. This provides an argument for the creation of multidisciplinary adolescent health care teams or increased training to raise the awareness of issues specific to adolescents with chronic health conditions.

4.8.3 Clinical implications from coping theory

As the present study provides evidence for both the process and the style approach to coping, the clinical implications of both will be discussed in brief. If coping response is believed to differ according to the interaction between the individual and the situation, young people with epilepsy could be reassured that they do not have to deal with all problems in the same way and could be empowered by increasing their repertoire of coping strategies. Clinical psychologists may need to recognise the limits of a problem solving approach based on the situation with which their client is faced. Frydenberg's (1997) view that adolescents tend to cope best when they adopt a problem solving approach, whilst remaining physically fit and socially connected may not be the best approach when coping with epilepsy. Perhaps responding in a more emotional, 'non productive' way to having epilepsy is in fact a part of a normal emotional response to an illness which is mostly outside the control of the individual. It may be that the first role of the clinical psychologist will be to contain and normalise this emotional response before attempting to enhance the individuals' ability to cope. With regard to epilepsy, although problem solving can be employed by encouraging clients to seek and use information, for example, cognitive reappraisal of the illness may be a more effective way of coping as found by Upton and Thompson (1992).

The process theory view that the response of the individual is important as well as the features of the situation could also be useful clinically. An examination of the particular resources of the individual, be they intellectual, physical or social may be helpful in identifying potentially useful strengths on which to build and enhance the individual's ability to cope with epilepsy.

With regard to clinical usefulness, the style theory of coping is less of a source for optimism than the process theory. If individuals respond in the same way across situations as a result of deep seated personality traits, there is less scope for enhancing or altering non adaptive coping with either epilepsy or more normative stresses. The most clinically constructive implication of the trait theory is that it allows the individual to predict how they will respond to any given situation, thus giving them an insight into their behaviour.

4.8.4 Increasing self efficacy

Clearly, an increase in self efficacy with regard to managing the effects of epilepsy would be desirable in the patient group. Making use of Bandura's (1982) model would necessitate a cognitive therapeutic approach, as he states that self efficacy is the self referent thought which is formed through experience. High self efficacy is achieved if one perceives one has mastered challenge through adaptive action. The experience of epilepsy may lead to less successful outcomes than the individual desires and lead to the formation of negative core beliefs as proposed by Tedman, Thornton and Baker (1995). It may therefore be helpful to encourage the individual with epilepsy to cognitively reframe their past experience. For example, by rewarding themselves for what they have achieved despite the added burden of epilepsy. A goal of therapy would be for individuals to attribute their successes internally, to their own efforts. Such an approach may increase their confidence in their abilities, enhance their sense of personal control and motivate them to attempt to cope with the more difficult challenges of their illness.

4.8.5 Increasing the acceptance of illness

The importance of acceptance of illness on the overall psychological adjustment of older adolescents with epilepsy is a good reason for clinical psychologists to work to increase levels of acceptance of illness with this client group. It would seem that a teenage diagnosis of epilepsy is particularly distressing and intervention in the year following diagnosis may be crucial to future psychological well being and also to how the individual copes with the transition to adulthood. This finding is also a cause for optimism, as it implies that even though there may be limits to the medical management of epilepsy, individuals still may benefit from an intervention at a psychological level.

Schneider and Conrad (1981) described the acceptance of, or adjustment to epilepsy as the neutralisation of the actual or perceived impact of epilepsy and Morse and Johnson (1991) described the stages involved in accepting illness. Suggestions to facilitate the adjustment to epilepsy in older adolescents will be made in relation to cognitive therapeutic strategies, identity development and coping with felt stigma. The ideas for increasing perceived control over epilepsy outlined above in relation to increasing self efficacy are also relevant to increasing the individual's acceptance of epilepsy.

Following Schussler's (1992) work with chronic illness, the individual's perception of epilepsy could be explored by using Lipowski's (1970) concepts of disease to establish whether epilepsy is seen as a challenge or a threat, for example. Epilepsy could be perceived as a challenge and thus stimulate individual growth or it may be construed as overwhelming and constitute a threat to mental health. Further exploration may reveal that the client's perception of epilepsy is a core belief resulting from the individual's experience of cultural or family beliefs. The individual may develop insight into why they find the diagnosis of epilepsy unacceptable and may subsequently be able to form a different view of their illness. The clinical psychologist could facilitate cognitive reappraisal of the experience of epilepsy as more of a challenge than a threat.

The impact of epilepsy on the identity of the individual could be explored with the goal of helping the client develop an identity outside of the illness. Therefore, instead of being overwhelmed or 'debilitated' (Schneider and Conrad 1981) by epilepsy and having the identity of an 'epileptic', individuals could be encouraged to focus on other areas of their life and develop more of an identity as 'a person who has epilepsy' in addition to many other aspects of their life. Consideration of the development of identity in the adolescent with epilepsy may be crucial in warding off the identity confusion described by Erikson (1968) as the struggle to forge an identity which fits both personality and environment. Young people with epilepsy may struggle to reconcile having epilepsy with the cultural norms of their society described by Scambler (1984), which make it difficult for them to feel accepted.

It is difficult for individuals with epilepsy to contend with the social construction of stigma. The clinician can model acceptance of the young person with epilepsy which may go some way to helping them feel accepted in society and reduce the impact of epilepsy. Also, the present study revealed that young people with epilepsy were reluctant to seek help or share their problems with others. Felt stigma may have been the source of this reluctance and a positive experience of attending a sympathetic clinician may help dissipate this feeling. As Scambler and Hopkins (1980) found felt stigma to be far more common in people with epilepsy than enacted stigma, the cognitive technique of reality testing or Socratic questioning may be helpful. This technique encourages the individual to reflect on their experience in order to test whether evidence in fact exists for their belief, in this case that

they are stigmatised. If no evidence of enacted stigma is found to exist, then a corresponding reduction in felt stigma may result.

If the young person with epilepsy feels accepted by others, they may find it easier to accept their illness. Attendance of a self help group with other young people with epilepsy may help the individual to feel less stigmatised and increase their adjustment to epilepsy if they see others coping with it. The need for positive role models of adults with epilepsy is important for adolescents to help increase their confidence in their own abilities. Wider publicity of famous people with epilepsy may also demonstrate to society that people with epilepsy can achieve and thus reduce the social construction of epilepsy as a stigmatising illness.

4.9 Study limitations and strengths

There are a number of limits to the present study that could have affected the results found. These limits include the sample, the measures, procedure and analysis used. Whether the results of the study can be generalised to other populations is also discussed. The strong points of the study are acknowledged at the end of this section.

4.9.1 Study sample

The sample of patient participants may not be representative of the population of young people aged 16 to 21 years with epilepsy. This is because the response rate of 30 per cent is low in comparison to the 40 per cent or above more commonly found in postal surveys. The sample also shows a gender imbalance of 66 per cent females compared to 33 per cent males. This is unrepresentative of the population who received the questionnaire which contained approximately equal numbers of males and females. In other studies of epilepsy, there are usually slightly more males than females Scambler (1989). Therefore, it may not be possible to generalise the results found to young people with epilepsy of both sexes. However, multiple regression equations did not identify sex as a variable which greatly influenced the outcome variables. The reason for the low response rate in young male participants is unknown. It is likely that the prospect of filling in a questionnaire about feelings and illness was less attractive to males than females. The use of a postal survey may also have excluded potential participants who had literacy difficulties. The results of

the present study could be compared with those from a more gender balanced sample in future research.

There was substantial variation within the patient group regarding the condition characteristics of epilepsy shown in the wide range of age at diagnosis and seizure severity. In particular, the majority of individuals were diagnosed at age 16 and therefore had not had experience of epilepsy in the long term. The patient group showed an abnormal range of both seizure frequency and seizure type compared to community based samples of young people with epilepsy recruited from General Practitioners as opposed to hospital Consultants. A comparison of hospital based and community based samples of young people with epilepsy is an important area for future research. The distribution of seizure severity was fairly normal, indicating that the sample may have been representative of young people with both mild and severe forms of epilepsy. Although there are obvious advantages to a normal distribution of seizure severity the numbers of participants in the study may have been insufficient for an overall effect of epilepsy to emerge. The results of the study may have been clearer had it focused on a distinct group within the population, for example, individuals experiencing only one seizure type. However, this would have greatly reduced the number of participants as the majority experienced more than one type of seizure.

The method of recruiting the control participants by asking the participant to recruit a relative or friend can be criticised. The lives of members of the control group may have been affected by their friend or relative's epilepsy and their own psychological adjustment or identity may have been influenced. However, the advantage of this method of recruitment was that it resulted in well matched control and patient groups on the grounds of education and social class. As the control participants returned their questionnaires anonymously, it is not possible to establish how many were relatives or friends of the person with epilepsy.

4.9.2 Study measures

A general criticism that can be made of all but one of the measures used is that they were not standardised on an epilepsy population.

Comparison of results from the 20 item Seizure Severity Scale with those from the original scale could be criticised. The calculation of original means for each subscale from the

published figures used data from four distinct seizure subgroups. The same proportions of seizure type did not exist in the present study, thus the comparison with the original sample needs to be made with caution. The calculation of pro rating means for each subscale, can only be considered as an estimate of participants scores if the scale had been 16 items long. Also, the pro rating calculation does not take into account which particular questions were added to the original scale.

The ACS does not contain items which could be categorised as cognitive reframing which according to Upton and Thompson (1992) is the most effective way of coping with epilepsy. Therefore, the limitations of the questionnaire could have prevented the measurement of this coping strategy which is of particular importance to epilepsy. Future research should ensure that coping measures include a dimension that allows the measurement of cognitive reframing.

The choice of considering what decisions to make regarding one's future as a potentially stressful situation could be judged as lacking specificity and being less easy to consider than a single issue. However, it would have been difficult to identify a specific issue which would be relevant to all participants in the same way as this more general area. An alternative would have been to present participants with a scenario relevant to their age group where a young person had to cope with a difficult situation and ask them how they would have coped if it had been them. However, individuals differ in their ability to relate to such scenarios and it was felt that it was better for participants to draw on their own experience. In the same way, the issue of coping with epilepsy could have been made more specific, as coping with the illness as a whole differs from coping with a specific seizure attack. The need for more specific measures echoes Somerfield's (1997) call for research which focuses on a specific aspect of illness in order to increase the potential for applicable research implications.

Although the inclusion of more open questions allowed participants to express themselves more freely, it could be argued that the use of content analysis is a less rigorous method than using standardised measures such as the ACS. It is also more difficult to relate the findings of the content analysis to other variables. With regard to the content analysis itself, it would have been advisable to have involved a second researcher to arrive at a consensus

with regard to the categorisation of raw data themes to common themes. Without such verification the findings of the content analysis should be interpreted with caution.

The 'openness' of the two questions regarding self efficacy can be debated. Asking participants to write about how much influence they felt they had over epilepsy/the transition to adulthood resulted in some 'closed' answers such as 'a lot'. Such replies focused on amount of influence without expanding further. Therefore, it would be advisable to construct more open questions regarding self efficacy for the purposes of future research.

Certain factors which could potentially have influenced both coping and psychological adjustment were not measured. For example, social support networks may have influenced the use of coping style, the cognitive effects of epilepsy may have had an impact on the ability to make decisions about the future and knowledge of epilepsy may have influenced both acceptance of illness and ways of coping with it. Inclusion of these factors in future research may provide a better explanation of coping and psychological adjustment.

4.9.3 Procedure

The reason for the discrepancy between the degree of cross situation difference using content analysis and the ACS is hard to explain, as the standardised questionnaire does contain items relating to the coping strategies which emerged from the content analysis (e.g. items, 4, 11, 13: 'worry about what will happen to me'; 'shut myself off from the problem so that I can avoid it'; 'don't let others know how I'm feeling'). If the ACS provided an accurate measure of coping in each situation, the mostly negative results could be attributed to the fact that the effect of epilepsy pervades all areas of life and therefore makes discrimination between coping with it and with those areas of life it may effect impossible. However, an alternative explanation could have been the close proximity of presentation of the specific forms of the ACS, despite the reminder included in the instructions to focus on the topic in hand. The ACS relating to epilepsy was presented first which may have stimulated answers which were still in mind when completing the ACS relating to coping with the future and created a 'response set'. The authors of the ACS (Frydenberg and Lewis 1993b) found high correlations between the general and specific forms of the ACS and believe that this may be due to adolescents ignoring the different instructions provided

on each form. Confusion over distinguishing between coping with issues of the future or epilepsy may have been reduced by alternating the order of presentation of the two ACS, giving half the participants the ACS relating to epilepsy first and half the ACS relating to the future or by presenting one ACS a month after the other.

It is possible that the specific form of the Adolescent Coping Scale is less adaptable than it claims and is not an appropriate tool to assess coping with specific situations. This may be true of the majority of general coping scales and highlights the need for specific coping scales for the measurement of coping with illness. Such scales might constitute measures in between the symptom focused (e.g. pain scales) scales and general coping measures.

A separate study could have been conducted using a between groups design with half of the participants receiving the coping with epilepsy ACS and half the coping with the future ACS. However, this design would require very close matching of the participants particularly in terms of the medical characteristics of their epilepsy as well as on demographic variables. Participants may simply have felt more able to express themselves in response to an open question, whereas they may have found the structured replies required by a standardised instrument constraining. If this was the case, a qualitative method may have been more appropriate as the main method of investigation in the study.

If resources had allowed, a longitudinal study would have been a way of monitoring whether use of coping strategies altered in the long term and which individuals had the most successful outcomes in future years. Successful outcome could be measured psychologically and in terms of variables such as occupation. A longitudinal study could measure the fluctuation of the effects of epilepsy over time and whether this resulted in corresponding changes in coping or psychological adjustment.

4.9.4 Analysis

The above finding regarding the importance of acceptance of illness to psychological adjustment and coping is open to criticism. Due to the small number of participants, the inclusion of variables in the multiple regression equations was limited by necessity. Variables were carefully chosen to favour those measured psychometrically. However, several condition characteristics such as frequency or type of seizure were not considered

and could potentially have explained additional variance in the dependent measures. The results could be explained by the fact that the Acceptance of Illness Scale as a measure of psychological adjustment itself, is too similar to the outcome measures in the regression analysis and that this masked the effect of condition characteristics on psychological adjustment. All but one of the items on the AIS are negative statements about illness, which could have artificially decreased acceptance of illness expressed by participants. This apparent negative slant of the AIS may explain the fact that only the more negative, non productive and not the more positive, problem solving coping style were explained by acceptance of illness. Further research with a larger number of participants could allow the analysis of a wider number of condition characteristics.

The analysis in the present study did not provide an explanation for the use of the 'solve the problem' coping style in either the patient or the control group using the chosen variables of self esteem, positive affect and self efficacy. This finding indicates that conceptually, the 'solve the problem' and 'non productive' coping styles are not polar opposites. If this were the case, one would expect the variance associated with 'solve the problem' to be explained in equal proportion to that in 'non productive' coping, by the same variables, but with the association of those variables and the coping style in the opposite direction. The fact that explanations were found for the use of 'non productive' coping style indicates that where the same variables were used they were measured reliably. Also, that the sample size was great enough and the population representative enough to reveal an effect .

There are a number of possible explanations for the lack of explanation of the 'solve the problem' coping style. The first explanation is that the theory that positive affect, high levels of self esteem and self efficacy are unrelated to a problem solving coping approach, this is unlikely in the light of the literature. It is possible that the measure of self esteem which explained some of the variance in the use of 'non productive' coping was negatively biased. This would have increased the likelihood of a stronger relationship with 'non productive' coping. However, this could not be said for the measures of positive affect and self efficacy which also failed to explain the use of 'solve the problem'. It is possible that the outcome measure of 'solve the problem' was unreliable and Frydenberg and Lewis (1993) do acknowledge the need for further validation of the measures of coping style on the ACS. However, as 'solve the problem' produced interesting findings in other parts of the analysis this explanation is unlikely too. A final explanation is that the relationship

between 'solve the problem' and the other variables was non linear. If the relationship was for example, curvilinear it would not have been identified by the analysis which used a linear regression model.

Use of a more exploratory method of analysis, such as the stepwise, rather than the enter method of multiple regression may have provided more of an explanation of the use of the 'solve the problem' coping style. This would have allowed all of the variables relating to psychological adjustment to be considered and could have revealed their relative explanation of this coping style. If a curvilinear relationship was found between 'solve the problem' and the other variables, scores could have been transformed using a logarithmic scale prior to conducting a linear regression analysis.

4.9.5 Can the results of the study be generalised?

Whether the results of the present study can be generalised to other populations in other contexts is debatable. It has been suggested that the fact that the population consisted of adolescents may have had a powerful impact on the results. Therefore, in order to establish whether adults or older adults with epilepsy show a similar coping style or levels of psychological adjustment, requires research with these populations at a time of transition. Perhaps a similar study could be done with adults when they reach the transitional phase of facing retirement.

Whether the findings regarding epilepsy are generalisable to other chronic illnesses raises the debate between the disease specific and general factors models of illness. Repeating the present study with other chronic illnesses is necessary to answer this question. Perhaps it is easier to generalise the findings to chronic illnesses with similar characteristics to epilepsy, for example, insulin dependent diabetes where individuals are similarly dependent on medication and may suffer from periods of unconsciousness in the form of hypoglycaemic attacks.

The gender bias towards females in the sample raises doubts as to whether the findings of the study can be applied equally to males and females. However, when gender was included in the multiple regression equations it did not emerge as an influential variable on the outcome variables.

4.9.6 Strengths of the study

There were a number of strong points of the present study. The design permitted the testing of the process theory of coping across specific situations which has been lacking in coping research. The use of a postal method ensured that the entire population of regional young people with severe epilepsy who had been referred to hospital were contacted. Recruiting a control from the acquaintance of the patient participants resulted in a well matched sample demographically. The use of a mixed method of standardised instruments and content analysis allowed participants free expression whilst taking advantage of the findings generalisable to the population.

5 Conclusion

The present study gives rise to the conclusion that the experience of epilepsy in older adolescence has no significantly detrimental effect on psychological adjustment per se, until it is combined with a stressful situation, such as the transition to adulthood. At this point, psychological adjustment and the experience of epilepsy interact with the particular demands of the stressful situation to produce a negative effect on the individual's coping response. This finding has important clinical implications for the monitoring of adolescents with epilepsy in order to offer them appropriate psychological intervention during the times they need it most.

The importance of the interaction between person and situation and the resulting influence on coping style is consistent with the 'transactional' concept of process theory. Evidence was found both for and against the process theory of coping, contrary evidence was attributed in part to the procedure of the study. Regarding the measurement of coping, it was recognised that more specific measures of coping are required.

A second conclusion that may be drawn, is that the psychological acceptance of illness has more influence on the psychological adjustment and coping behaviour of the adolescent with epilepsy than the condition characteristics of the illness. This highlights the value of psychological intervention with this population.

In order to establish whether the findings of the present study can be generalised, further research needs to be done with populations of different ages and with chronic illnesses other than epilepsy.

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Appendix 1 Initial contact letter to patient participants

December 1997

Dear

I am a Clinical Psychologist (in Training) working at the Queen's Medical Centre and am doing a project to find out more about young people with epilepsy. I am writing to ask if you would be willing to take part in the project. I have contacted your Consultant Neurologist Dr _____ and he is happy for me to write to you.

Your part in the project would involve answering some questions on questionnaires, which would take about an hour of your time. There would be no need for extra visits to the hospital, as I could post the questionnaires to your home. I have enclosed more information about the project on the Information Sheet.

If you would be willing to take part in the project, please fill in the slip below and return it in the envelope provided or telephone me on the above number. Your help would be very much appreciated and helpful in increasing our understanding of what it is like for young people to have epilepsy.

I look forward to hearing from you.

Yours sincerely

Dawn Reeve
Clinical Psychologist (in Training)

Supervised by:
Arleta Starza
Consultant Clinical Psychologist in Neuropsychology

.....
Please tear-off strip

I would/would not (please circle) be willing to take part in the project about young people with epilepsy.

Name.....
Age.....
Address.....
Telephone number.....

Please return to Dawn Reeve, Clinical Psychology, Linden House, 261 Beechdale Road, Aspley, Nottingham, NG8 3EY.
Telephone: 0115 9428632

Appendix 2 Second letter to patient participants

Dear

I am writing following my recent letter which asked you take part in a project to find out more about young people with epilepsy. As mentioned in the letter I have enclosed a questionnaire for you to fill in. When you have filled it in, could you please post it back to me in the stamp addressed envelope provided within the next week or two.

Filling in the questionnaire

Please read the directions for filling in each part of the questionnaire. Don't spend too much time on each part but give the answer you feel describes best how you feel. Remember, there are no right or wrong answers to any question and your view is important.

Signing the consent form

Please remember to sign the enclosed consent form. This is to show that you are willing to take part in the project.

Asking a friend or relative

I want to compare the experience of people with epilepsy with people who do not have epilepsy. It would help me to do this if you could give a copy of the questionnaire to a friend or relative such as a brother or sister who does not have epilepsy. Your friend or relative needs to be between 16 and 21 years old and if possible around same age as you, give or take a couple of years. It is also important that they do not have a long-standing illness such as asthma for example.

I have enclosed a pink questionnaire marked 'friend' for your friend or relative to fill in. Please could they return it to me in the stamp addressed envelope provided. They will also need to sign a consent form, which I have enclosed with their questionnaire.

If you have problems filling in the questionnaire

If you have any difficulties in filling in the questionnaire or would like any more information on this project, please do not hesitate to contact me at the above address or telephone numbers.

After the project has finished

If you would like to know what this project has told us about young people with epilepsy, please contact me on the above telephone numbers.

Thankyou very much for your time and your help in helping us to understand more about what it is like for young people to live with epilepsy.

Yours sincerely

Dawn Reeve

Clinical Psychologist (in Training)

Appendix 3 Patient information sheet

Information Sheet

Study title:

An investigation of how older adolescents with epilepsy cope with the transition to adulthood compared to their peers and compared to how they cope with epilepsy.

What is this study about?

I am asking you to take part in this study to find out how young people cope with having epilepsy and whether having epilepsy makes it more difficult for young people to handle issues such as deciding what to do with their future. I hope to do this by comparing young people with epilepsy with people of the same age who do not have epilepsy.

What am I asking you to do?

I will be asking you for about an hour of your time to fill in some questionnaires which will ask you: how you cope with having epilepsy; how you cope with deciding what to do with your future; how good you feel about yourself and how happy or sad you have been feeling recently. I will also ask you some questions about your epilepsy and about your current circumstances.

Will your identity be protected?

All of the questionnaires and any information which has your name on it will be kept confidential and under lock and key. At the end of my study I may publish it, but it will not be possible to identify any of the people who took part.

An invitation to take part

I am now asking you if you are willing to take part in the study. If you say 'yes' you can still change your mind at any time and say that you no longer want to take part. Saying that you do not want to take part will not affect any of the medical care you receive, this will go on as normal. If you would like more information before making a decision, please feel free to ask me. You or a relative or friend can call me or write to me:

Dawn Reeve
Clinical Psychologist in Training
Clinical Psychology Services
Nottingham Community Health NHS Trust
Linden House
261 Beechdale Road
Aspley
Nottingham
NG8 3EY

Telephone: 0115 9428632
24 hr ansaphone 0115 9345353

Appendix 4 Patient consent form

Consent Form

An investigation of how older adolescents with epilepsy cope with the transition to adulthood compared to their peers and compared to how they cope with epilepsy.

Please complete the following:

Please cross out as necessary

Have you read and understood the patient information sheet?

YES/NO

Have you had the opportunity to ask questions and discuss this study?

YES/NO

Have you received satisfactory answers to all your questions?

YES/NO

Have you received enough information about the study?

YES/NO

Do you understand that you are free to withdraw from the study

■ at any time?

YES/NO

■ without giving a reason for withdrawing?

YES/NO

■ and without affecting your future medical care?

YES/NO

I agree to take part in this study

YES/NO

Signed (patient) Date

Name in block capitals

Signed (researcher) Date

Name in block capitals

Appendix 5 Control information sheet

Information Sheet

Your friend or relative has asked you to take part in a study to help us understand how young people cope with life and the challenges it presents. If you would like to take part in the study, please fill in the questionnaire and sign the consent form and post them back to me in the stamp addressed envelope provided. There is more information on the study below. Thankyou very much for your help.

Study title:

An investigation of how older adolescents with epilepsy cope with the transition to adulthood compared to their peers and compared to how they cope with epilepsy.

What is this study about?

I am asking you to take part in this study to find out how young people cope with having epilepsy and whether having epilepsy makes it more difficult to handle issues such as deciding what to do with their future. I hope to do this by comparing young people with epilepsy with people of the same age who do not have epilepsy. As a young person who does not have epilepsy, it will help me to compare your experiences with a person who has epilepsy to see if there are any differences.

What am I asking you to do?

I will be asking you for about half an hour of your time to fill in some questionnaires which will ask you how you cope with deciding what to do with your future; how good you feel about yourself and how happy or sad you have been feeling recently.

Will your identity be protected?

All of the questionnaires and any information with your name on it will be kept confidential and under lock and key. In fact, you do not have to put your name on the questionnaire, just your age and sex. At the end of my study I may publish it, but it will not possible to identify any of the people who took part.

An invitation to take part

I am now asking you to take part in the study. If you say 'yes' you can still change your mind at any time and say that you do not want to take part. Saying that you do not want to take part will not affect any current or future medical care that you receive. If you would like more information before making a decision, please feel free to ask me. You or a relative or friend can call me or write to me:

Dawn Reeve
Clinical Psychologist in Training
Clinical Psychology Services
Nottingham Community Health NHS Trust
Linden House
261 Beechdale Road
Aspley
Nottingham
NG8 3EY

Telephone: 0115 9428632
24 hr answerphone: 0115 9345353

Appendix 6 Control consent form

Consent Form

An investigation of how older adolescents with epilepsy cope with the transition to adulthood compared to their peers and compared to how they cope with epilepsy.

Please complete the following:

Please cross out as necessary

Have you read and understood the information sheet? YES/NO

Have you had the opportunity to ask questions and discuss this study? YES/NO

Have you received satisfactory answers to all your questions? YES/NO

Have you received enough information about the study? YES/NO

Do you understand that you are free to withdraw from the study

■ at any time? YES/NO

■ without giving a reason for withdrawing? YES/NO

■ and without affecting your future medical care? YES/NO

Who explained this study to you?

I agree to take part in this study YES/NO

Signed Date

Name in block capitals

Signed (researcher) Date

Name in block capitals

Appendix 7 Patient questionnaire (including items used in the control questionnaire)

Questionnaire for Young Adults

By filling in this questionnaire you will help increase our knowledge of how young adults with epilepsy cope with life and the challenges it presents.

All of your answers will be kept strictly confidential. You do not have to write your name on the questionnaire, just your age and your sex.

Please read the instructions carefully and answer every question. If you do not know the answer to a question, please make a guess or put 'do not know'.

When you have filled in the questionnaire, please put it in the stamp addressed envelope provided and post it back to me as soon as possible

If you would like any more information please contact me at the address below:

Dawn Reeve
Clinical Psychologist in Training
Nottingham Community Health NHS Trust
Clinical Psychology
261 Beechdale Road
Aspley
Nottingham
NG8 3EY

Telephone: 0115 9428632
Or: 0115 9345353

THANKYOU VERY MUCH FOR YOUR HELP



HOW YOU FEEL ABOUT HAVING EPILEPSY

INSTRUCTIONS: Please respond to each of the following items by choosing the number from 1-5, on the scale which you feel best describes you. Then circle the number you have chosen. There are no right answers to any of the questions.

For example

1

2

3

4

5

Strongly agree

Strongly disagree

1. I have a hard time adjusting to the limitations of having epilepsy

1

2

3

4

5

Strongly agree

Strongly disagree

2. Because I have epilepsy, I miss the things I like to do most

1

2

3

4

5

Strongly agree

Strongly disagree

3. Having epilepsy makes me feel useless at times

1

2

3

4

5

Strongly agree

Strongly disagree

4. Having epilepsy makes me more dependent on others than I want to be

1

2

3

4

5

Strongly agree

Strongly disagree

5. Having epilepsy makes me a burden on my family and friends

1

2

3

4

5

Strongly agree

Strongly disagree

6. Having epilepsy does *not* make me feel inadequate

1

2

3

4

5

Strongly agree

Strongly disagree

7. I will never be self-sufficient enough to make me happy

1

2

3

4

5

Strongly agree

Strongly disagree

8. I think people are often uncomfortable around me because I have epilepsy

1

2

3

4

5

Strongly agree

Strongly disagree

HOW YOU FEEL ABOUT YOURSELF

INSTRUCTIONS:

Here is a list of statements dealing with your general feelings about yourself. If you **agree** with the statement circle A. If you **strongly agree**, circle SA. If you **disagree**, circle D. If you **strongly disagree**, circle SD.

	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
1. On the whole I am satisfied with myself	SA	A	D	SD
2. At times I think I am no good at all	SA	A	D	SD
3. I feel that I have a number of good qualities	SA	A	D	SD
4. I am able to do things aswell as most other people	SA	A	D	SD
5. I feel I do not have much to be proud of	SA	A	D	SD
6. I certainly feel useless at times	SA	A	D	SD
7. I feel that I'm a person of worth, at least on an equal plane with others	SA	A	D	SD
8. I wish I could have more respect for myself	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure	SA	A	D	SD
10. I take a positive attitude towards myself	SA	A	D	SD

HOW YOU COPE WITH HAVING EPILEPSY

INSTRUCTIONS: Young people have a number of concerns about how to best cope with having epilepsy and having seizures or the possibility of having a seizure (by seizure, we mean fits, convulsions, or episodes of unconsciousness). Some people find that having epilepsy can limit their activities, make them feel embarrassed or the ‘odd one out’. People choose different ways of coping with the effect epilepsy has on their lives. There are no right or wrong ways of coping with epilepsy.

On the page opposite is a list of ways in which people of your age cope with a wide variety of concerns. Please think about how you deal or have dealt with having epilepsy, even if you have been seizure-free for some time. Please indicate by circling the appropriate number the things you do to deal with having epilepsy. Work down the page and circle 1,2,3,4 or 5 as you come to each statement. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which best describes how you feel.

For example, if you **sometimes** cope with having epilepsy by ‘Talk to others to see what they would do if they had the problem’ you would circle 3 as shown in the example in the table below.

	Doesn't apply or don't do it	Used very little	Used some- times	Used often	Used a great deal
1. Talk to others to see what they would do if they had the problem	1	2	3	4	5

REMEMBER YOU ARE THINKING ABOUT HOW YOU DEAL WITH HAVING EPILEPSY.

	Doesn't apply or don't do it	Used very little	Used some- times	Used often	Used a great deal
1. Talk to other people about my concern to help me sort it out	1	2	3	4	5
2. Work at solving the problem to the best of my ability	1	2	3	4	5
3. Work hard	1	2	3	4	5
4. Worry about what will happen to me	1	2	3	4	5
5. Spend more time with boy/girl friend/partner	1	2	3	4	5
6. Improve my relationship with others	1	2	3	4	5
7. Wish a miracle would happen	1	2	3	4	5
8. I have no way of dealing with the situation	1	2	3	4	5
9. Find a way to let off steam, for example cry, scream, drink, take drugs etc.	1	2	3	4	5
10. Join with people who have the same concern	1	2	3	4	5
11. Shut myself off from the problem so that I can avoid it	1	2	3	4	5
12. See myself as being at fault	1	2	3	4	5
13. Don't let others know how I'm feeling	1	2	3	4	5
14. Pray for help and guidance so that everything will be all right	1	2	3	4	5
15. Look on the bright side of things and think that all is good	1	2	3	4	5
16. Ask a professional person for help	1	2	3	4	5
17. Make time for leisure activities	1	2	3	4	5
18. Keep fit and healthy	1	2	3	4	5
19. List any <i>other</i> things you do to cope with your main concern	1	2	3	4	5

Please show how much you agree with the following statement by circling a number on the scale below:

I am confident that I can influence the effect that epilepsy has on my life.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree
(Not at all confident)						(Very confident)

HOW YOU COPE WITH THE FUTURE

INSTRUCTIONS: Young people have a number of concerns about what they should do with their future. It is usual to start thinking about this when leaving school. Decisions about your future often need to be made in the years after leaving school too.

For example, people choose what kind of career they want, whether to continue studying or to do a training course. Some people choose to care for the home or to become parents and look after their children at home. All of these options for the future are equally important.

On the page opposite is a list of ways in which people of your age cope with a wide variety of concerns. Please consider any current decisions you are making about the future or think back to the times in the last few years when you made decisions about what to do with your life. Please indicate by circling the appropriate number, the things you do or did to deal with making decisions about your future. Work down the page and circle 1,2,3,4 or 5 as you come to each statement. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which best describes how you feel.

For example, if you **sometimes** cope with deciding what to do in the future by ‘Talk to others to see what they would do if they had the problem’ you would circle 3 as shown in the example in the table below.

	Doesn't apply or don't do it	Used very little	Used some- times	Used often	Used a great deal
1. Talk to others to see what they would do if they had the problem	1	2	3	4	5

REMEMBER YOU ARE THINKING ABOUT HOW YOU DEAL WITH YOUR FUTURE.

	Doesn't apply or don't do it	Used very little	Used some- times	Used often	Used a great deal
1. Talk to other people about my concern to help me sort it out	1	2	3	4	5
2. Work at solving the problem to the best of my ability	1	2	3	4	5
3. Work hard	1	2	3	4	5
4. Worry about what will happen to me	1	2	3	4	5
5. Spend more time with boy/girl friend/partner	1	2	3	4	5
6. Improve my relationship with others	1	2	3	4	5
7. Wish a miracle would happen	1	2	3	4	5
8. I have no way of dealing with the situation	1	2	3	4	5
9. Find a way to let off steam, for example cry, scream, drink, take drugs etc.	1	2	3	4	5
10. Join with people who have the same concern	1	2	3	4	5
11. Shut myself off from the problem so that I can avoid it	1	2	3	4	5
12. See myself as being at fault	1	2	3	4	5
13. Don't let others know how I'm feeling	1	2	3	4	5
14. Pray for help and guidance so that everything will be all right	1	2	3	4	5
15. Look on the bright side of things and think that all is good	1	2	3	4	5
16. Ask a professional person for help	1	2	3	4	5
17. Make time for leisure activities	1	2	3	4	5
18. Keep fit and healthy	1	2	3	4	5
19. List any <i>other</i> things you do to cope with your main concern	1	2	3	4	5

Please show how much you agree with the following statement by circling a number on the scale below:

I am confident that I can influence my future.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree
(Not at all confident)						(Very confident)

HOW YOU ARE FEELING AT THE MOMENT

INSTRUCTIONS

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few days.

Use the following scale to record your answers.

	1 Very slightly or not at all	2 A little	3 Moderately	4 Quite a bit	5 Extremely
1. Interested	1	2	3	4	5
2. Distressed	1	2	3	4	5
3. Excited	1	2	3	4	5
4. Upset	1	2	3	4	5
5. Strong	1	2	3	4	5
6. Guilty	1	2	3	4	5
7. Scared	1	2	3	4	5
8. Hostile	1	2	3	4	5
9. Enthusiastic	1	2	3	4	5
10. Proud	1	2	3	4	5
11. Irritable	1	2	3	4	5
12. Alert	1	2	3	4	5
13. Ashamed	1	2	3	4	5
14. Inspired	1	2	3	4	5
15. Nervous	1	2	3	4	5
16. Determined	1	2	3	4	5
17. Attentive	1	2	3	4	5
18. Jittery	1	2	3	4	5
19. Active	1	2	3	4	5
20. Afraid	1	2	3	4	5

YOUR PERSONAL OPINIONS (PLEASE CONTINUE ON EXTRA PAPER IF YOU NEED TO)

1. **In the space below please write about how you deal with having epilepsy.**

2. **In the space below please write how you deal with making decisions about the future.**

3. **In the space below please write about how much influence you feel you have over what happens to you in the future.**

4. **In the space below please write about how much influence you feel you have over your epilepsy.**

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOURSELF:

1. How old are you? Years
2. Are you **male** ☐ **female** ☐ (Please tick)
3. What is your marital status **single** ☐ **married** ☐ **living with partner** ☐ (Please tick)
4. How would you describe your ethnic origins? (Please tick below)

White	<input type="checkbox"/>	Black Caribbean	<input type="checkbox"/>
Black African	<input type="checkbox"/>	Black other	<input type="checkbox"/>
Indian	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>	Chinese	<input type="checkbox"/>
Other (Please state)	<input type="text"/>		

5. Please state your mother and father's job (if retired what did they do before retirement?)

Father's job

Mother's job

6. How old were you when you left school? Years
7. How many GCSEs did you get at grade C or above? Number of GCSEs
8. How would you describe your current occupation? (Please tick below)

Employed	<input type="checkbox"/>	College course	<input type="checkbox"/>
Job training scheme	<input type="checkbox"/>	Self employed	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>	Employed but off sick	<input type="checkbox"/>
Caring for the home	<input type="checkbox"/>	Caring for your children in your home	<input type="checkbox"/>
Unable to work	<input type="checkbox"/>	Other (Please state)	<input type="text"/>

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOUR HEALTH:

1. How old were you when you had your first epileptic attack? Years
(By epileptic attack we mean any fits, seizures, convulsions or episodes of unconsciousness.)
2. How old were you when the doctor said that you had epilepsy? Years
3. When did you last have an epileptic attack? Day Month Year
4. How many epileptic attacks have you had in the last year? Tick below
- | | |
|-----------------------|----------------------|
| None | <input type="text"/> |
| Less than 1 per month | <input type="text"/> |
| 1 or more per month | <input type="text"/> |
5. Do you take any medication for epilepsy? Yes No
If yes, please give the name of the tablets and how much you take every day
- | | |
|------|----------------------|
| Name | <input type="text"/> |
| Dose | <input type="text"/> |
6. Do you suffer from any other long-standing illnesses apart from epilepsy for which you have had medical care? (Examples of such an illness could be asthma, diabetes, or arthritis)
Yes No (Please tick)
- If you answered Yes please give the name of the illness
7. Have you ever had a head injury that required hospitalisation?
Yes No (Please tick)
- If Yes please give details
8. Have you ever had a stroke?
Yes No (Please tick)

9 Below are some descriptions of different kinds of epileptic attacks. Which of these descriptions matches the attacks you have? (You may of course have more than one kind of attack. If so, please tick all of the boxes that apply to you)

A grand mal attack. Unconsciousness with the body becoming stiff with jerking of all the limbs and frothing at the mouth, possibly with difficulty breathing. Followed by a period of sleepiness and confusion lasting for at least 5 minutes before a full recovery. ☐ 1

A petit mal attack. A brief episode of no more than a few seconds with blankness without falling and possibly flickering of the eyelids. ☐ 2

Attacks with a trance-like state, sometimes with lip-smacking, swallowing, gesturing or fidgeting, followed by confusion, usually with at least a minute before full recovery ☐ 3

Attacks of falling with brief loss of consciousness preceded by a feeling of light headedness which comes on gradually, but which may be followed by sweating, clamminess. Shakiness and sickness ☐ 4

Brief jerks of the arms and body (sometimes the legs) occurring usually within an hour or two of waking without any blackout. ☐ 5

Some other kind of attack ☐ 6
(Please describe below)

.....
.....

NOW SOME MORE DETAILED QUESTIONS ABOUT THE ATTACKS YOU HAVE. PLEASE ANSWER THEM ONLY IF YOU HAVE HAD ATTACKS IN THE LAST YEAR.

Please take care to answer every question. Ring the number that applies to you.

10 How often have your attacks occurred at a particular time of day or night?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never - my attacks occur at any time 4

11 When your attacks have happened, how often have you been able to tell when you will have them?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

12 How often have you been able to fight off your attacks?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

13 How often have you had an aura or warning with your attacks?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

14 In the last year, how much control have you had over your attacks?

- a) very good control 1
- b) fairly good control 2
- c) little control 3
- d) no control 4

15 When you have had attacks, how often have they occurred together, in clusters, with quite long periods between each cluster?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

16 How often did your attacks occur when you were asleep?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

17 How many of the things you want to do have your attacks stopped you from doing?

- a) all of them 1
- b) a lot of them 2
- c) a few of them 3
- d) none of them 4

18 Overall, how severe have your attacks been in the last year?

- a) very severe 1
- b) severe 2
- c) mild 3
- d) very mild 4

19 In the last year, have you blacked out/lost consciousness during attacks? If yes, generally for how long?

- a) Yes, for less than 1 minute 1
- b) Yes, for between 1-2 minutes 2
- c) Yes, for between 2-5 minutes 3
- d) Yes, for more than 5 minutes 4
- e) No, I have not blanked out/lost consciousness 5

20 When you had an attack did you smack your lips, fidget or behave in an unusual manner?

- a) Yes, always 1
- b) Yes, usually 2
- c) Yes, sometimes 3
- d) No, never 4

21 When you recovered from your attacks, did you feel confused? If yes, for how long?

- a) Yes, for less than 1 minute 1
- b) Yes, for between 1-5 minutes 2
- c) Yes, for between 6 minutes - 1 hour 3
- d) Yes, for over 1 hour 4
- e) No, I did not feel confused at all 5

22 When you recovered from your attacks how confused did you feel?

- a) very confused 1
- b) fairly confused 2
- c) slightly confused 3
- d) not feel confused at all 4

23 When you had your attacks, how often did you fall to the ground?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

24 When you recovered from your attacks, how often did you have a headache?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

25 When you recovered from your attacks, how often did you feel sleepy?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

26 When you recovered from your attacks, how often did you find that you had wet yourself?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

27 When you recovered from your attacks, how often did you find that you had bitten your tongue?

- a) always 1
- b) usually 2
- c) sometimes 3
- d) never 4

28 When you recovered from your attacks, how often did you find that you had injured yourself (other than biting your tongue)?

- | | |
|--------------|---|
| a) always | 1 |
| b) usually | 2 |
| c) sometimes | 3 |
| d) never | 4 |

29 When you had your attacks, how quickly could you usually return to what you were doing?

- | | |
|----------------------------------|---|
| a) in less than 1 minute | 1 |
| b) in between 1-5 minutes | 2 |
| c) in between 6 minutes - 1 hour | 3 |
| d) in over 1 hour | 4 |

Appendix 8 Standard instructions for the Specific Form of the Adolescent Coping Scale

Students have a number of concerns or worries about things such as school, work, family, friends, the world, and the like. Which is the main concern for you in terms of your life? Please describe your main concern, very briefly, in the space below.

My main concern is

Below is a list of ways in which people of your age cope with a wide variety of concerns or problems. Please indicate by circling the appropriate number, the things you do to deal with the particular concern or worry you have just described. Work down the page and circle 1,2,3,4 or 5 as you come to each statement. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which best describes how you feel.

For example, if you **sometimes** cope with your concern by 'Talk to others to see what they would do if they had the problem' you would circle 3 as shown below.

	Doesn't apply or don't do it	Used very little	Used some- times	Used often	Used a great deal
1. Talk to others to see what they would do if they had the problem	1	2	3	4	5

Appendix 9 Feedback questionnaire for the pilot study

Questionnaire Feedback

Thankyou for filling in the questionnaire. Please could you give your opinion on whether the questionnaire was 'user-friendly' or not. This will help me to make changes to make it easier for other people to fill in the questionnaire.

Please answer the questions below:

1 On the whole, how easy was it to fill in the questionnaire? Please circle below:

1	2	3	4	5	6	7
Very easy						Very difficult

3. How easy were the questions to understand? Please circle below:

1	2	3	4	5	6	7
Very easy						Very difficult

3. How long did it take to fill in the questionnaire?Minutes

4. Was there any part of the questionnaire that you did not like? Yes/No

5. If you answered 'yes' to question 4, please describe which part of the questionnaire you did not like below:

.....
.....
.....

6. Would you recommend filling in this questionnaire to a friend? Yes/No Circle

7. If you have any other comments about how the questionnaire could be improved, please write them below:

.....
.....
.....
.....
.....
.....
.....
.....

Thankyou for your feedback

Appendix 10 The Standard Occupational Classification System of the Office of Population Censuses and Surveys

Participants' socioeconomic class was estimated from the classification of their father's occupation according to the Standard Occupational Classification System of the Office of Population Censuses and Surveys. Occupations are classified into the following nine groups and the types of occupation to which they refer. The category of 'unemployed' was added to the classification system.

Classification	Constituent occupations
1 Managers & Administrators	Corporate managers and administrators, Managers/proprietors in agriculture and services
2 Professional Occupations	Science and engineering professionals, health professionals, teaching professionals, other professional occupations
3 Associate Professional & Technical Occupations	Science and engineering associate professionals, health associate professionals, other associate professional occupations
4 Clerical & Secretarial Occupations	Clerical and secretarial occupations
5 Craft & Related Occupations	Skilled construction and engineering trades, other skilled trades
6 Personal & Protective Service Occupations	Protective service occupations, personal service occupations
7 Sales Occupations	Buyers, brokers and sales representatives, other sales occupations
8 Plant and Machine Operatives	Industrial plant and machine operators, assemblers, drivers and mobile machine operators
9 Other Occupations	Other occupations in agricultures, forestry, fishing and other elementary occupations
10 Unemployed	

Appendix 11 Occupational status of the participants and their fathers

Occupational status of the participants in the patient and control groups

	Patient group N36		Control group N31	
Participant occupation	Employed	6	Employed	7
	Job training scheme	5	Job training scheme	0
	Unemployed	4	Unemployed	4
	Unable to work	2	Unable to work	1
	College course	11	College course	11
	Self employed	2	Self employed	0
	Employed but off sick	2	Employed but off sick	0
	Caring for children at home	0	Caring for children at home	1
	School	4	School	7

Occupational information regarding the fathers of the participants in the patient and control groups according to the Office of Population Censuses and Surveys Standard Occupational Classification System

	Patient group N31		Control group N30	
Fathers occupation	Managers	2	Managers	1
	Professionals	4	Professionals	9
	Associated professional & technical	7	Associated professional & technical	6
	Clerical & secretarial	0	Clerical & secretarial	0
	Craft	9	Craft	3
	Personal & protective service	1	Personal & protective service	4
	Sales	2	Sales	2
	Plant & machine operatives	4	Plant & machine operatives	3
	Other	2	Other	1
	Unemployed	0	Unemployed	1

Appendix 12 Anti-epileptic medication taken by each participant in the patient group

The different anti epileptic drugs were classified in the following way:

0	No medication
1	Sodium Valproate, Epilim
2	Lamotrigine, Lamictal
3	Carbamazapine, Tegretol, Tegretol Retard
4	Gabapentin, Neurontin
5	Vigabatin
6	Phenytoin, Epanutin
7	Clobazam, Frisium
8	Ethosuximide, Zarontin

Participants provided details of the anti-epileptic medication they were currently taking. This information is summarised in the table below. In column three of the table, each drug is identified by a number to avoid confusion over the various brand names it is sold under.

Participant	Anti-epileptic medication	Medication classification No.
1	Sodium valproate	1
2	Lamotrigine	2
3	Sodium valproate	1
4	None	0
5	Sodium valproate, Tegretol Retard	1,3
6	Sodium valproate	1
7	Sodium valproate	1
8	Epanitun, Frisium	6, 7
9	Sodium valproate	1
10	Carbamazapine	3
11	Lamotrigine	2
12	Sodium valproate	1
13	Tegretol, Lamotrigine	3,2
14	Tegretol	3
15	Gabapentin, Carbamazapine	4
16	Sodium valproate	1
17	Sodium valproate	1
18	Sodium valproate	1
19	Sodium valproate	1
20	Tegretol	3
21	Carbamazapine	3
22	Neurontin	4
23	Sodium valproate	1
24	Zarontin	8
25	Carbamazipine	3
26	Sodium valproate	1
27	Sodium valproate, Vigabatrin	1,5
28	Sodium valproate	1
29	Sodium valproate	1
30	Sodium valproate, Tegretol Retard, Lamictal	1,3,2
31	Tegretol	3
32	Sodium valproate,	1
33	Sodium valproate, Tegretol Retard, Lamictal	1,3,2
34	Sodium valproate	1
35	Lamictal	2
36	Tegretol Retard	1