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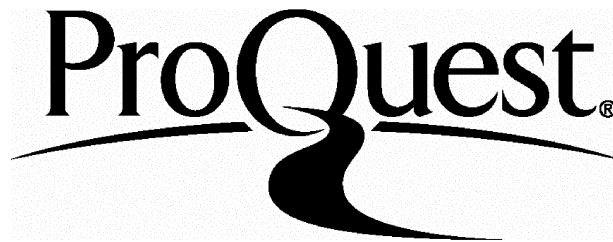
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ABSTRACT

The effects of developing epilepsy in childhood upon later psychological well-being were investigated by comparing a group of 16 people who developed epilepsy as children with a group of 16 people who developed the condition in adulthood. It was hypothesised that adolescence is a crucial period in psychological development and that the effects of developing epilepsy on body image, self-concept and social relationships during adolescence will have long term negative effects on psychological well-being. Self-esteem and self-perception were assessed using repertory grids, an assessment technique developed from personal construct theory. On measures of depression, the adult onset group demonstrated significantly higher scores than the childhood onset group. On measures of self-esteem and self-perception, both groups demonstrated a positive construction of self but some differences between the two groups were observed that appeared to reflect the view that other people construed people with epilepsy negatively. Further differences were observed between men and women, employed and unemployed people and those people who were involved in a significant intimate relationship and those who were not. Overall results were encouraging, indicating that people with epilepsy can demonstrate high levels of psychological well-being, regardless of the age of onset of the condition. The potential clinical and research implications of the results were considered, as well as the limitations of the study.

DEPRESSION, SELF - ESTEEM
AND SELF - PERCEPTION IN PEOPLE WITH EPILEPSY.
A COMPARISON OF CHILDHOOD AND ADULT ONSET GROUPS

INTRODUCTION

Epilepsy is a chronic, and complex, neurological condition that is characterised by isolated, recurrent episodes, known as *seizures*. It is these seizures that produce the sudden and dramatic disruption of the persons normal senses (Walsh, 1994). Epilepsy is not a rare disorder affecting few people. Indeed, it is one of the most prevalent of all neurological disorders (Hermann and Whitman, 1992; McLin, 1992)). The condition is estimated to have a prevalence rate in the United Kingdom of between 0.5 and 2%, with single seizures occurring at a rate of about 2 - 6 %. These figures suggest that perhaps as many as 300,000 to 500,000 people in the United Kingdom will have epilepsy at any one time, (Brown et al., 1993).

Such a seemingly simple and straightforward description of epilepsy, as a chronic condition characterized by recurrent seizures, belies the real complexity of epilepsy as a disorder. The disruption of the senses can take numerous forms, and, as a result, there is often considerable confusion as to

the cause of the disruption. Indeed, one of the most remarkable clinical features of epilepsy, and associated epileptic disorders, is the discontinuity of the symptoms associated with them. The interval between seizures can vary widely - being minutes, hours, weeks or even years. It is, therefore, extremely difficult to provide a basic set of symptoms that are to be expected in all, or even most, people with the condition (Kolb and Wishaw, 1985). Although there are many different forms of epilepsy and many different manifestations, however, there are three symptoms that do tend to predominate in many forms: (1) an *aura*, or warning, of an impending seizure. This may take the form of sensations such as smell and noise, or may simply be a vague feeling that a seizure is about to occur. (2) *Loss of consciousness*. This may take the form of a total collapse or may simply take the form of staring into space. The loss of consciousness is often accompanied by a period of amnesia where the person involved can forget both the seizure itself and the period of lost consciousness. (3) *Movements*. Seizures often have a motor component, which can vary considerably in form and degree. In some cases there are shaking movements or writhing, in others there are automatic movements such as rubbing the hands or chewing (Kolb and Wishaw, 1985).

Because of the great variety of disturbances of movement, sensation, behaviour, and/or consciousness that have been associated with epilepsy, the condition has proved difficult to diagnose with any degree of certainty. It is known that the seizures themselves occur as a result of excessive, temporary neuronal discharging, (Gillham, 1986), although the actual cause of the abnormal

electrical discharge within cells is still poorly understood (Kolb and Wishaw, 1985). Because excessive electrical activity is known to be the cause of seizures, EEG recordings, which demonstrate the abnormal electrical rhythms in the brain, are often used when attempting to make a diagnosis. Useful as it can be, however, the EEG is not a fool proof measure, and cannot always be relied upon to produce an accurate result. Some seizures, for example, are induced only under special circumstances and, conversely, some people with abnormal EEG results show no evidence of seizures (Kolb and Wishaw, 1985). As is becoming evident, diagnosis of epilepsy is far from an exact science, and the difficulties associated with making a diagnosis are aggravated by the vast array of terms which have been, and continue to be, used to define what are essentially the same or at least very similar conditions (Walsh, 1994).

As well as having numerous manifestations, epilepsy can have numerous causes, although epilepsies are generally thought of as belonging to one of two major groups. The so-called *idiopathic epilepsies* appear to arise spontaneously and have no obvious or identifiable cause. Furthermore, people with such epilepsies have no obvious structural damage to their brains. *Symptomatic epilepsies*, on the other hand, develop as a consequence of organic brain damage, resulting either from strokes, surgery or head injury for example, or from disease such as meningitis, or encephalitis, and even exposure to toxic chemicals can produce the necessary damage (Kolb and Wishaw, 1985).

Seizures, too, vary widely in both aetiology and presentation, but some division into distinct types has been attempted. Seizures are usually divided

initially according to whether the disturbance in neuronal functioning originates in a localised, or focal, area of the brain, resulting in so-called *partial seizures*, or whether the disturbance is generalised, affecting both cerebral hemispheres from the beginning, resulting in what are termed *generalized seizures*. Some seizures do not fit neatly into either category (Chadwick and Usiskin, 1987). Within the two major groups there can be some further division and delineation (see Table 1.).

Table 1. Types of epileptic seizure. (Walsh, 1994).

Generalized Seizures (bilaterally symmetrical without local onset)

Tonic - clonic seizures (*grand mal*)

Absences (*petit mal*)

Other forms

Partial Seizures (seizures beginning locally)

Seizures with elementary symptomatology

With motor symptoms

With sensory or somatosensory symptoms

With autonomic symptoms

Seizures with complex symptomatology

With impairment of consciousness only

With cognitive or affective or psychomotor symptoms

Unilateral Seizures

Unclassified

Table 1. depicts an international classification based on the criteria described earlier. It is a classification that has been developed and adopted by many clinicians. Although it is widely used, however, it does not enjoy the

universal support amongst all professionals that was envisaged during its original development (Walsh, 1994.).

The major feature of most generalized seizures is disordered muscular contraction. The term *tonic - clonic* describes the two main phases of what used to be called *grand mal* seizures. In the tonic phase muscles contract, which can cause a grunt or cry if the respiratory muscles are affected. Swallowing is lost, muscle contraction may produce incontinence, and a lack of oxygen may cause the person to become cyanosed. After a brief time, often only a few seconds, the clonic phase of the seizure begins, being marked by rhythmic contraction of limbs and trunk. When the clonic phase has passed, the person generally passes from stupor to confusion and then to a normal conscious state. In *absence seizures*, which were formerly known as *petit mal* seizures, attacks are usually brief with abrupt onset and termination. Ongoing activity is disturbed, with mental function being interrupted, and activity is usually resumed suddenly after the seizure concludes (Walsh, 1994).

Partial seizures have two main types: (a) those with elementary symptoms, and (b) those with complex symptoms. The former (also known as *simple partial seizures*) generally occur without any loss of consciousness, while the latter (also called *complex partial seizures*) result in some impairment of consciousness. The nature of the observed disturbance with simple partial seizures will depend on the site of origin of the neuronal disturbance . For example, abnormality in the temporal or parietal area may produce temporary dysphasia, whereas abnormality in the frontal region may result in motor disturbance. Complex partial

seizures most commonly originate in the temporal lobe (hence the term *temporal lobe epilepsy*) and are characterized by three common manifestations: (a) subjective feelings, such as repetitive thoughts, mood changes, déjà vu or hallucinations; (b) automatisms, such as lip smacking or repetitive acts; (c) postural changes, such as frozen posture (Kolb and Wishaw, 1985).

The other major group of seizures, the so - called *Unilateral seizures*, are distinct in that the excessive neuronal discharge is restricted to only one hemisphere, and the physical manifestations are generally exhibited on the *contralateral* side of the body. A distinctive and interesting feature of unilateral seizures is that EEG recordings from people who have these seizures will generally show no signs of abnormal brain wave activity between attacks (Walsh, 1994).

Whilst it may appear useful, and, indeed, has proved useful to many clinicians, the division of seizures outlined above has not been wholly embraced by all professionals, and is certainly not without its problems. There is often considerable difficulty in distinguishing between the points of origin of seizures; partial seizures may spread to become secondary generalized seizures, and original symptoms reflecting a focal origin may not always be recalled or their significance noted (Hockaday, 1986; Walsh, 1994). Such confusion can have a more widespread effect than the inability to pinpoint the origin of the seizure, and can lead to mis-diagnosis of the condition (Walsh, 1994).

The actual *precipitants* of seizures are as many and varied as the seizures themselves. They can include: sensory stimuli, such as flashing lights, lines of

text on a page, or particular sounds; hormonal changes such as menses, puberty, changes associated with pregnancy, or the use of steroid medication; emotional stressors; sleep deprivation or, conversely, too much sleep; the use of some stimulants, such as alcohol, and certain drugs such as tricyclic antidepressants and, perhaps surprisingly, the over-use of anticonvulsant medication; and physical states such as hyperventilation and fever. Any one individual may be affected by one or many of these precipitant factors and the precipitants that affect people can alter at various stages of their life. At puberty, for example, precipitants can change, requiring an alteration in medication (Kolb and Wishaw, 1985). Although all of the above have been implicated in epilepsy, however, there is no definitive list of precipitating factors that can be applied with certainty in all cases. As a result, difficulties with diagnosis can be further complicated.

Whatever the origin of the seizures, however, it is clear that they can have some extremely distressing effects. Moreover, some precipitating factors can lead to limits and restrictions being imposed on the everyday lives of people with epilepsy. For example, they may have to avoid certain types of lights or sounds, and may thus be restricted in where they can go and what leisure activities they can pursue (Chadwick and Usiskin, 1987). Some control over seizures is possible by the careful use of anticonvulsant medication, which works by 'dampening down' the excessive neuronal activity, but successful control is largely reliant on an accurate diagnosis and a careful assessment of seizure activity (Kolb and Wishaw, 1985). As is already apparent, however, seizure

activity is so varied and diagnosis, therefore, so complicated, that accuracy in diagnosis is not always possible.

This is not to undermine or criticize the clinician faced with making such a diagnosis, however. Indeed, given the complexities surrounding epilepsy as a disorder, it is hardly surprising that mis-diagnosis has not been an uncommon event, (Chadwick, 1988). It is important, however, that care is taken to try and ensure that a correct diagnosis is made, since it is widely accepted that there are many deleterious effects of epilepsy. These effects can be widespread and significant, extending beyond the actual occurrence of seizures and threatening the quality of life of those affected as well as the quality of life of their families (Hermann and Whitman, 1992; Hermann, 1992; Chadwick, 1990).

To the general public, epilepsy has traditionally been a condition that is associated with fear and stigma, and has often led to those people with epilepsy suffering both social and public ostracism (Wilde, 1995). The stigma that is associated with epilepsy may be related to the very obvious and distressing physical manifestations of some seizures. As we have seen earlier, the effects of some seizures are quite dramatic and can engender both fear and prejudice in the outsider who may not fully understand what is happening (Wilde, 1995). On the other hand, stigma has, perhaps, been encouraged historically by some of the hypotheses that have been put forward by professionals about both epilepsy and those people with epilepsy. A good example of this is Cesare Lombroso's theory that epilepsy was the essential neurological basis for criminal behaviour. This had a profound impact on thinking at the time, however erroneous a theory

it may subsequently have proved to be, encouraging those with epilepsy to be thought of as somehow 'evil' or lacking in morality, and it may ultimately have led to the development of the pejorative idea of the "epileptic personality"(Hermann and Whitman, 1992; Pasternak, 1981). Thankfully, with an increase in understanding of the condition and greater control of seizures, the stereotyped image of the epileptic personality has been largely rejected as both a medical and psychological concept. Unfortunately, however, both the term and the beliefs associated with it may still persist in lay perceptions about both epilepsy and those with the condition (Wilde, 1995).

Other reported effects of epilepsy have included academic underachievement, emotional distress, and higher than average levels of stress (McLin, 1992), as well as increased bullying from peers in school (Wilde, 1995). Moreover, the normal learning process can be severely disrupted by the effects of seizures, anticonvulsant medication, possible cognitive deficits, and a school environment that both ill understands and fails to support the child concerned (Hauser and Hesdorffer, 1990a). Similarly, as regards the employment of people with epilepsy, it would appear that the unemployment rate for those people with the condition is proportionally much greater than that for the general population (Floyd, 1986; Hauser and Hesdorffer, 1992b). Potential employers are often ignorant of what is and is not appropriate employment for people with epilepsy and potentially good employees are denied the chance to work as a result of this. Furthermore, some employers will not take on a person with epilepsy either because they do not understand the condition, or because they are afraid of the

consequences of it (Seidenberg and Berent, 1992).

There is also a substantial amount of evidence that some people with epilepsy are at higher risk than people without epilepsy for a whole variety of different emotional and mental disorders (McLin, 1992). With some forms of epilepsy, the effects of the condition itself may be associated with irritability and more subtle mood disorder (Blumer et al., 1988; Mendez, 1988), but there is evidence that people with epilepsy are also at higher risk of depression, anxiety and some forms of psychosis (Mendez, 1988). Evidence also suggests that people with epilepsy are at higher risk than the general population for suicide (Barracough, 1981; Mendez et al., 1988). Such psychopathology may be more prevalent amongst individuals with epilepsy than it is amongst individuals with other neurological conditions, as well as those with other chronic, non - neurological, disorders (Hauser and Hesdorffer, 1990).

It is important to note, however, that such consequences are certainly not inevitable, and many people with epilepsy appear to go through life with no difficulties at all, or at most only minimal difficulties (Seidenberg and Berent, 1992). It is certainly possible that the reported estimates of the psychological and social disability associated with epilepsy are *overestimates*. This may be because of a tendency to use hospital based research participants, and the study of *patients* does not always inform about *people in general* (Hermann and Whitman, 1992). Nonetheless, there can be little doubt that some people with epilepsy *do* have associated emotional and psychological difficulties that cannot always be treated pharmacologically, requiring instead a more psychologically

based intervention (McLin, 1992). If these difficulties are to be minimized, or perhaps even eradicated, it is necessary to provide interventions that are appropriate to both the *difficulty*, be it reported or observed, and to the *individual* concerned. A considerable task is involved, therefore, in identifying those risk factors that may predispose people to psychopathology, as well as the likelihood of any of the identified potential risk factors being applicable to the particular individual concerned.

Chronic illnesses, as a whole, have long been recognised as being generally associated with an increased risk of psychopathology (Wells, Golding and Burnam, 1988). The potential risk factors for such psychopathology in people with chronic illnesses are numerous and several attempts have been made to categorise them. Eiser (1992) outlined three major groups of factors, namely, *disease-related*, *intrapersonal*, and *environmental* factors, which she identified as being important determinants of the psychological well being of children with chronic disease. The disease-related factors, according to Eiser, include severity of the condition, degree of chronicity and the imposed restrictions on activities enforced by the condition; intra-personal factors include the affected individuals personality, their intelligence and their social background; environmental factors, according to Eiser, may be thought of as encompassing the attitudes of parents, particularly the mother, and others to the condition (Eiser, 1992).

A similar group of factors is identified by Varni and Wallander (1988). They stress the *intrapersonal* variables, such as the severity of the disease, the

amount of functional dependence associated with the disease, and the temperament and coping style of the sufferer ; *socio-ecological* factors, such as marital and family functioning, socio-economic status of the family, family size and the extent of the families utilisation of services; and the *interpersonal* variables, which include the temperament and coping style of the mother.

Interestingly, whilst many studies have focussed on the role of the mother, possibly because the additional demands a chronic disease induces tend to fall more heavily on the mother (Wilde, 1992), little specific research attention has been paid to *fathers* of chronically sick children. What evidence *is* available indicates that the fathers most crucial role lies in supporting the mother. For example, Walker, Ford and Donald (1986) demonstrated that mothers' estimates of the severity of a child's condition tended to be mediated by the level of *paternal* support available. Thus, the more supportive the father was, the less severe the condition was perceived to be by the mothers.

The potential risk factors for psychopathology that have been identified as being more specifically associated with *epilepsy* are similarly numerous to those identified in other conditions. As with chronic diseases in general, some attempts have been made to categorize these factors, and one of the more useful attempts has seen them conceptualized into *three* major categories - biological factors, psychosocial factors, and factors deemed to be related to medication (Hermann and Whitmann, 1984; 1992; See Table 2.).

Table 2. Potential Aetiological Factors for Psychopathology in Epilepsy.
(Hermann and Whitman, 1992)

NEUROLOGICAL

Age at onset; duration; seizure type; aetiology; seizure control;

Phenomenological aspects of seizures; presence/absence structural damage

PSYCHOSOCIAL

Perceived stigma; perceived discrimination; employment status;

fear of seizures; financial stress; parental overprotection; social support

MEDICATION

Monotherapy vs polytherapy; presence of barbiturate drugs; folate deficiency;

hormonal/endocrine effects; alteration of monoamine metabolism;

effects on cerebral metabolism

As can be seen from this table, many of the factors identified by Eiser and Varni and Wallander as being important in chronic illnesses *in general* can also apply to epilepsy *in particular*. Thus, the attitude of others, particularly that of family members, the severity of the condition, the duration of the condition and the financial implications of the condition are considered to be important variables. Other factors, however, which could be deemed as being more specific to epilepsy, are also considered important.

Some of these factors have received a reasonable amount of research attention. Drug treatment is usually the treatment of choice for people with

epilepsy, and, as a result, medication has received much research interest. Whilst being important in the control of seizures, and being effective for the majority of people with epilepsy, anticonvulsant medication can nonetheless have numerous unpleasant and unwanted side-effects. One such effect is a reduction in the individuals cerebral metabolic rate which can have a subsequent effect on their cognitive function (Leiderman et al., 1991; Theodore et al., 1989). Moreover, some medications can alter mood state, particularly in those individuals who have a family history of depression (Brent et al, 1987). Such side effects are not necessarily known about or fully understood by, for example, teachers, colleagues and employers, and can lead to the misinterpretation of certain behaviours. For example, effects such as a lack of concentration may be misinterpreted as laziness on the part of the individual concerned, or a lack of interest in the task at hand. This can only serve to compound the negative effects of the medication, and may possibly further increase the prejudiced beliefs that are held by some people about epilepsy and those with epilepsy (Hermann and Whitmann, 1992).

By virtue of the fact that epilepsy is a disorder of the central nervous system, biological factors have also received a fair amount of research interest. A whole variety of neurotransmitters and neurohormones are altered during seizures and it has been postulated that these and other similar variables may play a role in certain behaviour problems (Meldrum, 1991; Reynolds, 1991). The type of seizure experienced, the laterality and localization of the underlying epileptogenic activity and the degree of EEG abnormality have also been

proposed as important aetiological factors in psychopathology (Smith et al., 1991; Hermann and Whitman, 1992). In those individuals with temporal lobe epilepsy, there is some evidence that ictal fear, (that is, a sense of fear experienced in the *ictal period* immediately preceding a seizure), can also be associated with behavioural changes (Devinsky et al., 1991).

Whilst it is possible to have *some* control over biological and pharmacological factors, there is little, if anything, to be done about the aetiology of the epilepsy or the type of seizure a person has. This is not to belittle the value of research in these areas, however. As Devinsky et al., (1991), have pointed out, recognition of the biological factors associated with adverse behavioural changes may allow for the development of instruments to monitor behaviour and hence of treatment protocols to help minimise progressive pathology. Moreover, if more is known about the possible behavioural manifestations of different types of seizure, and of the side effects of pharmacological compounds used, it provides a useful base line from which to measure the effectiveness and side effects of newly developed pharmacological treatments. Such aims notwithstanding, however, biology and pharmacology have, to a greater or lesser extent, received such substantial research attention because of the potential leads they provide into the more *general* relationships of neurological dysfunction to neurobehavioural disorder, rather than because of any specific interest in epilepsy (Hermann and Whitmann, 1992).

By contrast, the psychosocial/intrapersonal factors, have been afforded what may be considered a disproportionately small amount of research

attention. This is perhaps surprising given the considerable social and psychological ramifications of chronic illness, and means that this category of factors remains somewhat speculative in nature (Hermann and Whitman, 1992). None the less, these factors may be of considerable importance, and psychosocial difficulties are some of the most frequently observed problems amongst those people with epilepsy (Hermann and Whitman, 1992).

As has already been noted, however, the negative consequences of epilepsy described above, whilst being relatively common, are not inevitable. There are many people with epilepsy who appear to have adapted well to the demands of the condition, and to have successfully negotiated the many potential pitfalls associated with the condition. This may be a facet of the coping strategies used by the individual to try and cope with the implications and demands the condition imposes. It does appear that the coping strategies used by people are important modulators of stress, and that they may have some influence on the aetiology and maintenance of those psychological disorders that are associated with anxiety and depression (Davey, Burgess and Rashes, 1995). Furthermore, it seems that the coping strategies employed by the individual will play an important part in determining their psychological response to threats, responses which, in their turn, may affect the coping strategies used subsequently in similar situations (Kennedy et al., 1995, b).

Folkman and Lazarus (1980), have identified many different coping strategies, which are generally organised into eight different groups: confrontive coping, distancing, self - control, seeking social support, accepting

responsibility, escape - avoidance, planful problem solving and positive reappraisal. There is some empirical evidence to suggest that the manner of employment of these different strategies can influence later psychological well-being. An example of this is provided by Reidy, Caplan and Shawaryn, (1991), who found that, amongst spinal cord injured patients, depression was strongly positively correlated with the use of escape-avoidance coping strategies, whereas positive mood states were associated with distancing , seeking social support, positive reappraisal and planful problem solving. A further example is provided by Charlton and Thompson (1996), who, when investigating a group of survivors of traumatic life - events attending a stress clinic, demonstrated that the coping strategy most associated with psychological distress was escape - avoidance. On the other hand, those people who were predominantly employing the techniques of positive reappraisal and distancing were more likely to have a good psychological outcome. There would appear, therefore, to be a very complex relationship between coping and psychological well-being, and this relationship may account for the difficulties that some people with epilepsy experience if the coping strategies they are employing are those demonstrated to be more closely associated with psychological distress.

According to Seidenberg and Berent, (1992), however, there is another, more salient and yet quite simple, explanation for the difficulties some people with epilepsy encounter, and this explanation is to be found in the relatively early onset of the condition. They put forward the suggestion that many of the psychosocial difficulties that can affect adults with epilepsy develop because

most people with epilepsy exhibit the first signs of the condition prior to adolescence.

Adolescence can be considered to be a critical time for both the physical and the psychological development of an individual (Kennedy et al, 1995, a). It is generally accepted that it is a period of both rapid change and experimentation, as well as a period when individuals start to establish a stable and coherent identity and develop a self concept (Erikson, 1963). As well as being a period of great personal change, it is also a period where environment and social relationships tend to change. This is an important point, since it is widely accepted that an individuals conscious perceptions of the environment around them, and of themselves as seen in relation to that environment, are important determinants of both that individuals behaviour and their sense of self-esteem and self-worth (Harvey & Greenway, 1984). Clearly adolescence is an important, some may say crucial, life-stage.

The stage of life that a person is at has been highlighted as an important determinant in their vulnerability to depression (Champion and Power, 1995). Life-stage can determine, to some extent, the stressors that a person faces. Transition from one life-stage to another is often characterised by significant alterations in available roles and goals. In adolescence, which can be seen as the transition from childhood to adulthood, this alteration is usually a signal for increased opportunity. Traditionally, the opportunity now exists to become more independent, obtain full-time employment, marry and have children. If the transition from one stage to another does not result in the hoped for outcome,

however, disappointment and depression can often ensue (Champion and Power, 1995).

The great majority of people who have epilepsy begin having seizures before the age of 20, and more than 50% of cases begin in childhood (Seidenberg and Berent, 1992; Chadwick and Usiskin, 1987). Thus, most people with epilepsy will have experienced their first seizure before a period of time that is considered critical to the acquisition and development of the basic cognitive and social competencies that are deemed crucial for long-term intrapersonal, interpersonal, academic, and vocational adjustment (Seidenberg and Berent, 1992).

Coleman (1980), has stressed the importance of change in, and heightened awareness of, body image during the development of the self-concept. Certainly there is evidence that physical handicaps can be associated with a lower sense of self-worth, greater anxiety, and a less integrated view of self (e.g. Varni et al, 1989; Kinn, 1962; Pless, Roghmann and Haggerty, 1972; Harvey and Greenway, 1984). This evidence, however, is contradicted by the findings of Kennedy et al. (1995, a), looking at those affected by spinal cord injury, and Orr et al. (1989), looking at those affected by burn injury, where levels of self-esteem appeared unaffected by the quite marked alterations in body image and presentation.

Kennedy et al. (1995, a) suggest that pre-existing knowledge of your physical limitations may have a positive effect on your expectations for the future, and may thus be a protective factor that helps maintain higher levels of self-

esteem and self - worth. Such pre-existing knowledge may be possible in the more *acute* conditions, such as spinal cord injury or burn injury, but in a *chronic* condition, such as epilepsy, those affected face a rather more uncertain future with possibly a lifetime of treatment ahead and no guarantees as to the course their condition is likely to take or its ultimate outcome (Eiser, 1992). Thus it seems reasonable to assume that those people with chronic conditions will lack the certainty, and hence the protection, outlined by Kennedy et al. (1995, a), and, as has already been highlighted, chronic illness does seem to be associated with an increased risk of psychopathology (Wells, Golding and Burnham, 1988). Epilepsy, in particular, has often been associated with low self-esteem and a lower sense of self-worth (eg, Collings, 1990; Matthews et al., 1982; Dulac and Bulteau, 1993).

Seidenberg and Berent (1992), highlight the importance of stigma (whether it is real or perceived) as an important element in the person's view of themselves. Such felt or perceived stigma can have a variety of consequences, such as a pervading sense of shame and a resultant nondisclosure of the condition to others (Scambler, 1987; Scambler and Hopkins, 1990). Such nondisclosure can have serious and unwanted effects if a seizure then occurs at school or in the workplace. Whilst many people, especially children, seem quite accepting of those who are obviously physically disabled, those with epilepsy are often subjected to far more ridicule (Wilde, 1995). This may be related to Bagley's (1972) suggestion that the individual who has previously been regarded as 'normal', and is now revealed to be somehow 'abnormal' or discredited, is

subjected to far more disapproval than those who have never attempted to pass as normal in the first place.

The separation of stigma into *real* or *perceived* is an important distinction. Whilst it is probably true that to the world at large epilepsy is still a subject to be kept “in the closet” (Schneider and Conrad, 1980) studies conducted in this area appear to demonstrate that *overt* discrimination towards people with epilepsy (what we may term real or *enacted* stigma) is actually less prevalent than might be expected, with a highest reported rate of around 30 per cent (Scambler and Hopkins, 1986). Perceived (or *felt*) stigma, on the other hand, with its concomitant feelings of shame and embarrassment as well as fears of discrimination and rejection, may be significant for up to as many as 90 per cent of people with epilepsy (Scambler and Hopkins, 1986). This is an important finding, and suggests that the individuals own reaction to their condition is a more relevant consideration than the reaction of others. There are several possible explanations for this discrepancy between felt and enacted stigma. If a person already has a low opinion of themselves they may be more likely to interpret what are actually innocuous comments or events in a negative light (Wilde, 1995). Furthermore, fears and concerns about the consequences of having epilepsy, some of them justified, others rooted in lack of knowledge, misperception, or misinformation, appear to have a significant influence on psychosocial adjustment (Goldstein et al., 1990; Mittan, 1986). This is also an important factor in how well families adjust to a member having the condition. There is evidence that family members’ *perceptions* of the degree of disruption

caused by seizures is more important than the *actual* disruption in predicting how well families adjust to someone having epilepsy (Appalone-Ford et al., 1983).

Perhaps one of the more important findings of research on felt and enacted stigma is that of Wilde (1995) who reports that the experience of enacted stigma seems to change in relation to the peer group a person associates with. Thus, in school, reports of enacted stigma are quite high, whereas in the work place far fewer incidents are reported (Wilde, 1995). It could be hypothesised that such overt stigmatisation may have more serious consequences to the child or adolescent than to the adult. As has already been mentioned, adolescence is a time of great change, and experimentation, as well as a time for developing ideas of self. It is also, however, a period where individuals are under pressure to conform to a sense of social order established by the peer group (Wilde, 1995). People with epilepsy, suffering from a condition that is little understood and may be erroneously associated with mental illness and learning disability, may be viewed as posing a threat to this delicate social order and hence may be rejected from the social group and scorned by its members (Scambler, 1984). Furthermore, schools are often totally unprepared and teachers poorly-informed about the condition, about how far the child with epilepsy should be pushed to participate in school activities, or about how to explain the condition to other pupils (Eiser and Town, 1987). This can only serve to further isolate the child with epilepsy. Moreover, extensive, and sometimes unnecessary, absences from school are often reported, further limiting the opportunity not only to learn but

also to forge meaningful links with peers (Fowler et al, 1985).

From the forgoing evidence, it would appear that Seidenberg and Berent (1992) may be justified in claiming that the negative psychosocial consequences of epilepsy are closely related to the relatively early onset of the condition in most people. Certainly it would seem reasonable to assume that children with epilepsy embark on the demanding tasks of adolescence at a distinct disadvantage. Conversely, it could be hypothesised that those who have already negotiated the difficulties of adolescence, and have established a coherent sense of self, prior to developing epilepsy would have higher levels of self-esteem and better psychosocial adjustment.

As has already been touched on, among the crucial determinants of the sense of self-worth and self-esteem an individual has are their conscious perceptions of their environment and of themselves in relation to that environment (Harvey and Greenway, 1984). The term environment, of course, does not merely mean the *physical* environment, although this is one important aspect of an environment. Also subsumed under the heading of environment, however, are other people and the relationships that develop between them, groups that people may form and the relationships that develop between these groups, events that occur, and the relationships that occur between people, groups and events. All of these different aspects of relationships within the wider environment may at first appear somewhat disparate. They can, however, be brought together in a coherent whole. This is possible by the application of the theories of George Kelly, the founder of *Personal Construct Psychology*.

Theoretical basis of personal construct psychology.

The theory of personal construct psychology was first put forward by George Kelly in 1955, and took as its subject matter the whole person rather than separate fragments of the individuals psychological functioning (Winter, 1992)

At the heart of personal construct theory are the twin notions of *constructive alternativism*, and *man - the - scientist*, (Blowers and O'Connor, 1995). The former of these is based on an assumption Kelly himself put forward, the assumption that ' all of our present interpretations of the universe are subject to revision or replacement' (Kelly, 1955, p. 15, quoted in Winter, 1992). This then leads, quite naturally, to the second tenet of man - the - scientist. Each of us, according to Kelly, takes an active, interpretive stance to the world and develops our own unique view of the world around us. This highly individualised view of the world is obtained through the creation of progressive approximations to the world, based upon our own expectations and anticipations, which are then tested against outcomes and consequences . If, on the basis of the eventual outcome, our approximations are found to be wrong, or to be lacking in some way, we alter them allowing them to better fit the actual outcome (Blowers and O'Connor, 1995). In more simple terms, we could describe this process as being one where 'patterns' are created, which the individual then attempts to ' fit' onto the realities of the world. Thus Kelly's choice of words in describing man as a scientist seems entirely appropriate. Each individual attempts to make sense of their world, give meaning to it, and predict future events within it, by making hypotheses, testing them out and, if necessary, revising them on the basis of the evidence that is

collected. This process of hypothesis testing, or construing is active and ongoing. If we were to try and put this in terminology more appropriate to Kelly, we would say that the individual *construes* the world around them (Winter, 1992).

The individual person will search for repeated themes in their experience of the world and will attempt to make predictions about future events and outcomes based on these repeated themes. All of us are continually surrounded by a host of different people, objects and events, and one way in which we are able to organize our impressions of these things is by examining them and attempting to make predictions about them (Blowers and O'Connor, 1995). Some people, objects or events (which could collectively be called *elements* of the world) will appear unique. On the other hand, some elements will share certain similarities that differentiate them from other elements (Winter, 1992). The organisation of these elements, according to their similarities and differences, paves the way for the individual to create a consistent reality that fits their own unique experience. Thus, an entire system evolves, a so-called *construction* system, composed of a finite number of dichotomous *constructs*.

Constructs develop as elements are examined and organised in terms of whether they are alike or different. The consequence of this discrimination of elements as being alike and yet different from others, is a series of polarized dimensions (Blowers and O'Connor, 1995). Each resultant dimension is called, in Kelly's terminology, a construct. All constructs are bipolar in nature, having both an *emergent pole* that indicates the *similarities* between at least two

elements, and, at the other end, an *implicit pole*, that defines their *contrast* with another element or elements (Winter, 1992).

The construction system encompasses the relationships of different constructs to each other, and it is the nature of the relationships between an individuals constructs that will determine their predictions about the world. These predictions and assumptions may or may not be found to have validity when tested by actual consequences and events (Winter, 1992). Returning to the notion of man - the - scientist, each construct could be viewed as a pair of rival hypotheses, either of which may be applied to a situation . By applying our constructs to any given situation, we test them out in order to see how valid they are in that situation (Blowers and O'Connor, 1995). Thus, constructs are not to be regarded as absolutes or as truths in and of themselves. Whether or not a construct can ever be regarded as *true* is not the important issue. What *is* important is how much convenience or utility a construct has for the construer in any particular situation. If the construct is not convenient, the task is to find better alternative, one that predicts better and leads to better outcomes (Mischel, 1986). If, having used this approach, the construct is found to be valid, the construct may be retained and strengthened; if, on the other hand, it is found to be invalid the construct may subsequently be completely replaced, or at least modified to better fit the individuals experience (Winter, 1992; Blowers and O'Connor, 1995). It would follow, therefore, that those hypotheses we are most often able to replicate will produce the stronger, more robust constructs.

Constructs, then, develop from our exposure to different elements and

situations, the predictions we make about these, and the validation of these predictions through hypothesis testing. Each of us is exposed to a slightly different set of elements and situations and, as a result, our predictions will be slightly different. It should be apparent, therefore, that each individual will have a slightly different construction of the world around them, or, to put it in more simple terms, each person will view any given situation differently. Each person will construe events according to their own experience and their own constructional system. Different reactions to events would therefore follow, and it would seem a natural consequence that different behaviours would subsequently result. This is not to say, however, that all people are automatically isolated and solitary, construing events solely for the purposes of self - confirmation. Individuals may have construct systems so similar to those of others that these people will share a common outlook on life. Moreover, through the process of construing other people in a social context, these people will be apportioned roles, and these roles can serve to regulate the individuals behaviour towards others (Blowers and O'Connor, 1995).

These two latter points find confirmation in the observation that within *groups* of people, especially within particular *cultural* groups, there is often a significant degree of similarity in both construing and, as a consequence, behaviour, (Winter, 1992). This does not, however, mean that, because they belong to a particular group, people will lose their individuality. Even if they do belong to or are identified as belonging to a particular group, people would still be regarded as individuals within a group context. Furthermore, in spite of the

fact that they may share some similar constructions with other group members, the individuals construction of *themselves* may differ significantly from their construction of others within the group or, indeed, other peoples construction of *them*.

The above phenomenon is clearly demonstrated in research conducted by Hoy, (1973; 1977), investigating the meanings and beliefs about alcoholism amongst alcoholics, and Fransella, (1968), investigating self-concepts amongst people who stutter. Hoy's 1973 study demonstrated that alcoholics had a tendency to construe alcoholics as being of weak character, sexually frustrated, lonely and unhappy (although, interestingly enough, not necessarily solitary), not especially interested in food and as feeling suicidal. A further study in 1977 revealed that this construction was closely similar to that held by staff working with alcoholics and staff working in a psychiatric hospital. Perhaps the most interesting finding, however, is that, as a group, the alcoholics did not actually construe *themselves* as being alcoholic or as demonstrating the characteristics they had identified as applicable to alcoholics. Thus, members of a particular group did not relate their self-concept at all closely to a stereotype which they themselves had used for that particular class of people (Hoy, 1973). This is similar to the findings of Fransella, who demonstrated that stutterers tended to view other stutterers in the same rather stereotypical way as most non - stutterers might, but nevertheless viewed *themselves* as being intrinsically different from other stutterers. There was no relationship between the way stutterers saw the group formed by other stutterers and the way they saw themselves, and

constructs that were *not* used to describe themselves *were* used to describe other stutterers (Fransella, 1968).

The construction a person has of themselves, therefore, has to be considered within a wide frame of reference, and must take into consideration the persons perceptions of how others are construing *them*, as well as how they construe themselves. In addition, in certain instances, it may also be necessary to take into consideration the situations people may find themselves in. It is important that investigators appreciate that, for some groups of people, different situations may make certain behaviours more or less likely to occur, and each situation may thus elicit totally different constructs. This is highlighted in a study by O'Connor et al, (1994), who looked at personal constructs associated with facial tics. They found that the personal constructs elicited in situations that were deemed at high risk of inducing tics differed from those elicited in situations perceived as somehow being of lower risk. This study is also useful in other ways. It not only further illustrates that constructs can vary according to different situations, it also emphasises the important role played by anticipation, perception and expectation in the development and maintenance of constructs (O'Connor et al., 1994).

The work of Hoy and Fransella is of particular interest in that it highlights the importance that is often attached to the self-concept. It is probably true to say that the way in which the self is construed might be of particular importance and relevance when trying to develop an understanding of any difficulties an individual may have. Certainly this would appear to be the case when dealing

with somebody who demonstrates low levels of self - esteem.

Self-esteem, in personal construct terms, is generally operationally defined as being the similarity between the construing of the actual and the ideal selves, or as the tendency to apply the positively evaluated poles of constructs to the self (Winter, 1992). Investigations that have used such operational definitions have demonstrated that *low* self-esteem is a feature of many groups of people who demonstrate a form of psychopathology. It has been observed, for example, in those clients diagnosed as depressive (eg. Axford and Jerrom, 1986), and those diagnosed as having neurotic disorders (eg. Button, 1990). Amongst the latter group, agoraphobics seem to have particularly low levels of self-esteem (eg Lorenzi and Sassaroli, 1988). There are also reports of low self-esteem amongst those with anorexic symptoms (eg. Button, 1987), and female teenagers with perceived heavy weight (Worsley, 1981). Moreover, depressed individuals often construe themselves negatively not only when describing the present but also when asked to construe themselves in the future (R. Neimeyer et al., 1985), and those diagnosed as having neurotic conditions will often construe not only themselves, but also relationships involving other people deemed important, in a negative vein (Ryle, 1981).

Clearly, the construction one has of oneself is an important factor in psychological well-being, and the relationship one has with others and with the wider environment is going to be affected by this. Thus, we may propose that those who construe themselves in more positive terms will similarly construe the wider environment in more positive terms. Conversely, the experiences one has

of the wider environment and of other people is likely to have some bearing on the way in which one perceives oneself. In accordance with this, if one's experience of, and construction of, outside events and other people is consistently negative it is hardly surprising if a negative concept of self is developed.

Returning to the aforementioned negative consequences of epilepsy, and the suggestion that onset of the condition before adolescence puts an individual at greater risk of these consequences, this theory could be re-framed in personal construct terms. It could be postulated that those who develop epilepsy relatively early in life will demonstrate a constructional system in which the self is construed in more negative terms when compared to others, whereas those who develop epilepsy later in life would have a construct system in which the self is rather more positively construed.

One of the most robust findings in psychological research has been that women are more likely to suffer from depression than men (Whiffen and Clark, 1997; Roberts and Gotlib, 1997). Many possible explanations for this finding have been suggested over the years, but it would seem reasonable to assume that men and women may be exposed to different experiences and may thus present with somewhat different constructional systems. There is considerable evidence to suggest that people's vulnerability to depression and low self-worth is related to the extent to which they pursue a single, highly valued, role (Arieti and Bemporad, 1978; Beck, 1983; Rowe, 1983; Champion and Power, 1995), and those people who have had their goals frustrated are considered to be at greater

risk of becoming depressed and having lower self - worth. If men and women invest in different roles, and to different extents, we might expect different constructional systems, and different profiles of well - being, to emerge.

In the past, it has been proposed that something of a sex difference exists in the value ascribed to either the professional or the domestic role. In general terms, it was assumed that those who focused most strongly on professional achievement tended to be men, whereas women tended to focus more strongly on a domestic and interpersonal goal (e.g. Arieti and Bemporad, 1978; Chevron et al, 1978; Beck, 1983). As has already been noted, it is often assumed that epilepsy will automatically impose a series of limitations on an individuals potential for professional achievement, and we might therefore propose that, with such a sex difference in existence, men with epilepsy, being more professionally goal orientated, would be more likely to perceive their goals as being frustrated by the condition and would, therefore, show a different pattern of psychological well - being to women, whose more interpersonal goals may not have been thwarted to the same degree. The result of this perceived difference, if such a sex bias existed, would be that the two groups would indeed show different constructional systems as well as different profiles of psychological well - being as highlighted earlier.

Whether a sex difference such as that outlined above continues to exist, however, is open to debate. Simon (1992) has noted that , although women overall may still be more committed to the role of parent than men, men who do show high commitment to the parental role are equally as vulnerable to

depression as women when faced with such role strains as conduct problems in the child. This would tend to suggest that the importance of the domestic role to men may well have been underestimated in the past and that a potentially important area of concern is only now starting to become more evident (e.g. Perry - Jenkins, 1993) . Furthermore, the importance of a career and paid employment to women may have changed in more recent times. Champion and Power (1995) make the point that a woman currently in her late 50s, who has possibly never been employed since marriage, may have no expectation of, or, indeed, desire to establish, a career. A woman in her 30s, on the other hand, having been brought up in a supposedly more egalitarian society, may both desire and expect such a career. The option of having a career has become more widely available to those women born from the 1960s onwards, as the advent of more effective forms of contraception has allowed women an increasing degree of choice as to whether and when to have children, and thus provides the option for combining family and career that was not available to previous generations (Ulvik, 1993). Taking these issues into consideration, the sex differences highlighted by earlier researchers may well prove to be far less evident now in comparison to the periods in which earlier researchers were working (Nolen - Hoeksema, 1990).

Whilst it is important to highlight such issues, however, some more recent empirical evidence continues to support a gender bias that emphasizes the domestic role for women and the work role for men (e.g. Bornstein, 1992; Nietzel and Harris, 1990). This may be a function of a society which, despite paying lip

service to equality and choice, continues to perceive womanhood and motherhood as synonymous (Phoenix and Woollett, 1991) and which also perceives childcare very much as 'women's work', expecting women to compromise both education and careers for the sake of the family (Smith, 1991; Lee, 1997). Thus, although both the domestic aspect of mens roles and the work aspect of the role of women may have been underestimated, popular construction amongst much of the western world still expects a more traditional division of the sexes (Lee, 1997). With such an ethos still predominating in society, it would seem reasonable to assume that the constructional systems of men and women would reflect this ethos and would thus differ. Having epilepsy may thus be a further complication to an already fraught, if somewhat artificial, dichotomy.

If the relationships between the wider environment, other people and the construction of self are to be better understood, it is necessary to investigate an individuals construing of various aspects of their world, of the relationships between constructs, and of the structural properties of the construct system. In addition, it is necessary to investigate how an individual construes themselves, how they construe others, and how they construe themselves in relation to others. All of this is possible using a technique known as repertory grid technique.

Repertory Grid Technique

Administration of Grids

The repertory grid is essentially a structured interview procedure that

allows the researcher to look at the world according to the construct system of the subject, and, in so doing, to better understand the individual's position and view of themselves and others. The initial step is to encourage the subject to provide a list of *elements*, that is, a list of a whole variety of different aspects of their experience (Winter, 1992). The most usual procedure adopted in order to produce this list is to ask the subject to supply the names of people who fit certain role titles. These usually include the names of people likely to be deemed significant in the subject's life, such as 'your mother', 'your father', 'your partner', 'your best friend', as well as some rather more obscure, less well-defined roles such as 'a man/woman you like', 'a man/woman you dislike'. In addition, various aspects of the self will also be added, such as 'yourself as you are now', 'your ideal self', or 'yourself in a year's time'.

The idea of roles was a particularly important one to Kelly. He believed that humans, rather than possessing fairly stable, broadly generalized traits, were capable of enacting many different roles and thus of engaging in continuous change. Roles, according to Kelly, provided the means of understanding others through their own constructs, and to structure your own behaviour accordingly. In essence, being able to act out any particular role, requires that your behaviour is guided by your perceptions of what others expect that role to be. Thus, when asked to describe or role play your best friend, you would try to think and behave as if you were your best friend (Mischel, 1986). Whilst different people fitting roles is the commonest list of elements used, this is not necessarily always the case. Elements may be as varied as situations (Parker, 1981), photographs (Hoy, 1973;

Fransella, 1968), or pictures, which can be more convenient when a researcher is working with children (eg. Ravenette, 1975).

Once the list of elements has been produced, the subject is usually presented with three of these written on separate cards, and is then asked to say in what important way two of the elements are alike and therefore different from the third. This provides one pole of a construct, some examples of which may be 'depressed', 'understanding', or 'intelligent'. The contrast pole is then produced by asking how the subject would describe the third element or by asking how the subject would describe someone who was not depressed, understanding or intelligent. This procedure is repeated with another group of three elements, usually produced by replacing one of the elements in the first group of three with the next element in the list, and the process continues until sufficient constructs have been produced. If the researchers main area of interest is the subjects construction of themselves, the elicitation of self-relevant constructs will be important and thus some form of self element will be retained in every group of three presented (Winter, 1992).

The procedure outlined above will generally produce a representative sample of the subjects constructs, and requires minimal interference on the part of the investigator and hence is less likely to be 'corrupted' by any preconceived ideas the researcher may have about the client group they are investigating. Some constructs, however, may require the investigator to ask further questions if they are to be clearly understood. These are outlined below. It should always be borne in mind when questioning the subject, however, that questioning of the

constructs elicited should be regarded as a *clarification* process rather than an attempt *to change* particular constructs. What may seem superficial, illogical or strange to the investigator or the general public, may not appear so to the participant and, on the contrary, may be very meaningful to them. It is, therefore, essential to remember that the purpose of grids is to better understand the *individuals* own dimensions, and not the researchers or therapists dimensions (Mischel, 1986). Having said this, for the sake of clarity some further questions and enquiries may be necessary. Constructs requiring further elaboration, (taken from Winter, 1992), include:

- a) identical constructs to those already elicited; researcher should ask whether the two constructs actually have the same meaning for the subject.
- b) situational or superficial constructs, eg 'same colour eyes'; researcher may ask for a more important similarity.
- c) excessively permeable constructs which can be applied to all the elements but only in a dichotomous fashion, eg 'male-female'.
- d) excessively impermeable constructs which can be applied to very few of the elements, eg 'Orthodox Jew-Reform Jew'.
- e) vague constructs, eg 'they're not bad'; researcher would normally ask in what way they are not bad.
- f) constructs concerning the relationship between elements, eg 'members of the same family'; an alternative construct may be requested.
- g) 'unusual' constructs, eg 'sad-Scottish'; this may actually be the emergent poles of two different constructs, further questioning may reveal the two separate

constructs.

In some instances, the researcher may actually *provide* the subject with constructs. This procedure, of course, takes away somewhat from the personal nature of the constructional system, but it does have some advantages. The researcher may then be able to 'tap into' the subjects construing of a particular area of interest to the researcher, and providing constructs may facilitate the making of group comparisons. A compromise method may be the use of a grid in which some of the elements and/or constructs are elicited and some are supplied (Winter, 1992).

If the researchers interests lie solely in the *content* of the subjects constructs the assessment can be terminated at this stage. If examination of the *structure* of the subjects construct system is also desired, however, the elements must be sorted in terms of the constructs elicited. The most common manner in which this is done is that the subject is asked to rate or rank the elements in terms of each construct. For example, if the construct elicited is 'informed-ignorant', the subject will be asked to rate each element on a scale of, perhaps 1 to 5 , with 1 being 'informed' and 5 being 'ignorant'.

Analysis of Grid contents

The end-product of the procedure described above is a matrix of numbers. This matrix will indicate the degree to which the subject believes each construct applies to each element. For example, if the construct being considered is 'friendly', the subject may rate all elements as being equally

friendly, may rate half the elements as friendly, half as unfriendly, or they may consider all the elements to be very different in their degree of friendliness.

The remaining task is to examine the nature of the elements and constructs that have been derived from the administration of the test. Numerous methods of analysing grids by hand have historically been employed, but computer packages are also available which conduct a principal component analysis of individual grids. The most widely used of these, in both research and clinical practice, is INGRID, which is described below.

First of all, the mean rating on each construct is listed, followed by the variation about the mean. This variation is a measure of the extent to which the construct concerned discriminates between elements, and therefore of its usefulness (Winter, 1992). A measure of bias is also provided, which indicates the extent of deviation of construct means from the midpoint of the rating scale, plus a measure of the variability of element assignment on the scale. Following this, a matrix of the correlations between constructs is provided. These range from +1.0 (maximum) to -1.0 (minimum), and are assumed to reflect the psychological relationships between the person's constructs. Winter (1992), provides the example of a correlation of -0.90 obtained between the constructs 'feminine - masculine' and 'successful - unsuccessful', in one particular subject. This indicates that, for this subject, success implies a lack of femininity.

Following this, a list of the sum of squares accounted for by each element is provided, essentially denoting the meaningfulness of each element for the subject. A high score would indicate that the element concerned is salient to the

subject. Elements are further analysed by measuring the distances between each pair of elements. A distance of 0 indicates that the two elements are construed in identical terms, a distance of 1 would be expected by chance, and the measured distance rarely exceeds 2 (Winter, 1992).

A principal component analysis follows, which starts with the percentage of variance accounted for by each of the components extracted. This is followed by a table of the vectors and loadings of each element and each construct on each component. These loadings can be used to obtain a visual representation of the construct system, produced by plotting the loadings on the first two components. As a general rule, elements in opposing quadrants of a grid would be considered most dissimilar, whilst those furthest from the origin are the most extremely perceived. The output concludes with measures of the relationships between constructs and elements, which allows for a full examination of the subjects entire constructional system, or at least as much as has been gleaned on the administration of that one grid.

Many adaptations of the INGRID package have been developed in recent years, such as GAB (Higginbotham and Bannister, 1983), CIRCUMGRIDS (Chambers and Grice, 1986) and OMNIGRID (Mitterer and Adams - Webber, 1987). The most widely used, however, tend to incorporate the principal forms of analysis found in INGRID, one of these being the FLEXIGRID package of Tschudi (1984, described in Winter, 1992).

Use of personal construct theory in this study

The theory of personal construct psychology is clearly an extremely useful

one in drawing together many, or indeed all, aspects of an individual and the world they inhabit. Given the complex nature of epilepsy as a condition and also of the situations in which many people with epilepsy find themselves, personal construct theory would seem to provide a helpful basis from which to explore these different complexities. Furthermore, the repertory grid technique, as outlined above, provides both a neat and convenient method of exploration, allowing as it does the consideration of both the researchers interests and, more importantly, those areas of importance to the individual.

This study uses a form of repertory grid as a central measure of evaluation whilst attempting to address the issue of whether the age of onset of epilepsy, or, more specifically, whether onset prior to adolescence, is an important factor in determining subsequent psychological well-being. The study attempts to address this question by examining both a group of adults who developed epilepsy as children, and a group who developed the condition in adulthood, and comparing their 'psychological well - being through their constructions of themselves and their wider environments. As has been previously mentioned, many studies of people with epilepsy have tended to focus on a hospital based population, and the resultant findings may not have been more widely applicable to those living in the community. This is despite the fact that those living ordinary lives in the community account for the vast majority of people with epilepsy. This study makes some attempt to redress this issue by examining a population living in the community rather than using a hospital based sample.

In addition to measuring self-esteem by means of rep grids, it was considered important to analyse the levels of depression amongst participants as well as the coping strategies they tended to employ. Depression may be considered as an important factor governing the psychological well-being of individuals. Levels of depression have certainly been shown to be useful predictors of length of hospital rehabilitation following serious injury and of psychological state in the longer term (Kennedy, et al., 1995, b). Moreover, as already outlined above, the coping strategies that are employed by people may have some effect on their mood state, and, conversely, mood state may influence the coping strategies adopted, making the analysis of both an important issue. Furthermore, some analysis of social support was deemed necessary. As highlighted above, levels of social support may be a crucial factor in determining the well-being of people with chronic illness, and therefore need to be considered when assessing psychological well-being.

It was hypothesised that the people who had developed epilepsy as children (a) would have lower levels of self-esteem, higher negative self-perceptions and be more depressed than those who had developed the condition as adults; (b) that males and females would differ, with males showing lower psychological well-being; (c) that those involved in meaningful relationships would have higher levels of self-esteem, either because relationships themselves may improve the self-esteem of those involved in them or because people with higher levels of self-esteem may find it easier to actually form meaningful relationships in the first place.

METHOD

Participants

Recruitment of Participants

Participants were recruited through the regional support groups run by members of the National Society for Epilepsy (NSE). THE National Society for Epilepsy is an organisation run by and for people with epilepsy and their families, that aims to provide support, information and education to all those whose lives have been affected by epilepsy. The organisation also strives to increase public awareness and understanding of the condition and of those who have the condition. Initial contact was made with the named coordinator for each regional group, these names having been provided by the NSE's central office. Through the coordinators, arrangements were made for the researcher to attend one of the regular monthly meetings that the individual groups organise.

At these meetings, the researcher explained who they were and the institution they were associated with. An outline of the study was provided, explaining its purpose, as well as the reasons for the researchers particular interest in epilepsy. Group members were then given an outline of what participation in the study would involve. This comprised of a single session with the researcher, expected to last approximately an hour to an hour and a half, wherein the participant would be required to fill out three questionnaires and take part in a semi-structured interview. It was made clear that participation in the

study was entirely voluntary and that any and all information provided would be confidential and that all participants would remain totally anonymous. Interviews would be held at a time and a place to suit the potential participants.

In addition, and at the suggestion of one group member, an item was published in the newsletter of one group giving details of the study, and providing a contact number, and asking for anyone willing to take part in the study to contact the researcher.

Details of Participants

Two groups of participants were compared. The first group consisted of sixteen adults with epilepsy who had developed the condition in childhood. For the purposes of this study, a cut-off age of 16 was adopted. Thus, any individuals who had developed epilepsy before their sixteenth birthday were included in this group. The second group (adult-onset group) consisted of a further sixteen people who had developed epilepsy in adulthood, that is after the age of sixteen. Inclusion criteria for both groups were that participants should all be adults over the age of eighteen and that they should have been diagnosed as having epilepsy. Exclusion criteria for both groups were that the participants should not be suffering from any serious psychiatric illness and should not be incapable of giving informed consent to participate. Details of both groups, including ages, marital status and employment status are presented in Table 3.

(Table 3 overleaf.)

Table 3. Details of participants

Child Onset Group (n=16)	Adult Onset Group (n=16)
(Males n = 8 Females n = 8)	(Males = n 7 Females n = 9)
Age Range (Males) = 27 - 50 (mean age = 41; SD = 11.4)	Age Range (Males) = 33 - 64 (Mean age = 46; SD = 8.7)
Age Range (Females) = 24 - 47 (mean age = 33; SD = 8.7)	Age Range (Females) = 28 - 62 (mean age = 45; SD = 11.2)
Absences Only n = 3 (19%)	Absences Only n = 2 (13%)
With 'Aura' n = 5 (31%)	With 'Aura' n = 6 (14%)
Frequent Seizures n = 4 (25%)	Frequent Seizures n = 5 (31%)
Married n = 9 (56%)	Married = n 11 (69%)
Single n = 6 (38%)	Single n = 5 (31%)
Divorced n = 1 (6%)	Divorced n = 0 (0%)
Employed n = 8 (50%)	Employed n = 9 (56%)
Unemployed n = 6 (37.5%)	Unemployed n = 6 (37.5%)
Retired n = 2 (12.5%)	Retired n = 1 (6.5%)
Mean Age Onset = 5.6 (SD = 4.2)	Mean Age Onset = 24.8 (SD = 6.1)
Mean No. Drugs Taken = 2 (Range = 1 - 3)	Mean No. Drugs Taken = 2 (Range = 1 - 3)

Materials employed

Four different measures were used:

(1) Levels of depression were measured using the Beck Depression Inventory or BDI (Beck and Steer, 1987). This is a 21 item measure consisting of groups of four statements that describe how the individual has been feeling over the past week, including today. The individual circles whichever statement in each group of four most closely applies to them. Each statement is rated on a scale of 0 to 3. Individual item scores are added together to provide a total score, which has a minimum lower level of 0 and a maximum upper level of 63. A series of different cut-off scores are adopted to indicate different severities of depression. Score of 0 to 9 are considered within the normal range or asymptomatic; scores of 10 to 18 indicate mild-moderate depression; score of 19 to 29 indicate moderate - severe depression; and scores of 30 to 63 indicate extremely severe depression (Beck and Steer, 1988). The BDI is widely used in clinical and research practice. It is considered to both a valid and reliable measure.

(2) Coping strategies were measured using the Ways of Coping Scale (Revised) (Folkman and Lazarus, 1988). This measure consists of 68 items designed to assess the type of coping strategies employed by the individual in stressful situations. The individual describes a recent, stressful situation, then reads through the items on the measure. Each item describes a different way in which the person may have dealt with the situation they have described, and alongside each item is a four point lykert scale measuring the extent to which that

item was used. Each item corresponds to one of eight potential methods of coping in a stressful situation that the scale delineates. These are: *confrontive coping* (items 5, 17, 34, 46, 47); *distancing* (items 3, 12, 13, 21, 41, 44, 50, 53); *self control* (items 14, 19, 35, 37, 43, 54, 65); *seeking social support* (items 8, 18, 22, 31, 42, 45, 60); *accepting responsibility* (items 9, 25, 29, 51, 61); *escape - avoidance* (items 4, 11, 16, 32, 33, 40, 55, 57, 58, 59); *planful problem solving* (items 1, 20, 26, 39, 49, 52, 62); and *positive reappraisal* (items 2, 15, 23, 30, 36, 38, 56). The respondents scores for each group of items are summed, giving a total score for each group. The coping measured used most frequently are deemed to be those with the highest total scores. The Ways of Coping Scale, like the BDI, is considered both valid and reliable as a measure.

(3) Levels of social support received by participants were measured using the brief (six item) Social Support Questionnaire (SSQ) (Sarason, et al., 1987). Participants are asked six questions concerning the number of and types of people who provide social support in various situations, plus satisfaction with this support. Two measures are thus provided: the SSQN, which is the combined total of the numbers of people providing the support indicated by each question; and the SSQS, which is the average rating (maximum = 6) of satisfaction with the quality of social support provided. The Six Item Social Support Questionnaire is again a valid and reliable measure.

(4) Levels of self-esteem and self-perception were measured using a form of Repertory Grid, (Kelly, 1955). Fifteen separate elements were used. These were as follows:

- a) Myself with epilepsy;
- b) Myself without epilepsy;
- c) My ideal self;
- d) Myself as others see me;
- e) How others would see me if I did not have epilepsy;
- f) Myself before I developed epilepsy;
- g) A man I like;
- h) A woman I like;
- i) A man I dislike;
- j) A woman I dislike;
- k) A typical person with epilepsy;
- l) My mother;
- m) My father;
- n) My partner;
- o) My best friend.

Elements were presented in groups of three, with each triad of elements retaining element a), 'Myself as someone with epilepsy'. This method ensured that participants were given the opportunity to supply a majority of their own constructs. In addition, two constructs, namely 'disabled - not disabled', and 'hindered - unhindered', were provided by the researcher. Elicitation of constructs was terminated after 15 constructs were achieved. Following the elicitation of constructs, participants were asked to rate each element on a scale of 1 to 7 for each construct. Grids were analysed using the FLEXIGRID computer

package (Tschudi, 1984; quoted in Winter, 1992), which produces a similar output to that of the INGRID system described above.

Procedure

Following the recruitment measures described, arrangements were made to meet all those who had volunteered to participate at a time and place most convenient to them. Participants were provided with an information sheet (appended) repeating the outline of both the study and what participation in the study involved. This sheet also made it clear to participants that they could withdraw from the study at any time without having to give any reason for their decision to withdraw. Participants were given the opportunity to ask any questions they may have, and were then asked to sign a consent form (appended) indicating that they had a clear understanding of what participation in the study involved and stating their willingness to take part in the study.

Initially, participants were handed the three questionnaires involved in the assessment, and given details of how to complete them. Completed questionnaires were then handed back to the researcher before the administration of the repertory grid. It was then explained to the participant how the administration of the repertory grids would proceed. Participants were presented with a series of triads of statements and their responses were noted. This was followed by the rating of elements on the recorded scales. Finally, demographic information on subjects was recorded.

When the formal assessment procedure was completed, participants were given a further opportunity to ask questions about the study, as well the

opportunity to discuss any issues that taking part in the study had raised for them. This debriefing period was considered essential, as it was felt that discussion of their lives, their relationships with others and their condition may be distressing for some participants and may raise difficult issues for them.

RESULTS

Several statistical analyses were made using the data obtained. First, to determine whether there were significant differences in the measures of depression, self - esteem and self - perception, or in the amount of and satisfaction with social support, and coping strategies employed by the two groups, mean scores from the child onset group were compared with those of the adult onset group. Secondly, within each group comparisons were made between men and women, between employed and unemployed people and between those in a significant relationship and those not. Any significant differences found when making these comparisons were then further analysed. Thirdly, all measures of depression, self - esteem and self - perception and measures of social support and coping strategies were intercorrelated to produce an overall guide to associations. Finally, to determine how much of the variance of each outcome measure of psychological well-being could be accounted for by age, sex, marital status, employment status or coping strategies, a forward stepwise multiple regression was used.

Table 4. Mean and standard deviations of depression, self - esteem and self - perception scores for child onset and adult onset groups

	Child onset (N=16)		Adult onset (N=16)	
	Mean	SD	Mean	SD
Depression/ BDI	9.69	(8.27)	16.0	(6.76)
Self - esteem/Grids:				
a)	1.14	(0.24)	1.08	(0.26)
b)	0.36	(0.21)	0.46	(0.25)
Self - perception/Grids:				
a)	0.74	(0.13)	0.79	(0.25)
b)	1.15	(0.19)	0.73	(0.24)
c)	0.40	(0.20)	0.54	(0.18)
d)	1.13	(0.23)	1.02	(0.16)
e)	1.12	(0.24)	1.07	(0.27)
f)	0.45	(0.16)	0.55	(0.22)
g)	0.94	(0.17)	1.03	(0.17)

Table 4 shows the mean scores obtained, and standard deviations, on the Beck Depression Inventory, together with the mean distances, and standard deviations, between the pairs of elements as outlined below. Together, these

make up the measures of depression, self - esteem and self- perception, for both subject groups.

Levels of self - esteem were examined by measuring the distances between the pair of elements a) 'Myself with epilepsy ' and 'My ideal self', and between the pair of elements b) 'Myself without epilepsy' and 'My ideal self'. Self perception was examined by measuring the distances between several pairs of elements. These were: a) 'Myself with epilepsy' and 'Myself as others see me'; b) 'Myself as others see me' and 'My ideal self'; c) 'How others would see me if I did not have epilepsy' and 'My ideal self'; d) 'Myself with epilepsy' and 'A man/woman I like'; e) 'Myself with epilepsy' and 'My best friend'; f) 'Myself without epilepsy' and 'My best friend'. In addition to these measurements of self - perception, the distance between the elements 'Myself with epilepsy' and 'A typical person with epilepsy' was measured, (comparison 'g'), in order to provide some indication of the degree to which participants felt they were like other people with epilepsy.

A series of one - way analyses of variance were carried out, which compared the mean scores obtained on the measures of depression, self - esteem and self - perception for each of the two groups.

A significant difference was found between the mean scores on the Beck Depression Inventory ($F = 4.55, p < .05, 1df$) with those participants developing epilepsy in adulthood showing significantly higher levels of depression. A significant difference was also found when comparing the mean measured distances between the elements 'Myself as others see me' and 'My ideal self',

($F=25.34$, $p<.05$, 1df) with those who developed epilepsy in childhood showing a greater distance between these two elements. Differences between the two groups did not approach significance on any of the other measures.

Within both groups, comparisons were made between the two measures of self esteem, that is the pair of elements 'Myself with epilepsy'/ 'My ideal self', and 'Myself without epilepsy'/ 'My ideal self', to see if these scores differed significantly. Paired samples t - tests revealed a significant difference between these measures in both groups (child onset group' $t=12.83$, $p<.05$; adult onset group, $t=55.90$, $p<.05$).

Comparisons were made between the mean scores for men and women within both groups. No significant difference was observed in either group between mean scores on the Beck Depression Inventory.

A significant difference was observed in the child onset group when comparing the mean distances for men and women between the elements 'How others would see me if I did not have epilepsy' and 'My ideal self' ($F=6.2$; $p<.05$, 1df), with men showing a greater distance between these elements. There were no significant differences between men and women on any other pairs of elements for the child onset group. The adult onset group showed a significant difference between men and women when measuring the distance between the elements 'Myself with epilepsy' and 'A man/woman I like' ($F=5.9$; $p<.05$, 1df), with women demonstrating a greater distance between these elements.

In order to further examine the observed differences between men and women, 3 - way multiple analyses of variance were performed within each group,

using marital status, employment status and sex of participant as independent variables and measures of depression, self - esteem and self - perception as dependant variables. No significant interactions were observed between any variables in either group.

Mean scores for the two groups for each of the eight coping strategies from the Ways Of Coping Questionnaire are presented in Table 5, together with mean SSQS and SSQN scores for each group for the Social Support Questionnaire. A series of one - way analyses of variance were performed, which compared the mean scores obtained on measures of coping style and social support. No significant differences were observed between the childhood onset group and the adult onset group on either of these measures.

(Table 5 overleaf)

Table 5. Mean scores of Ways of Coping Questionnaire variables and Social Support Questionnaire variables.

	Child onset (N=16)		Adult onset (N=16)	
	Mean	SD	Mean	SD
Ways of coping variables				
Accepting responsibility	5.1	(17.1)	5.1	(21.7)
Confrontive coping	6.9	(14.8)	7.9	(24.7)
Distancing	8.6	(14.6)	10.8	(22.8)
Escape avoidance	30.7	(16.6)	24.2	(16.4)
Planful problem solving	10.6	(10.2)	11.8	(19.4)
Positive reappraisal	15.2	(15.0)	13.9	(19.6)
Self control	8.4	(9.6)	9.0	(17.1)
Seeking social support	25.4	(12.3)	31.3	(23.2)
Social support variables				
SSQN	2.7	(0.48)	3.0	(0.7)
SSQS	5.4	(0.9)	5.5	(0.5)

Comparisons were made between male participants and female participants in both the adult onset group and the child onset group on both of

the measures in Table 5. Again, none of the comparisons approached significance.

Further comparisons were made between those participants who were employed at the time of the study and those who were unemployed. These comparisons were made for all measures used, and were made in both groups. The three participants who were retired at the time of the study were not included in this comparison.

No significant differences were observed between employed and unemployed participants on any of the measures in the adult onset group. In the child onset group, however, those participants who were unemployed at the time of the study showed significantly higher scores on the BDI than those who were employed ($F=17.1$; $p<.05$, 2df). No further significant differences were observed on any of the other measures in the child onset group.

In order to further explore the differences found within the child onset group, a 3 - way multiple analysis of variance was performed using marital status, employment status and sex of the participant as independent variables and BDI scores as the dependent variable. A significant interaction was found between marital status, employment status and depression with those who were unemployed *and* single being significantly more depressed ($F=12.31$; $p<.05$, 1df) than those who were in a meaningful relationship.

Those participants involved in a significant intimate relationship were compared for levels of depression, self - esteem and self - perception with those not involved in such a relationship, and this comparison was made for both

groups. Among those who had developed epilepsy as adults, there was no significant relationship between being involved in an intimate relationship and any of the measures used. Among those who developed epilepsy as children, however, those that were involved in an intimate relationship demonstrated a significantly smaller distance between the elements 'Myself with epilepsy' and 'a typical person with epilepsy' ($F=4.5$; $p<.05$; 2df) than those not involved in an intimate relationship. There were no significant differences on any of the other measures for the group developing epilepsy as children.

Further examination of the differences within the child onset group was made using a 3 - way multiple analysis of variance, with employment status, marital status and sex of participant as independent variables and distance between the elements 'Myself with epilepsy' and 'A typical person with epilepsy' as the dependent variable. No significant interactions were observed.

Within both the child onset group and the adult onset group, Pearson product moment correlation coefficients were calculated comparing what may be termed the 'moderating variables' of chronological age, SSQN scores (number of social supports), and SSQS scores (quality of social support) with the measures of 'psychological well - being', that is, the measures of depression, self - esteem and self - perception. The results of these correlations for the adult onset group are presented in Table 6. Results for the correlations from the childhood onset group are presented in Table 7.

Table 6. Correlations between measures of psychological well - being and moderating variables for the adult onset group.

	Age	SSQN	SSQS
BDI scores	.24	.02	.29
Self - esteem/grids			
a)	-.45	.48	.50
b)	.18	.10	.12
Self - perception/grids			
a)	-.54	.18	.31
b)	-.09	.19	-.23
c)	-.38	.32	-.13
d)	-.31	.11	.39
e)	-.46	.37	.51
f)	.10	.16	.05
g)	.35	-.31	-.45

The correlations indicate that chronological age, number of social supports and quality of social support had no influence on any of the measures used for the adult onset group.

Table 7. Correlations between measures of psychological well - being and moderating variables for the childhood onset group.

	Age	SSQN	SSQS
BDI scores	.04	.31	-.46
Self - esteem/grids			
a)	.63*	-.06	.38
b)	.58*	-.43	.69**
Self - perception/grids			
a)	-.43	-.26	.15
b)	.60*	.07	-.29
c)	.65*	-.06	.65*
d)	.09	.03	-.02
e)	.26	-.04	.07
f)	.74**	-.03	.57*
g)	.09	-.07	.19

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

The multiple correlations in Table 7 highlight a number of points. Chronological age was correlated to both measures of self - esteem and to three of the measures of self - perception. Number of social supports had no influence on any of the measures, whereas quality of social support was related to one

measure of self - esteem and two measures of self - perception.

Within both the childhood onset group and the adult onset group further Pearson product moment correlation coefficients were calculated, this time comparing identified coping methods with measures of depression, self - esteem and self - perception. None of the correlations approached significance.

A series of stepwise multiple regression analyses were performed on the combined data of the two groups. Each of the measures of psychological well - being was in turn used as the dependant variable, with coping strategies, level of and satisfaction with social support, chronological age, sex, marital status and employment status as independent variables. This resulted in a number of models which could account for a certain proportion of the variance of each measure of psychological well - being. The resultant models for measures of depression and self - esteem are presented in Table 8. Models for measures of self - perception are presented in Table 9.

The models produced by the stepwise multiple regression analyses indicate that satisfaction with support and chronological age were more important in explaining the variance of scores on the measures of psychological well - being than employment status, sex of participant, marital status, level of social support or the coping strategies employed.

One single variable appeared to be the most important predictor, by virtue of its being included in the greatest number of models. This was satisfaction with the level of support received, which was a positive predictor of every measure except one - the distance between the elements 'Myself with epilepsy' and 'My

best friend'.

Chronological age was found to be in the predictive equations of three measures, being positively associated with BDI scores, one measure of self - esteem (the distance between the elements 'Myself without epilepsy' and 'My ideal self'), and one measure of self perception (the distance between the elements 'Myself without epilepsy' and 'My best friend').

Table 8. Stepwise multiple regression analyses of combined data for measures of depression and self - esteem.

Dependent variable	Independent variable(s)	Coefficient	t value
Depression/BDI	Chronological age	0.61	4.74**
	adjusted R ² = .785		
Self - esteem/Grids:			
	a) Satisfaction with support	0.97	24.07*
	adjusted R ² = .957		
	b) Satisfaction with support	0.89	9.72**
	Chronological age	0.89	9.84**
	adjusted R ² = .787		

*p < .05; **p < .001.

Table 9. Stepwise multiple regression analyses of combined data for measures of self - perception.

Dependent variable	Independent variable	Coefficient	<i>t</i> value
a)	Satisfaction with support adjusted R ² = .903	0.95	15.78*
b)	Satisfaction with support adjusted R ² = .876	0.94	13.61**
c)	Satisfaction with support adjusted R ² = .867	0.93	13.01**
d)	Satisfaction with support adjusted R ² = .951	0.86	11.96**
e)	Satisfaction with support adjusted R ² = .945	0.97	21.23*
f)	Chronological age adjusted R ² = .885	0.94	14.20**
g)	Satisfaction with support adjusted R ² = .950	0.86	22.21*

p* < .05; *p* < .01.

DISCUSSION

The initially proposed series of hypotheses are only partly supported by the results of this study. Whilst some differences have been observed between the two groups, these differences are not as numerous as was originally expected and, furthermore, not all of them are in the direction initially proposed. The results do, however, produce some interesting findings that may be of some importance when considering clinical practice.

The first hypothesis was that people who developed epilepsy as children would have lower self - esteem, higher negative self - perceptions and be more depressed than those who had developed the condition as adults. This hypothesis is only partially borne out by the findings, with significant differences between the two groups being found on only two of the measures of psychological well - being.

In terms of the indicator of depression (the BDI scores), the results obtained are completely opposite to those originally hypothesised. The *adult* onset group show significantly higher BDI scores, which indicates higher levels of depression. Indeed, the child onset groups mean score of 9.69 is only fractionally above the cut - off score of 9 that is deemed to be within the normal or asymptomatic range. The norms provided for the BDI were obtained using a normative sample, and thus the child onset group could be said to be suffering only minimally higher levels of depression to the normal population. The adult onset groups mean score of 16.0 indicates only mild to moderate depression as defined using a normative sample. Whilst it is significantly higher than the mean

score of the child onset group, and of the normal population, it is still lower than that of single episode depressives, which is held to be 23.4 (Beck and Steer, 1987). Nonetheless, the discrepancy in scores between the child and adult onset groups is in the opposite direction to that hypothesised. There are several possible explanations for this rather unexpected finding. Perhaps the most obvious and simple of these is that the better affect of the childhood onset group is attributable to the length of time that they have had the condition. It has been suggested that psychological health can improve as a function of time and the healing processes associated with this time (Christo and Sutton, 1994), and it is possible the lower BDI scores in the childhood onset group simply reflect the fact that this group have had longer to come to terms with having epilepsy.

The above explanation, however, is probably too simplistic. A second possible explanation relates to the change in life - style that are often associated with the development of epilepsy. A condition such as epilepsy inevitably imposes some limitations and changes in life - style on the person with the condition and their families, and adjustment to these changes and limitations is an important factor in determining the vulnerability of an individual to depression (Kennedy et al, 1995, b). Something that is deemed to be of particular importance is the *flexibility* of an individual, in that the more flexible a person can be, the lower their vulnerability to difficulties in the face of stress (Champion and Power, 1995). It has been suggested, (eg, Craig et al, 1990), that younger people are rather more flexible in the methods they use to cope in difficult situations, and they may thus find it easier to change their life - style, than older people. If this

is so, we might expect younger people to adjust more easily to the limitations and restrictions epilepsy imposes and this flexibility would presumably, therefore, mean they would be less vulnerable to depression. This flexibility in younger people has certainly been demonstrated in those people who have suffered spinal cord injury, with younger spinally injured people seeming to adjust more readily than their older compatriots (Judd et al, 1989), and it seems reasonable to propose that the same pattern may be true of people with epilepsy.

A third possible explanation for the discrepancy in levels of depression is related to the second, but is rather more concerned with the *perception* the people affected by epilepsy have of the options available to them, or, in personal construct terms, their construction of what is available to them. According to Oatley and Bolton (1985) vulnerability factors for depression operate by reducing, or at least seeming to reduce, the options available to an individual following a severely threatening life - event. The development of epilepsy could be considered one such life - event. It seems reasonable to assume that those people who develop epilepsy in childhood will grow up being more fully aware of the restrictions the condition can impose. For example, there is the possibility that some people with epilepsy may not be able to drive, and they are also not able to take up certain professions, the most clear bar being to a career such as pilot or surgeon. For the child onset group, an awareness of these limitations will possibly have been longstanding and may have been built into their constructional system as they mature. Growing up with an awareness of *limitations*, however, is also likely to result in a greater awareness of the

remaining *possibilities* that are open to a person with epilepsy. This awareness of possibilities may not automatically be found in those who develop epilepsy as adults who may have grown up with a somewhat more prejudiced view of the condition and whose construct system will reflect this. This being so, they may perceive the condition as being more restrictive and limiting than it is, or than it needs to be, in reality. As a result of this, they may come to see themselves as having limited options available to them, increasing their vulnerability to depression in the manner proposed by Oatley and Bolton. Some support for this can be found in the elicited constructs of the two groups, with the adult onset group quite frequently putting forward the constructs 'Restricted' or 'Limited' as descriptions of themselves. This is in contrast to the childhood onset group who used such terms only rarely.

This has some important implications for clinical practice. If people who develop epilepsy later in life are to be helped to come to terms with their condition, it is important that they are made aware that, whilst it will inevitably enforce some changes, having epilepsy does not automatically have to mean the imposition of extreme restrictions on their lives. Awareness of how limiting the client sees the condition as being could be obtained, of course, by the administration of a repertory grid as a therapeutic tool rather than a research tool, and this could be used as a basis to tackle any negative constructions the person may have. Similarly, people should be encouraged to be as flexible as possible when attempting to cope with the condition, and should be encouraged to use any and all available resources whilst attempting to make any enforced

changes in their life - style. Their current flexibility or rigidity may actually show up in the 'tightness' of their grid, that is how polarised their attribution of the different elements along the construct scales is found to be. This finding also highlights the importance of good education and provision of information, which can dispel some of the myths surrounding epilepsy and its associated limitations, a necessity if people are to be assisted in coming to terms with having epilepsy. As important as the view of the individual, of course, is the view of the staff who may themselves hold somewhat prejudiced views about the capability of people with epilepsy.

Whilst the above explanations for the discrepancy in BDI scores are all equally plausible, it is important to note that the findings are potentially influenced by a variety of factors that could be considered biological or physiological rather than social and/or psychological. As was pointed out in Table 2, the potential aetiological factors for psychopathology in epilepsy are numerous and include such factors as the physiological effects of the anticonvulsant medication that is used, the actual site of the epileptogenic activity, and the phenomenology associated with an individuals seizures (eg, do they experience an aura, do they have absences or tonic - clonic seizures ?). In an attempt to control for at least some of these factors, the two groups of people in this study were relatively evenly matched for both type and predictability of seizures, as well as the number of anticonvulsant medications being taken. The *type* of anticonvulsant used, however, as well as the dosage of individual medications, has not been controlled for in the analysis and may complicate the findings. Some

anticonvulsant medications, particularly some of the older drugs, can have an adverse effect on mood (Berent et al, 1987) and in any future research this would need to be controlled for. Moreover, the site of epileptogenic activity was not known in any of the participants in this study. Indeed it is often impossible to determine the site of the epileptic activity with any accuracy, and many people with epilepsy are unaware of the site of origin of their seizures. This is particularly true of people whose epilepsy is of the idiopathic rather than the symptomatic form (Kolb and Wishaw, 1985). It is important to bear in mind that the site of activity may have some effect on mood, and this may further complicate the findings in any study concerned with mood state. If future research could identify a group of participants with a known site of activity this area could be better controlled for. Given the difficulties inherent in such identification, however, this would appear to be an optimistic aim.

Comparison of levels of self - esteem in the two groups reveals no significant difference between them. A comparison *within* each group of the participants views of themselves with epilepsy and without epilepsy, however, suggests that the individuals concerned would feel better about themselves if they did not have epilepsy. In both groups, the distance between the elements 'Myself with epilepsy' and 'My ideal self' is far greater than the distance between the elements 'Myself without epilepsy' and 'My ideal self'. This is clearly illustrated in both Figures 1 and 2, which are the graphical representations of complete, analysed grids of two participants in the study. Figure 1 is the grid from a participant in the childhood onset group, and Figure 2 is the grid from a

participant in the adult onset group. As can be clearly seen in both grids, element 'A' (Myself with epilepsy) is at a considerable distance from element 'C' (My ideal self). Element C, in its turn, is appreciably closer to element 'B' (Myself without epilepsy).

At first glance, this distance between what are quite fundamental elements may be assumed to indicate that the individuals concerned have low self-esteem. This would certainly follow given the operational definition of low self-esteem cited earlier, which has been the basis of much research on both normal and clinical populations, and which is generally held to be a large distance between the current construction of the self and the construction of the ideal self. This definition is used for all populations.

Furthermore, the significant discrepancy between the elements may actually indicate that the person concerned has a somewhat idealized and unrealistic assessment of the imagined self without epilepsy, and this, in turn, may indicate poor adjustment to having the condition. As Kennedy et al, (1995, a), point out in their work on spinally injured people, a *moderate* discrepancy between the present self and the self without injury is likely to suggest a helpful level of realism that allows for good adjustment, whereas a large discrepancy is unhelpful and may prevent the person developing a good level of adjustment to the new demands imposed by the injury. It seems reasonable to propose that adjustment to epilepsy may follow a similar pattern, and the distances between elements may be a reflection of this.

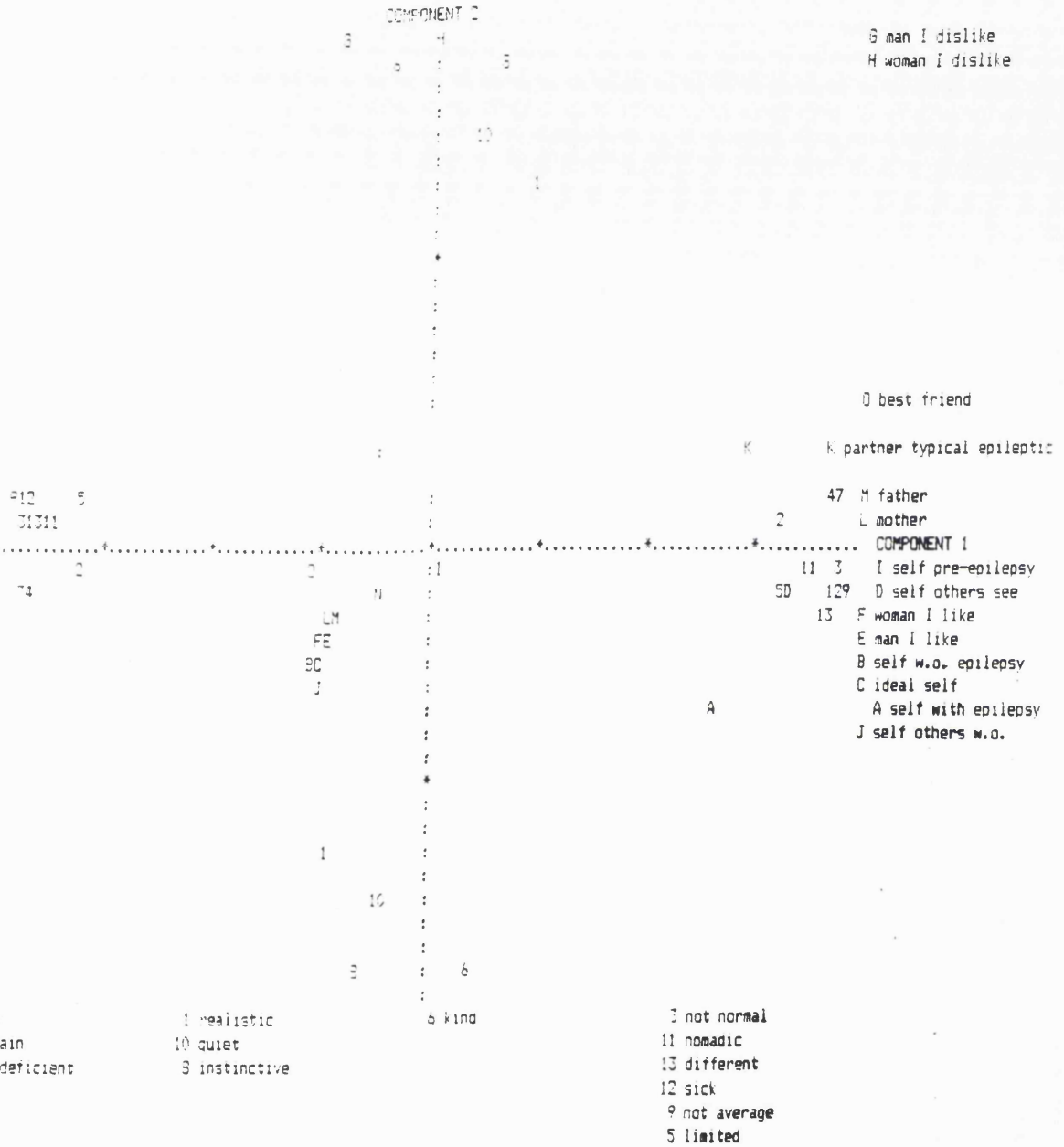
GRID TITLE: dl
 PLOT - unrotated results

5 unlimited
 7 average
 10 healthy
 13 alike
 11 settled
 3 normal

6 cruel

8 not instinctive
 10 hectic
 1 unrealistic

4 deficient
 7 uncertain
 2 disabled

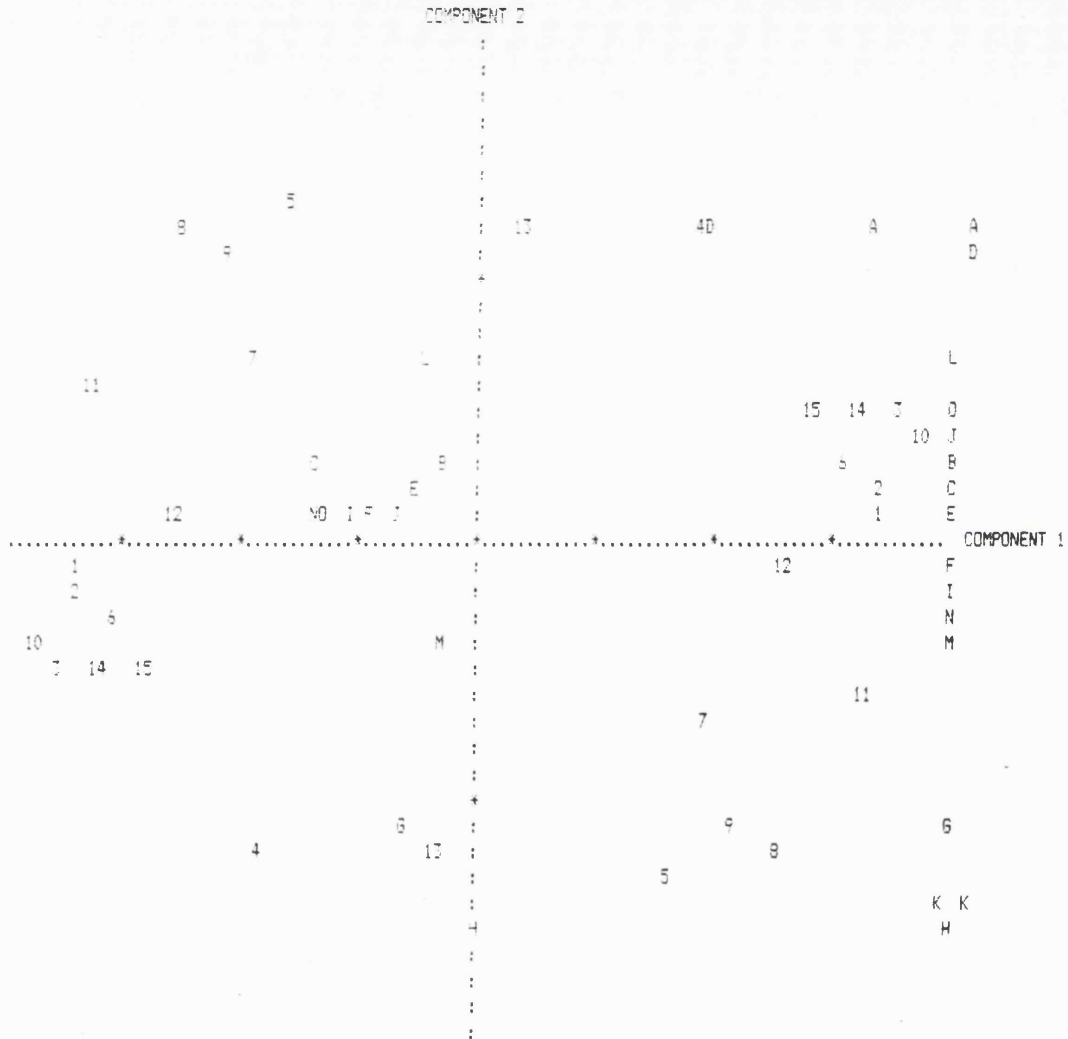


Time: 0 : 0 : 17

Figure 1. Graphical representation of repertory grid for participant 'A'.

FILE K I B R I D v4.2 May 1987. File: sh Time: 01-01-1980 00:36:44
 GRID TITLE: sh
 PLOT - unrotated results 4 picked as an IDEAL. Reflection of axis 2

- | | | | |
|------------------|-------------|-----------|---------------|
| 3 not clingy | 5 accepting | 13 kind | 15 fussy |
| 9 in real | 7 coping | 4 unaware | 14 vulnerable |
| 11 sociable | | | 3 different |
| 12 not epileptic | | | 10 insecure |
| | | | 6 guilty |
| | | | 2 abnormal |
| | | | 1 disabled |



- | | | | |
|-----------------|---------------|--------------|---------------|
| 1 able | 4 aware world | 7 not coping | 12 epileptic |
| 2 normal | 13 unkind | 5 rejecting | 11 unsociable |
| 3 not guilty | | | 9 loner |
| 10 secure | | | 8 clingy |
| 7 alive | | | |
| 14 invulnerable | | | |
| 15 not fussy | | | |

Time: 0 : 0 : 35

Figure 2. Graphical representation of repertory grid for participant 'B'.

The immediate assumption, then, when looking at the numerical distances between elements, or at the graphical representations, which indicate that the self without epilepsy is rated as closer to the ideal than the self with epilepsy, is that participants have construed an essentially negative view of themselves with epilepsy, and that this view would be enhanced if they did not have epilepsy. Following on from Kennedy et al, it could thus be proposed that the people concerned have not adequately adjusted to life with epilepsy and are unlikely to if they continue to idealise the self without epilepsy.

This, however, is far too simplistic an interpretation of the material, and is not supported by further analysis of the grids. As Blowers and O' Connor (1995) point out, whilst the distance between elements is important, if we are to get a full understanding of the constructional system of an individual it is also necessary to examine the distances between elements *and* constructs. If this is done, it becomes somewhat more apparent that the people with epilepsy in this study are actually more positive about themselves, or in Kelly's terms construe themselves in more positive terms than the distances between elements alone suggests.

This is illustrated in Figure 3. The distance between elements A and C on this graphical representation is again greater than the distance between elements B and C, but the emergent poles of both construct 1, ('Able/Disabled'), and construct 2, ('Normal/Abnormal'), can both be seen to be rated as closer to element A than to either element B or element C. This indicates that the participant concerned actually construes themselves as both normal and able, and that having epilepsy makes no difference to this view of the self.

FILEXIGF: D v4.2 May 1987. File: ch2 Time: 01-01-1980 00:10:18
 GRID TITLE: br2
 PLOT - unrotated results

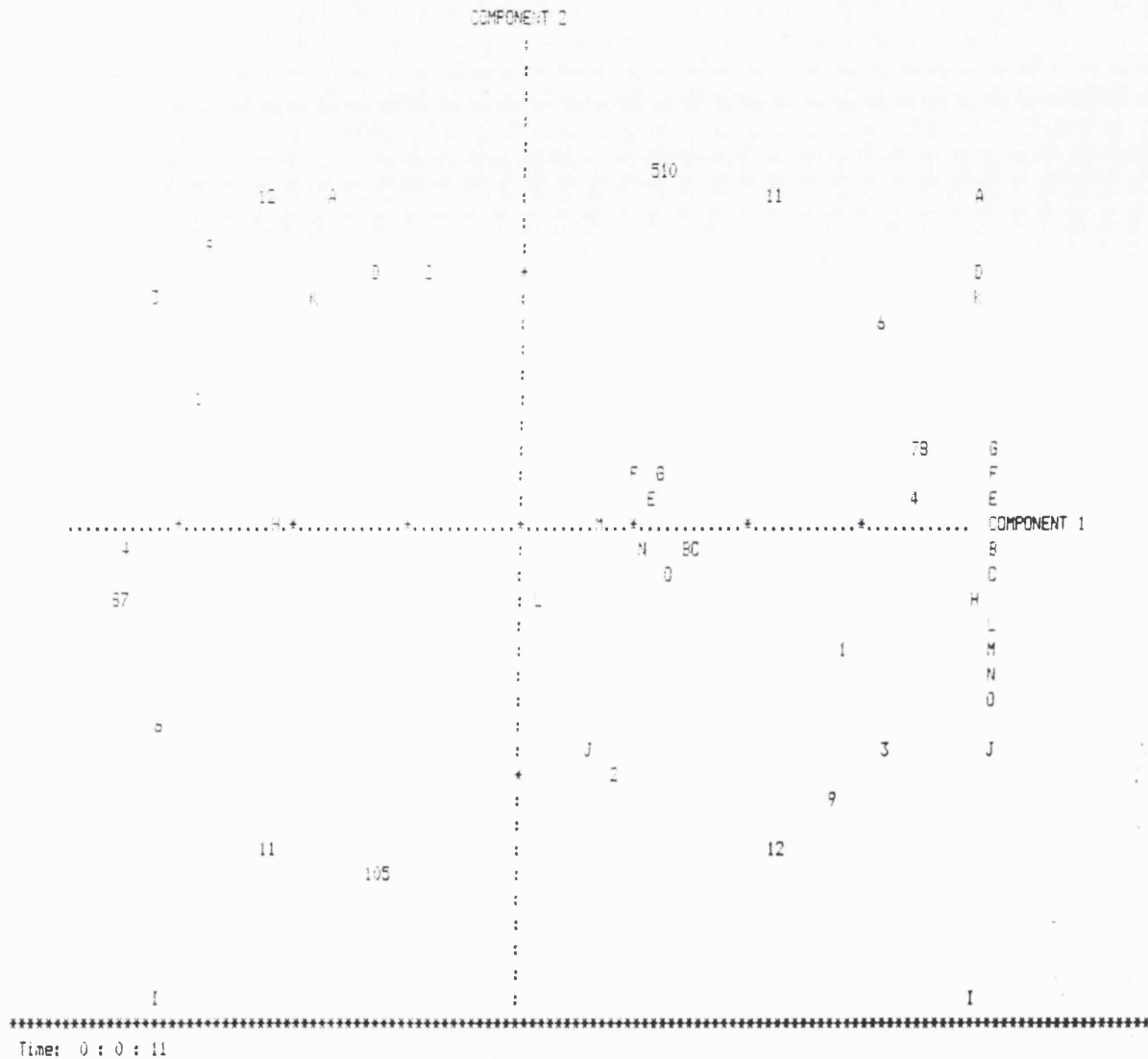


Figure 3. Graphical representation of repertory grid for participant 'C'.

If the view the people concerned have of themselves is actually

positive, the observed discrepancy in distance between the elements cannot be explained as simply being evidence of low self - esteem. Another possible explanation is that the observed discrepancy is reflective of how the participants believe *other people* see, or construe, them, and is related rather more to self - perception. This would seem to tie in with earlier observations that *perceived* stigma is as important as real or enacted stigma in determining an individuals view of themselves and the condition they have.

This is not to say that enacted stigma does not exist. As has already been highlighted, epilepsy is a condition that has had a long history of being associated with fear and stigma, and those people with epilepsy have often been viewed in a very negative light and ostracised as a result (Wilde, 1995). This being so, it is more than possible, and perhaps not surprising, that those people who have epilepsy may believe that other peoples construction of them depicts them as being somehow deficient or abnormal, and that this would not be the case if they did not have epilepsy. Again, there is some support for this proposition in analysis of the graphical representations of the repertory grids. In both Figures 3 and 4, the elements A ('Myself with epilepsy') and D ('Myself as others see me') are situated close together. On the other hand, element J ('How other people would see me if I did not have epilepsy') is situated more closely to elements B ('My self without epilepsy') and C (' My ideal self'). This may be reflective of the negative construction of the self, and hence the poor self - esteem of the participants, which results in them believing others cannot view them in a positive light and construe them accordingly.

P L E X I S R I D V4.2 May 1987. File: bdd Time: 01-01-1980 00:02:56
 GRID TITLE: bdd
 PLOT - unrotated results 1 - picked as an IDEAL. Reflection of axis 1 2

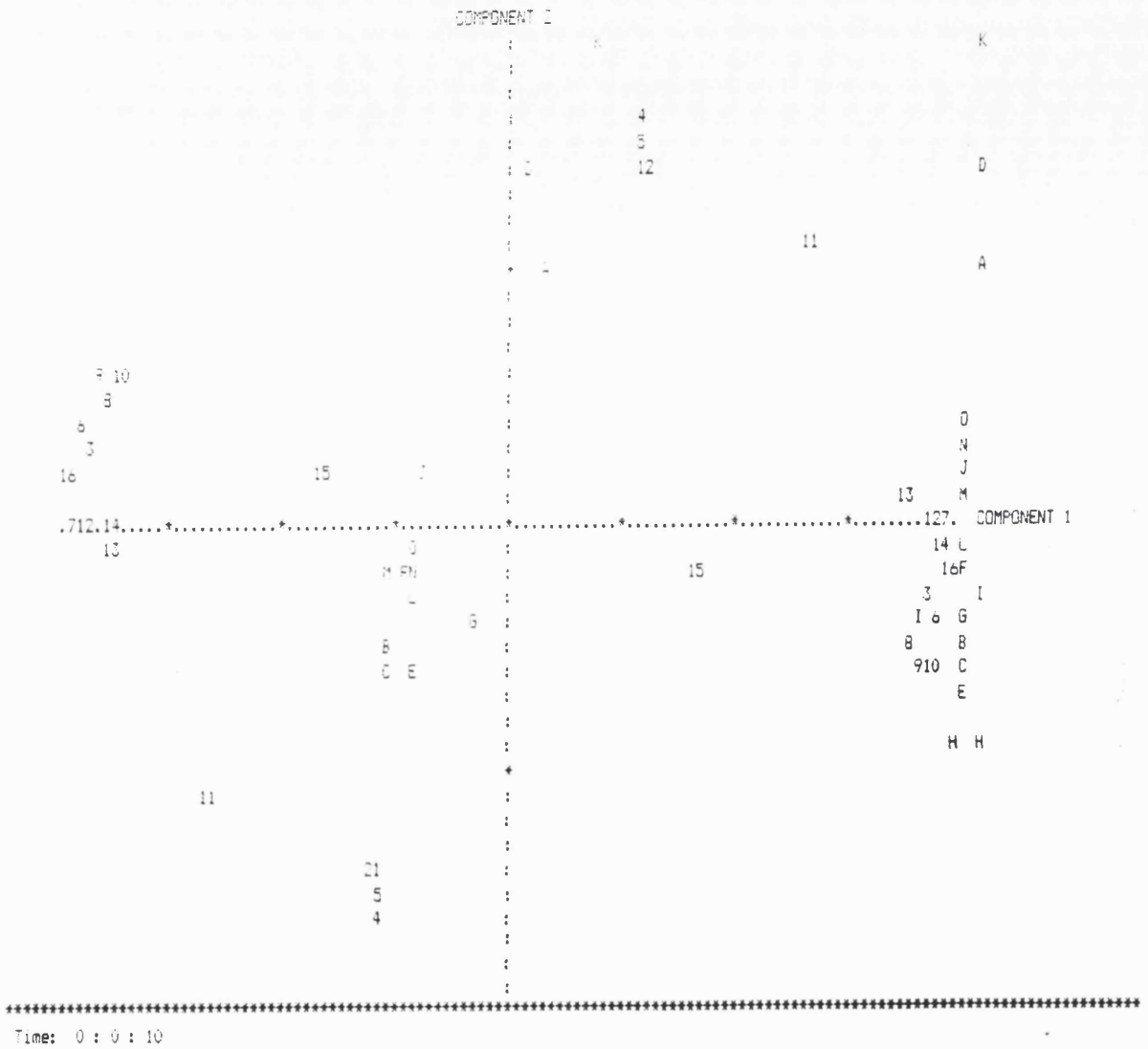


Figure 4. Graphical representation of repertory grid for participant 'D'.

An inspection of the constructs presented on these grids, however, indicates that the implicit poles of the constructs 'Normal/Abnormal' (construct

11, fig 3) and 'Able/Disabled' (construct 6, fig 4) are located close to element J, whereas the emergent poles are closer to element A . This indicates a belief that others see the participants in a more negative light than they see themselves.

The view of limitations and restrictions imposed by epilepsy, as well as the view an individual has of both themselves and the way others see them, may be influenced by how predictable seizures are and whether or not they are preceded by an aura, as well as the frequency of seizures and whether the individual experience absences rather than the more dramatic tonic - clonic seizures. It is, perhaps, reasonable to propose that those people who have very frequent seizures, and may thus be rather more restricted in their choice of activities and pursuits, may feel very differently about themselves and their condition than those who have seizures occurring infrequently. Similarly, those people whose seizures are preceded by an aura, and who could thus perhaps make some provision for their own immediate safety in the event of a seizure, may feel less restricted (and have a different view of themselves) than those people whose seizures occur without warning and who may, as a result, restrict their levels of activity, pursuits they follow and where they go. No comparison was made between those participants who experience an aura and those who do not, or between those with frequent and infrequent seizures (although the two groups were evenly matched for this, numbers were too imbalanced to make comparisons viable). Future research, possibly with a larger group of participants, could make such an interesting and informative comparison.

In a similar vein, it could be proposed that those people with absences

alone may feel very different about both themselves and their condition than those people who experience rather more dramatic seizures, and as a result we might expect the physical and social difficulties they face to also be very different. This could, in turn, lead to a difference in levels of depression, self - esteem and self - perception. The number of people experiencing absences in this study was very small in comparison to those experiencing other forms of seizure, and thus no meaningful comparisons could be made. In future research, however, with possibly larger numbers of participants, this would be a potentially fruitful area of consideration.

It is perhaps equally possible that the presentation of elements and constructs outlined above, reflects the participants view that other people see them first and foremost as someone *with epilepsy*, rather than a person in their own right. In other words, to the outside world the epilepsy masks the person within, whereas if they did not have epilepsy the person within would be seen. This may be felt more deeply by those people with dramatic seizure activity rather than absences, which are not always so obvious to the outsider.

These proposals are somewhat speculative, and highlight the need for ongoing clinical research as further investigation of this area would be required before any firm conclusions could hope to be drawn. This study provides some support for these theories, however, in the fact that the distance between the elements 'Myself as others see me' and 'My ideal self' is significantly greater in the child onset group than in the adult onset group. Following on from the discussion above , this could be seen to indicate that, for the child onset group,

the process of growing up and establishing a personality has taken place in the context of them having epilepsy. Thus, their entire construct system has been influenced by their having epilepsy, and their actions will be influenced by this constructional system. This may have resulted in outsiders seeing the epilepsy first and not the person. On the other hand, for the adult onset group their personality has been established *before* the onset of epilepsy and, as a result, other people see the person first and the epilepsy is more of a secondary issue that is fitted in to an already largely established construct system. This is further supported by the fact that at least some participants in the child onset group put forward the term 'epileptic' as the emergent pole for one of their constructs. This could indicate that having epilepsy (being 'epileptic') is prominent in their view of themselves and somewhat diminishes other aspects of them as people. This term was not put forward by any participant in the adult onset group. Whether the reported differences between child and adult onset groups would also be found in a comparison of those people with absences only compared to those with more dramatic seizures is another area of interest. Again, future research may help determine this as this study was unable to do so due to the limited numbers of participants with absence seizures.

Again, there are important clinical implications in the obtained results, as the view that others are construing them negatively may act as a barrier to good adjustment to the condition. Moreover, the need for public education and information as an adjunct to clinical practice is also clearly demonstrated here. Whilst those people with epilepsy are accepted somewhat more of today than

they once were, these findings illustrate that, as far as the people in this study are concerned, there is still considerable ignorance and prejudice surrounding epilepsy and those people with epilepsy. If clinicians are to be fully able to help people with epilepsy develop a positive construction of themselves, and therefore have greater self - worth, it is important that the negative, stereotypical perceptions of people with epilepsy, which the participants construe as still existing, are challenged with accurate and informative public educational material. Of course, of equal importance is that professionals should also be aware of their own potential prejudices that may prevent them being of full use to their client. Organisations such as the N. S. E. have an important role to play in the provision and availability of this information and should be utilised wherever possible. This process of education can, of course, be augmented by ongoing clinical research that furthers the understanding of the medical and scientific community about both epilepsy and the people who have epilepsy.

The coping strategies employed by the two groups did not differ significantly, with both groups using the same strategies to similar extents. In both groups, however, two particular strategies emerged as being most widely used. These were Escape - Avoidance and Seeking Social Support. This finding echoes the suggestion that a distinction is often found between those who use 'problem - focused' means of coping and those who use 'emotion - focused' strategies (Charlton and Thompson, 1996), both of the above strategies being emotion - focused. It does, however, contrast with previous research in the area of coping strategies used by people with epilepsy (eg, Upton and Thompson,

1992; Devlieger et al., 1994), which have demonstrated a greater use of the more proactive, problem - focused methods of Planful Problem Solving and Positive Reappraisal.

The Ways of Coping Questionnaire has been used extensively in research on both normal populations and clinical samples, and the various coping mechanisms it identifies have also been much researched (Kennedy et al., 1995). It is not a measure that assesses how well a person copes, but research has indicated that some ways of coping are more useful than others. Escape - Avoidance has been described as a somewhat maladaptive strategy that tends to be adopted by people when they believe a situation is not amenable to change (Carver, et al., 1989). It has also been positively correlated with depression (Reidy, et al., 1991). Seeking Social Support, on the other hand, has been regarded as being rather more adaptive and related to more positive affect (Reidy, et al., 1991). Were the relationship between coping strategies and mood state as clear cut as this research indicates, it might be expected that both groups would show similar levels of depression in as much as both groups demonstrate a similar utilisation of strategies. In reality, the results paint a rather more confusing picture, in that despite the similarity of the profile of use, the two groups demonstrate significantly different levels of depression. An obvious explanation for this difference is that the two groups actually face different *stressors* , and are using the same coping strategies but applied to different situations with consequently different outcomes. As Snyder, (1990), points out, very little is known about the stressors that people with epilepsy experience, and

it is possible that coping strategies deemed maladaptive in some situations may actually be adaptive in the face of some of the stressors encountered by people with epilepsy. There is an obvious area of future research here as clearly more needs to be known about the potential stressors people with epilepsy may face as well as their reactions to these stressors.

The clear implication of the analysis of coping strategies is that, despite the efforts of many researchers to provide a neat link, there is no single, simple relationship between these coping strategies and the psychological well - being of individuals. These findings amongst people with epilepsy echo and support those of Kennedy et al., (1995 b), who urge caution when making assumptions about the efficacy of coping strategies and in drawing any causal inferences between coping strategy and psychological adjustment to spinal cord injury. Current results indicate that similar caution should be exercised when trying to make inferences about people with epilepsy. Clearly, further, more detailed research is needed if the nature of the relationship between epilepsy, coping strategy and psychological well - being is to be better understood.

The second hypothesis, that men and women would differ, is again only partially supported and any significant differences there are between men and women are in the opposite direction to those originally proposed. No significant difference between the BDI scores for women and those for men was found in either group. This is contrary to the original proposition that men would show lower levels of well - being. Furthermore, this result does not reflect the widely accepted pattern of women being more prone to depression than men in

general, which has been described as one of the most established and robust findings in depression research (Whiffen and Clark, 1997). The 2:1 female to male ratio (Bebbington, 1990), which is described by Nolen- Hoeksema (1987) as being constant across different settings, regardless of whether diagnostic measurement or self - report is used, is not repeated here.

In the child onset group, a significant difference was found in the distance between the elements 'How others would see me if I did not have epilepsy' and 'My ideal self', this distance being considerably smaller in women than in men. This suggests that the women in the child onset group believe that other people would construe them as more like their ideal selves, and presumably in a more positive light, if they did not have epilepsy. This echoes the earlier discussion about how the general public may view people with epilepsy, and indicates once more that it is the epilepsy that may define an individual rather than the other way round. That is, the fact that a person has epilepsy may dominate the views and opinions other people have about them and may be the major feature in their construction of the person with epilepsy, whereas less consideration may be being given to the person within.

In the adult onset group, a significant difference was found in the distance between the elements 'Myself with epilepsy' and 'A man/woman I like', with women showing a greater distance between these elements. This suggests that, within their construct system, the women in the adult onset group are making unfavourable comparisons between themselves and people they hold in esteem. This contrasts somewhat with the earlier observation that people with epilepsy

do actually construe themselves in a relatively favourable light. This seeming anomaly may be related to the amount the women concerned invest in the relationships they have with the people they esteem, and their perception of how their role within this relationship should be construed. As already mentioned, Arieti and Bemporad (1978) suggest that investment in a highly valued role or goal can provide an individual with a sense of self - worth they may not otherwise have, as well as giving meaning and purpose to their life. Whilst this dominant role or goal is intact, negative aspects of the self tend to be subordinate and a positive view of the self predominates. If the role or goal is threatened, however, the negative aspects of self come to the fore (Power, 1987, 1991; Brown et al., 1987). If much has been invested in a role within a relationship with an esteemed other, a sudden threatening life - event, such as the onset of epilepsy, may substantially alter how an individual views this role and may disprove hypotheses that were originally supported within the initial construct system. This may culminate in the person redefining their construction of self within the construct system to take account of the 'new' relationship, and may culminate in them making unfavourable comparisons between themselves and the esteemed other where once they felt on something of a more equal footing. This is speculative, but is supported by the fact that in the child onset group, where presumably the individuals having epilepsy is taken into account when developing the role and the construction of self within the relationship, no such discrepancy between elements was found.

It is interesting to note that for both observed significant differences,

women presented with the more negative view of themselves in comparison to others. This is contrary to the direction of difference originally proposed. Initial proposals were that men with epilepsy would have a more negative view of self. This was because, in spite of relatively recent changes in both career opportunities for women and the domestic role of men, the perceived limitations for professional success might continue to be more salient for men, who still tend to focus on this area when pursuing goals, or are at least expected to, whereas women still tend to focus more on the domestic area or, again, are expected to (Lee, 1987) . Current findings do not support this theory. This may be reflective of sex biases becoming less evident since this diversity in roles was proposed (Nolen - Hoeksema, 1990), and provides some support for the points made in the introduction, that early research in this area miscalculated the importance of the domestic and professional role in both sexes. Thus, both underestimation of the importance of professional achievement and overestimation of the importance of domestic achievements to women may have occurred. On the other hand, less emphasis by men on professional success and a greater emphasis by them on domestic achievements would also have the same effect. This would be contrary to Lee's (1997) proposal that a more traditional division of the sexes is still evident, and the reasons for this remain somewhat unanswered, Clearly, this is a thorny issue, and needs much greater investigation that is beyond the scope of this study.

The topic of investment in a professional role leads into the comparison of those participants who were employed with those who were unemployed. This

comparison was made in both groups but only within the child onset group were any significant results observed. The major finding here was that those people in the child onset group who were unemployed at the time of the study revealed significantly higher scores on the BDI than those who were employed. At first sight this may not appear to be too surprising a finding, since unemployment has long been regarded as a risk factor for depression (eg Brown and Harris, 1978). What is surprising, however, is that, although the proportion of employed and unemployed was the same in both groups, no such discrepancy was found between the employed and unemployed participants in the adult onset group. What makes this all the more surprising is that the adult onset group as a whole had higher BDI scores than the child onset group.

An explanation for this seeming anomaly may be found in the previously mentioned flexibility of participants. As stated earlier, the flexibility to find new meaning in areas of experience is likely to be a vital component in an individual's vulnerability to depression (Champion and Power, 1995). Gotlib and Hammen (1992) and Champion and Power (1995), also make the point that, as well as vulnerable individuals being less likely to perceive value in certain other domains, which in personal construct terms we may describe as the ability to incorporate new information into the existing construct system, they may actually structure their social world in such a way that the likelihood of them experiencing negative events within an overinvested domain increases. This, in turn, would confirm beliefs held about the value of the domains (or proves their hypothesis about the domains being inadmissible to the construct system) and only serves to maintain

the depressed state (Champion and Power, 1995).

Following this pattern, it is conceivable that, for the childhood onset group, who will have had epilepsy *before* entering the job market, any lack of success in obtaining employment will be attributed to the fact that they have epilepsy rather than to other factors, such as unsuitable qualifications. In other words, they are unable to attribute value to domains other than that of them having epilepsy. In personal construct terms, the construction of self will reflect the experience of having epilepsy and thus not being able to find work. This may eventually result in the person becoming overinvested in the role of a person with epilepsy seeking employment and may actually increase the risk of failure in this domain, and will strengthen the construct of being unemployable due to the epilepsy. Their vulnerability to depression is thus increased. For the adult onset group, however, who may have had some experience of the job market, and may have been turned down for jobs, prior to the onset of epilepsy, failure to find employment may be attributed to other causes as well as the fact they have epilepsy. In other words, their prior experience increases their flexibility in attributing meaning to their lack of success in obtaining employment to domains other than that of having epilepsy, and their construct system is likely to reflect this. The net effect is that their vulnerability to depression is reduced.

This is not to say that people are necessarily wrong when attributing lack of success in the job market to the fact they have epilepsy. Prejudice towards and ignorance of both the condition and those with it certainly do exist (Wilde, 1995), and it is certainly possible that potential employers are deterred from

employing people out of fear and ignorance of both the and the capabilities of those people with the condition. Whilst the possibility exists, however, that the individuals concerned are in some way contributing to their own lack of success (however inadvertently) there are important clinical implications. With professional help it is presumably possible to break the pattern of over investment, alter the constructional system to reflect more adaptive constructs, and lessen the vulnerability of an individual to depression. Again, therapeutic administration of a repertory grid can help the therapist gain a clearer understanding of the clients constructional system, which is a first step towards altering or adapting it. This possibility should inform future research in this area, which may give a clearer indication of the relative contributions of the prejudice and misinformation of potential employers and the negative construction of potential success in the job market held by the people with epilepsy.

It is interesting to consider whether or not people who have been employed in the past but have now retired would show a similar profile of well-being to people currently in work or those out of work. Only three participants in this study had retired, and thus no valid comparisons could be made, but this is a potentially interesting area of future research.

The finding that, amongst the childhood onset group, those participants who were both unemployed and not married or involved in a meaningful relationship were significantly more likely to be depressed than those involved in a meaningful relationship, suggests that such a relationship may be a protective factor against depression. Indeed, one of the factors first identified by

Brown and Harris (1987) that has been most consistently replicated is the lack of a confiding relationship. In spite of the above, in this study those in a significant relationship were no less likely to have higher BDI scores than those who were not in such a relationship. This may be due to the fact that both groups expressed equal satisfaction with both the level and quality of the social support they received. Thus, the quality of social support a person receives seems to negate the potentially negative effects of not being married or having a significant relationship. This echoes the findings of people such as Cohen and Wills (1985) and Kennedy et al (1995 a, b), who stress the importance of social support as a protection against psychological ill health.

This having been said, however, the Pearson product moment correlation failed to produce any correlation between social support and BDI scores in either group. This may be due to the fact that the measure used, the Six Item Social Support Questionnaire, only measures *overall* satisfaction with the support received and does not take into account the different aspects involved in such support. There is growing evidence that social support has many functions other than intimacy, which tends to be more closely associated with *particular* meaningful relationships. Functions such as information - giving, practical help and companionship are of equal importance to intimacy in protecting against depression (Cohen and Wills, 1985), and may account for the current findings.

The analysis of those in relationships leads on to the third hypothesis, that those involved in meaningful relationships would have higher self - esteem , either because relationships improve self - esteem or because higher self -

esteem makes it easier to form relationships in the first place. Once again, only partial support was given to the original hypothesis. In fact, only one significant difference was observed between the two groups. Within the childhood onset group, those participants involved in a meaningful relationship demonstrated a significantly smaller distance between the elements 'Myself with epilepsy' and 'A typical person with epilepsy' than those not in such a relationship. In terms of the measures of self - esteem, no differences were observed.

The finding that those not involved in a significant relationship saw themselves as being less typical of people with epilepsy than the majority of people with the condition may be related to the earlier proposition that the childhood onset group, whilst having an essentially positive view of themselves, believe others may view them first and foremost as people with epilepsy and thus in a negative light. The persons construct system will thus also contain constructs relevant to this theory. Not being involved in a meaningful relationship may confirm this view, and therefore strengthen the constructs that are related to how others see the person concerned. The long term effect of this may be that the individuals concerned attempt to distance themselves from what they construe as 'typical' people with epilepsy in order that they themselves are not construed by others as being primarily people with epilepsy, and are therefore viewed in a more positive light. For those people involved in a significant relationship, the fact that another person has sought this relationship with them in spite of the epilepsy, may be enough to confirm the positive view of self, and strengthening the relevant constructs. As a result, distancing from any

construction of a typical 'typical' person with epilepsy is rendered somewhat unnecessary. Again, this is a speculative proposition, but it highlights an area of potential future research.

The investigation of the so - called mediating variables of age, amount of social support (SSQN) and satisfaction with social support (SSQS) reveals some interesting findings. For the adult onset group, no correlation was found between these variables and the measures of depression, self - esteem and self - perception used. For the childhood onset group, however, both chronological age and quality of social support were found to be correlated with some aspects of self - esteem and self - perception. The mean SSQS scores of the two groups were not significantly different from each other, which suggests that the actual satisfaction score attributed to the social support received is not the most salient factor here. This ties in with earlier observations regarding the multitude of aspects that are entailed in giving and receiving social support. Power et al, (1988) have defined the quality of social support as being the discrepancy between the actual state of a supportive relationship and the ideal or desired state of that relationship, a description that is somewhat similar to how personal construct theory might describe this concept, which would presumably be the distance between the elements 'The relationship as it is now' and 'The ideal relationship'. It is feasible that the two groups have different views as to the nature and purpose of this support, or, in personal construct terms are construing the nature and purpose of support differently.

The net result of this would be that the two groups are drawing on different

aspects of the support provided by those around them, and using it in different ways. This would explain the observed differences between the two groups in the results of the correlations. An interesting area of investigation in future research would be the inclusion of the elements 'My relationship as it currently is' and 'My ideal relationship'. This would reveal interesting aspects of the constructional system of participants that was not available within the current study. This further emphasises the need for more detailed research that attempts to delineate the different aspects of social support and their relative importance. There are also important lessons here for clinical practice. Whether or not the relevant contributions of the different aspects of social support are clearly understood, the importance of social support needs to be emphasised. Clinicians should be aware of those individuals who lack good social support and should encourage the development of social links and support from others. This highlights the vital role support groups can play in providing social contact for otherwise isolated individuals.

Chronological age was seen to be positively related to the measures of self - esteem and self - perception within the childhood onset group. This again seems to support the earlier observation that psychological well - being can improve as a function of time (Christo and Sutton, 1994). It is possible that participants in the child onset group, having had epilepsy longer than participants in the adult onset group, have also had longer to assimilate the idea of being people with epilepsy, or, in Kelly's terms, to have construed themselves as people with epilepsy and built this construction of self into the construct

system. If this is so, the older a person becomes the more likely they are to accept themselves with epilepsy and to demonstrate improved psychological well - being. This highlights the importance of longitudinal research in those with chronic conditions, which will provide a clearer picture of how constructional systems and profiles of well - being may change over time.

The stepwise multiple regression analyses on the combined data for both groups investigating the relationship between psychological well - being and moderating variables, reveals that social support is by far and away the most important factor in accounting for variance of outcome measures, with sex, employment status, marital status and age of development of the condition being far less important. This reconfirms earlier observations about the importance of social support, and suggests that it is a crucial factor in more than just a persons susceptibility to depression. The models produced using the data from this study indicate that it is also relevant to many different aspects of psychological well - being. Chronological age was the only other variable found to be important. This supports the earlier observation that longer an individual has had a particular condition the better adapted to it and more psychologically well they become. Chronological age was found to be important in the variance of scores on the BDI , a measure on which the adult onset group were found to have significantly higher scores. It would seem reasonable to propose that this group would show higher levels of depression, given that they would have had less time to come to terms with having epilepsy, less time to develop a new construction of the self as someone who has epilepsy, and less time to both fully understand and deal

with the inevitable changes accompanying the condition and build these into the constructional system. For the childhood onset group, there would have been more time to complete this process of acceptance and adaptation to change, as well as more time to build them into the constructional system, resulting in a more positive construction of self in relation to the outside world and hence lower levels of depression.

Whilst the results of this study provide some interesting and potentially useful findings, there are some important limitations to this study that mean it may not be possible to generalize the findings to the wider population of people with epilepsy. As a result, considerable caution must be exercised in any attempt to draw significant conclusions.

One of the first difficulties concerns the number of participants and the source of recruitment of participants. All participants were drawn from those people who attend support groups run by the National Society for Epilepsy (NSE), and it is highly likely that this may have produced a sampling bias. Given the importance of social support in adjustment to a condition such as epilepsy, belonging to a group such as those run by the NSE may provide extra support and encourage members of the group to feel more positive and better adjusted. This could be controlled for in future studies by also using participants who are in the community but not attending a support group. This, however, raises difficulties with accessing those people who have epilepsy. Quite rightly, medical information on people is confidential and, given the 'silent' nature of epilepsy (it is not a condition whereby those affected 'look' as if they have epilepsy) it is not

possible to know who has epilepsy without looking in medical files. This difficulty could, perhaps, be overcome by medical practitioners approaching those in their care on behalf of the researcher, but in practice this may not be possible. This can result in relatively small numbers of people being recruited to take part in research. Indeed, this study had only 32 participants, which is a rather small number and which can reduce the power of the results obtained. This is a long standing area of difficulty for researchers that is difficult to overcome. By increasing the amount of research into epilepsy, however, the condition could become less of a 'Cinderella' area and may encourage people to participate in future studies.

A further point as regards sampling bias is the possibility that those who are willing to take part in studies show a different psychological profile to those who are unwilling. As Kennedy et al (1995) point out, it is likely that the people with poorer psychological adjustment would be unwilling to take part in a research project. This difficulty would be encountered even if those people who do not belong to support groups are approached. Clearly, this is a difficult issue to overcome, and inevitably means that a degree of bias will be found in all studies of this kind, regardless of the condition being investigated. Considerable caution should therefore be applied to any conclusions that are drawn about the well - being of any people outside of the groups being studied.

As has already been pointed out on several occasions, this study made no comparison between those people with more dramatic, tonic - clonic seizures and those people who experience absence seizures and does mean that a

potentially important area of contribution to a persons view of self has been left unaccounted for. This was due to the relatively small number of participants experiencing absence seizures, and may reflect the difficulties inherent in obtaining a large enough sample. As has already been noted, all participants were recruited from the N.S.E. regional groups, and it is possible that people with absence seizures alone may not feel the same need to attend such groups. This would certainly appear to be a possibility, given the small number of people obtained for the present study. Any future research would certainly benefit from a comparison of these two groups, however, and would need to try and recruit a larger number of people with absence seizures.

Another criticism of this study is the time frame over which it is conducted. Self concepts are not the static patterns they may at first appear. Kelly himself has highlighted that the construct system undergoes continual revision as hypotheses are tested and the various constructs are either strengthened or modified, and it is probably true to say that some major changes can occur over time and following life events. This is a position echoed by Brewin et al, (1992) who emphasise that the time - frame over which a concept is assessed has a crucial effect on the manner in which it is reported. This highlights again the need for more longitudinal research, an approach that is beyond the scope of this study.

There is, perhaps, an argument to be made for this study requiring a control group of people without epilepsy. This is certainly a valid viewpoint, but the idea of the study was not to examine how people *with* epilepsy compares to

people *without* epilepsy but was more in the nature of a *within group comparison*, comparing one group of people with epilepsy with another. Given this, a control group could be regarded as being of limited value.

This having been said, a case can be made for a control group giving a useful comparison from which to judge how depressed the clinical sample are or how much self - worth they have. Claims have been made throughout this discussion that the people with epilepsy in this study show high levels of self - esteem and self - worth and low levels of depression. It could, therefore, be reasonably argued that for any claims of this nature to be valid, a comparison with a normative control group would be necessary. We must remember, however, the nature of the outcome measures used in this study.

The main assessment tool in this study was the repertory grids. As we have seen, grids are made up of numerous elements that are used to elicit constructs. The 15 elements used in this study included 5 that were concerned with the fact the participant had epilepsy (elements A, B, E, F and K) and it would not have been possible to administer these elements to a control group of people who did not have epilepsy as they would not have been applicable to them. The elements administered to the control group, therefore, would have differed considerably to those administered to the clinical sample and would not have provided any information with which to make a valid, matched comparison. The measure of depression used, the BDI, is a tool that has been standardised against a normal population anyway, and thus the scores obtained are matched against a normal population. This renders the use of a further control group

unnecessary for this measure. The two remaining measures, the Ways of Coping Scale and the Social Support Questionnaire, have also been standardised using normal populations but are also, by their nature, providing qualitative rather than quantitative information. Thus, they are not designed to evaluate how well a person copes or how well they are actually supported, rather they indicate the *way* in which people cope and *their subjective opinion* as to the quality of care they receive. Given this, it is debatable as to how informative results from a control group would be considering they would provide no hint as to the usefulness of the coping measures elicited or social support reported. Simply knowing whether or not people with epilepsy use the same means of coping as people without epilepsy is of little use, as the important thing is not *how* people cope but *how well* they cope. As we have already seen, explaining the relationship between coping and emotional well - being is fraught with difficulty and complexity and it is unlikely that a normative sample would have provided any more useful information. On balance, it would appear that a control group would not be necessary.

It is important to note the limitations of this study. Future research would benefit from taking into consideration the possible effects of medication, site of epileptogenic activity and medication, and may want to make further comparison between people with different types of epilepsy. Nevertheless, even with the limitations outlined above, the results of this study could be seen to be encouraging. The average depression (BDI) scores of both groups (9.69 and 16.0 respectively) are both relatively low. Indeed, the child onset group compare

very well to the normal population, and the adult onset group, whilst showing higher scores, still score lower than single episode depressives, whose mean score is held to be 23.4 (Beck and Steer, 1987). Furthermore, participants in both groups seem to construe themselves in positive terms as measured by the standard repertory grid indications of a comparison between present and ideal self. This having been said, the child onset group appears to believe that *other peoples construction of them* is rather negative, but this does not detract from the positive view of self that participants seem to hold. The results suggest that, regardless of age of onset of epilepsy, psychological well - being can remain good and results seem to negate the assumption that having epilepsy will automatically result in poor adjustment and well - being. The evidence is that, in spite of the frightening and potentially life - changing implications that accompany epilepsy, many of those who have this condition go on to lead full, active and rewarding lives.

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APPENDIX

Contents:

Pages 121 - 122: Information sheet provided for participants.

Page 123: Consent form signed by participants.

Page 124: Letter of formal consent and approval from joint UCL/UCLH hospitals

Ethics committee.



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INFORMATION SHEET

Date

Dear

I am a clinical psychologist in training at University College London studying for a Doctorate in Clinical Psychology. I am very interested in epilepsy and its wider consequences and am about to embark on a research study in this area. I am writing to ask if you would be willing to take part in this study.

Previous research suggests that having epilepsy can result in a wide range of personal consequences that extend beyond having seizures. High levels of stress, isolation and higher levels of unemployment have all been associated with epilepsy. In this study I am particularly interested in whether the age at which a person develops epilepsy is important in determining the extent of these possible wider effects. The results of this study might be beneficial in the future to help others who suffer from epilepsy.

If you agree to participate in this study you will be asked to complete a number of questionnaires and to take part in an interview with me, the researcher. These questionnaires and the interview are designed to assess your current levels of stress and social support as well as your views about epilepsy and what it means to you. No physical interventions are needed and you will not be asked to engage in any therapy. Any information that you provide will be anonymous and entirely confidential. You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. Your decision whether to take part or not will not effect your care and management in any way. Once the study is complete, feedback on the results will be available for all those who request it. This project has been approved by the joint University College London/University College London Hospitals committee on ethics.

Whilst great care will be taken to minimise discomfort, discussing your condition and any difficulties that have resulted from it may be distressing. I have several years clinical experience in psychology and will provide a full debriefing plus support and counselling for anyone who feels distressed.

If you are willing to participate, please inform Dr..... who will pass your details to me and I will contact you to arrange a suitable time for us to meet. The meetings will take place at the hospitals.

Thank you for your time,

Yours sincerely,

R. Greenhalgh (Miss)

Miss Ruth Greenhalgh,
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London WC1 6BT.



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CONSENT FORM

I, the undersigned, agree to take part in this study on the wider effects of epilepsy. I have read and understood the information sheet. I understand that any and all information I provide will be anonymous and strictly confidential.

I am participating in this study of my own free will and understand that I am free to withdraw from this study at any time, and need give no reason or justification for my withdrawal.

- Have you read the information sheet about this study?
- Have you had an opportunity to ask questions and discuss this study?
- Have you received satisfactory answers to all your questions?
- Have you received enough information about this study?
- Which doctor have you spoken to about this study?
- Do you understand that you are free to withdraw from this study
 - * at any time
 - * without giving a reason for withdrawing
 - * without affecting your future medical care (not required for healthy volunteers)
- Do you agree to take part in this study

Signed.....

Date.....

Investigator.....123.....
Ruth Greenhalgh.

The University College London Hospitals

St. Martin's House,
140 Tottenham Court Road, London W1P 9LN

Telephone: 0171 380.....

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The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee A Chairman: Dr F D Thompson

Please address all correspondence to:
Mrs Iwona Nowicka
Research & Development Directorate
9th Floor, St Martin's House
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Miss R Greenhalgh
Trainee Clinical Psychologist
Clinical Health Psychology, UCL
Gower Street

17 January 1997

Dear Miss Greenhalgh

Study No: 96/123 (*Please quote in all correspondence*)
Title: Childhood onset of epilepsy: Self-esteem and self-perception

Thank you for supplying further information at the request of the Committee. I am writing to let you know that this application is now approved and you may go ahead with your study.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project or indeed if the project is abandoned. Please remember to quote the above number in any correspondence.

Yours sincerely



Dr F D Thompson
Chairman



The University College London Hospitals

University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology & Neurosurgery, The United Elizabeth Garrett Anderson Hospital and Hospital for Women, Soho, and University College Hospital. gre17jan/ijn/17 January 1997