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A qualitative investigation into the social experiences of  
young people with epilepsy;  
perceived impact and sense of self  
& Clinical Research Portfolio

Part One  
(Part two bound separately)

*Submitted in partial fulfilment of the requirements for the degree of  
Doctorate in Clinical Psychology*

Katherine Bruce  
August 2007

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**Chapter 1: Small Scale Service Related Project**

Small Scale Service Related Project submitted in partial fulfillment of the requirements for  
the degree of Doctorate in Clinical Psychology

**Analysis of Referrals to a New Neuropsychology Assessment Service  
within Argyll and Bute Adult Clinical Psychology Service**

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## **ABSTRACT**

**Background:** This study examines referrals to a newly established Neuropsychology Assessment Service (NAS) within Argyll and Bute. In order for the service to successfully develop, it is essential that this provision be monitored to aid future planning.

**Methods:** Data were gathered from those referrals accepted for assessment by the NAS within the first 9 months of the service's establishment. Information was gathered from the clinical psychology department's database and relevant case-notes.

**Results:** A total of 15 referrals were analysed in terms of a) the profile of referrals to the service b) the nature of the assessment service received c) the outcome of cases. The most notable results were the attendance of all 15 referrals for the duration of assessment, especially in light of significantly high journey times for many patients to attend their appointments.

**Conclusions:** With initial results being positive, the service will need to plan the next steps for developing the NAS, and assess the resource implications for this. Staffing shortages and changes in the Health Board's management and structure may complicate these developments.



## **INTRODUCTION**

Within the Lomond and Argyll Division of NHS Argyll and Clyde, clinical psychology services have been historically split between provision to the areas of Lomond, and Argyll & Bute. Following a review of 'Clinical Psychology Services in Lomond and Argyll Primary Care Trust' (Peck. 2001), recommendations were made for a more area-wide focus on clinical psychology services within Lomond and Argyll. In response to this report plans for a specialist neuropsychology assessment service to the Argyll and Bute population were put in motion, as previously only patients within the Lomond catchment area had access to this service.

In March 2004 a Neuropsychology Assessment Service (NAS) was established, based at the Argyll and Bute Hospital in Lochgilphead, and covering the entire Argyll and Bute population. Limited resources mean that the clinic is only held one day a month, allowing the Grade B Neuropsychologist to make approximately 3-4 appointments per month. For clinical and administrative tasks, the Neuropsychologist's total allocated input to the service is 0.1 w.t.e. A condition of the Neuropsychologist's sessions in Lochgilphead was additional support from the Psychology Assistant based at Argyll and Bute Hospital. The number of sessions provided by the Psychology Assistant was not formalized, but it was agreed that they would assist in the administering of tests and in follow-up work. The NAS also provides the opportunity for Trainee Clinical Psychologists to work within the clinic. As a community neuropsychology service, assessment is available to both in- and out-patients, in a catchment area which covers 26 GP surgeries with an estimated 62, 750 registered patients (Smith, J. 2003). The geographic area of Argyll and Bute is mainly rural and covers approximately 2,600 square miles (NHS A&C Website. 2005). Referrals to the NAS are made via the Adult Clinical Psychology Service, where the Head of Service

screens referrals for suitability in discussion with the Neuropsychologist. Once the NAS has become more established, consideration may be given as to whether a direct access referral system should be adopted.

Within the framework of clinical governance it is hoped that in the future, the NAS may progress as part of an integrated care pathway for patients with neuropsychological deficits within Argyll and Bute. Whilst no such system exists, it is felt that by first establishing the NAS, more formal links to other services may then be established. Ideally the NAS would like to feed into a service similar to the Brain Injury Team, which exists within Lomond, however as yet Argyll and Bute does not have such a service. The development of links with alcohol and dementia services would be a possible progression for the NAS.

To date there has been no evaluation of who is being referred to the clinic, or of the assessments that have been required by this population. It is essential for clinical psychology to monitor this provision to assist future planning. This project therefore proposes an analysis of referrals to the new NAS as a baseline for identifying the current provision and as an aid to future service development.

Specific attention must be paid to the rural nature of Argyll and Bute, which includes a number of island populations. Transport is a critical issue in rural areas, however it has been reported that rural residents are often realistic about the kinds of services they expect to be provided locally (Scottish Executive, Rural Affairs Department. 2000). It will be important to assess whether patients appear to be willing to make long journeys in order to access this specialist service. Similarly it would be important to identify the geographic spread of referral origin.

Guidelines and recommendations exist for specific patient populations, predominantly alcohol-related brain damage (Fuller Life. 2004) and dementia (SIGN. 1998). Both documents recommend the value of neuropsychological assessment, and given that patients can now access this service, such documents may be useful in shaping the future development and direction of the NAS.

### **Aims and Objectives**

The aim of this project is to provide an analysis of the referrals to a new neuropsychology assessment service provided within Argyll and Bute. This shall be achieved by exploring the following:

1. Who used the service and what types of referrals were received?
  - To establish which population sub groups are accessing the service, both in terms of demographics, geographic location and problem type.
2. What is the nature of the assessment service provided to the referred population?
  - It is important to identify whether the current staffing provision is sufficient to meet the referral demand, and to establish the assessment needs of this population.
3. What were the outcomes of cases seen within the service?
  - This has implications for the development of services.

### **METHOD**

A retrospective analysis of referrals to the NAS was carried out, based on data acquired from their case-notes. Data were collected from all referrals accepted for assessment by the NAS in the first 9 months of the service. This included referrals accepted from 1<sup>st</sup> May

2004 to 31<sup>st</sup> January 2005. Information was gathered from individual files using a data collection form (see Appendix 1:1 for copy of form), the creation of which was guided by data collection in previous audits (Townsend & Irvine. 2003, and Smith. 2003). A database was established in Access to hold this information, and then the data transferred to Excel for subsequent analysis. To protect patient confidentiality, data remained anonymous via a randomly allocated identification number, with personal identifiers such as name and date of birth excluded from data collection.

## **RESULTS**

### **Referral Rates**

In total, 15 referrals were accepted for assessment by the NAS between 1<sup>st</sup> May 2004 and 31<sup>st</sup> January 2005. As referrals are accepted by the NAS via the screening of referrals made to Adult Clinical Psychology Services, the nature of this system means there are no rejected referrals. Figure 1 represents the profile of referrals accepted each month, and highlights the 5 referrals which had been waiting for the NAS to begin accepting referrals.

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Insert Figure1 here

---

### **Age and gender of referrals**

Of the 15 referrals accepted by the NAC for assessment, 9 were male and 6 were female.

The mean age was 50 (SD = 12) and the median age was 52 (Inter-quartile range = 15).

### **Referral Source**

Figure 2 represents the referral source, highlighting that nearly half of referrals (47%) were received from Psychiatry.

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Insert Figure 2 here

---

### **Referral Problem**

Problem areas requested for assessment by the referral letter can be grouped broadly into 3 main areas, as highlighted in Figure 3. Assessments for cognitive impairment represent the majority of referrals, with approximately one third of these questioning a possible link with alcohol/substance abuse. One referral requested the assessment of deficit related to a previously diagnosed Axis II Disorder.

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Insert Figure 3 here

---

### **Geographic Location of Patients**

Figure 4 illustrates the catchment areas of those patients accepted for assessment. Within the 4 Mid Argyll cases, 3 of them were assessed as inpatients and were therefore based on the same site as the NAS. Distance travelled by patients to reach appointments within the NAS was calculated from their home postcodes (calculations made by AA Route Planner). Due to the rural location of many addresses within the catchment area, particularly those located on islands, estimated time-taken to attend appointments were also calculated (AA route-planner). The following results represent a one-way journey. The mean distance traveled by patients to a single appointment was 33.5 miles (SD = 23) and the median distance was 40.7 miles (range = 0 - 69.9 miles). The mean length of time taken to travel to a single appointment, as estimated by AA Route Finder, was 87.6 minutes (SD = 64) and

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Insert Figure 4 here

---

## **Waiting Time**

In those patients who attended the NAS, the mean waiting time between referral and the first appointment offered was 30 days (SD = 20) and the median waiting time was 25 days (range = 8 – 90 days). For these calculations, referrals made before the start of the NAS were recorded as 20<sup>th</sup> April 2004, which is 2 weeks before the NAS first began seeing people, and therefore takes into account when the NAS first began accepting referrals.

## **Attendance Rate**

Figure 5 highlights attendance status to first offered appointments. Despite DNAs and cancellations, all 15 patients eventually attended the service for assessment.

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Insert Figure 5 here

---

## **Formal Neuropsychological Testing**

Two of the 15 cases were unsuitable for formal neuropsychological testing. One of the patients presented as being under the influence of alcohol and in the other case formal testing was not felt to be appropriate. Table 1 shows the variety and frequency of tests used within the NAS for the 13 cases administered formal neuropsychological tests. Within the 13 cases which underwent formal testing, then mean number of tests administered per case were 4 (SD = 2) and the median number of tests administered were 4 (range = 1 – 7 tests)

---

Insert Table 1 here

---

## **Appointments**

The mean number of appointments attended by patients is 2.8 appointments (SD = 1) and the median number is 3 (range = 1-5). The Neuropsychologist attended 48% of all

appointments, and the Trainee Clinical Psychologist and Psychology Assistant each attended 26% of all appointments.

### **Assessment Episode Length**

One patient attended his appointment under the influence of alcohol, and therefore could not be assessed within the NAS. The remaining 14 patients attended the service for the duration of their assessment. The mean length of a completed episode of assessment was 97 days ( $SD = 56$ ) and the median length of assessment was 91 days with the range of 0 to 209 days (0 days refers to assessments which were completed in one day). Length of assessment was calculated from 1<sup>st</sup> appointment attended to the date stated on the patient's assessment report.

### **Problem Type Following Assessment**

Figure 6 shows the basic problem types identified by the Neuropsychologist following assessment. It highlights that acquired cognitive deficit was identified in 80% of cases assessed.

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Insert Figure 6 here

---

Of the 12 cases with acquired cognitive deficit, Figure 7 highlights the most likely cause of the problems as identified by the Neuropsychologist. In some cases there are multiple possible causes, e.g. closed head injuries combined with a past history of alcohol abuse. For the pie chart below only the most prominent/likely cause has been categorized.

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Insert Figure 7 here

---

### **Other service involvement**

From the psychology notes it appeared that 53% (n=8) of the cases analysed were only currently receiving input from the NAS and the referring service. In the 7 cases with additional services involved, these included: Occupational Therapy, Neurology, Psychiatry and the Physically Disabled Rehabilitation Unit.

### **Outcome of cases**

Following assessment, 67% (n=10) of the cases were returned to the referrer. At the time of writing (July 2005), 33% (n=5) of the cases remain open to the NAS. Two of these cases are awaiting re-assessment in order to monitor any change, and 3 cases remain open in order to receive follow-up by the Psychology Assistant.

### **Recommendations Following NAS Assessment**

Figure 8 highlights the Neuropsychologist's recommendations to the referrer following assessment, as specified within the assessment report.

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Insert Figure 8 here

---

## **DISCUSSION**

The results of this study provide a description of referrals accepted by the NAS in its first 9 months.



## **Accepted Referrals**

A total of 15 referrals were accepted for assessment between 1<sup>st</sup> May 2004 to 31<sup>st</sup> January 2005. Despite a small build-up of referrals before the service began, referrals appear to have been infrequent but regular throughout the 9-month period. With an average waiting time of 30 days (approximately 1 month) between referral and 1<sup>st</sup> appointment, initial results on wait times appear to be satisfactory. However, these results may be expected in a new service, therefore continued monitoring will be required to establish the stability of these results.

## **Demographic Characteristics**

The results do not suggest a significant bias towards the assessment of males or females within the NAS, with 9 males and 6 females assessed. The majority of patients assessed are within the age range between 36 and 70 years old.

Despite appointments with the Neuropsychologist only being available at Lochgilphead, the service has been accessed by patients within all 6 catchment areas of Argyll and Bute. The average distance travelled one-way from a patient's home address to the clinic is 33.5 miles. Estimates suggest that the mean length of time taken to travel by car to a single appointment was 87.6 minutes. Taking into account the return journey this is an average travelling time of 175.2 minutes per appointment. Such lengthy travelling times are inevitable with island populations and poor infrastructure. The attendance of all 15 referrals for assessment suggests that patients have not been deterred from seeking specialist assessment. Whilst such long journey times are undesirable, the current study does not demonstrate any negative impact of the Lochgilphead site as the base for this service.

### **Referral Source and Reason**

Five referral sources were identified (Psychiatry, GP, Clinical Psychology, General Medicine and Occupational Health), with almost half of accepted referrals received from Psychiatry. Fourteen of these referrals required assessment for cognitive impairment, with just over a third suggesting a link with alcohol/substance abuse. With referrals being made from all 6 catchment areas, there does not appear to be evidence at this stage, that referrers from more distant localities are reluctant to refer.

### **Attendance**

In terms of attendance rate, all 15 individuals offered appointments attended the service for the duration of their assessment. Whilst cancellations and DNAs did occur, all assessments were completed, therefore there were no non-attenders. These are positive results, since within the health service, non-attendance rates of between 10 and 50% have been quoted within the literature (Henry et al. 1998). It should also be acknowledged that these results are in the context of a population who by their very nature are often unreliable, for example, due to memory impairments. It is difficult to know why these results are so positive, but it would be interesting to see whether this trend continues.

### **Formal Neuropsychological Testing**

The results demonstrate a wide variety of tests used within the NAS, with on average 4 tests being administered for each patient receiving formal testing.

### **Appointments**

Within the first 9 months of the service almost half of appointments involved the Neuropsychologist, which reflects the Neuropsychologists attendance at all initial

assessments. The Trainee Clinical Psychologist and Psychology Assistant were involved in approximately a quarter of appointments each. The mean number of appointments attended were 2.8 appointments, per assessment episode.

### **Assessment Episode Length**

The mean length of a completed assessment episodes were 97 days (approximately 3 months). Through further analysis of those cases with a larger episode length, this appeared to be due to a delay in the writing of assessment reports. In some cases this was due to waiting for information from other services. However, in the majority of cases it is not clear why such long gaps exist between the patient's last appointment and the completion of their assessment report. All assessment reports are completed by the Neuropsychologist, and by nature are lengthy and detailed. There may therefore be an issue regarding whether the balance of time between clinical work and administrative work is currently functioning at the correct level. This is something the service will need to consider.

### **Problem Type Following Assessment**

Following assessment, 80% of cases were identified as having acquired cognitive deficits. Whilst multiple possible causes may exist, closed head injuries and alcohol related brain damage have been the most prominent causes. Of the patients with closed head injuries, some included the victims of road traffic accidents. It may be predicted that the NAS will continue to regularly assess the victims of such accidents, since the incidence of serious road traffic accidents within Argyll and Bute has been reported as being significantly higher than the Scottish average (Argyll and Bute Council. 2004). Patients with dementia have been seen less frequently within this referral population. These results may be a

reflection of 'suspect' dementia referrals going to another service; especially since a rural dementia service exists within the area. If this is the case, it is positive that such patients are accessing a service, but also of some concern that mis-diagnosis may result from a lack of specialist neuropsychological assessment. It is recommended by SIGN (1998) and NICE (2001), that all patients with dementia receive neuropsychological assessment.

### **Other Services Involved**

53% of the cases did not appear to have other services simultaneously involved in the assessment/care of the case, other than the NAS and the referring service. As this data were gathered only from clinical psychology case-notes, a clear picture of other service involvement may not have been provided by the referrer or patient, therefore these results may be inaccurate.

### **Outcome of cases**

Following assessment the majority of cases (67%) were returned to the referrer, with recommendations for further referrals or future management. Recommendations from the neuropsychology assessment reports vary greatly, and with only the analysis of 15 cases no patterns have currently been identified. One possible implication of the new NAS may be an increase in referrals for neuro-imaging, which may therefore begin to affect their service. This would be an area in which future links with the NAS may be established more formally.

At the time of writing (July, 2005) 33% (n=5) of cases remain open to the NAS. The Neuropsychologist has been providing supervision to the Psychology Assistant in the

follow-up of 3 of the cases. This is mainly in the form of advice and support for patients in the management of their specific cognitive impairments.

## **SUMMARY AND CONCLUSIONS**

This study was only able to look at 15 referrals, and it is usually considered preferable to have a larger number of referrals to analyse when making inferences. Due to a low referral rate, this small data set is unavoidable, but may be viewed as a valuable baseline for future audit, and as providing useful information regarding a newly established service.

### **Future Implications**

Following the departure, approximately 5 years ago, of the Neuropsychologist based within Argyll and Bute, clinical psychology services were unable to offer a specialist neuropsychology service. Referrals for neuropsychological assessment were therefore unable to be accepted, with referrers having to find alternative services, which were possibly less appropriate or outwith Argyll and Bute. The presence of the current specialist service may therefore now reduce the incidence of inappropriate referrals and increase the incidence of appropriate referrals to other services within Argyll and Bute. Ultimately the NAS allows for more accurate assessment and diagnosis, which can only enhance the effectiveness of other service's for the benefit of the patient.

The most positive results from this study were the 0% rate in non-attenders to the service, especially in the context of long traveling times by many patients to reach their service. Whilst results to date are encouraging, the NAS may wish to consider the future planning of appointment times to suit patient's individual journeys.

With the results of this study being generally positive, the NAS will now need to consider the future development and marketing of the service. This may involve the promotion of the NAS to GPs, psychiatry, the rural dementia team, neurology, alcohol services etc., to allow for the development of more formal links between services for adults with neuropsychological deficits within Argyll and Bute. The service may also begin to consider whether a direct access referral system should now be adopted. Whatever plans are made to take the NAS forward, the resource implications will have to be carefully considered, which may need to be facilitated within another study.

### **Possible Complications**

A condition of the Neuropsychology provision was input from the Psychology Assistant based at Lochgilphead. In April 2005 the Psychology Assistant left the service which resulted in the clinic temporarily ceasing to function. The service will have a Psychology Assistant in post by July 2005, when the service will resume. This has implications for those cases which remain open to the NAS, and is likely to result in a backlog of referrals. Such a backlog may result in longer assessment episodes, and whilst this may not be as devastating for a service with such a low referral rate, it may be important for this to be monitored.

In May 2005, during the completion of this project, the future dissolution of NHS Argyll and Clyde was confirmed (NHS A&C News Release. May 2005). At the time of writing, a consultation process is currently underway, which proposes that the responsibility for the services provided for the people of Argyll and Clyde could be shared between NHS Greater Glasgow and NHS Highland. It is not clear how long this consultation process will

take, and therefore the development of the NAS may be affected due to uncertainties regarding structure and management.

## **Conclusion**

Whatever the future outcome of Argyll and Clyde it is important that services continue to monitor and evaluate their provision. The results of this study shall be presented to members of the service in August 2005 for discussion (Appendix 1:2 contains the PowerPoint slides to this presentation). Hopefully this study will provide a valuable baseline for future audit and service development, despite the uncertain climate.

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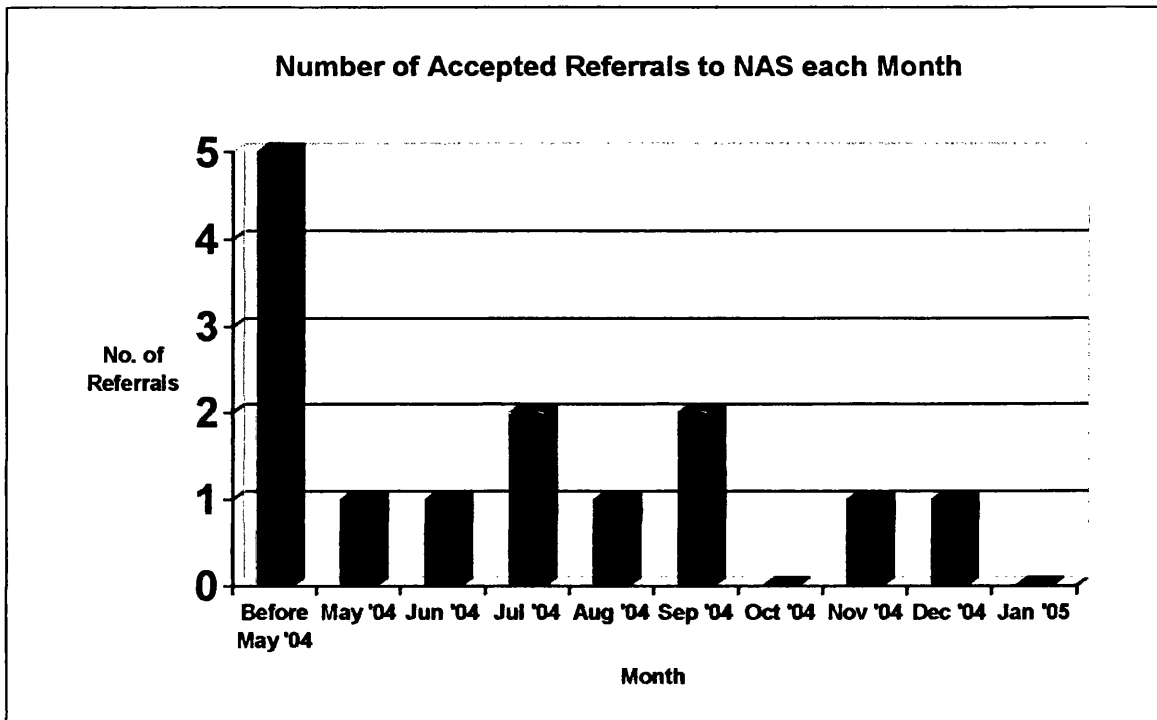


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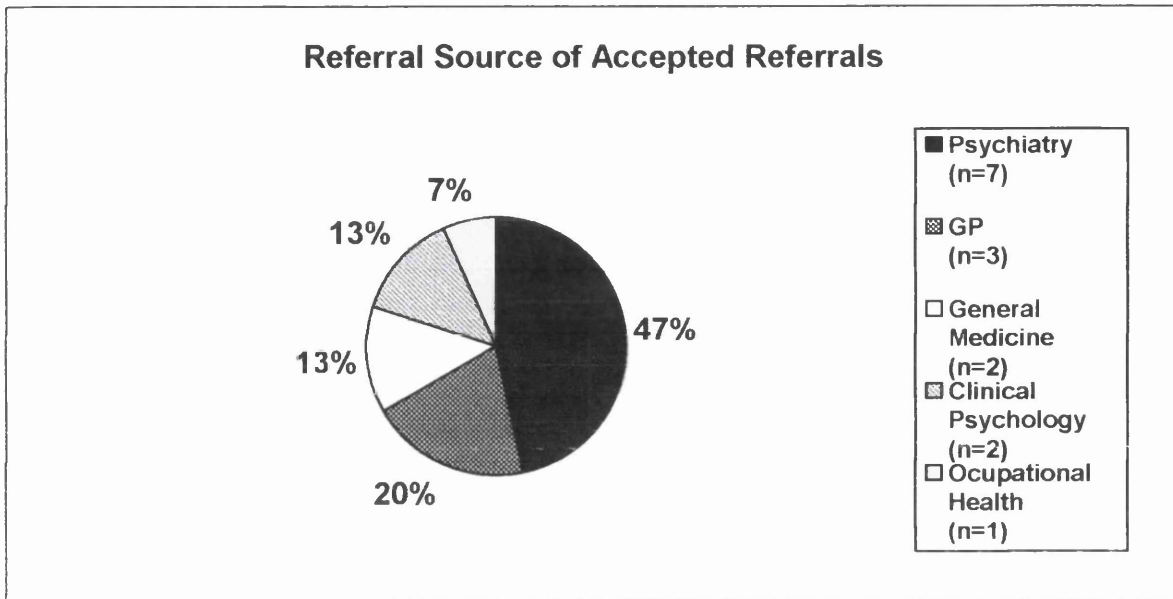
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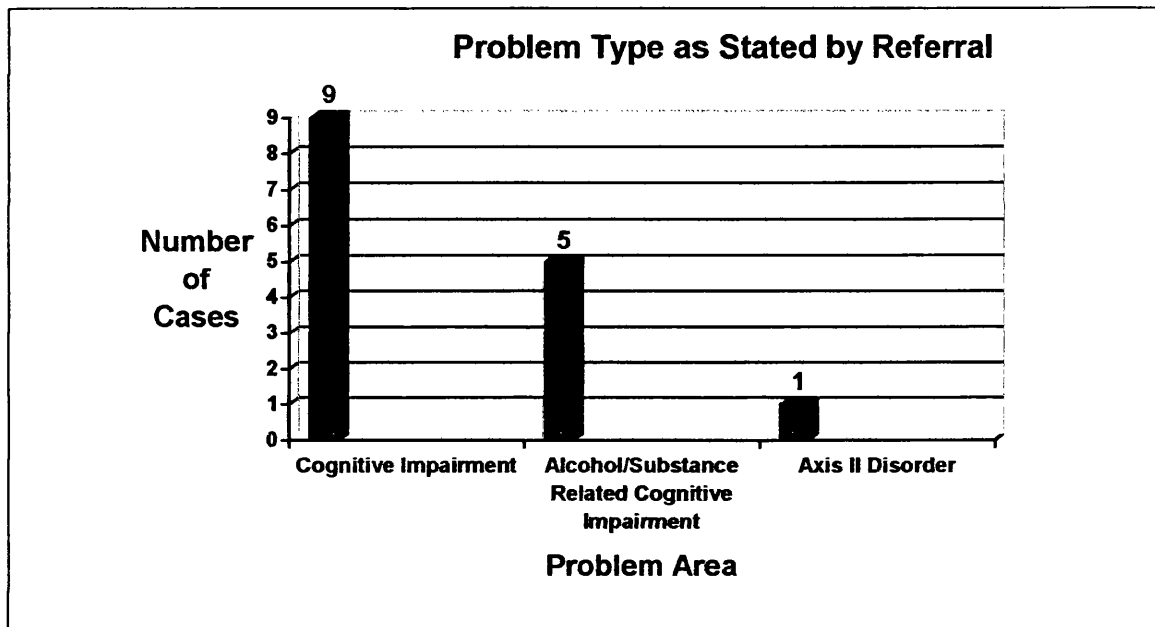
**FIGURE 1: Number of Accepted Referrals to NAS each Month**



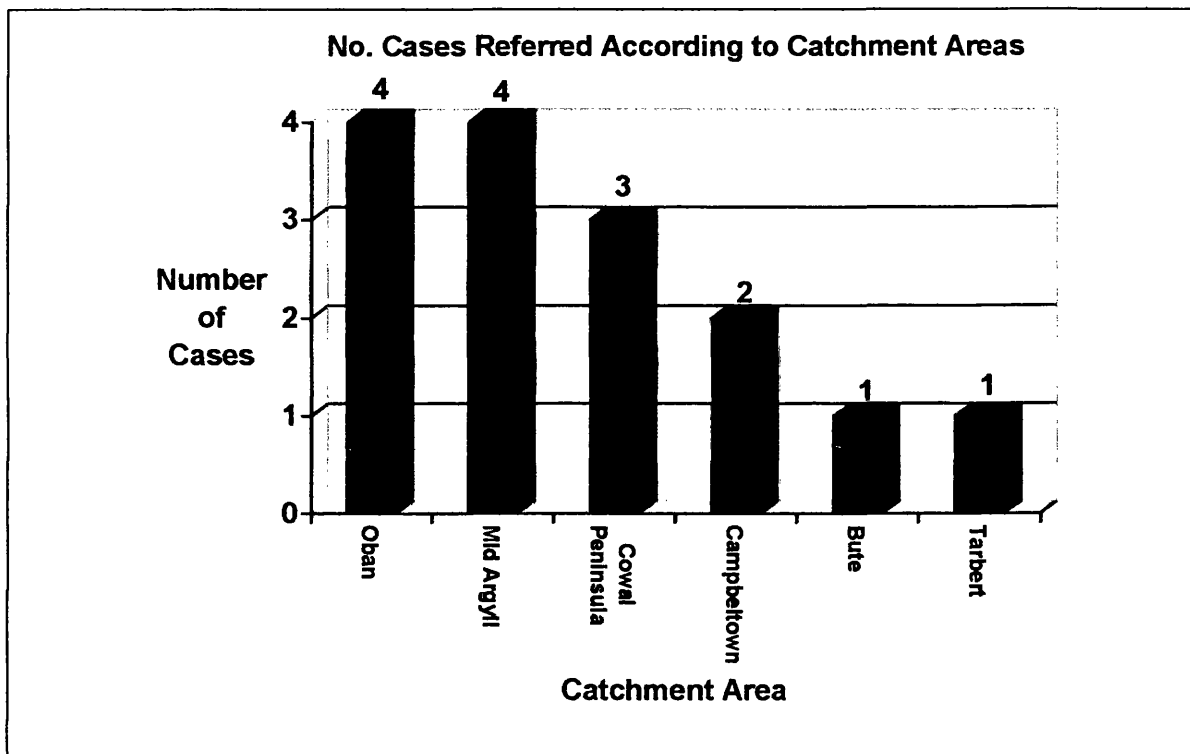
**FIGURE 2: Referral Source of Accepted Referrals**



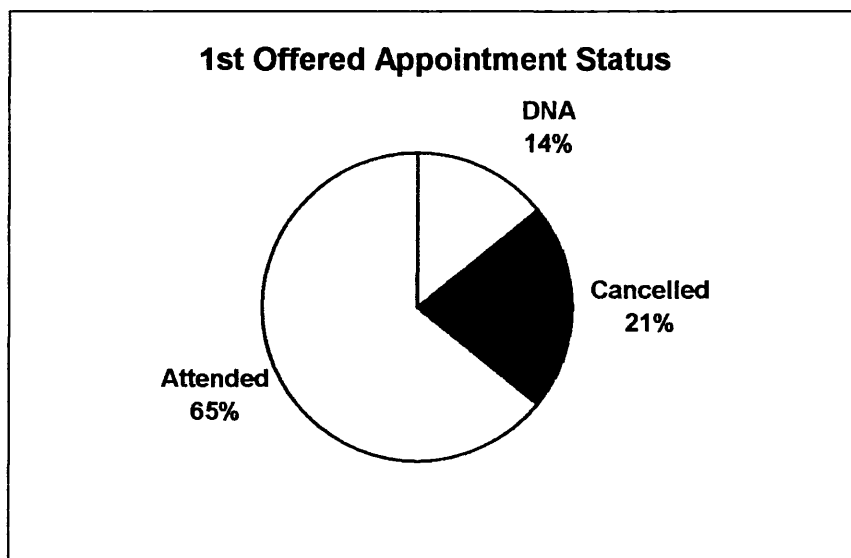
**FIGURE 3: Problem Type as Stated by Referral**



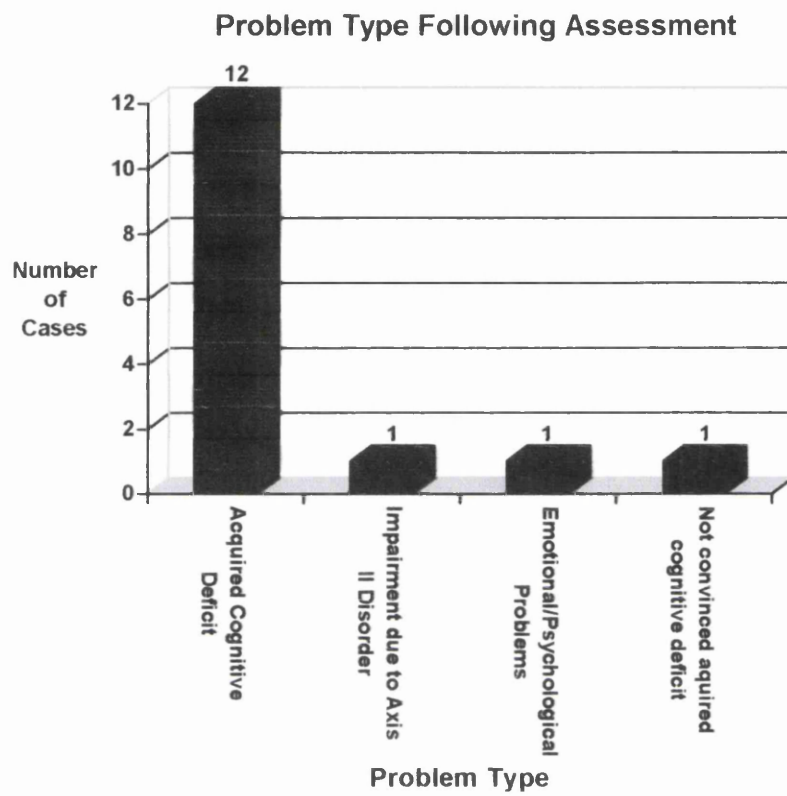
**FIGURE 4: Number of Cases Referred from Each Catchment Area**



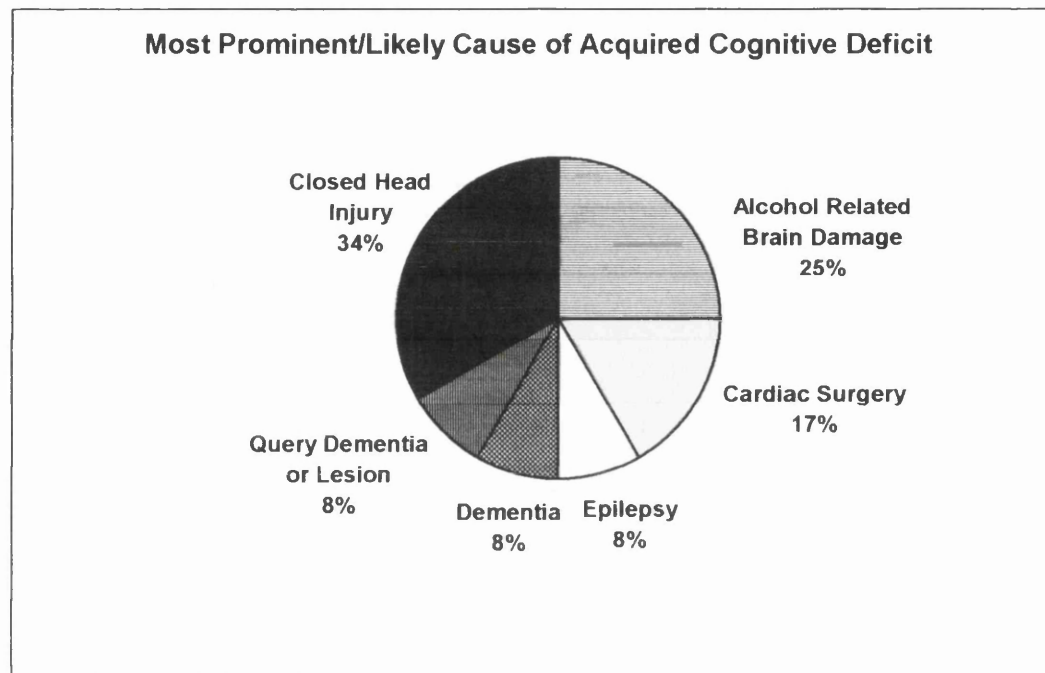
**FIGURE 5: 1<sup>st</sup> Offered Appointment Status**



**FIGURE 6: Problem Type Following Assessment**

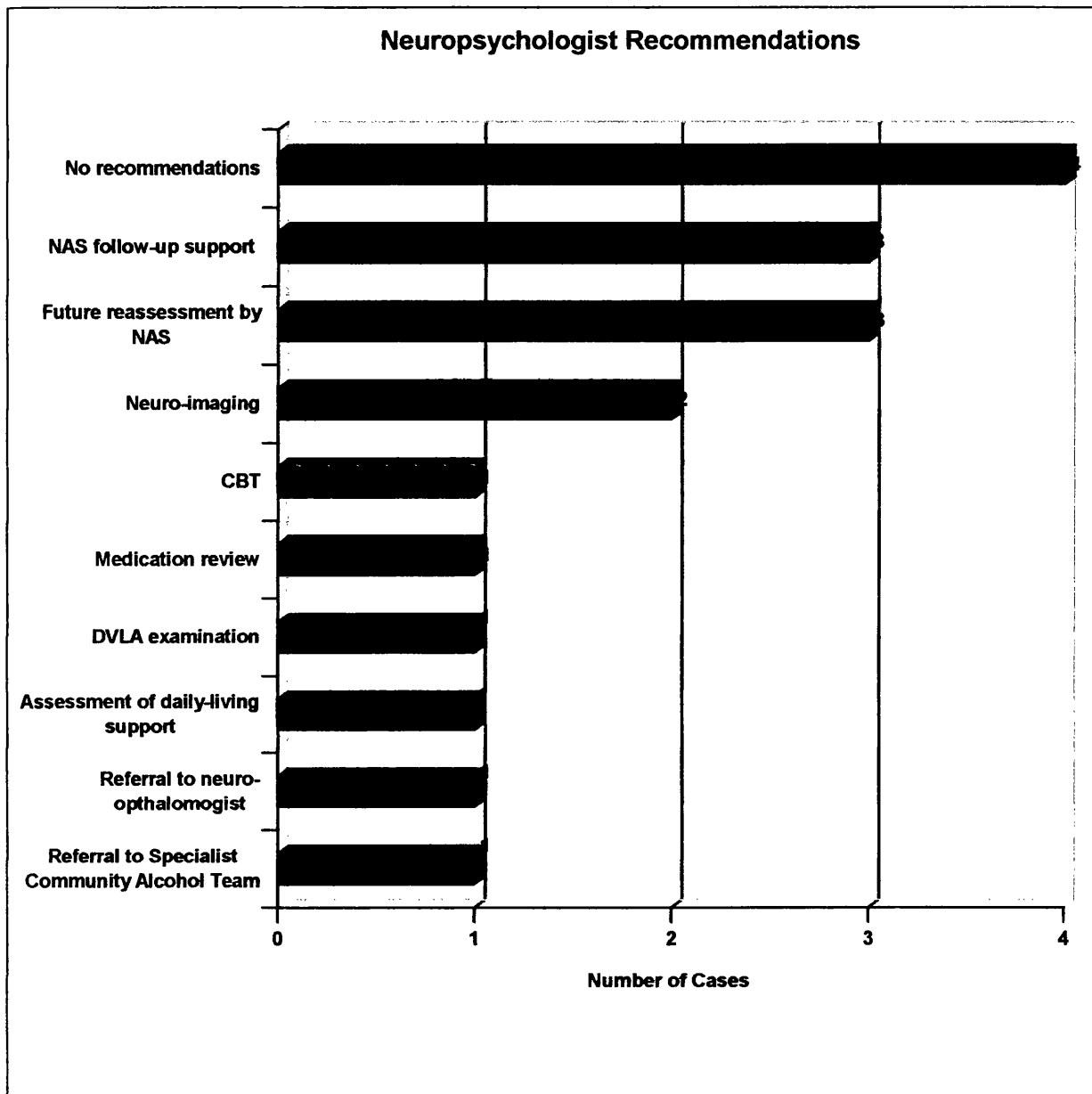


**FIGURE 7: Most Prominent/Likely Cause of Acquired Cognitive Deficit**





**FIGURE 8: Neuropsychologist Recommendations**



**Table 1: Table to Show the Frequency of Tests Used**

<b>Test Name</b>	<b>No. of Times Administered</b>	<b>% of Total Frequency of Tests Administered</b>
Repeatable Battery for the Assessment of Neuropsychological Status	9	16.7%
Wechsler Test of Adult Reading	8	14.8%
Wechsler Adult Intelligence Scale	6	11.1%
Hayling and Brixton Tests	4	7.4%
Rivermead Behavioural Memory Test	4	7.4%
Wechsler Memory Scale	4	7.4%
Controlled Word Association Test	3	5.6%
Addenbrook's Cognitive Examination	2	3.7%
Behavioural Assessment of Dysexecutive Syndrome	2	3.7%
Behavioural Inattention Test	2	3.7%
Cardiovascular Risk Analysis Questionnaire	2	3.7%
Letter Verbal Fluency Task	2	3.7%
Category Verbal Fluency Test	1	1.9%
Controlled Oral Word Association Test	1	1.9%
Raven Standard Progressive Matrices	1	1.9%
Revised Token Test	1	1.9%
Rohmberg Test	1	1.9%
Visual Retention Test	1	1.9%

## Chapter 2: Systematic Review

Systematic review submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

### **The impact of perceived stigma on psychopathology in people with epilepsy: A systematic review of the literature.**

Prepared in accordance with the requirements for submission to *Seizure*  
(See Appendix 2.1)

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## **ABSTRACT**

**Background:** Hermann and Whitman (1986) proposed a Multietiologic Model regarding the aetiology of psychopathology in people with epilepsy. Within this model they hypothesised a range of psychosocial variables that may contribute towards the development of psychopathology. One of the proposed variables was perceived stigma, however there was limited evidence to support this hypothesis when the model was initially proposed. The current paper therefore presents a systematic review of the literature in order to evaluate the impact of perceived stigma on psychopathology in people with epilepsy.

**Method:** An electronic search of databases and a manual search of relevant journals identified 327 articles. Studies which were repeated or irrelevant were excluded, leaving 51 papers that were subjected to the inclusion/exclusion criteria.

**Results:** Thirteen studies met the inclusion criteria. They were assessed on their methodological quality and assigned a quality rating. Study characteristics were described, methodological strengths and weaknesses discussed, and results evaluated.

**Conclusions:** This review suggests that there is evidence of an association between perceived stigma and psychopathology in people with epilepsy. However our understanding of the nature of this association is limited. There is a need for representative, longitudinal studies to further investigate the relationship and attribute causality.

**Keywords:** epilepsy, stigma, psychopathology

## INTRODUCTION

Research has identified that people with epilepsy have increased psychiatric morbidity compared with normal controls [1] [2] [3]. There has therefore been interest by researchers into the causes of these elevated levels of psychopathology. Hermann and Whitman (1986) [4] proposed a Multietiologic Model regarding the aetiology of psychopathology in epilepsy. In conceptualising the relationship between epilepsy and psychopathology, their model refers to three categories of etiologic factors; 1) neuroepilepsy factors 2) medication factors and 3) psychosocial factors. Neuro-epilepsy factors refer to a range of biological and seizure-related variables; for example seizure frequency, seizure type and duration of disorder. Medication factors are also considered; including the number, type and dosage of medication. Hermann and Whitman developed their model in response to a historical focus on the biological causes of psychopathology in people with epilepsy; which generally neglected the impact of psychosocial factors. Their psychosocial hypothesis acknowledges the ‘unique social and interpersonal stresses’ that people with epilepsy may be exposed to, and the effect these stresses can potentially have on psychopathology [4]. Additional stresses associated with epilepsy include embarrassment and loss of personal dignity which may be associated with seizures; and the uncertainty around when or where seizures will occur. Hermann and Whitman’s model proposes a range of psychosocial factors which may predispose the individual to various forms of psychopathology, including perceived stigma, discrimination, social exclusion, sense of alienation, lack of social support, fear of seizures, feelings of helplessness, hopelessness and loss of control. It is proposed that these psychosocial variables may interact with neurological factors in complex ways towards the development of psychopathology, but hypotheses regarding the nature of these interactions were not made explicit.

In theorizing about the development of depression in epilepsy, Hermann [5] has referred to the learned helplessness model, which suggests that depression is a consequence of a person's belief in their ability to control the outcome of events. Hermann proposes that people with epilepsy are regularly exposed to uncontrollable aversive events, which can produce a pattern of emotional, motivational and cognitive disorders that present as anxiety. If these events are prolonged or perpetuated they may result in depression. Hermann suggests that learned helplessness may be associated to seizure-related factors, given the unpredictable, uncontrollable and potentially dangerous nature of seizure events. In addition, psychosocial factors associated with epilepsy may also be considered unpredictable and outwith the control of the person with epilepsy e.g. discrimination, employment difficulties, and social exclusion.

The current review is concerned with perceived stigma, which is a particular psychosocial factor highlighted in Hermann and Whitman's Multietiological Model. In defining the social phenomena of stigma, Goffman [6] describes it as an attribute that is discreditable to one's personal identity. He observes stigma as the relationship between an attribute and a stereotype, therefore highlighting how people can be linked with socially undesirable characteristics when they are seen to have a discrediting attribute such as epilepsy. Quantitative measures of perceived stigma have been adapted and developed for people with epilepsy [7] [8], allowing researchers to measure levels of perceived stigma alongside other psychosocial variables within epilepsy research. For example, Jacoby [7], developed a scale in which subjects are asked whether, because of their epilepsy, they felt that other people (1) were uncomfortable with them (2) treated them as inferior and (3) preferred to avoid them. The Multietiological Model therefore hypothesised that a person's perception of

being negatively defined by their epilepsy may contribute towards the development of psychopathology.

In 1986 when Hermann and Whitman [4] included perceived stigma in their model, they were unaware of any published empirical evaluations regarding the relationship between measures of perceived stigma and psychopathology. The proposed review therefore attempts to identify whether the research over the past 20 years has attempted to evaluate this relationship, and investigate the extent to which perceived stigma impacts on psychopathology. A number of reviews have made reference to the research on the stigma of epilepsy and its relationship with psychopathology and quality of life [9] [10]. However, these studies did not include a thorough analysis of methodology, and did not focus specifically on the relationship between perceived stigma and psychopathology.

Psychopathology has been defined as ‘the systematic study of abnormal experiences, cognition and behaviour; the study of the products of a disordered mind’ [11]. However, a recent review paper on psychiatric co-morbidity in epilepsy acknowledges the ‘diverse and confusing ways’ in which the term psychopathology has been used within epilepsy research [12]. Hermann and Whitman [4] also acknowledge ‘psychopathology’ as a non-specific term. They describe the epilepsy literature as having 6 major areas of investigation: psychosis, aggression, sexual dysfunction, affective disorder, personality and behavioural change. In addition they refer to ‘a large and heterogeneous category – general psychopathology – characterised by the use of standardised measures of personality and other indications of psychopathology (e.g. rated as psychiatric hospitalisations)’. Thus, whilst investigators speak of “psychopathology in epilepsy” there are at least six distinct areas that are the focus of investigations. For the purpose of this review, the term

psychopathology shall remain wide; including the areas outlined by Hermann and Whitman [4], and any other measures of general emotional well-being. In addition, this review shall also reflect upon studies which include variables viewed as indicators or symptoms of psychopathology, for example low self-esteem. This will allow for a more comprehensive discussion of the literature.

The objective of this paper is to investigate the impact of perceived stigma on psychopathology in people with epilepsy. This shall be achieved through a systematic review of the available research and an evaluation of the methodological quality of these studies. Whilst the current review is concerned with the impact of a single psychosocial variable on psychopathology, it will also be important to identify any factors which may influence this relationship. In consideration of the learned helplessness model, the significance of factors such as seizure frequency, perceived seizure severity, adjustment to epilepsy, employment difficulties and social isolation, will be important when considering the results of this review.

## **METHODS**

### **Search Strategy**

#### **Computerised Database Search**

The following electronic databases were searched:

- PsychINFO (1967 – 2006)
- Medline (1966 – 2006)
- CINAHL (1982 – 2006)
- EMBASE (1980 – 2006)
- British Nursing Index (1985 – 2006)



- EBM Reviews – Cochrane Database of Systematic Reviews
- EBM Reviews – Database of Abstracts of Reviews of Effects
- EBM Reviews – Cochrane Central Register of Controlled Trials

The following key words were used as search terms: [epilepsy] combined with [stigma] or [discrimination] and the results from this combined with the results gained from searching [psychosis] or [aggression] or [sexual dysfunction] or [affective disorder] or [personality change] or [behaviour change] or [psychopathology] or [psychosocial functioning] or [psychological outcome] or [mental health] or [psychological wellbeing] or [quality of life] or [anxiety] or [depression] or [self-esteem] or [hopelessness].

### **Reference Searching**

The references of all papers considered for inclusion were also searched, in order to identify further relevant papers.

### **Hand Search of Related Journals**

Any journals that had published three or more of the papers considered for inclusion were also searched for any further relevant studies. Journals included in the manual search were:

*Seizure, Epilepsia, Epilepsy and Behaviour, Social Science and Medicine.*

### **Article Inclusion and Exclusion Criteria**

Studies were included if they met the following criteria:

- Include a measure of participant's perceived stigma in relation to their epilepsy.
- Consider the relationship between levels of perceived stigma and psychopathology in adults with epilepsy. Including:

- Studies measuring ‘psychopathology’, ‘mental illness’ or ‘psychological/emotional well-being’
- Studies measuring a specific type of mental illness e.g. depression, anxiety.
- Studies measuring variables which may be indicative of impaired psychological functioning e.g. symptoms of depression and anxiety or low-self-esteem.

The following exclusion criteria were applied:

- Case studies.
- Selective reviews, expert opinions or editorials.
- A qualitative methodological approach.
- Unpublished dissertations.
- Studies not reported in English.
- Non-clinical studies (statistics papers, discussion papers, commentaries).
- Studies reporting the development/validation of a clinical measurement tool.
- Studies on children and/or adolescent populations.

## **RESULTS**

### **Outcome of Search Process**

#### **Electronic Search**

The electronic search initially generated 217 papers. Repeated titles were excluded leaving 143 papers. Sixty-two papers were excluded on the basis of their titles, and 52 further papers were excluded after scrutinising their abstracts. This left 29 papers that were read and the contents checked against the inclusion and exclusion criteria. Eight papers from this search were identified as meeting the inclusion criteria.

## **Reference Search**

A further 63 titles were identified by a hand search of the eight identified paper's reference sections. Of these, 46 were excluded once the abstracts were checked and 12 were excluded after reading the papers, leaving the remaining 5 to be added to the review.

## **Hand search of Relevant Journals**

Six journals were identified as having published at least 3 of the studies considered for inclusion. The contents of these six journals were searched from 1986 and from this 47 titles were considered for inclusion. Of these, 42 abstracts were checked and 5 original papers were checked. None of them were included in the review.

The outcome of the search process is shown schematically in Figure 1.

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Insert Figure1 here

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## **Study Quality and Rating Criteria**

The studies being reviewed all used observational methods. Criteria were therefore devised to assess the quality of studies specific to this review. These were guided by expert opinion (Greenhalgh. 1997) [13] and formal guidelines produced by the Scottish Intercollegiate Guideline Network [14] and the Cochrane Collaboration [15].

The first stage of quality assessment referred to the design of the studies, as this is a key consideration in assessing the extent to which the studies are able to evaluate the impact of perceived stigma and psychopathology in people with epilepsy. Longitudinal designs are

the most appropriate design for answering this question as they are able to ‘establish the direction and magnitude of causal relationships’ [16], unlike cross-sectional designs. Within the first stage of quality assessment studies were therefore assigned according one of the following ratings:

1: Longitudinal design

2: Cross-sectional design

Within these principle ratings, the studies were further assessed according to three further quality areas:

a) Generalizability of the findings:

Whether the sample is representative is an important quality criterion, as it reflects the extent to which the results can be generalised to the target population. To account for selection bias, the quality criterion therefore considers whether studies utilised an appropriate sampling strategy to select their participants.

b) Confounding variables:

The Cochrane Collaboration highlight that in observational studies it is important to identify and account for potential confounds, by making judgements about what confounds are important and the extent to which these were appropriately measured and controlled for [15]. As highlighted within Hermann and Whitman’s Multi-etiological Model [4] a variety of variables have been proposed to influence psychopathology in people with epilepsy; including demographic, neuro-epilepsy, psychosocial and medication variables. Swinkels et al. [17] recommend that all these factors should be considered when investigating psychopathology in epilepsy. It is therefore an important quality criterion to establish whether the papers reported variables within each of these four categories and considered them in the analysis. The quality criteria takes into account the extent to which studies have considered possible confounding factors, such as those highlighted in Table 1.

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Insert Table 1 here

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c) Reliability/validity of assessment measures:

In order to establish whether perceived stigma and psychopathology are being measured in a reliable and valid way, the quality criteria assesses the reliability and validity of the measures used.

Each study was assessed on how well they met these three quality areas and assigned a rating of either 'Good', 'Adequate' or 'Poor' within each area. An overall quality rating of i) ii) or iii) were subsequently allocated according to the following criteria:

- i) = Two or more ratings of 'Good'
- ii) = Two or more ratings of 'Adequate' or one of each ('Poor', 'Adequate', 'Good')
- iii) = Two or more ratings of 'Poor'

This was combined with the initial quality rating assigned according to the design of the study i.e.) 1 = longitudinal, 2 = cross-sectional. Appendix 2.2 contains the rating system for these quality criteria, in which 1(i) represents the highest quality rating and 2(iii) represents the lowest. Whilst the overall quality ratings were dependent upon key areas of quality, the results section also gives more detailed consideration to the strengths and weaknesses of each of the reviewed studies.

### **Data Extraction**

Thirteen papers were identified as meeting criteria for this review. To increase reliability each study was evaluated by the author and an independent rater, using the quality criteria outlined in Appendix 2:2. The raters assigned the same overall quality rating to nine of the

papers. The other four papers were discussed between the two raters in order to establish an agreed rating for all of the studies.

## **RESULTS**

Of the 13 studies reviewed, four papers were rated 2(i), three papers were rated 2(ii) and six papers were rated 2(iii). The summarised characteristics and quality ratings of each study are provided in Table 2.

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Insert Table 2 here

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The key question in this review concerns the possible relationship between stigma and psychopathology, and as discussed in the introduction, one of the problems has been a clear definition of the term psychopathology. For this reason, the results are presented in three sections, with each concerning a distinct way in which psychopathology has been measured. As some studies adopted a wide range of measures, this means they may be referred to in more than one section of the results. For ease of reference, Table 3 presents the studies corresponding to each section of results, alongside their assigned quality ratings.

### **1) Perceived Stigma and General Psychopathology**

General psychopathology was seen to be measured by the assessment of overall emotional well-being, regardless of specific types of disorders. Four of the reviewed studies were found to have considered the association between perceived stigma and overall emotional well-being (Hermann et al. [18], Herodes et al. [19], Lee et al. [20] and Jacoby [21]). Details of these studies are outlined in Table 2.

### ***i) Findings***

Each of the studies used samples of participants from a different country. Nevertheless, they all found a significant association between their measures of emotional well-being and perceived stigma. Perceptions of stigma were associated to lower emotional well-being; however the nature of this relationship varied amongst the studies. Lee et al. [20] aimed to identify factors which contributed to feelings of stigma, and found that emotional well-being was independently and significantly associated with perceived stigma. Similarly, Herodes et al.[19] found that perceived stigma independently and significantly contributed to scores of emotional well-being, alongside ‘seizure frequency’ and ‘duration of disease’. Unlike other papers, Jacoby [21] did not account for confounding variables within their analysis, however they found higher scores on the stigma scale were associated to lower emotional well-being. The paper by Hermann et al [18] is a significant study within this review, because it was completed by the authors who originally proposed the Multietiological Model of psychopathology in epilepsy. In order to contribute evidence for this model, neurological, psychosocial, demographic and medication variables were investigated. Whilst perceived stigma was found to be significantly associated with psychopathology, it was not identified as an independent predictor of psychopathology. The most powerful predictors of psychopathology were ‘increased number of stressful events in the past year’, ‘poor adjustment to epilepsy’ and ‘financial stress’. Psychosocial factors were generally identified as having the strongest relationship with overall psychiatric distress.

### ***ii) Methodological issues***

As highlighted in Table 3, the quality of the studies outlined were varied; two received a quality rating of 2(i) and two received a quality rating of 2(iii). The studies were all cross-

sectional in design, which means causality cannot be inferred between the relationship of perceived stigma and overall emotional well-being. There was variability in the extent to which confounding variables were considered in the analysis. Table 2 shows that one study did not take into account any confounding variables, while the other three considered a wide range of neuro-epilepsy psychosocial and demographic factors. Despite this, only two studies accounted medication variables.

The generalizability of the results are limited due to sampling biases, as highlighted in Table 2. Three studies recruited participants from specialist inpatient units, whilst the other focused on a sample of participants with well-controlled epilepsy. In addition, due the exclusion criteria, the results are not generalisable to people with a learning disability. In measuring psychopathology, none of the studies utilised standardized clinical diagnostic systems. They each used self-report questionnaires, only one of which was specifically designed to assess overall psychiatric status (General Health Questionnaire [22]). The other three studies used questionnaires of quality of life or health status, which included domains that assessed overall emotional functioning (RAND 36-Item Health Survey (RAND-36) [23], Nottingham Health Profile [24] and Quality of Life in Epilepsy Scale [25]).

### ***iii) Conclusions***

The results provide strong support for an association between perceived stigma and overall emotional well-being. Each study measured a different range of variables; therefore it is difficult to draw conclusions about which variables are most significant to how stigma relates to psychopathology. Within the four main categories of variables, psychosocial factors appeared to be most strongly associated with psychopathology.



## **2) Perceived Stigma and Specific Forms of Psychopathology**

Seven studies considered the association between perceived stigma and specific types of psychopathology. Three studies investigated the association of stigma with depression and anxiety (Baker et al. [26], Arntson et al. [27] and Lee et al [20]), two studies investigated only depression (Hermann and Whitman (1989) [28] and DiIorio et al. (2004) [29]) and two studies investigated depression and neuroticism (Olley [30] [31]). The measure of neuroticism may be regarded as an assessment of anxiety, as it was an instrument used to screen for generalised anxiety disorder (The Crown Crisp Experiential Index [32]). It should also be noted that the studies by Olley [30][31], presented different analyses of the same set of data.

### ***i) Findings***

Six studies found that higher scores of depression were significantly associated to perceived stigma [20][27][28][29][30][31]. Some studies provided analysis of factors predicting perceived stigma, whilst others reported analysis of factors predicting depression. In addition, the study by DiIorio et al. [29] investigated a psychosocial model of medication self-management among people with epilepsy. The results supported the model's prediction that perceived stigma was directly related to self-efficacy and depressive symptoms. The studies by Olley et al [30][31] found that depression and stigma were both independently related to each other; when other clinical and demographic variables were accounted for. Depression and social support were the only variables identified as being independently and significantly associated with perceived stigma. In addition, perceived stigma, emotion adjustment and adjustment to seizure were the only variables identified as being independently and significantly associated with depression. These results were in contrast to the findings of Lee et al [20], who did not identify

depression as being an independent predictor of stigma; suggesting the relationship was influenced by other significant variables. This relationship may have been influenced by a variety of other factors found to be significantly related to stigma; including reduced quality of life, introverted or neurotic personality, helplessness, low problem solving control and problem solving confidence, anxiety, and low self-esteem. Similarly, Hermann and Whitman [28] found that stigma was not an independent predictor of depression. Whilst eight variables were found to have a significant association with depression, only four were found to be independent predictors of depression; an increased number of stressful life events during the past year, poor adjustment to epilepsy, financial stress and female gender. However, Hermann and Whitman's analysis does not allow us to make inferences about the relationship between perceived stigma and these variables. This is an important paper, as it aimed to determine the relationship between psychosocial variables and depression, in the context of the multi-etiological model they originally proposed. It is interesting that they did not identify any significant correlations between their measure of depression and potential neuro-epilepsy or medication risk factors. It is unclear whether the study by Baker et al [26] found a significant association between perceived stigma and depression; however their stepwise multiple regression analysis did not identify stigma as a predictor of depression, or depression as a predictor of stigma.

Within the studies which measured anxiety, they all identified a significant association between perceived stigma and anxiety. Baker et al. [26] examined the relationship between clinical, demographic and psychosocial variables and found perceived stigma was one of eight significant predictor variables for anxiety. When perceived stigma was the dependent variable there were four significant predictor variables; perceived impact of epilepsy, age, anxiety and seizure frequency. However, Lee et al. [20] found that anxiety was not

independently associated with feelings of stigma, suggesting the association with stigma was influenced by other variables. These variables may have included quality of life, introverted or neurotic personality, helplessness, low problem solving control and problem solving confidence, depression, and a low self-esteem; which were also found to have a significant relationship with stigma. Similar results were found by Olley [28][29], who did not identify neuroticism as being independently associated to stigma following a multiple regression analysis. In additional analysis, stigma was also found not to be an independent predictor of neuroticism.

## ***ii) Methodological issues***

The seven studies varied in quality; one was rated 2(i), three were rated 2(ii) and three received ratings of 2(iii). As shown in table 2, all of these studies were cross-sectional; therefore causality could not be established between perceived stigma's association with anxiety and depression. In addition, the generalizability of the results is limited, as most of the studies reported sampling biases. For example, samples were recruited from specialist epilepsy centres, inpatient units and self-help groups. One study used a geographical cohort, however it also had methodological limitations. A third of the sample were diagnosed by their GP and not an epilepsy specialist, therefore increasing the possibility of mis-diagnosis. Due to exclusion criterion, the results are not generalisable to people with a learning disability. In addition, participants within these studies were recruited from Korea, America and Nigeria; therefore the relationships between perceived stigma and anxiety/depression have not been investigated within a European sample of participants. Studies varied according to the extent to which they considered confounding variables in the relationship between perceived stigma and specific forms of psychopathology. As highlighted in Table 3, some papers did not account for any variables within the analysis

[29][27] whilst others considered a wide range of neuro-epilepsy, medication and demographic variables [26][20]. In the measurement of anxiety and depression, all of the studies utilised previously published self-report questionnaires. The results of these studies do not therefore evaluate the relationship between perceived stigma and clinically diagnosed levels of anxiety and depression. Olley [28][29] took care to establish the validity of the measures for use with a Nigerian sample; however it was not clear whether this had been considered within the Korean study by Lee et al. [20].

### ***iii) Conclusions***

The reviewed studies provide evidence to support an association between perceived stigma and symptoms of anxiety and depression. However, variability in the design of these studies makes it difficult to draw further conclusions regarding the strength and nature of these associations. In the investigation of specific forms of psychopathology, the research is limited to anxiety and depression.

### **3) Perceived Stigma and Factors Related to Psychopathology**

Six studies considered the association between perceived stigma and measures which were considered relevant to psychological well-being [20][21][27][32][33][34]. These include factors which were viewed as being significantly related to psychopathology, or had implications for participants' level of psychological well-being. Amongst the studies, data were collected from participants living within the USA, Korea and a wide range of European countries. It should be noted that the studies by Jacoby [21][31] present different results on the same the same sample of participants.

### *i) Findings*

Whilst not being diagnostic, epilepsy related worries refer to specific anxieties and may therefore be considered relevant to psychopathology. Five studies referred to levels of epilepsy related worries and perceived stigma (Lee et al [20], Jacoby [21][33], Baker et al. [32], Ratsepp et al. [35]). They demonstrated similar results, finding that greater levels of perceived stigma were related to higher levels of anxiety about epilepsy. The types of worry which were measured included fear of having a seizure during the next month, worry about embarrassment resulting from having a seizure, and worry about the adverse effects of medication if taken for a long time. Only Lee et al. [20] performed regression analysis on their data; and whilst epilepsy-related worries were significantly correlated to feelings of stigma, they were not independently associated with stigma [20]. This suggested that the impact of epilepsy-related worries on stigma related to other significant variables; which may include quality of life, introverted or neurotic personality, helplessness, actual discrimination, problem-solving control, problem solving confidence, anxiety and depression. Of significant note, were the results of Baker et al [32] which recruited participants from a range of European countries. Following the analysis of data from eight European countries, worry about epilepsy was only significantly associated with stigma within four of the countries; France, Germany, Netherlands and UK. These results therefore suggest important cross-cultural variations in the way perceived stigma relates to other clinical and demographic variables.

Three studies measured self-esteem, which is a significant symptom of depression and reflects an area of psychological well-being (Jacoby [21] Arnston et al. [27] and Lee et al. [20]). The studies all showed support for a relationship between perceived stigma and low self-esteem. Only one study performed regression analysis on their data; and whilst low

self-esteem was found to be significantly correlated with feelings of stigma, it was not independently associated to stigma [20]. This suggests that the impact of self-esteem on stigma was related to other significant variables; although it cannot be inferred which variables or in what way.

Two studies provided measures related to life satisfaction (Arnston et al. [27] and Baker et al. [32]). Both studies reported results which identified that perceived stigma was negatively and significantly associated to life satisfaction. However, within the study by Baker et al [32] these results were not replicated across all cultures. Analysis within eight European countries found that negative feelings about life as a whole were only significantly associated to stigma within the samples from Italy, Germany, Spain and UK.

## ***ii) Methodological issues***

As highlighted in Table 3, the quality of studies investigating this area of psychopathology were generally quite poor; only one study received a quality rating of 2(ii) whilst the other five received quality ratings of 2(iii). All of the studies were cross-sectional and therefore limited by their design, as causality cannot be inferred in the relationships between perceived stigma and the variables measured within these studies. The majority of studies demonstrated sampling bias; recruiting from support groups, specialist epilepsy centres and populations with well-controlled epilepsy. Exclusion criteria also mean that the majority of results are not generalisable to people with a learning disability. There was significant variability in the extent to which studies accounted for confounding variables in their analysis. Two studies accounted for a wide range of neuro-epilepsy, psychosocial and demographic factors. However, four of the studies only conducted simple analysis between the relationships of variables and therefore did not account for other significant factors. In

addition, there may some criticism of the measures used to assess the psychological variables within these studies. The reliability and validity of some of the assessment measures used was unclear; particularly with regards to the cultural validity of measures used within the Korean sample of participants.

### ***iii) Conclusions***

The reviewed studies support an association between perceived stigma and epilepsy related-worries, low self-esteem and reduced life satisfaction. These are therefore identified as possible mechanisms by which perceived stigma and psychopathology may be associated. Unfortunately, it is not possible to infer causality, therefore it remains unclear how these variables are related to the association of stigma and psychopathology.

## **DISCUSSION**

### **Overview**

The objective of this review was to investigate the impact of perceived stigma on psychopathology in people with epilepsy. Through a systematic search of the literature 13 studies were reviewed in order to explore this relationship. Overall, the results of these studies provide evidence to support a significant association between perceived stigma and psychopathology across a wide range of cultures. Symptoms of anxiety, depression and overall emotional well-being were all found to be associated with perceived stigma. However, our insight into the nature strength of these relationships remains limited. In addition, research into specific forms of psychopathology was restricted to the study of anxiety and depression.

It is a significant finding that none of the studies adopted a longitudinal design, therefore no conclusive evidence can be drawn from the research regarding causality. It therefore remains unclear whether perceived stigma contributes to the development of psychopathology, or whether the presence of mental health difficulties increases the likelihood for people to perceive themselves as being stigmatised.

The complex way in which variables (neuro-epilepsy, psychosocial, demographic and medication) are likely to interact with each other to cause psychopathology has not been adequately investigated. This may be a consequence of the limited number of studies which focused specifically on investigating the multi-etiological causes of psychopathology in epilepsy. Even amongst studies which accounted for a wide range of factors, there was variability amongst which factors were included. The learned helplessness model may be a useful way to conceptualise these relationships, but the evidence does not allow firm assumptions to be made. As stigma exists within a social context, it seems inevitable that other psychosocial factors will influence its association with psychopathology. Potential factors identified from the review which may be relevant include increased number of stressful events in the last year, poor adjustment to epilepsy, financial stress and an external locus of control.

None of the studies utilised standardized clinical diagnostic systems to measure psychopathology. The relationship between perceived stigma and clinically diagnosed levels of psychopathology has therefore not been investigated. In considering studies which investigated variables associated with psychopathology, the review highlighted some support for an association between perceived stigma and low self-esteem, epilepsy-related worries and negative feelings about life as a whole. Whilst these are not specific



measures of psychopathology, they provide some insight into the mechanisms by which stigma and psychopathology may be related. However, limitations in design mean that causality between these relationships has not been established. One could hypothesise that perceived stigma may result in low-self esteem and therefore contribute to the development of depression. However it could also be hypothesised that someone with depression and low-self esteem may experience thinking biases that result in perceptions of stigmatisation. The studies in this review do not provide insight into answering these questions.

Many of the studies also contained a variety of methodological weaknesses, including sampling biases, thus limiting the generalizability of the results. Within the 13 studies reviewed, participants were sampled from over 10 different countries. Results from the only study to collect data from a wide range of countries, suggests cross-cultural differences between the way perceived stigma relates to other clinical and demographic variables [32]. Jacoby et al. [36] suggest that this may be due to differences in sociocultural biases against epilepsy, healthcare systems, equal opportunity provisions and legal protections for people with epilepsy. These findings therefore highlight caution regarding the generalizability of results across different cultures. In conclusion, as proposed by Hermann and Whitman [4], this review highlights strong evidence to suggest an association between perceived stigma and psychopathology. However, further research is needed in order to gain a more comprehensive understanding of the nature of this association within the context of a Multietiological Model.

### **Implications for future research**

In over 20 years of research we still have a limited understanding regarding the role of perceived stigma in the development of psychopathology; and how this relationship

interacts with other significant variables. Further research is required, using longitudinal studies, preferably with newly diagnosed patients. Future research in this area would also benefit from studies adopting sampling techniques aimed at reducing bias, in order to produce results that are more generalisable to the populations as a whole. Cultural differences will also need to be considered when interpreting results from different countries. Whilst the Multi-etiological Model refers to overall psychopathology, research investigating more specific disorders such as anxiety and depression are perhaps more clinically useful. A better understanding of the causes of psychopathology in people with epilepsy has important clinical implications; allowing for more informed approaches to prevention of psychopathology and the development of appropriate interventions in this population.

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**Table 1: Possible Confounding Variables**  
**(Hermann and Whitman, 1986 [4])**

<b>Demographic Variables</b>	<b>Neuroepilepsy Variables</b>	<b>Psychosocial Variables</b>	<b>Medication Variables</b>
Age Sex Race	Age at onset Seizure control Duration of disorder Seizure type Multiple seizure types Etiology of epilepsy Type of aura Neuropsychological status	Fear of seizures Perceived discrimination Adjustment to epilepsy Locus of control Life event changes Social support Socio-economic status Childhood home environment	Number of medications Serum level Medication type Folic acid level



**Table 2: Characteristics and Quality Rating of Studies Included in this Review**

Study and Quality Rating	Aim of Study	Participants	Measures	Results relating to the relationship between perceived stigma and psychopathology	Methodological Issues
<b>Arntson et al (1986)</b> <b>2(iii)</b>	Aimed to examine the relationship between psychopathology and reported seizure occurrence, perceptions of control, stigmatisation, and psychosocial measures of health.	Sample: Questionnaire distributed to people with epilepsy via a) article in national Newsletters, b) interested individuals and self-help groups invited c) medical and social service professionals in a number of locations asked to distribute questionnaires. Age range: Mean 32.7 N=355 (m=141, f=214) Description of sample: Seizure frequency – range of seizures per week = .01 to 98. Median rate 2 seizures per month. Country recruited from: USA	<b>Measure of stigma:</b> 10 items taken from Liberman and Borman (1979). <b>Measure of psychopathology:</b> Psychopathology was assessed via measures of depression, anxiety and somatic symptoms (taken from dimensions of the Hopkins Symptom Checklist); and attitudinal variables included measures of self-esteem (Coopersmith's Self-Esteem Inventory), life satisfaction (3 items taken from Robinson and Shaver, 1972) and helplessness (adapted from items taken from Liberman and Borman, 1979).	<ul style="list-style-type: none"> <li>The correlation coefficients showed that the stigma scale was positively and significantly related to perceived helplessness (<math>r = .39</math>), depression (<math>r = .30</math>), anxiety (<math>r = .30</math>) and somatic symptoms (<math>r = .39</math>).</li> <li>Stigma was also negatively and statistically significantly related to self-esteem (<math>r = -.35</math>) and life satisfaction (<math>r = -.27</math>).</li> </ul>	<p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>Cross-sectional design.</li> <li>Analysis did not adequately account for confounding variables.</li> <li>Sampling bias (two thirds of the sample were at one time in self-help groups)</li> <li>Reliability and validity of measures was not clear.</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>Despite sampling bias, the authors found their sample to be demographically similar to a typical clinic population.</li> </ul>
<b>Baker et al (1996)</b> <b>2(i)</b>	Aimed to examine the aetiology of psychopathology in epilepsy.	Sample: Identified through trawl of records of 31 randomly selected general practitioners in the Mersey region of England. Age range: Adults. Age range unclear. Mean age 46 (median ages at 25th and 75th percentiles were 31 and 62).	<b>Measure of stigma:</b> The Stigma scale. Adapted for epilepsy from a stigma scale developed for stroke. Reliability and validity documented by Jacoby et al. (1994, 1996). <b>Measure of psychopathology:</b> Self-esteem and life satisfaction (Impact of Epilepsy Scale).	<ul style="list-style-type: none"> <li>Using stepwise multiple regression, anxiety was one of 4 significant predictor variables for stigma (depression was not).</li> <li>Using stepwise multiple regression, stigma was a significant predictor variable for anxiety, but not for</li> </ul>	<p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>Cross-sectional design</li> <li>One third of participants were diagnosed as having epilepsy by their GP and not a specialist.</li> <li>Results cannot be generalisable to people with learning disabilities</li> </ul>

		N= 691 (m=339 , f= 352 ) Description of sample: tonic-clonic (34%), tonic-clonic and others (18%) and other types of seizures only (48%). Country recruited from: UK Sample excluded: people with learning disabilities or severe physical disabilities.	anxiety and depression (HADS).	depression.	or severe physical disabilities. <b>Strengths:</b> <ul style="list-style-type: none"><li>• Geographical cohort.</li><li>• Valid and reliable measures adopted.</li><li>• Good range of confounding variables accounted for.</li></ul>
<b>Baker et al (1999)</b>  <b>2(ii)</b>	Aimed to study the stigma of epilepsy in a European sample, through clinical and demographic details and information about patient perceived stigma.	Sample: The sampling frame was epilepsy support groups or, in countries where these did not exist, neurology outpatient clinics. Age range: Age range unclear. Mean age 35 (median ages at 25th and 75th percentiles were 27 and 46). N=5211 (m=49%, f=51%) Description of sample: Seizure type – Tonic-clonic only (n=29), Tonic-clonic and others (n=39), others only (n=32). Country recruited from: France, Sweden, Italy, German, Switzerland, Spain, Netherlands and United Kingdom. Sample excluded: participants known to have a learning disability.	<b>Measure of stigma:</b> The Stigma scale. Adapted for epilepsy from a stigma scale developed for stroke patients. <b>Measure of psychopathology:</b> Extent of worry over epilepsy (Jacoby et al. 1996).	<ul style="list-style-type: none"><li>• The results varied according to country, but the analysis for the United Kingdom identified increased levels of reported stigma associated with lower age at onset, greater likelihood of injury, more negative feelings about life as a whole and more worry about epilepsy.</li></ul>	<b>Weaknesses:</b> <ul style="list-style-type: none"><li>o Cross-sectional design</li><li>o Reliability and validity of measures was not clear.</li><li>o Sampling bias</li></ul> <b>Strengths:</b> <ul style="list-style-type: none"><li>• Good range of confounding variables accounted for.</li></ul>
<b>Dilorio et al (2004)</b>	Aimed to test a psychosocial	Sample: Recruited patients attending regularly scheduled	<b>Measure of stigma:</b> Modified version of The Parent Stigma	<ul style="list-style-type: none"><li>• The results supported the models prediction that stigma</li></ul>	<b>Weaknesses:</b> <ul style="list-style-type: none"><li>• Convenience sample</li></ul>

<b>2(iii)</b>	model of medication self-management among people with epilepsy.	appointments from 2 epilepsy centres and 1 neurology clinic. Age range: N= 317 (m=158, f=159) Description of sample: Seizure Type – Partial (38.8%), General (41.3%), other (3.5%), unknown (16.4%) Country recruited from: USA.	Scale developed by Austin et al. (1998) <b>Measure of psychopathology:</b> Depressive symptoms (CES-D, Centre for Epidemiologic Studies Depression Scale).	was associated with self-efficacy and depressive symptoms.	<ul style="list-style-type: none"> <li>• Analysis did not adequately account for confounding variables.</li> <li>• Cross-sectional design.</li> </ul> <b>Strengths:</b> <ul style="list-style-type: none"> <li>• Valid and reliable measures adopted.</li> </ul>
<b>Hermann and Whitman (1989) 2(i)</b>	Aimed to determine whether some of the psychosocial complications associated with epilepsy are predictive of interictal depression.	Sample: Referrals to an in-patient monitoring unit. Age range: Adults. Age range unclear. Average age 31.2 (9.3) N= 102 (m=45, f=57) Description of sample: Seizure type – Partial (n=97) Generalised (n=5) Country of recruitment: America.	<b>Measure of stigma:</b> Perceived Stigma scale (Ryan et al. 1980). <b>Measure of psychopathology:</b> Self-reported depression measured by the Center for Epidemiological Studies – Depression scale (CES-D; Radloff. 1977).	<ul style="list-style-type: none"> <li>• The results identified eight predictor variables that showed a significant relationship with the depression scale, and these included 'increased perceived stigma'.</li> <li>• Along with three of the other predictor variables, 'Increased perceived stigma' did not remain statistically significant when entered into a stepwise multiple regression analysis.</li> </ul>	<b>Weaknesses:</b> <ul style="list-style-type: none"> <li>• Convenience sample</li> <li>• Cross-sectional design</li> <li>• Results cannot be generalisable to people with IQ&lt;70 or significant reading disability.</li> </ul> <b>Strengths:</b> <ul style="list-style-type: none"> <li>• Valid and reliable measures adopted.</li> <li>• Good range of confounding variables accounted for.</li> </ul>
<b>Hermann et al (1990) 2(i)</b>	Measured neurological, psychosocial, medication and demographic variables in order to attempt to determine the multiaetiological	Sample: Referrals to an in-patient monitoring unit. Age range: Adults (age range unclear. Average age 31.2 (s.d. 9.3)). N= 102 (m=45, f=57) Seizure type – Partial (n=97) Generalised (n=5) Country recruited from:	<b>Measure of stigma:</b> Perceived Stigma scale (Ryan et al. 1980). <b>Measure of psychopathology:</b> Overall psychiatric status measured by the General Health questionnaire (GHQ; Goldberg, 1972).	<ul style="list-style-type: none"> <li>• Seven variables showed a significant relationship with the GHQ, including 'increased perceived stigma' (<math>r = 0.30, p = 0.003</math>).</li> <li>• When the seven significant variables were entered into a stepwise multiple regression analysis, only three variables</li> </ul>	<b>Weaknesses:</b> <ul style="list-style-type: none"> <li>• Convenience sample</li> <li>• Cross-sectional design</li> <li>• Results cannot be generalisable to people with IQ&lt;70 or significant reading disability.</li> </ul> <b>Strengths:</b> <ul style="list-style-type: none"> <li>• Valid and reliable</li> </ul>

	correlates of psychopathology in adults with epilepsy.	America. Sample excluded: people with a learning disability or a significant reading disability.		remained significant, and 'increased perceived stigma' was not one of them.	measures adopted. • Good range of confounding variables accounted for.
<b>Herodes et al (2001)</b>  <b>2(ii)</b>	Aimed to study the impact of epilepsy and its treatment on people with epilepsy in Estonia, and to analyse how it is affected by the characteristics of epilepsy.	Sample: Randomly picked from preliminary lists from an epidemiological study, which included residents of a city and had before or within 1991 and 1996 at least 2 unprovoked seizures, at least one of them within the previous 5 years. Age range: Mean age 41 (median ages at 25th and 75th percentiles were 29 and 57). N= 203 (m=99, f=104) Description of sample: Seizure type – Tonic-clonic only (41.4%), Tonic-clonic and others (30%), others only (n=28.6%). Country recruited from: Estonia	<b>Measure of stigma:</b> The Stigma scale. Adapted for epilepsy from a stigma scale developed for stroke. Reliability and validity documented by Jacoby et al. (1994, 1996). <b>Measure of psychopathology:</b> RAND-36 Health Survey variables. The variables most relevant to the investigation of psychopathology were the 'emotion' domains.	<ul style="list-style-type: none"> <li>• In the Role-limitations-emotional domain, mean scores were significantly lower for those who felt stigmatised and for those who expressed very strong feelings of stigma, compared with those who expressed themselves stigmatised less strongly.</li> <li>• In the emotional well-being domain, those who felt stigmatised had significantly lower scores than those who were not.</li> </ul>	<b>Weaknesses:</b> <ul style="list-style-type: none"> <li>• Did not consider medication variables as possible confounding factors within analysis.</li> <li>• Cross-sectional design</li> </ul> <b>Strengths:</b> <ul style="list-style-type: none"> <li>• Geographical cohort.</li> <li>• Valid and reliable measures adopted.</li> </ul>
<b>Jacoby (1992)</b>  <b>2(iii)</b>	Drew upon a model of quality of life which incorporated physical, social and psychological domains.	Sample: Identified through participants in a multi-centre randomised controlled trial. Recruited from 39 neurology outpatient clinics in UK and abroad. Non randomised patients from 4 study centres were also included. Age range: Mean age 39 years.	<b>Measure of stigma:</b> Scale adapted for epilepsy from stigma scale developed for use with stroke patients (Hyman. 1971). <b>Measure of psychopathology:</b> Expressed levels of anxiety/worry about epilepsy (Participants asked whether they worried about epilepsy a) a lot b) some c) a little d) not at all.	<ul style="list-style-type: none"> <li>• Scores on the stigma scale were related to expressed levels of anxiety over epilepsy.</li> </ul>	<b>Weaknesses:</b> <ul style="list-style-type: none"> <li>• Cross-sectional design</li> <li>• All participants were seizure free for two years and on anti-epileptic medication.</li> <li>• Reliability and validity of measures was not clear.</li> <li>• Analysis did not take</li> </ul>

		<p>N=607 (m=45%, f=55%)</p> <p>Description of sample: Criteria of study meant all had epilepsy which was in remission, they had been free from seizures for 2 years and were on AEDs.</p> <p>Country recruited from: UK and abroad (countries abroad not specified).</p> <p>Sample excluded: People with a learning disability and those who had experienced a seizure in the past 2 years.</p>			<p>into account possible confounding variables.</p> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Adequate measures.</li> </ul>
<p><b>Jacoby (1994)</b></p> <p><b>2(iii)</b></p>	<p>Aimed to describe the nature and extent of stigma in a group of individuals with epilepsy in remission.</p>	<p>Sample: Identified through participants in a multi-centre randomised controlled trial. Recruited from 39 neurology outpatient clinics in UK and abroad. A further group of patients were identified as eligible but not randomised. Age range: 16 years and over N= 607 (sex ratio not reported)</p> <p>Description of sample: Criteria of study meant all had epilepsy which was in remission, they had been free from seizures for 2 years and were on AEDs.</p> <p>Country recruited from: UK and abroad (countries abroad not specified).</p> <p>Sample excluded: People with a learning disability and those</p>	<p><b>Measure of stigma:</b> Scale adapted for epilepsy from stigma scale developed for use with stroke patients (Hyman. 1971). Internal consistency examined and found to be satisfactory. In addition single items were used which referred specifically to feelings of stigma in employment and leisure, and instances of enacted stigma.</p> <p><b>Measure of psychopathology:</b> Emotional reaction subscale of the Nottingham Health Profile.</p> <p>A questionnaire using a combination of precoded and open questions, together with a number of previously validated scales investigated (a) the affective state and sense of well-being of patients (b) an estimate of their social adjustment, social</p>	<ul style="list-style-type: none"> <li>• Subjects who scored positively on the stigma scale had lower mean scores of self-esteem and mastery and higher mean scores for three domains of the Nottingham Profile; energy, emotional reaction and social isolation.</li> <li>• Subjects who scored positively on the stigma scale were more than twice as likely as the rest to say that they felt 'uncertain' about the future.</li> <li>• Subjects who score positively on the stigma scale were less likely to describe it as a mild illness and were more likely to say that they worried about it a lot or some.</li> </ul>	<p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>• Cross-sectional design</li> <li>• All participants were seizure free for two years and on anti-epileptic medication.</li> <li>• Reliability and validity of measures was not clear.</li> <li>• Analysis did not take into account possible confounding variables.</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Adequate measures</li> </ul>

		who had experienced a seizure in the past 2 years.	networks and support information about recent employment history.	
<b>Lee et al (2005)</b>  <b>2(iii)</b>	Aimed to evaluate the factors, including personality and coping styles, likely to be influential in enhancing the social stigma of epilepsy.	Sample: Recruited from 10 epilepsy centres. Age range: 19-64 years N= 400 (m=204 , f=196) Description of sample: Epilepsy type – Idiopathic generalized (8.5%), Crypto/symptomatic partial, (88.8%) undetermined/others (2.8%) Country recruited from: Korea	<b>Measure of stigma:</b> Felt stigma assessed by scale originally developed for stroke patients but adapted for epilepsy (Jacoby, 1994). Subjects were also asked whether, because of their epilepsy, they experienced actual discrimination in their daily lives. This was asked using a 10 item questionnaire developed for the purpose of the study. <b>Measure of psychopathology:</b> Self-esteem (Rosenberg Self-Esteem Scale), anxiety and depression (HADS).	<ul style="list-style-type: none"> <li>Univariate analyses showed several variables were significantly correlated with stigma of epilepsy, including lower scores on the quality of life measure, more introverted or more neurotic personality, a greater degree of helplessness or a lower degree of problem solving control and problem solving confidence, higher degrees on anxiety and depression, and a lower degree of self-esteem.</li> <li>Logistic regression analysis revealed several factors independently associated with feelings of stigma, including introverted personality, problem solving controllability and the emotional subscale of the quality of life measure.</li> </ul> <p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>Cross-sectional design.</li> <li>Sampling bias.</li> <li>Participants recruited from epilepsy centres and not people with epilepsy spread throughout the population.</li> <li>Cultural validity of measures not clear.</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>Good range of confounding variables accounted for.</li> </ul>
<b>Olley (2001)</b>  <b>2(ii)</b>	Aimed to test a model suggesting the relationship between characteristics (seizure control, age at onset, duration of epilepsy, seizure	Sample: Patients on follow-up management at the clinics of 2 psychiatric facilities. Age range: Mean age 32.6 (SD 10.2) N=264 (m=154 , f=110 ) Description of sample: primary generalized (44.3%), partial secondary generalized	<b>Measure of stigma:</b> Perceived stigma scale modified from the work of Westbrook (1992). Internal consistency evaluated. <b>Measure of psychopathology:</b> Neurotic disorders were measured by the Crown Crisp Experiential Index (CCEI), which is a self-reported	<ul style="list-style-type: none"> <li>Five variables were found to be significantly related to stigma, which included depression and neuroticism. Following a multiple regression analysis, depression and social support were the only variables to remain significant.</li> </ul> <p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>Cross-sectional design.</li> <li>Convenience sample</li> <li>Analysis did not take into account possible confounding variables</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>Reliable and valid</li> </ul>

	type) depression, neuroticism, social support and perceived stigma among Nigerian adults with epilepsy	(42.0%), partial complex type (14.9%). Country recruited from: Nigeria.	questionnaire for screening generalised anxiety disorder within an overall score for emotionality or neuroticism. Symptoms of depression were measured by the Beck Depression Inventory.	measures
<b>Olley (2004) 2(ii)</b>	Aimed to establish the effect of psychosocial and seizure factors on Depression and Neurotic Disorders among clinically diagnosed Nigerian patients with epilepsy.	Sample: Patients on follow-up management at the clinics of 2 psychiatric facilities. Age range: 33.6 (S.D=10.2) recruited from age range 21-65yrs. N= 264 (m=154, f=110) Description of sample: primary generalized (44.3%), partial secondary generalized (42.0%), partial complex type (14.9%). Country recruited from: Nigeria.	<p><b>Measure of stigma:</b> Perceived stigma scale modified from the work of Westbrook (1992). Internal consistency evaluated.</p> <p><b>Measure of psychopathology:</b> Neurotic disorders were measured by the Crown Crisp Experiential Index (CCEI), which is a self-reported questionnaire for screening generalised anxiety disorder within an overall score for emotionality or neuroticism. Symptoms of depression were measured by the Beck Depression Inventory.</p>	<p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>• Cross-sectional design</li> <li>• Convenience sample</li> <li>• Analysis did not take into account possible confounding variables</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Reliable and valid measures</li> </ul>
<b>Ratsepp et al (2000) 2(iii)</b>	Aimed to examine the impact of epilepsy and its treatment on employment status and the extent of stigma among patients with epilepsy.	Sample: Randomly picked from preliminary lists from an epidemiological study, which included residents of the city of Tartu who had before or within 1991 and 1996 at least 2 unprovoked seizures, at least one of them within the previous 5 years. Age range: 16-70. N=90 (m=41, f=49)	<p><b>Measure of stigma:</b> Perceived stigma measured by the Stigma of Epilepsy Scale developed originally for stroke but adapted for epilepsy. Used by other quality of life studies (Baker et al. 1997 and Jacoby et al. 1996)</p> <p><b>Measure of psychopathology:</b> A questionnaire employing open questions was used to ask about 1) demographic characteristics</p>	<p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>• No standardised measure of psychopathology.</li> <li>• Cross-sectional design</li> <li>• Analysis did not take into account possible confounding variables.</li> </ul> <p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>• Geographical cohort</li> </ul>

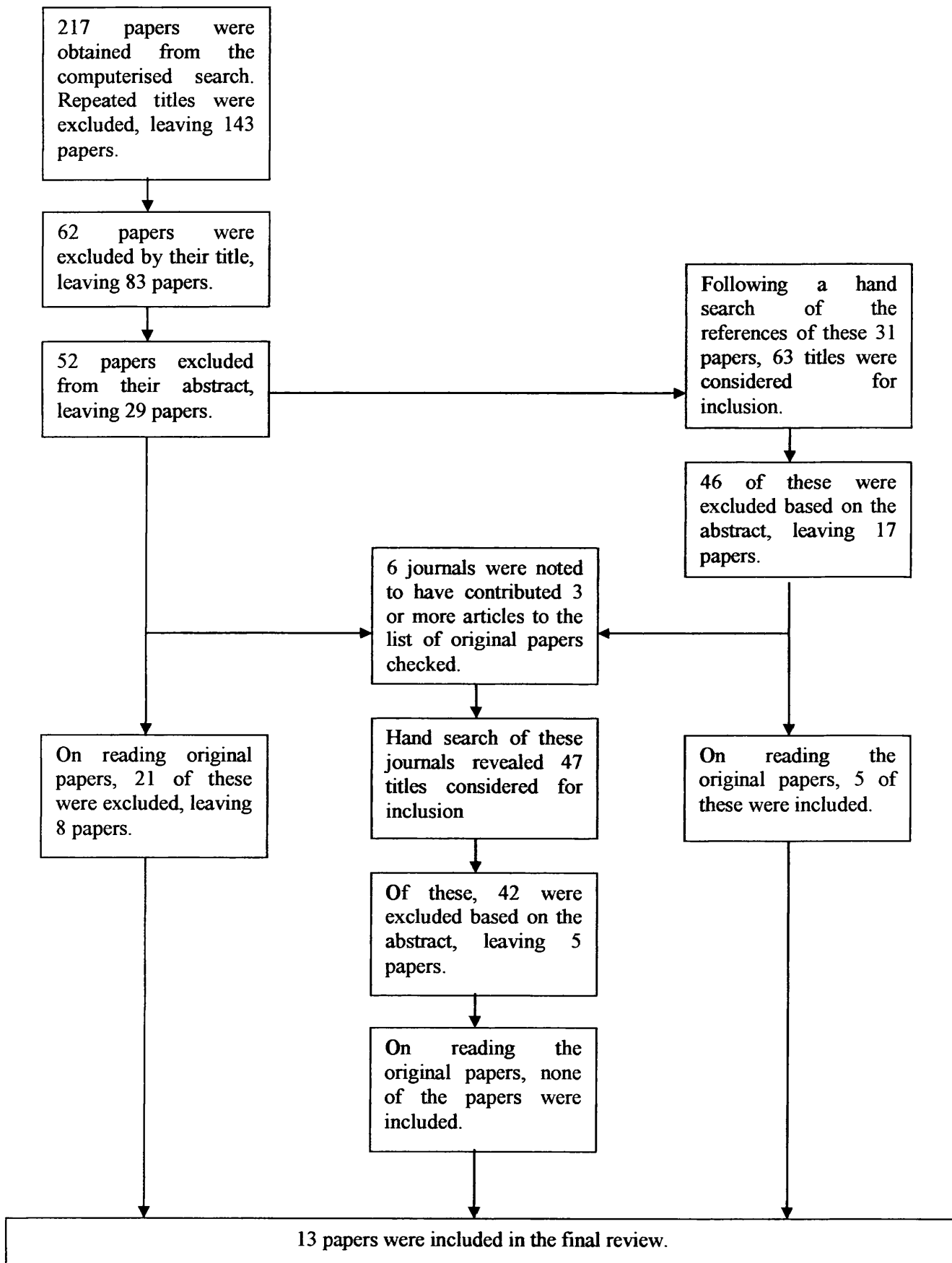
		<p>Description of sample: Country recruited from: City of Tartu, Estonia.</p>	<p>2) Economical and financial status 3) Seizure frequency 4) Perception of severity of seizure disorder 5) AED treatment and side-effects 6) Compliance with medication. The answers to these questions highlighted some epilepsy-related worries, which may be viewed as symptoms which may be indicative of mental illness.</p>		
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**Table 3: Studies Corresponding to Each Section of Results**

Studies corresponding to each section of the results	Quality Rating	Design	Generalizability of the Findings	Confounding Variables	Reliability/ Validity of Measures
<b>1) General psychopathology</b>					
Hermann et al. (1990) [18]	2(i)	Cross-sectional	Poor	Good	Good
Herodes et al. (2001) [19]	2 (i)	Cross-sectional	Good	Adequate	Good
Jacoby (1994) [21]	2 (iii)	Cross-sectional	Poor	Poor	Adequate
Lee et al. (2005) [20]	2(iii)	Cross-sectional	Poor	Good	Poor
<b>2) Specific forms of psychopathology</b>					
Baker et al. (1996) [26]	2(i)	Cross-sectional	Good	Good	Good
Hermann and Whitman (1989) [28]	2(i)	Cross-sectional	Poor	Good	Good
Olley (2001) [30]	2(ii)	Cross-sectional	Poor	Adequate	Good
Olley (2005) [31]	2(ii)	Cross-sectional	Poor	Adequate	Good
Arnston et al. (1986) [27]	2(iii)	Cross-sectional	Adequate	Poor	Poor
Lee et al. (2005) [20]	2(iii)	Cross-sectional	Poor	Good	Poor
DiIorio et al. (2004) [29]	2(iii)	Cross-sectional	Poor	Poor	Good
<b>3) Factors related to psychopathology</b>					
Baker et al. (1999) [32]	2(ii)	Cross-sectional	Adequate	Good	Poor
Lee et al. (2005) [20]	2(iii)	Cross-sectional	Poor	Good	Poor
Jacoby (1994) [21]	2(iii)	Cross-sectional	Poor	Poor	Adequate
Jacoby (1992) [33]	2(iii)	Cross-sectional	Poor	Poor	Adequate
Arnston et al. (1986) [27]	2(iii)	Cross-sectional	Adequate	Poor	Poor
Ratsepp et al. (2000) [34]	2(iii)	Cross-sectional	Good	Poor	Poor

**Figure 1: The Search Process**



Chapter 3: Major Research Project Proposal

Major Research Project Proposal submitted in partial fulfilment of the requirements for the  
degree of Doctorate in Clinical Psychology

**A qualitative investigation into the social experiences of  
young people with epilepsy;  
perceived impact and sense of self.**

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## **TITLE**

A qualitative investigation into the social experiences of young people with epilepsy;  
perceived impact and sense of self.

## **SUMMARY**

Stigma has been found to have a significant impact on the lives of people with epilepsy. The stigma of epilepsy has been associated with low self-esteem, worry, negative feelings about life and depression (e.g. Westbrook et al. 1992, Jacoby et al. 1994, Baker et al. 1999 and Lee et al. 2005). Whilst there has been much research conducted in this area, there has been relatively little focus on understanding the issues of stigma specific to adolescents. In a review of the literature Macleod et al (2003) conclude that 'What we do not yet fully understand is how to capture the experience of stigma and the meaning of this experience to adolescents with epilepsy in a way that is sensitive enough to test hypotheses about stigma theory or correlate stigma to health outcomes like depression'. The current study therefore aims to use qualitative methods to explore the experiences and perceived impact of stigma in adolescents with epilepsy.

## **INTRODUCTION**

Epilepsy has been historically associated with stigmatising responses from the general population, and research has demonstrated associations between the stigma of epilepsy and psychological distress (e.g. Westbrook et al. 1992, Jacoby et al. 1994, Baker et al. 1999 and Lee et al. 2005). In defining the social phenomena of stigma, Goffman (1963) describes it as an 'attribute that is deeply discrediting' which can reduce a person 'from a whole and usual person to a tainted, discounted one'. Goffman (1963) further observes stigma as the relationship between an 'attribute and a stereotype', therefore highlighting

how people can be linked with socially undesirable characteristics when they are seen to have a discrediting attribute such as epilepsy. In the case of epilepsy, it may not be immediately apparent that the person is different, therefore allowing the person with epilepsy to choose who, when and what they disclose to others about their condition. This is complicated by the fact that such anonymity may be threatened through the event of a public seizure. Scambler and Hopkins (1986) therefore suggest that the effects of stigma in people with epilepsy may be experienced in two ways; via enacted and felt stigma. Enacted stigma refers non-legitimate discrimination such as teasing, and felt stigma refers to the fear of enacted stigma and feelings of shame associated with being epileptic. Felt stigma may therefore occur even if the person's condition remains undisclosed, as they attach undesirable characteristics to themselves, resulting in a negative impact on self-identity. Whilst some studies have found that more than 60% of their participants did not feel stigmatised by their epilepsy (e.g. Westbrook et al. 1992 and Buck et al 1997), it is still a significant problem for many people.

The negative impact of stigma in the lives of adolescents with epilepsy has also been identified by research. Austin et al (2004) developed an instrument to measure stigma in children with epilepsy, and identified that higher scores of perceived stigma were correlated with more negative attitude, greater worry, poorer self-concept, and more symptoms of depression. In a study by Westbrook et al (1992), they found that adolescents with epilepsy who felt stigmatised reported low self-esteem more than those who did not feel stigmatised. Research exploring the stigma of epilepsy has mainly focused on adult populations, but it cannot be assumed that children and adolescents experience stigma via the same processes. Adolescence is acknowledged as a critical time for the development of self-identity and the formation of peer relationships, therefore stigma during this period

may disrupt such processes and have detrimental effects on psychosocial health and self-esteem (Abraham et al. 1999). The disruption of relationships with peers, and self-perceptions of being different are therefore possible mechanisms by which adolescents with epilepsy may be negatively impacted by stigma, but these processes are not yet fully understood.

As part of the Glasgow Epilepsy Outcome Scales (Espie et al. 2001; Watkins et al 2006), the Glasgow Epilepsy Outcome Scale for Adolescents (GEOS-AD) was developed in order to measure the impact of epilepsy on quality of life in adolescents (Townsend, 2004). The scale was developed using qualitative data collected from adolescents with epilepsy, and was based on a conceptual model in which it is proposed that good quality of life requires that adolescents successfully adjust to having epilepsy, both in terms of illness-related factors and in identity formation (McEwen et al. 2004). To establish concurrent validity, Townsend (2004) conducted inter-correlations between the subscales of the GEOS-AD and the subscales of another quality of life measure (QOLIE-AD; Cramer, 1999). The GEOS-AD does not contain a specific subscale pertaining to measure stigma, however the strongest correlations were found between the QOLIE-AD subscale “Stigma” and the GEOS-AD subscales ( $r=0.246$  to  $0.583$ ). Therefore, whilst the GEOS-AD appears to measure stigma, this was not a theme explicitly identified from within the focus groups. McEwen et al (2004) however, found that disclosure of epilepsy to their peer group was perceived as being a ‘particularly difficult and complex issue’, and in reference to the work of Scambler and Hopkins (1986), this may be viewed as an indication of felt stigma. The study’s focus on quality of life may therefore have prevented the subtleties of stigma theory being specifically acknowledged within data analysis.

Following from the research of McEwen et al (2004) and Townsend (2004), the current study therefore attempts to focus specifically on the experiences of stigma in adolescents with epilepsy. MacLeod et al. (2003) in their review of the literature state that although research shows that stigma is an important factor in the health-related quality of life of adolescents with epilepsy, we do not yet know how to capture the experience and meaning of stigma to adolescents. They advise that qualitative research methods may be better suited to uncovering these experiences, 'as the concept of stigma may not be blatantly obvious'. Whilst there are qualitative studies which describe adolescent's personal accounts of stigma, these are within studies exploring the general effects of epilepsy, and do not focus specifically on stigma (e.g. Elliot et al., 2005 and Wilde et al., 1996). It is therefore proposed that the present study shall focus on exploring the experiences of stigma by adolescents with epilepsy, using qualitative techniques. Data shall be analysed via Interpretative Phenomenological Analysis (IPA), a method commonly used in health psychology research (Smith et al, 1999).

One could hypothesise that age-related differences may exist amongst adolescents, for example stigma may be a more salient issue in the lives of older adolescents, in terms of their future goals and being more aware of the perceptions of their peers. However, McEwan et al's (2004) study into quality of life in adolescents with epilepsy found that, within their sample, there were no age-related differences between the issues raised. It would be interesting to identify whether these results would be replicated within a study focused specifically on stigma, therefore age-related differences shall also be explored. In order to aim for a more comprehensive picture of stigma in adolescents with epilepsy, participants shall not be excluded on the basis of having a mild/moderate learning disability.

## **AIMS AND OBJECTIVES**

### **Aims**

The aim of this study is to explore and describe the social experiences of adolescents with epilepsy, with a specific focus on stigma. The following objectives shall be explored in relation to different stages during adolescence, by looking separately at the experiences of participants within early and late adolescence.

### **Objectives**

- 1) To describe experiences of stigma in adolescents with epilepsy.
- 2) To describe and explore the perceived impact of stigma in the lives of adolescents with epilepsy.
- 3) To describe and explore coping strategies for dealing with stigma.

## **PLAN OF INVESTIGATION**

### **Participants and Recruitment**

It is anticipated that participants will be recruited from the Fraser of Allander Neurosciences Unit at the Royal Hospital for Sick Children, Glasgow and from Dr. Brodie's clinic at the Epilepsy Unit within the Western Infirmary, Glasgow.

Data collection shall be based on purposive sampling. Participants will be included in the study if they a) are aged above 12 years 0 months and under 18 years 0 months b) have a diagnosis of epilepsy c) have had epilepsy for at least 6 months duration d) have had experience of at least one seizure in the past year and e) are able recall and provide a verbal account of recent events in their lives. Participants will be excluded from the study if they



a) have deteriorating neurological health and/or b) have established non-epileptic seizure disorder as the primary clinical problem c) have a severe learning disability.

The following socio-demographic and epilepsy data will be obtained in order to enable a description of participants: date of birth, gender, postcode, seizure type, seizure frequency, medication and date of diagnosis. This information is essential for situating the sample, as Henwood and Pidgeon (1992) state it is important for the readers 'to explore the extent to which the study may, or may not, have applicability beyond the specific context within which the data were generated'. Data shall be stored on a computerised database, and anonymised to ensure confidentiality.

In order to identify whether stigma has a different impact at specific stages of adolescence, participants shall be recruited into two groups; early adolescents (between 12 years 0 months and 15 years 0 months) and late adolescents (between 15 years 0 months and 18 years 0 months). As this is a qualitative study, the number of participants required cannot be predetermined, therefore data collection should continue until thematic saturation is reached in each of the groups. However, as acknowledged by Willig (2002) 'theoretical saturation functions as a goal rather than a reality', as modifications of categories or changes in perspectives are always possible. Turpin et al (1997) proposed guidelines for qualitative research submitted as DClin Psy theses, and suggested that a sample of between eight and twenty participants is desirable.

## **Measures**

The main method of data collection will be from an in-depth semi-structured interview with each adolescent. In their review of the literature on stigma in the lives of adolescents

with epilepsy, MacLeod and Austin (2003) advise that ‘qualitative research methods may be better suited to uncovering the subtleties and complexities of how adolescents with epilepsy experience stigma and how it affects their lives’. They suggest that using open-ended questions may allow the adolescents more freedom to describe situations where they felt different, rather than direct questioning specifically about stigma.

Weber et al. (1994) highlight that adolescence poses some distinct challenges to the interview process. Building rapport and facilitating communication will therefore be given careful consideration when planning the format and conduct of the interviews. Greig et al (1999) acknowledges that in interviewing children, the use of a familiar setting and materials (e.g. drawings, games, exercises) are valuable in assisting motivation and reducing anxiety. The proposed study will give consideration to an appropriate ice-breaker game, and the interviews shall be piloted on approximately 4 adolescents to facilitate the development of a suitable approach.

### **Design and Procedures**

Adolescents identified as meeting the inclusion criteria will be invited by post to participate in the study. Those adolescent interested in participating will be sent written information about the study and invited to complete and return a consent form. A separate information sheet and consent form will also be sent to the parents or guardians of adolescents under 16 years old.

Each participant shall be audio-taped during a one-hour semi-structured interview. It may be necessary to invite some adolescents back for a follow-up interview, if it was not possible to finish the interview within the allocated hour. Adolescents shall be interviewed

within a comfortable environment, and ideally at a location familiar to them, for example, participants recruited from The Royal Hospital for Sick Children will be interviewed within The Royal Hospital for Sick Children.

IPA shall be used to analyse the data, as this is an approach which ‘aims to gain an understanding of how participants view and experience their world’ (Willig, 2002). It is a method commonly used within health psychology research (Smith et al 1999); and has been used to investigate experiences of stigma in people with schizophrenia (Knight et al 2003). IPA may be criticised by Discourse Analysts, for its attempts to map verbal reports onto underlying cognitions. Smith (1999) responds to this by acknowledging that whilst a person’s thoughts are not transparently available from interview transcripts, IPA ‘engages in the analytic process in order to, hopefully, be able to say something about that thinking’. In contrast to Grounded Theory, IPA accepts that the results of analysis are a product of interpretation; therefore it does not deny the influence of the researcher on analysis. In preparation for this study the current author has become familiar with the stigma literature, therefore in order not to disregard the influence this may have on analysis, IPA has been chosen as an appropriate approach. Whilst a line-by-line analysis will not be used within this study, the analysis of data shall adopt a systematic process following procedures described in detail within the research literature (Smith et al. 1999; Willig. 2002). This will involve data being transcribed and thematically coded in order to identify central themes from individual interviews. The computer programme QSR NUD\*IST 4.0 for Microsoft Windows will be used to facilitate this analysis (Microsoft. 1997).

## **Settings and Equipment**

It is anticipated that it will be possible for interviews to take place at the Epilepsy Unit at the Western Infirmary, Glasgow and the Fraser of Allander Neurosciences Unit at the Royal Hospital for Sick Children, Glasgow. Participants will be offered travelled expenses from their home address to the interview location. A tape recorder, microphone and blank tapes will be required to audiotape individual interviews, and in order to aid the transcription process a transcription machine will be required.

## **Data Analysis**

Audiotaped recordings of interviews will be transcribed onto a word processing package. Data shall then be analysed within four stages, as outline by Willig (2002), and assisted by the computer package QSR NUD\*IST 4.0. The initial process of analysis will involve reading each transcript several times, and making notes on statements which appear particularly relevant to what is important for each adolescent's understanding and experiences of stigma. Willig (2002) describes this as 'simply a way of documenting issues that come up for the researcher upon his or her initial encounter with the text'. Within the second stage, themes which emerge from the text will be identified. In stage three, these themes will be considered in relation to each other through the formation of clusters, in order to introduce structure within the analysis. Willig (2002) highlights 'it is important to ensure that clustering of themes identified at this stage make sense in relation to the original data', therefore the original text will be continually referred to when looking at themes. Within the fourth stage of analysis a summary table of structured themes will be produced, including quotations relating to each theme. To check for validity, another researcher familiar with IPA shall read one third of the transcripts alongside the identified themes. Smith (1996) describes this task as 'ensuring the final report is a credible one in

terms of the data collected and that a logical progression runs through the chain of evidence'. It is acknowledged that this is not a test of inter-rater reliability, but an attempt to validate the interpretation of the main researcher. Throughout the study guidance will be sought from researchers experienced in IPA analysis.

## **PRACTICAL APPLICATIONS**

The study aims to describe the experiences of stigma in adolescents with epilepsy. By contributing to the research in this area, it is hoped this study will help to develop our understanding of stigma in the lives of adolescents with epilepsy. MacLeod et al. (2003), in their review of the literature, make specific recommendations for the need for further qualitative research within this area. By attempting to improve our understanding of the mechanisms by which stigma affects adolescents with epilepsy, this knowledge may then be used to assist clinicians and families in finding ways to reduce or prevent any negative impact on well-being. If appropriate support can be provided during adolescence, this may then help to reduce the likelihood of difficulties persisting into adulthood. In addition to the existing Glasgow Epilepsy Outcome Scales, the data from the current study may subsequently be used for the development of a scale specific to measuring the impact of stigma in adolescents with epilepsy. The measure of stigma developed by Austin et al (2004) was based on data collected from American children aged 9 to 14, therefore data from the current study could support the development of a scale which is more similar in situation and age-range to the GEOS-AD.

## **TIMESCALE**

Ethical approval will be sought in June/July 2006. Following this, the semi-structured interview schedule will be piloted and evaluated. A review of the databases will commence

in July 2006. Recruitment of participants will begin between July and August 2006. Data collection will commence in September 2006 and continue until March 2007. Data analysis will be ongoing, and the write up will take place between the months of May and July 2007.

### **ETHICAL APPROVAL**

Ethical approval will be sought from NHS Greater Glasgow Primary Care Division, NHS Greater Glasgow Yorkhill Division and NHS North Glasgow University Hospital Division.

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## **AMENDMENTS TO PROPOSAL**

The original design proposed recruiting two samples of participants, in order to look separately at issues relevant to young people within early and late adolescence. On further consideration it was felt that this design was not necessary, as a developmental perspective would be acquired through participants reflecting on both their current and past experiences. In addition, it was felt that the proposed design would result in a comparative study, which should not be the function of IPA methodology. Within the inclusion criteria, the original proposal stated that participants should have experienced at least one seizure in the past year. This was subsequently amended to include participants who had experienced at least one seizure in the past two years. Widening the inclusion criteria had practical advantages for recruitment, whilst still producing a sample of young people who had experienced seizures in recent memory.

Chapter 4: Major Research Project Paper

Major Research Project Paper submitted in partial fulfilment of the requirements for the  
degree of Doctorate in Clinical Psychology

**A qualitative investigation into the social experiences of  
young people with epilepsy;  
perceived impact and sense of self.**

Prepared in accordance with the requirements for submission to *Seizure*  
(See Appendix 2.1)

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## **ABSTRACT**

**Background:** Stigma has been found to have a significant impact on the lives of people with epilepsy. Research in this area has primarily focused on adult populations, resulting in a limited understanding of young people's experiences of stigma. The current study therefore aims to use qualitative methods to explore the experiences and perceived impact of stigma in adolescents with epilepsy.

**Method:** Semi-structured interviews were carried out with nine adolescents aged between 12 years 11 months and 17 years 10 months, in order to explore their social experiences of living with epilepsy.

**Results:** Data were analysed using Interpretative Phenomenological Analysis, with five superordinate themes emerging from the data. They highlighted the unique social limitations faced by young people with epilepsy and the pro-active ways in which young people responded to them. Whilst participants reported that other people's responses were mainly positive, three of the young people described being teased and bullied. The disclosure of epilepsy emerged as a significant theme, and was related to fear of discrimination.

**Conclusions:** Participants had experienced stigma at school. Felt stigma was also shown through participants' reports of embarrassment and fear of discrimination. The results highlight the important role of educational establishments in supporting young people with epilepsy, through collaboration with families and health services.

**Keywords:** Adolescence, epilepsy, stigma, social experiences, qualitative

## INTRODUCTION

Epilepsy has been historically associated with stigmatising responses from the general population, and research has demonstrated associations between the stigma of epilepsy and psychological distress [1] [2] [3]. In defining the social phenomena of stigma, Goffman (1963) [4] describes it as an 'attribute that is deeply discrediting' which can reduce a person 'from a whole and usual person to a tainted, discounted one'. Goffman further observes stigma as the relationship between an 'attribute and a stereotype', therefore highlighting how people can be linked with socially undesirable characteristics when they are seen to have a discrediting attribute such as epilepsy. In the case of epilepsy, it may not be immediately apparent that the person is different, therefore allowing the person with epilepsy to choose who, when and what they disclose to others about their condition. This is complicated by the fact that such anonymity may be threatened through the event of a public seizure. It has been proposed that the effects of stigma in people with epilepsy may be experienced in two ways; via enacted and felt stigma [5]. Enacted stigma refers non-legitimate discrimination such as teasing, and felt stigma refers to the fear of enacted stigma and feelings of shame associated with being epileptic. Felt stigma may therefore occur even if the person's condition remains undisclosed, as they attach undesirable characteristics to themselves, resulting in a negative impact on self-identity. Whilst some studies have found that more than 60% of their participants did not feel stigmatised by their epilepsy [1] [6], it still presents as a significant problem for many people.

The negative impact of stigma in the lives of adolescents with epilepsy has also been identified by research. Austin et al [7] developed an instrument to measure stigma in children with epilepsy, and identified that higher scores of perceived stigma were correlated with more negative attitudes, greater worry, poorer self-concept, and more

symptoms of depression. In another study, adolescents with epilepsy who felt stigmatised reported lower self-esteem than those who did not feel stigmatised [1]. Research exploring the stigma of epilepsy has mainly focused on adult populations, but it cannot be assumed that children and adolescents experience stigma via the same processes. Adolescence is acknowledged as a critical time for the development of self-identity and the formation of peer relationships, therefore stigma during this period may disrupt such processes and have detrimental effects on psychosocial health and self-esteem [8]. The disruption of relationships with peers, and self-perceptions of being different are therefore possible mechanisms by which adolescents with epilepsy may be negatively impacted by stigma, but these processes are not yet fully understood.

As part of the Glasgow Epilepsy Outcome Scales [9] [10], the Glasgow Epilepsy Outcome Scale for Adolescents (GEOS-AD) was developed in order to measure the impact of epilepsy on quality of life in adolescents [11]. The scale was developed using qualitative data collected from adolescents with epilepsy, and was based on a conceptual model which proposes that good quality of life requires adolescents to successfully adjust to having epilepsy, both in terms of illness-related factors and in identity formation [12]. To establish concurrent validity, they conducted inter-correlations between the subscales of the GEOS-AD and the subscales of another quality of life measure (QOLIE-AD [13]). The GEOS-AD does not contain a specific subscale pertaining to measure stigma, however the strongest correlations were found between the QOLIE-AD subscale 'Stigma' and the GEOS-AD subscales ( $r=0.246$  to  $0.583$ ). Therefore, whilst the GEOS-AD appears to measure stigma, this was not a theme explicitly identified from within the focus groups. However, the focus groups did identify that disclosure of epilepsy to their peer group was perceived as being a 'particularly difficult and complex issue' [12], which may be viewed



as an indication of felt stigma. The study's focus on quality of life may therefore have prevented the subtleties of stigma theory being specifically acknowledged within data analysis.

Following from the previous research with Scottish adolescents [11] [12], the current study therefore attempts to focus specifically on the experiences of stigma in adolescents with epilepsy. MacLeod et al.[14] in their review of the literature state that whilst research shows that stigma is an important factor in the health-related quality of life, we do not yet know how to capture the experience and meaning of stigma to adolescents. MacLeod et al. advise that qualitative research methods may be better suited to uncovering these experiences, 'as the concept of stigma may not be blatantly obvious' [14]. Whilst there are qualitative studies which describe adolescents' personal accounts of stigma, these are within studies exploring the general effects of epilepsy, and do not focus specifically on stigma [15] [16]. It is therefore proposed that the present study shall focus on exploring the experiences of stigma by adolescents with epilepsy, using qualitative methods. In order to achieve a more comprehensive picture of stigma in adolescents with epilepsy, participants shall not be excluded on the basis of having a mild/moderate learning disability.

## **AIMS AND DESIGN**

This study aimed to explore and describe the social impact of epilepsy on adolescents, with a specific focus on stigma. Utilizing a qualitative design, data were gathered through semi-structured interviews and analysed using Interpretative Phenomenological Analysis (IPA). The specific aims of the study were:

- 1) To describe experiences of stigma in adolescents with epilepsy.

- 2) To describe and explore the perceived impact of stigma in the lives of adolescents with epilepsy.
- 3) To describe and explore coping strategies for dealing with stigma.

IPA was chosen as an appropriate framework within which to analyse the data, as it is an approach which aims to gain an understanding of how participants view their personal and social world (Smith, 2003). It is a method which accepts that the results of analysis are a product of interpretation and is commonly used within health psychology research (Smith et al 1999). Quality criteria for qualitative research were considered in the design of the study, by referring to CASP (Critical Appraisal Skills Programme) guidelines [17].

## **METHODS**

### **Participants**

Following IPA methodology [18], the study attempted to recruit a homogeneous sample. Purposive sampling was therefore employed, with nine participants recruited from two specialist epilepsy centres in Scotland; the Fraser of Allander Neurosciences Unit at the Royal Hospital for Sick Children, Glasgow and the Epilepsy Unit at the Western Infirmary, Glasgow. The young people had all attended out-patient clinics within these services, where they were seen by professionals specialised in the assessment and intervention of epilepsy. Participants were included in the study if they a) were aged above 12 years 0 months and under 18 years 0 months b) had a diagnosis of epilepsy c) had epilepsy for at least 6 months duration d) had experience of at least one seizure in the past two years and e) were able recall and provide a verbal account of recent events in their lives. Participants were excluded from the study if they a) had deteriorating neurological health and/or b) had established non-epileptic seizure disorder as the primary clinical problem c) had a severe

learning disability. Therefore, participants who were able to talk and reflect upon their experiences of living with epilepsy were not excluded on the basis of having a learning disability. Like their adolescent peers, young people with epilepsy may also be living with additional difficulties which may impact on their social experiences. This may include a learning disability, mental health difficulty, motor-difficulty or specific learning difficulty. However, these young people share experiences unique to living with epilepsy and each have their individual contributions to add to our understanding of epilepsy. If the young person had something to say about being an adolescent living with epilepsy, we were interested in hearing their story. The study therefore attempted homogeneity through recruiting a sample of young people with active epilepsy whom had accessed specialist epilepsy services; whilst acknowledging the diversity which inevitably exists within this group.

The sample consisted of 9 adolescents (5 male, 4 female) between the ages of 12 years 11 months and 17 years 10 months (mean age: 15 years 7 months). The sample characteristics are presented in Table 1. As highlighted in the table, all participants were on anti-epileptic medication, with four receiving polypharmacy. In addition, two participants had Vagus Nerve Stimulation systems implanted. Six participants experienced more than one type of seizure; seven experienced generalised seizures and eight experienced partial seizures. Seizure frequency within the sample was varied, ranging from daily seizures to less than one a year. The mean age of diagnosis within the sample was 7 years 10 months. Two participants had attended special needs schooling and both experienced frequent seizures.

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Insert Table 1 here

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Clinicians within the respective epilepsy centres identified adolescents whom they considered met the study's inclusion and exclusion criteria. Potential participants were posted information and invited to participate in the study (Appendix 3.1 contains information sent to participants). Individuals who were interested in taking part in the study completed an opt-in form, and were contacted to arrange an appointment to meet with the researcher. Adolescents with a learning disability or who were under 16 years of age also required parental consent to participate in the study. Informed consent was obtained prior to the interview being conducted (see Appendix 3.2) and participants were offered travel expenses. Participants gave consent for their clinicians to provide the researcher with clinical information about their seizure type, seizure frequency, medication and date of diagnosis. Full ethical approval was obtained from Greater Glasgow & Clyde NHS (see Appendix 3.3).

Sample size is not predetermined in qualitative research and recruitment continued until theoretical saturation had been achieved [19]. Therefore recruitment was discontinued when no new themes emerged from the final two participants. However, as acknowledged by Willig [19] 'theoretical saturation functions as a goal rather than a reality', as modifications of categories or changes in perspectives are always possible. In total, 66 young people were invited to participate in the study. Of these, 13 agreed to participate, however 5 subsequently opted-out of being interviewed. This was due to reasons such as exam and work commitments, or the young person no longer being interested in taking part in the study.

## **Procedure**

Nine semi-structured interviews were conducted, each lasting approximately one hour. Interviews were recorded using a digital recording device and took place in rooms based at the clinics from which participants were recruited. It was arranged for one participant to be interviewed at their GP surgery, due to difficulty arranging travel to the hospital. Weber et al. [20] highlight that adolescence poses some distinct challenges to the interview process. Hence, building rapport and facilitating communication were given careful consideration when planning the format of the interviews. To aid the development of an appropriate interview procedure, trial interviews were conducted with two colleagues and one adolescent. In addition, the first three interviews were considered as pilots, allowing further reflection on the interview process. Interviews began with the completion of a poster about the main areas of the participant's life; family, friends, school and interests. This was then referred to throughout the interview, helping the interviewer to prompt the participant to reflect on their experiences of living with epilepsy in different areas of their life. The use of visual materials has been found to be valuable in assisting motivation and reducing anxiety when interviewing young people [21]. It was anticipated that this format would aid communication, by encouraging the young person to begin talking about themselves and prompt memories about their experiences during different times in their life. The interview schedule progressed developmentally through 1) experiences when first diagnosed 2) experiences growing-up 3) current experiences 4) future experiences. The schedule was constructed in-line with guidelines for semi-structured interviews in IPA [18] and functioned as a guide, with the aim of facilitating the participant to tell their own story and for the interviewer to explore novel areas. The structure of the interviews aimed to be broad and flexible, with general questions followed by prompts as necessary (see Appendix 3.4).

## Data Analysis

All interviews were transcribed verbatim, with personal identifiers removed. IPA was used as a framework for analysing interview transcripts; following step-by-step guides as detailed by Smith et al. [18] [22]. A flowchart of the process of analysis is shown in Figure1. Transcripts were read by the researcher several times, in order to become familiar with the data. During this process notes were made in the left-hand margin, in order to highlight statements which appeared particularly relevant or interesting. In further readings, the titles of emerging themes from the text were identified and written in the right-hand margin. These themes were considered in relation to each other through the formation of clusters, which were given a title in order to represent superordinate themes. A summary table of structured themes was then produced, including quotations relating to each theme. This process was completed for each transcript, with later transcripts being oriented by earlier analyses. Similarly, earlier transcripts were re-read in light of new themes emerging from the analysis of later transcripts. During all stages of analysis transcripts were re-read and the original text was continually referred to in order to ensure that the themes were grounded in what was actually said. Analysis was therefore an evolving and circular process and sometimes resulted in themes being dropped. At the end of the analysis process, a final table of themes was constructed.

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Insert Figure 1 here

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Analysis of the first three transcripts was done under close supervision by the research supervisor. Smith et al. [18] refer to this as a mini-audit, whereby the supervisor checks the validity of initial annotations and the clarity of the system adopted. Following this process a researcher experienced in IPA conducted an independent audit on the first three interviews, to advise whether the analysis process was coherent and explicit. Once the final

table of themes had been established, another researcher familiar with IPA read two of the transcripts alongside the identified themes. The outcome of these audits confirmed the appropriateness of connections made between the text and themes. Smith (1996) [23] describes these tasks as ensuring the final report is credible in terms of the data collected and that a logical progression runs through the chain of evidence. It is acknowledged that these are not a test of inter-rater reliability, but an attempt to validate the interpretation of the principle researcher.

## **RESULTS**

Five superordinate themes emerged from the data relevant to participant's social experiences of living with epilepsy and its impact. Table 2 displays the final table of themes and indicates the participants from whose transcripts they emerged. It should be recalled that interviews took a developmental approach therefore, the results reflect upon participants' experiences within both childhood and adolescence. The following results are presented in five sections, and deal with each of the superordinate themes in turn. The different dimensions of superordinate themes are described, alongside selective quotes (see Appendix 3.5 for a comprehensive table of illustrative quotes for each theme).

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Insert Table 2 here

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### **1) Limitations on Activities**

The following superordinate theme concerns the way in which epilepsy can impact on participants' social lives and activities. These experiences may set individuals with epilepsy apart from their peers and provide the basis for stigmatisation to occur. The nature of these limitations varied greatly amongst the young people. However, the extent to which

participants perceived themselves as having ordinary lives appeared to be key to their sense of social difference, rather than the nature of the limitations themselves.

### Restricted Independence

Participants described restrictions on their independence, as a consequence of living with epilepsy. Some participants referred to activities where they required supervision, due to the potential risks a seizure could have in those situations; for example whilst swimming or baby-sitting:

I: So what are the biggest things in your life that have changed because of it?

P02: Erm... Can't do certain things with my niece, can't baby-sit her. I can't go and take her to the shops and that by myself. Just like daft things, but it's quite a lot to you.....

Whilst acknowledging the necessity of supervision, this was perceived by some young people as being a negative restriction on their lives. There were also examples whereby the young person did not feel the supervision was justified and therefore felt over-restricted:

P02: Like when I was in the class and I wanted to go to the toilet, you'd to wait for somebody to come with you, and like...I can go myself...just things like that....I didn't have any more privacy any more.

The strongest sense of restriction was felt from the young people with a learning disability, who appeared to have a greater dependency on others:

P06: I am fed up that I cannot go out because I need someone beside me cos I get epilepsy and I just drop down.

I: So you've not been able to go to the cinema, as you've been growing up, on your own without an adult. What else haven't you been able to do on your own?

P06: Basically everything



For these young people, limited independence related to a sense of reduced autonomy and perceptions of being set-apart from their peer group.

### Restricted activities

Many participants described either externally or self-imposed restrictions on their participation in a range of activities. Externally-imposed restrictions came from parents, doctors and providers of leisure activities. Some related to issues of safety and risk whilst others were enforced in an attempt to avoid triggering seizures:

P07: Actually one thing that really, really annoyed me....at the time I was playing for a football team and I was a striker, and I wasn't too bad and I was getting better and better and then they told me I had to take a while out to see if headering the ball was effecting it...

Participants also described restricting their own activities, by avoiding situations which were more likely to trigger a seizure or in order to avoid experiencing a seizure in those situations. One person avoided competitive sports events as a consequence of an unpleasant seizure experience. Young people felt most strongly about restrictions in activities which they enjoyed, were skilled in or which offered opportunities for socialising with their friends:

P07: It has instructions, the rules, for the people that like do the paintballing, that say epileptics can't come... so that annoyed me as well... when all my friends went for a birthday party and I couldn't join them, because of my epilepsy.

### Disruption of activities

The young people described a variety of experiences where their activities were disrupted as a consequence of having epilepsy. These included disruptions caused by seizure events

or taking a break from physical activity to avoid a seizure being triggered. Most participants had the same range of social interests as their peers, but there was the potential for disruption due to having a seizure.

I: So what sort of stuff does it get in the way of then...if say you're having a bad day?

P08: Anything...anything I happen to be doing at the time. I'm always dead distracted at the time, because I'm always thinking... am I going to be ok without having to go home, or am I going to have to go home and take some tablets or whatever.

There were also descriptions of existing hobbies being disrupted following the onset of epilepsy, through effecting their skills and performance:

P09: Just cos I was so bad at it, cos I was losing 16 nill and that, cos I just kept...the ball just kept going past me. Just couldn't save anything, so I tried to go outfield and I was even worse, then I just kind of...was fed-up with it...

The participant described this as being a consequence of having epilepsy. However, it was not clear from their account whether this was due to the effects of seizure-activity or the side-effects of medication. Disruptions caused by seizures appeared more significant if they led to the young person feeling embarrassed:

P02: It was ages ago, it was like when I was having fits all the time, and I was in the shopping centre, and then I was looking at some of the clothes and then, I got a two second warning before a fit came on, and then I had a fit.

I: So you were in...where were you in? (*I was in a shopping centre*) yeh.

P02: And then...I can remember waking up and everybody's staring at me...I felt embarrassed  
{{participant laughed}}

In the case of one participant who did not report embarrassment in the event of a public seizure, this appeared related to them not feeling socially defined by their epilepsy:

I: What's like? Having a seizure in...cos that's quite a public place I guess...

P06: Well because I'm so out of it I don't really care what I look like. Later on I think...once again, I'm a really laid back person, I don't really care, I don't know anyone there, so...so it doesn't matter, but you know if I did know anyone there I would be like 'Who cares anyway?'. If it's someone I don't like, I don't care, if it's someone I do like, they won't care, so I don't care.

### Minimal limitations

Some participants described the social impact of epilepsy as being minimal. One young person in particular did not feel their life had changed in any way following their diagnosis of epilepsy. It is noteworthy, that this young person did not experience frequent seizures, and was very selective about disclosing his epilepsy. Other participants acknowledged some social limitations, but perceived them as being minimal, with little impact on their life. In some cases this was influenced by their level of interest in the activities:

I: ...any other things at school which epilepsy - - you mentioned the... *{{Referring to impact of epilepsy at school, participant previously stated that he stopped playing basketball}}*

P08: Apart from the sports I suppose. I wasn't really bothered about them to tell you the truth. They were just something I did in my spare time.(ok)None of my friends do that either, so...I wasn't really that bothered when I left.

## **2) Response to Epilepsy from Others**

The way participants describe other people's responses provided a valuable insight into the extent to which they felt stigmatised by having epilepsy. Reports of rejection and teasing were contrasted with experiences of support and acceptance. Only a minority of interactions were described as being negative.

## Teasing/Bullying

Three participants described being teased or bullied by peers within the school environment. These experiences ranged from teasing to being ignored and avoided by peers:

P02: I get treated sometimes differently at college. Cos, a lot of the people they do say to me wee jokes about my epilepsy and they think its funny but I don't, so...it's pretty annoying.

I: Can you tell me what sort of things they say?

P02: Like they imitate me taking a fit and just like things like that...one falls on the ground and that and starts shouting, 'oh I'm taking a fit, I'm taking a fit', but it's not really that funny....

These negative experiences were limited to specific people, and participants did not report being teased or bullied throughout their entire time in education. Teasing and bullying were therefore described as being the exception, in terms of other people's responses to epilepsy. Peer avoidance and rejection was experienced by one participant during their time in mainstream primary school, which was in contrast to their subsequent experiences within special needs education.

## Support

Participants made frequent reference to the provision of support from people who knew they had epilepsy; including family, friendship groups and teachers. This ranged from practical help with seizures to more psychological support, including concern for their well-being and encouragement to lead a full life:

I: Where do you get the most support from?

P02: My friends.

I: In what way?

P02: They do loads of stuff with me, and they don't put my epilepsy as an excuse all the time...like they kid on that I don't have it...so...that's what I like

Participants were explicit in their preference for more supportive environments. For example some schools had put considerable effort into making sure the young person was looked after and comfortable when they had a seizure at school:

I: What are the teacher's like generally? I don't know, at {{Name of previous secondary school}} and at...

P07: They're not too bad. They're quite good up here. Yeh, they were good down there as well. But err - - in {{Name of previous school}}... when I'd had a few fits, in the medical room, they bought a new bed and it had a side... a kinda of cushion side which hung down and you just bring it up around and push it into place so its nice and firm, so that I wouldn't fall out of the bed and the medical room was right beside the office... and they had a part of the wall replaced with a window, so that if I felt a fit coming on I would just knock on the window and they would come through ...but up here, it's not so good. There's a bed here, but its got no side, so I can't really go up there and there is no way of me telling the office I'm going to have a fit, so they don't know...so they often leave me either on the floor on top of some blankets or something...erm but I mean they won't know I'm having a fit unless there is someone else in the medical room with me, which I find quite annoying.

### Not a significant issue

The majority of participants did not perceive their epilepsy as being a significant issue to others, particularly within friendship groups. Epilepsy was not described as having a negative impact on existing friendships and many described it as being of little relevance:

I: I was just wondering what your friends and your classmates kind of made of you having epilepsy as you were growing up?

P05: Erm. - - They don't really take much notice of it actually. It doesn't really affect any things - - it doesn't really have much relevance to be honest.

These participants believed that their peers were not judgemental about their epilepsy, and either offered support and inclusion, or simply didn't raise it as an issue.

### Anxiety

Participants described others being worried about their well-being and anxious in response to seizure events. In some instances the young person perceived people as being over-worried, whilst others acknowledged that their worry was justified:

I: What are things like at school? I don't know maybe in terms of how the teachers reacted to you?

P05: Ummm. They were always a bit, sort of too cautious. They kind of... I don't know... exaggerated a little bit, which is kind of a bit annoying, but I don't know, that's it really...

I: Can you give me an example of what sort of stuff...

P05: I don't know - - like if we went on school trips or anything everyone was always just constantly asking me like if I was alright and everything? Which was quite annoying, but?

Other people's worry could cause some annoyance, but this anxiety was also able to demonstrate that people cared about them. Participants described others being apprehensive about the potential for seizures to occur and anxious responses from people witnessing seizures. There were accounts of people being terrified, shocked, screaming, panicked and not knowing what to do. In some instances this anxiety was viewed as being unhelpful:

I: The people that don't understand. How do they react then? The people that don't really...

P07: Err - - scream for help... and just like before I go completely into the fit, I'll maybe ask them to do something, maybe hold my head or something, make sure I don't hit it off the ground, but they'll just stand there looking at me - - and I'd think to myself... if I was that guy over there I'd punch him. But, err - yeh it can be frustrating when I ask them to do something which can help me from hurting myself too much and they just stand there watching me (*yeh?*) rather than do anything about it.

Anxious reactions were not limited to people who were unfamiliar with the young person's diagnosis, as parents were also described as becoming panicked in response to seizures. However, in some cases people's anxieties appeared to reduce once they had become familiar with seeing seizures.

### **3) Potential Negative Impacts**

The following cluster of themes highlighted awareness of the potential ways in which epilepsy could negatively impact on their social world. These themes all highlight a sense of uncertainty about the future.

#### Discrimination

One young person feared epilepsy would provide people with the ammunition to bully them, which was in the context of knowing that people get bullied and teased for things less significant than epilepsy:

P03: ...everyone takes the piss out of everyone for the slightest reason.

I: Right ok, so epilepsy would be...

P03: Err...something that I'd never be able to live down.

Fear of being bullied influenced participants' choices around disclosing their diagnosis to others. One participant referred to her parent's fears that others would not perceive her as being clever due to having epilepsy. However she believed that the potential for discrimination would only be from people that did not know her, as people she knew would judge her by the abilities she demonstrated:

P06: I never thought of it until dad like mentioned it, but that's people that don't really know me. People at school know I am pretty bright. I've had quite a few pretty good praise like from teachers, so I don't really...so I don't really care if people I don't know think I'm dumb, again erm...just people in school know I'm not dumb and people in school don't really care about my epilepsy so... they think "oh she's smart" - - epilepsy is nothing to do with it anyway.

Some young people were also aware that they may face difficulties around employment, due to the risk of them having seizures. However, in the case of one participant who feared they may be discriminated by their work, their fears were not realised after disclosing their diagnosis to their employer.

#### Risk of seizure-related death

Participants acknowledged that seizures could be potentially dangerous in certain situations, and that they faced greater risks than their non-epileptic peers. One young person who saw someone die during a seizure event, had become anxious that it could happen to her. Although no-one said that they avoided activities due to the risk of death or fatal accident, they acknowledged the need for extra supervision in places like swimming pools.

#### Future limitations

Participants were aware that epilepsy would have an impact on their adult lives. They knew that there could be lifestyle restrictions, including not being permitted to drive and the risks associated with living in accommodation independently. Yet there remained uncertainty about the extent to which epilepsy would impact on their lives, as this was dependent upon how their condition progressed regarding seizure severity.



#### **4) Disclosure of Epilepsy to Others**

Approaches to disclosure reflected participants own feelings about having epilepsy and their perceptions of how other people would respond to the diagnosis. All of the participants had disclosed their condition to at least some of their peers; however this was done with varying degrees of comfort.

##### Selective disclosure

Decisions around disclosure were raised as a significant issue, with participants being selective about whom they told. Participants often chose to disclose their diagnosis to close friends, with trustworthiness highlighted as an important consideration when choosing who tell:

I: How many people is that that you've told then, that are close?

P03: Two.

I: And what makes them trustworthy? What makes you be able to trust them?

P03: Well erm...one of them I've known since primary and erm... another one, basically, she stays far away, so she'll never get to see my friends.

Choosing to tell people who could be trusted not to disclose their diagnosis to others, was a protective response to the fear of being teased. In addition, one participant described being selective about disclosure because they felt embarrassed about having epilepsy:

I: Why did you decide not to tell them?

P05: Erm - - I don't know, I think I just found it quite embarrassing to be honest

### Comfortable with disclosure

A range of participants described being comfortable about disclosing their epilepsy to others and made no attempt to conceal it. For one young person, the fact that they attended a special needs school appeared to eliminate the issue of disclosure:

I: And did you tell him that you had epilepsy, or did someone else tell him?

P01: Well they know. There is a reason for why they do these schools you know. {1st School}'s a special needs school, the {2nd School}'s a mixture and {current school}'s a special needs school. So, I'd be in the section of special needs in the {2nd School}, so {friend 3} would have known yes, or he would have found out. Somebody told him. Or maybe I would have told him. I probably told him.

I: If you were to make a new friend, would you probably tell them you have epilepsy (*yes*) - - Would that be easy to do?

P01:Erm, - - yes. I'd just tell them.

One young person suggested it was easier to talk about their epilepsy with others who had a disability. This suggests that there may be a benefit to mutual disclosure. Participants described disclosing their epilepsy when it came up in conversation or as an explanation to a seizure event. Some participants did not feel they had a choice about concealing their diagnosis, and talked about disclosure as something that just needed to be done:

P02:...there's no point hiding it cos they'll find out sooner or later. Just in case you take a fit in front of them. So....might as well just tell them...

Young people who appeared to be most comfortable about disclosing their epilepsy also appeared to be the least embarrassed about their diagnosis:

P08: I've got no problem hiding it, I mean I don't need to hide it. I've never hidden it from anybody actually...erm...its always something I can admit to... Not really a problem.

## 5) Pro-active Responses to Social Impact

Participants described how they dealt with the social impact of living with epilepsy, and their ability to reduce social difference through seeking to lead a 'normal life'.

### Getting on with life

In response to the disruption of activities and risk to safety, participants described an attitude of getting on with life, thus reducing the impact of epilepsy. For some participants that involved accepting risk and ignoring their worries:

P05: I love skiing.

I: And your epilepsy... does that limit that in any way?

P05: No - - well I do - - I sometimes do get quite worried, but I would rather ski than not ski, so...

(ok) - - So I just sort of forget about it.

Whilst this could conflict with other people's concerns for their safety, there were also instances where they were encouraged not to let epilepsy interfere with their social activities:

P02: I told my dance teacher and then she said 'don't let it effect your dancing', so I just didn't...I just got on with my dancing as usual.

In some instances this involved making adaptations to their lives, for example by taking rests during activities or developing new interests:

P09: I was kind of gutted about football, erm, but then I tried to think, tried to find other sports I was good at..(ok) I found skateboarding for a while, but then...I couldn't improve and I hit myself in the face with a skateboard once (oh dear) But then I found golf and that was pretty good.

### Confront teasing

In response to being teased about epilepsy, participants spoke about confronting the people who were teasing them. This highlighted their belief that it was not acceptable for them to be treated that way and they felt empowered to say this to people. One young person reported that he had never been teased, but described that his reaction would be to fight back:

P07: But no, no-one's teased me (*that's great*) - - I'd have them if they did (yeh?) Yeh - - I mean I don't often get in fights and that, but if someone were to tease me about something that I have to put up with, and I've got to put up with, like throughout my life, or so it has been for four years, I wouldn't be so happy.

## **DISCUSSION**

In exploring the social experiences of young people with epilepsy, the results highlight some distinct social challenges associated to living with seizures. The impact of these varied dramatically and in some cases appeared to be influenced by the presence of a learning disability and frequency of seizures. Amongst participants there was a strong sense of resilience, demonstrated through an attempt to limit the impact epilepsy could potentially have on their lives. The participants sought a sense of normality in their lives and attempted to reduce the distinctions between themselves and their peers. Few people reported experiencing negative responses from others towards their epilepsy, with most of the young people feeling accepted and supported.

Scrambler and Hopkins [5] definition of enacted stigma refers non-legitimate discrimination, which was highlighted within the current study in the form of bullying and

teasing. However, it is noteworthy that these experiences were limited to peer responses within the school/college environment. This was consistent with other studies which found the majority of their subjects did not feel they were stigmatised by their epilepsy [1] [2]. In general, limitations due to seizure activity and risk were of greater significance than restrictions based on discrimination.

As suggested by stigma theory, people may still feel stigmatised even in the absence of directly experiencing discrimination or social rejection. This is described as felt stigma, which can be related to the shame associated with having epilepsy or the fear of enacted stigma [24]. Evidence of felt stigma was identified through accounts of young people feeling embarrassed by their epilepsy. Felt stigma was also apparent through participants' fears that they might be bullied or discriminated against in employment. There was also evidence that the way some young people managed disclosure of their epilepsy indicated their sensitivity to the stigma associated with epilepsy. Selective disclosure emerged as a theme, and is a concept referred to by Goffman [4], who talks of people disclosing their epilepsy to 'sympathetic others'. In these cases the participants' fear of teasing resulted in careful consideration regarding who could be trusted not to tell others about their illness. It is interesting that the young person who felt their epilepsy had the least social consequences on their life, was also the most selective in terms of disclosing his diagnosis to others. He talked about his uncertainty of how peers would react if they saw him having a seizure and fear of being bullied if people knew of his diagnosis. Therefore whilst the social burden of epilepsy was low, in many respects the psychological burden of his felt stigma was greater. Issues of felt stigma are an important consideration for adolescents with epilepsy, given the potential impact on self-perceptions and identity formation.

Felt stigma was not evident in all participants, as some spoke of not being embarrassed by their epilepsy and comfortable about disclosing their diagnosis to others. There was also a widespread feeling of positive acceptance regarding other people's responses to disclosure, with the majority of people being either supportive or indifferent.

Accounts of other people's anxious emotions to their epilepsy, was another issue raised by participants. Albrecht et al. [25] identified that ambiguity in social interactions was the most frequent reason for people distancing themselves from a stigmatized person. Scambler [24] highlights that in response to people with epilepsy, this may be due to the unpredictability, the drama or a fear of coping. Although, the reasons for other people's anxieties cannot be inferred from the participants' accounts, the impact of these responses appeared limited to the annoyance of people over-worrying or being unhelpful around seizures. Link and Phelan [26] theorize that personal contact can reduce stigmatisation through humanising the condition. This is able to help ensure the stigmatised person is seen as an individual and not an illness. As none of the participants described losing existing friends as a result of disclosure, this may provide some support for this theory. This concept was highlighted by one participant in particular, who believed she was not defined by epilepsy amongst her friends, but acknowledged that strangers may form judgements in reaction to the diagnosis.

In addition to stigma theory, other researchers may have put a greater emphasis on other theoretical perspectives when reflecting upon the themes which emerged from this study; for example through focusing on resilience or social identity theory. Many of the young people appeared to demonstrate resilience through their accounts of positive adaptations to living with epilepsy. Research in resilience development has proposed three main

influential factors 1) individual attributes of the young person themselves, 2) aspects of their families, and 3) characteristics of their wider social environments [27]. These factors were evident within the present study, particularly through descriptions of supportive, encouraging and accepting responses from other people; including family, friends, teachers and peers. Social identity theory also provides a useful perspective for conceptualising the current data; which proposes that individuals strive to maintain a positive self-image, both in terms of personal and social identity (Tafjel, 1978) [28]. Personal identity includes specific individual attributes such as competence, talent and sociability, whilst social identity refers to the part of a self-concept which derives from group membership and the value of emotional significance attached to that membership [29]. The theme of ‘teasing/bulling’ may be the consequence of others attempting to enhance their own self-concept, through being hostile against those categorised as having epilepsy. Further, the salience of participants’ personal and social identities in relation to epilepsy was also apparent within the interviews, and undoubtedly impacted upon their behaviour. Many of the accounts suggested a strong sense of personal identity and for one participant in particular was notably protective against the potential stereotypes attributed to having epilepsy. Some participants also talked in a way which suggested they had a stronger sense of social identity towards their friendship groups than within an ‘epilepsy group’ which may have been a strategy employed to promote their own resilience.

In conclusion, whilst the interviews did not explicitly ask participants whether they felt stigmatised, the detailed accounts provided by the young people suggest that the majority did not. Despite this, there was some evidence of enacted and felt stigma which did have an impact on the young people’s lives. However, what resonated from the majority of interviews was a sense of resilience in response to the unique social challenges they faced.

### **Implications for Practice**

The finding that all experiences of enacted stigma took place within the school environment, suggests that schools have a significant responsibility in supporting young people with epilepsy and changing the attitudes of young people's peers. Education is regarded as the best method of reducing stigma, through eliminating fear of the unknown. Therefore first aid training and education may be valuable in reducing this fear. Strong links between families, health services and educational establishments may help to produce the most appropriate balance of support for the young person. This will involve being mindful of the young person's changing needs throughout the various stages of their development.

The young people were pro-active in reducing the impact of epilepsy on their lives, in an attempt to lead similar lives to their peers. Whilst being mindful of the risks, encouraging young people to find ways to adapt to living with epilepsy were identified as important. In addition, despite the impact of epilepsy on adulthood being potentially unclear, young people may still benefit exploring any worries they may have in relation to the future.

### **Implications for Future Research**

This study focused on a specific population of young people with epilepsy; they were on anti-epileptic medication and had experienced at least one seizure in the past two years. Further research could explore experiences of young people in a sample with well-controlled epilepsy, who are no longer experiencing seizures. As identified in the study, young people with infrequent seizures demonstrated signs of felt stigma as well as those with frequent seizures. In addition to the existing Glasgow Epilepsy Outcome Scales, the



data from the current study may potentially be used to guide the development of a scale specific to measuring the impact of stigma in adolescents with epilepsy in a Scottish population. Whilst similar themes emerged amongst young people regardless of whether they had a learning disability, there appeared to be some differences in the social experiences of young people with a learning disability. Further research could therefore focus on the unique experiences of this population, particularly given the potential for stigma to be associated with both epilepsy and the learning disability. Given the limited amount of research into stigma in the lives of adolescents with epilepsy, further research is necessary in order to help develop a clearer understanding of how stigma is experienced within this population.

### **Study Limitations**

Due to the small sample size the results are not generalizable, although it should be acknowledged that this is not an aim of qualitative research. It is relevant that the accounts within this study are based on a sample of young people who volunteered to talk about their epilepsy with someone they did not know. It may be hypothesised that young people with a strong sense of stigma would not volunteer to take part in a study of this type. Consequently, important insights into adolescents' experiences of stigma may not have emerged from within the present study. We do not have information about the young people who did not opt-in, therefore it is not possible to make inferences about their reasons for not participating. Further research adopting longitudinal design may assist researchers in gaining a broader perspective of stigma in the lives of young people with epilepsy.

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**Table 1: Participant Characteristics**

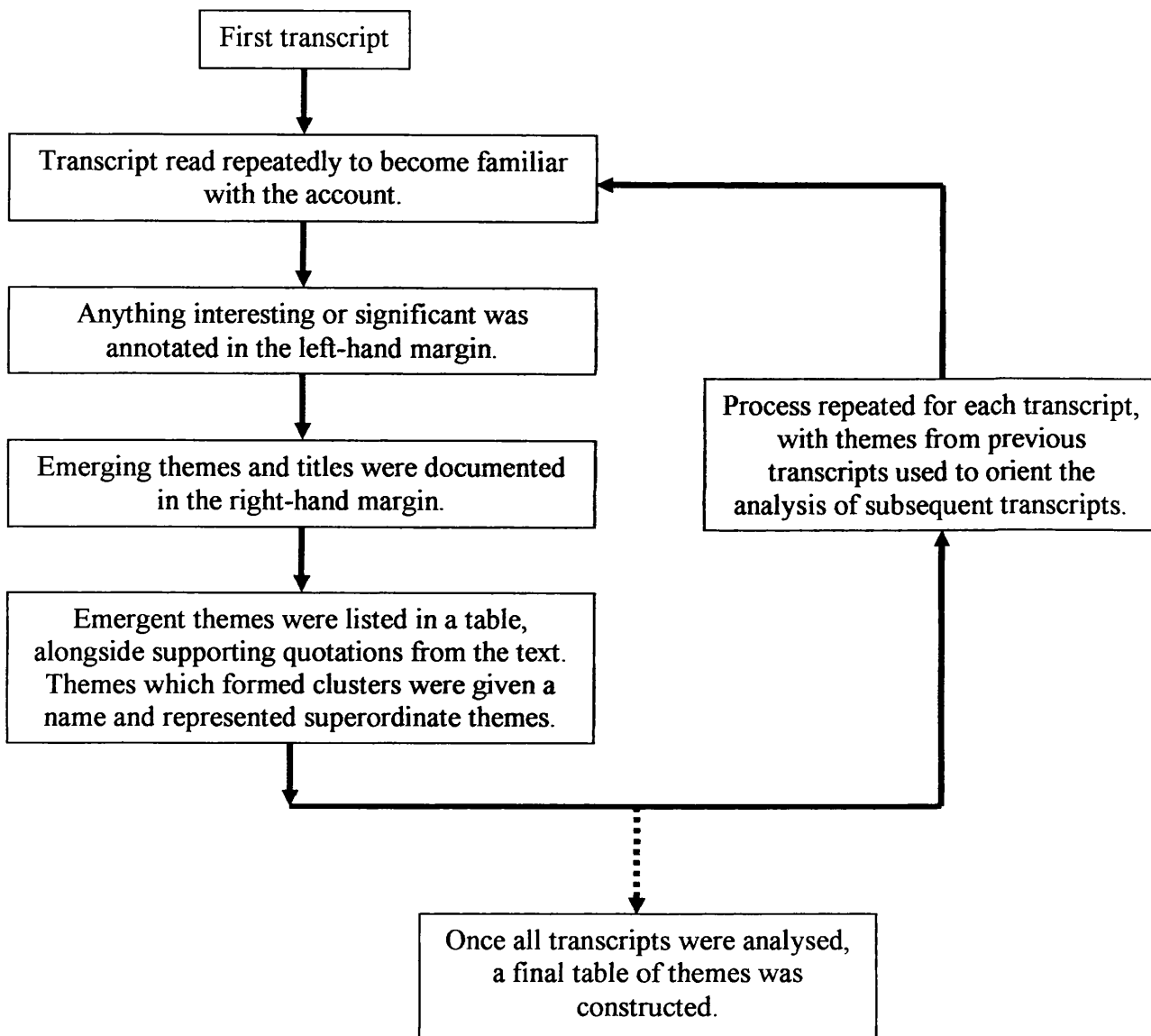
<b>Participant Characteristics</b>	
<b>Gender (number)</b>	
Male	5
Female	4
<b>Age (year.month)</b>	
Mean	15.7
Range	12.11 – 17.10
<b>Seizure Type (number)</b>	
Simple partial	1
Complex partial	7
Generalised Tonic Clonic	7
Absence	1
More than one seizure type	6
<b>Age at diagnosis (year.month)</b>	
Mean	7.10
Range	1.0 – 15.10
<b>Seizure Frequency (number)</b>	
Daily	1
Weekly	3
Monthly	1
Several times a year	2
Once a year	0
Less than one a year	2
<b>Medication (number)</b>	
Sodium Valporate	1
Carbamazepine	5
Levetiracetam	2
Lamotrigine	1
Zonisamide	1
Clobazam	1
Oxcarbamazepine	2
Phenytoin	1
None	0
Polypharmacy	4
Vagus Nerve Stimulation	2
<b>Education Status</b>	
Mainstream school	6
Special needs school	1
College*	2

\* One of the participants attending college, previously attended a special needs school

**Table 2: Final Table of Themes**

Themes	Participant Number (✓ = themes reflected by each participant)								
	P01	P02	P03	P04	P05	P06	P07	P08	P09
<b>Limitations on Activities</b>									
• Restricted independence	✓	✓		✓		✓			
• Restricted activities		✓		✓	✓	✓	✓	✓	✓
• Disruption of activities		✓			✓	✓	✓	✓	✓
• Minimal limitations			✓					✓	✓
<b>Response to Epilepsy from Others</b>									
• Teasing/Bullying		✓		✓		✓			
• Support	✓	✓		✓			✓	✓	✓
• Not a significant issue		✓	✓	✓	✓	✓	✓	✓	✓
• Anxiety		✓		✓	✓	✓	✓		✓
<b>Potential Negative Impacts</b>									
• Discrimination		✓	✓	✓		✓			✓
• Risk of seizure-related death	✓	✓			✓				
• Future limitations	✓	✓			✓	✓	✓	✓	
<b>Disclosure of Epilepsy to Others</b>									
• Selective disclosure			✓	✓	✓				✓
• Comfortable with disclosure	✓	✓			✓	✓	✓	✓	✓
<b>Pro-active Responses to Impact</b>									
• Getting on with life	✓	✓			✓	✓	✓		✓
• Confront teasing		✓				✓	✓		

**Figure 1: Analysis Flowchart**



**Key Processes of Analysis**

- If a superordinate theme emerged late in the analysis, earlier transcripts were reviewed in the light of the new superordinate theme.
- During all stages of analysis the researcher constantly checked their own interpretations against what the person actually said.
- Themes were not only selected by their prevalence within the data, but also on the power of their expression and the extent to which they illuminate other themes.
- Themes were dropped if they did not fit well with the emerging structure, nor were rich in evidence within the transcript.



Chapter 5: Single N Proposal

Single N Proposal submitted in partial fulfilment of the requirements for the degree of  
Doctorate in Clinical Psychology

**The contribution of a solution-focused approach to  
deliberate self-harm in adolescence:  
A single case design.**

Katherine Bruce

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## **ABSTRACT**

**Background:** Deliberate self-harm is a significant problem within the adolescent population, however there remains a poor evidence-base for effective interventions. Solution focused therapy may provide a valuable contribution, through its focus on strengths, coping-skills and hope for the future.

**Aims:** The proposed study aims to investigate the effectiveness of solution focused brief therapy as part of an intervention for reducing the frequency of deliberate self-harm in an adolescent. The effects of intervention on associated psychological factors shall also be evaluated.

**Method:** A single-case ABCD design shall be utilised, incorporating phases of baseline assessment, traditional intervention, solution-focused intervention and follow-up. Measurements of outcome will include frequency of self-harm, symptoms of depression, self-esteem, problem solving, self-efficacy and impulsivity.

## **Appendices**

**Page no:**

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**Section 1: Appendices for Small Scale Service Related Project**

## **Appendix 1.1: Data Collection Form**

<b>Data Collection Form</b>	
ID	<i>Randomly allocated to each referral</i>
Age at referral	<i>In years only</i>
Gender	<i>Male/Female</i>
Referral source	<i>GP, Psychiatry etc.</i>
Presenting problem as assessed by the referrer	<i>1. Cognitive impairment 2. Axis II Disorder (e.g. LDS, ADHD etc.) 3. Alcohol/substance related cognitive deficit?</i>
Neuropsychologist's formulation	<i>Descriptive (post-hoc categorization used)</i>
Postcode	<i>Of patients address</i>
Catchment area of Lochgilphead service	<i>Tarbert, Oban, Mid Argyll, Campbeltown, Cowal Peninsula, Bute</i>
Attendance at first appointment	<i>Attended/Cancelled/DNA</i>
Date of referral	<i>dd/mm/yy</i>
Date of first appointment given	<i>dd/mm/yy</i>
Date of first appointment attended	<i>dd/mm/yy</i>
Date of discharge from assessment clinic	<i>dd/mm/yy</i>
Tested	<i>Yes/no</i>
If not tested why?	<i>Descriptive</i>
Test 1	<i>Name (In the case of only individual subtests being given, they shall be addressed by the whole test name)</i>
Test 2	<i>Name</i>
Test 3	<i>Name</i>
Test 4	<i>Name</i>
Test 5	<i>Name</i>
Test 6	<i>Name</i>
Number of sessions seen by Neuropsychologist	<i>Number</i>
Number of sessions seen by Trainee Clinical Psychologist	<i>Number</i>
Number of sessions seen by Assistant Psychologist	<i>Number</i>
Other services involved with case	<i>List (post-hoc categorization used)</i>
Neuropsychologist recommendations following assessment	<i>List (post-hoc categorization used)</i>
Outcome of case	<i>1. Returned o referrer unseen 2. Returned to referrer seen 3. Returned to another service 4. Returned to another psychologist 5. Case currently still open to NAS</i>
Followed-up within NAS	<i>Yes/no</i>
Nature of follow-up	<i>Descriptive</i>

## **Appendix 1.2: Power Point Presentation**

### **Analysis of Referrals to a New Neuropsychology Assessment Service within Argyll and Bute Adult Clinical Psychology Service**

Small Scale Service Related Project submitted in partial fulfilment of the  
requirements for the degree of Doctorate in Clinical Psychology

Katherine Bruce

#### **Argyll and Bute Neuropsychology Assessment Service (NAS)**

- Peck report (2001)
- Service established (March 2004)
- Covering Argyll and Bute population
- In-patient and out-patient
- Based at Argyll and Bute Hospital
- Referrals screened by Head of Argyll and Bute Clinical Psychology Services

## NAS: Staffing

- Neuropsychologist – 1 day a month
- Assistant Psychologist – Supervised in administering of tests and follow-up work
- Opportunity for Trainee Clinical Psychologists to work within NAC

## Considerations for Future Development

Formal Links with Other Services/ Integrated Care Pathway

Guidelines and recommendations for specific patient populations

The rural nature of Argyll an Bute

## Aims and Objectives of the Study

- 1) Who used the service and what types of referrals were received?
- 2) What is the nature of the assessment service provided to the referred population?
- 3) What were the outcomes of cases seen within the service?

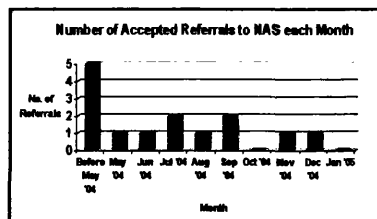
## Method

- Data collected from case-notes
- Referrals accepted from 1<sup>st</sup> May 2004 to 31<sup>st</sup> January 2005
- Data collection form used
- Database created in Access
- Data analysed within Excel
- Patient confidentiality protected

## Results

### Accepted Referrals

15 referrals accepted for assessment in the first 9 months

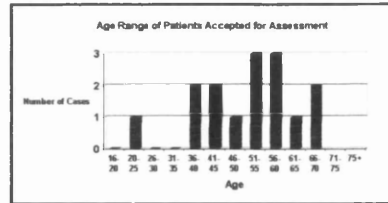


Average waiting time = 30 days



## Demographic Characteristics

9 males and 6 females assessed



## Demographic Characteristics

Average distance travelled one-way from a patient's home address to the clinic

= 33.5 miles

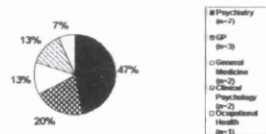
Estimated mean length of time taken to travel one-way by car to a single appointment

= 87.6 minutes

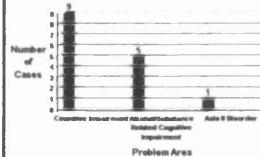
Referrals made for patients living within all 6 catchment areas

## Referral Source and Reason

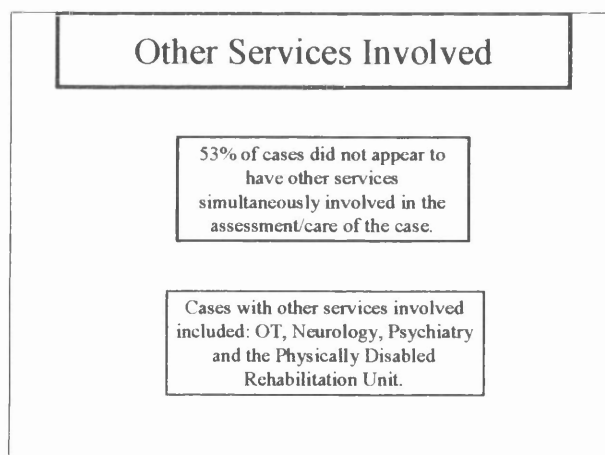
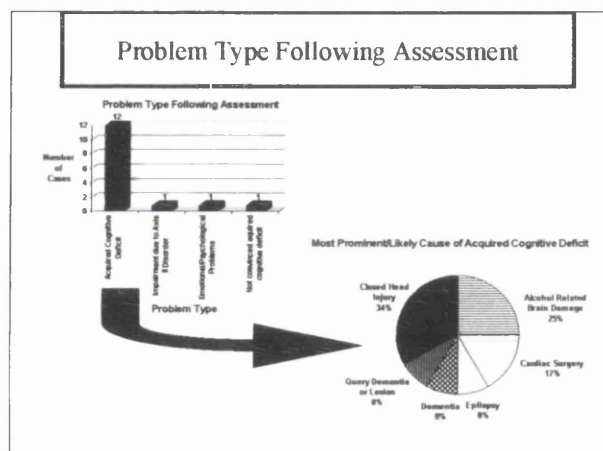
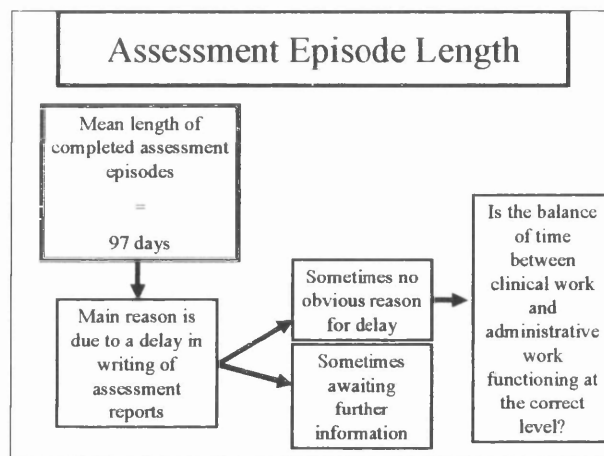
Referral Source of Accepted Referrals



Problem Type as Stated by Referral







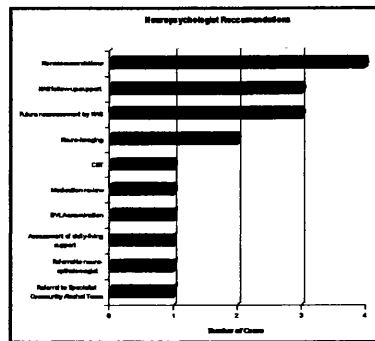
## Outcome of Cases

\*10 cases returned to the referrer with recommendations

\*5 cases remain open

\*3 of the open cases are awaiting follow-up from the Psychology Assistant

\*2 of the open cases are awaiting re-assessment within the NAS to monitor change



## Conclusions/Future Implications

- Implications for other services
- Positive results are 0% rate of non-attenders within the context of long journey times
- Consideration to future planning of appointments to suit patient's journeys?
- Future service developments
- Impact of temporary loss of Psychology Assistant input
- Impact of dissolution of NHS Argyll and Clyde

## Discussion and Further Action

## **Section 2: Appendices for Systematic Review**

## **Appendix 2.1: Elsevier Guide for Authors (for submission to *Seizure*)**

### **Guide for Authors**

#### **Submission checklist**

It is hoped that this list will be useful during the final checking of an article prior to sending it to the journal's editor for review. Please consult this Guide for Authors for further details of any item.

#### **Ensure that the following items are present:**

- One author designated as corresponding author
- E-mail address
- Full postal address
- Telephone and fax numbers
- All necessary files have been uploaded
- Keywords
- All figure captions
- All tables (including title, description, footnotes)
- Further considerations
- Manuscript has been "spell checked"
- References are in the correct format for this journal
- All references mentioned in the Reference list are cited in the text, and vice versa
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Submission to this journal proceeds totally on-line. Use the following guidelines to prepare your article. Via the "Author Gateway" page of this journal (<http://authors.elsevier.com/journal/seizure>) you will be guided stepwise through the creation and uploading of the various files. Once the uploading is done, our system automatically generates an electronic (PDF) proof, which is then used for reviewing. It is crucial that all graphical and tabular elements be placed within the text, so that the PDF is suitable for reviewing. All correspondence, including notification of the Editor's decision and requests for revisions, will be by e-mail. In general, no separate proof is sent to you: the PDF is your proof. A proof will be provided only when the final layout of the article has to differ significantly from that in the initial PDF.

The above represents a very brief outline of this form of submission. It can be advantageous to print this 'Guide for Authors' section from the site for reference in the subsequent stages of article preparation.

#### **Electronic format requirements for accepted articles**

##### **General points**

We accept most word-processing formats, but Word, WordPerfect or LaTeX is preferred. Always keep a backup copy of the electronic file for reference and safety. Save your files using the default extension of the program used.

##### **Word processed documents**

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word-processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. Do not embed 'graphically

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To avoid unnecessary errors you are strongly advised to use the 'spellchecker' function of your word processor.

## **Preparation of text**

### **Presentation of manuscript**

#### **General**

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Italics are to be used for expressions of Latin origin, for example, *in vivo*, *et al.*, *per se*. Use decimal points (not commas); use a space for thousands (10 000 and above).

Set out the entire manuscript using double spacing and wide (3 cm) margins. (Avoid full justification, i.e., do not use a constant right-hand margin.) Ensure that each new paragraph is clearly indicated. Present tables and figure legends on separate pages at the end of the manuscript. If possible, consult a recent issue of the journal to become familiar with layout and conventions. Number all pages consecutively.

Provide the following data on the title page (in the order given):

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Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

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Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author.

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If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

#### **Abstract**

A concise and factual abstract is required (maximum length 250 words). The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone.

References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

#### **Keywords**

Immediately after the abstract, provide a maximum of six keywords, avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

#### **Abbreviations**

Define abbreviations that are not standard in this field at their first occurrence in the article: in the abstract but also in the main text after it. Ensure consistency of abbreviations throughout the article.

#### **Acknowledgements**

Collate acknowledgements in a separate section at the end of the article and do not, therefore, include them on the title page, as a footnote to the title or otherwise.

#### **Arrangement of the article**

##### **Subdivision of the article**

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text.'

##### **Introduction**

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

##### **Experimental/Materials and methods**

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

##### **Theory and/or calculation**

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

##### **Results**

In this section the findings should be described clearly, concisely, and in logical order without extended discussions of their significance. Only in case of short communications, the results and discussion sections may be combined. Results should usually be presented in graphic or tabular form, rather than discursively. There should be no duplication in text, tables and figures. Experimental conclusions should normally be based on adequate numbers of observations with statistical analysis of variance and the significance of differences. The number of individual values represented by a mean should be indicated.

#### Discussion

This section should present conclusions to be drawn from the results accompanied by an assessment of their significance in relation to previous work. Speculative discussion is not discouraged, but the speculation should be based on the data presented and identified as such. In general, the discussion should be as concise as possible.

#### Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

#### Acknowledgements

Place acknowledgements, including information on grants received, before the references, in a separate section, and not as a footnote on the title page.

#### References

See separate section, below.

#### Figure legends, tables, figures, schemes

Present these, in this order, at the end of the article. They are described in more detail below. High-resolution graphics files must always be provided separate from the main text file (see Preparation of illustrations).

#### Text graphics

Present incidental graphics not suitable for mention as figures, plates or schemes at the end of the article and number them 'Graphic 1', etc. Their precise position in the text can then be defined similarly (both on the manuscript and in the file). See further under the section, Preparation of illustrations. Ensure that high-resolution graphics files are provided, even if the graphic appears as part of your normal word processed text file.

#### Specific remarks

##### Mathematical formulae

Present simple formulae in the line of normal text where possible. In principle, variables are to be presented in italics. Use the solidus (/) instead of a horizontal line, e.g.  $X/Y$  rather than  $\frac{X}{Y}$

$X$

$Y$

Powers of  $e$  are often more conveniently denoted by  $\exp$ .

Number consecutively any equations that have to be displayed separate from the text (if referred to explicitly in the text).

#### Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many word processors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves on a separate sheet at the end of the article. Do not include footnotes in the Reference list.

#### Table footnotes

Indicate each footnote in a table with a superscript lowercase letter.

#### Tables

Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

#### Nomenclature and units

Follow internationally accepted rules and conventions: use the international system of units (SI). If other quantities are mentioned, give their equivalent in SI. The nomenclature for seizures should be that employed by the Commission on Classification of the International League Against Epilepsy of 1981 (*Epilepsia* 1981; 22: 489-501).

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Authors are encouraged to check accession numbers used very carefully. An error in a letter or number can result in a dead link. In the final version of the **printed article**, the accession number text will not appear bold or underlined. In the final version of the **electronic copy**, the accession number text will be linked to the appropriate source in the NCBI databases enabling readers to go directly to that source from the article.

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#### **Protection of patients' rights to privacy**

Patients have rights to privacy that should not be infringed without informed consent. Identifying information should not be published in written descriptions, photographs, or pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written consent for publication. Informed consent for this purpose requires that the patient should be shown the manuscript to be published.

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#### **Statement of conflict of interest**

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#### **References**

*Responsibility for the accuracy of bibliographic citations lies entirely with the authors.*

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Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications should not be in the reference list, but may be mentioned in the text. Citation of a reference as 'in press' implies that the item has been accepted for publication.

#### **Citing and listing of web references**

As a minimum, the full URL should be given. Any further information, if known (author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

#### **Text**

Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.

Example:

"..... as demonstrated [3,6]. Barnaby and Jones [8] obtained a different result ...."

List: Number the references (numbers in square brackets) in the list in the order in which they appear in the text.

Examples:

Reference to a journal publication:

[1] Slater, E. and Beard, A.W. The Schizophrenia-like psychoses of epilepsy. *British Journal of Psychiatry* 1963;109:95-150.

Reference to a book:

[2] W. Strunk Jr., E.B. White, *The Elements of Style*, third ed., Macmillan, New York, 1979.

Reference to a chapter in an edited book:

[3] Betts, T.A. A follow up study of a cohort of patients with epilepsy admitted to psychiatric care in an English city. In: *Proceedings of the Hans Berger Centenary Symposium* (Eds P. Harris and C.Maudsley). Edinburgh, Churchill Livingstone, 1974: pp.326-338.

Note that journal names are not to be abbreviated and that "et al." is used if there are seven or more authors.

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- Supply files that are optimised for screen use (like GIF, BMP, PICT, WPG); the resolution is too low;
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

#### **Captions**

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## **Appendix 2.2: Quality Criteria Rating System**

Title of Study: ..... Initials of Rater: .....

### **1) Design**

What is the design of the study?

- a) Longitudinal ☐
- b) Cross-sectional ☐

### **2) Generalizability of the findings**

How representative were participants of the defined population?

- a) The study utilised a good sampling technique (e.g. geographical cohort), to recruit participants representative of the defined population. Good ☐
- b) Criteria a) was not fully met, but the authors justified an adequate sampling method, to attempt to ensure a representative sample. Adequate ☐
- c) The study did not utilise an adequate sampling technique (e.g. convenience sample), which may have comprised the generalizability of the findings. Poor ☐

### **3) Confounding Variables**

How well were confounding variables accounted for?

- a) The study identified and accounted for key possible confounding variables in the analysis. These included variables within each of the following four categories: 1) demographic variables 2) neuro-epilepsy variables 3) psychosocial variables 4) medication variables (examples highlighted in table 1). Good ☐
- b) Criterion a) was not fully met, but analysis took into account some possible confounding variables. These included variables within at least two of the following categories: 1) demographic variables 2) neuro-epilepsy variables 3) psychosocial variables 4) medication variables (examples highlighted in table 1). Adequate ☐
- c) Key possible confounding variables were not adequately considered in the analysis. This includes studies which took into account variables from only one or none of the following categories: 1) demographic variables 2) neuro-epilepsy variables 3) psychosocial variables 4) medication variables (examples highlighted in table 1). Poor ☐

**Table 1: Examples of Key Possible Confounding Variables**

<b>Demographic Variables</b>	<b>Neuroepilepsy Variables</b>	<b>Psychosocial Variables</b>	<b>Medication Variables</b>
<input type="checkbox"/> Age <input type="checkbox"/> Sex <input type="checkbox"/> Race	<input type="checkbox"/> Age at onset <input type="checkbox"/> Seizure control <input type="checkbox"/> Duration of disorder <input type="checkbox"/> Seizure type <input type="checkbox"/> Multiple seizure types <input type="checkbox"/> Etiology of epilepsy <input type="checkbox"/> Type of aura <input type="checkbox"/> Neuropsychological status	<input type="checkbox"/> Fear of seizures <input type="checkbox"/> Perceived discrimination <input type="checkbox"/> Adjustment to epilepsy <input type="checkbox"/> Locus of control <input type="checkbox"/> Life event changes <input type="checkbox"/> Social support <input type="checkbox"/> Socio-economic status <input type="checkbox"/> Childhood home environment	<input type="checkbox"/> Number of medications <input type="checkbox"/> Serum level <input type="checkbox"/> Medication type <input type="checkbox"/> Folic acid level

#### **4) Reliability/Validity of Assessment Measures**

How reliable/valid are the assessment measures?

- a) The study utilised reliable and valid measures for the assessment of perceived stigma and the assessment of psychopathology (or symptoms/indicative of psychopathology). Good ☐
- b) Criteria a) was not fully met, but adequate measures of perceived stigma and psychopathology were justified by the authors of the study. Adequate ☐
- c) The study did not utilise adequate measures for the assessment of perceived stigma and the assessment of psychopathology. Poor ☐

#### **Quality Rating**

1 = Longitudinal design

2 = Cross-sectional design

i) = Two or more ratings of Good

ii) = Two or more ratings of Adequate or one of each (Poor, Adequate, Good).

iii) = Two or more ratings of Poor

Overall Quality Rating: \_\_\_\_\_

### **Section 3: Appendices for Major Research Project Paper**

### **Appendix 3.1.1: Participant Invite Letters**

*(Letter sent when only participant consent required)*



*[On Headed Paper of Unit]*

Dear *(insert name)*

I would like to invite you to take part in a study being carried out by Katherine Bruce, a Trainee Clinical Psychologist at the University of Glasgow. The aim of her study is to investigate young people's experiences of living with epilepsy, and how they feel this impacts on their life.

To help you decide whether you want to take part, Katherine has written an information sheet which tells you all about the study. The information sheet also has contact numbers if you wish to discuss the study in more detail. If you do not wish to take part, you do not have to do anything else. Deciding not to take part will not affect the standard of care you receive in any way.

If you decide you do want to take part in the study, please complete the opt-in form and return it in the FREEPOST envelope provided.

Best wishes

Signed by clinician at appropriate unit.

***(Letter sent when parental consent required)***



*[On headed paper of Unit]*

Dear *(insert name)*

I would like to invite your child to take part in a study being carried out by Katherine Bruce, a Trainee Clinical Psychologist at the University of Glasgow. The aim of her study is to investigate young people's experiences of living with epilepsy, and how they feel this impacts on their life.

To help you and your child decide whether to take part, Katherine has written information sheets which tells you all about the study. The information sheets also have contact numbers if you wish to discuss the study in more detail. If you do not wish your child to take part, you do not have to do anything else. Deciding not to take part will not affect the standard of care your child receives in any way.

If your child decides they do want to take part in the study, and you are in agreement with this, please complete the opt-in form and return it in the FREEPOST envelope provided.

Best wishes

Signed by clinician at appropriate unit.

## **YOUNG PERSON INFORMATION SHEET**

**Study title: A qualitative investigation into the social experiences of young people with epilepsy; perceived impact and sense of self**

Thank you for reading this information sheet. My name is Katherine Bruce, and I am a psychologist at the University of Glasgow. I am doing a study which is looking at how epilepsy affects young people in their daily lives, by speaking with young people themselves.

You are being invited to take part in this research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what you will be asked to do. Please take time to read the following information carefully and discuss it with others if you wish. You can contact myself if there is anything that is not clear or if you have any questions. Take time to decide whether or not you wish to take part.

### **What is the study for?**

This study is looking at young people's experiences of living with epilepsy, and how they feel this impacts on their life. We want to know about young people's experiences at school and in their social life, so people have a better understanding of what it is like to live with epilepsy. Sometimes studies ask parents and teacher what their views are, but we are interested in speaking to young people themselves, as they are the experts. The results of this study should help medical staff provide better care, and would be useful in informing future public information campaigns.

### **Why have I been chosen?**

All young people aged between 12 and 18 years old who have epilepsy and attend either the Fraser of Allander Unit or the Epilepsy Unit, could be invited to take part in the study. This is to get a really good understanding of what it's like to have epilepsy as a young person, by talking to young people themselves. You are the experts about what it is like to live with epilepsy, therefore we are interested in listening to your experiences.

### **Do I have to take part?**

It is up to you if you decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

### **What will happen to me if I take part?**

If you decide to take part in the study, then I will arrange a time for us to meet at the {*Fraser of Allander Neurosciences Unit/the Epilepsy Unit*}. We will use a room there to sit and talk, which should take approximately one hour. There will be no physical examination, just a chance for you to talk to me about some your



experiences of living with epilepsy. Our conversation will be audio-taped, so that I can remember what was said, but only my research supervisor and myself will be allowed to listen to these tapes. A contribution towards your travel expenses will be provided for any visits to the clinic required for the purpose of the research.

**What are the possible disadvantages of taking part?**

There are no real risks of taking part. You will not be asked to do anything other than talk about your experiences of living with epilepsy. If during our meeting there are any things you are particularly worried about, let me know and I will arrange and appointment for you to talk to a clinician at the Fraser of Allander Unit.

**What are the possible benefits of taking part?**

The information you and others give us will help people better understand what it is like for young people living with epilepsy. The results of this study should help medical staff provide better care, and would be useful in informing future public information campaigns.

**Will my taking part in this study be kept confidential (private)?**

All information which is collected about you will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be identified. Only my supervisor and myself will be able to listen to the audio-tape recordings of the interview. The tapes and any other information will be stored in locked cabinets and will be destroyed after 10 years of the study being completed. The only reason I would have to break confidentiality, is if I was worried about your or someone else's safety. If this were to happen, and with your knowledge beforehand, I would have to tell the appropriate people.

**What will happen to the results of the research study?**

This research is being carried out as part of the Doctorate in Clinical Psychology. It is intended that the results be published in a journal specialising in epilepsy research. Quotations from the interviews may be used within the write-up of the study, but there will be no way of identifying you, as all names and personal information will be removed. You will be able to get a copy of the article from me once it is published.

**Contact for Further Information**

If you have any questions you would like to ask, you can contact my supervisor or me:

Katherine Bruce,  
Trainee Clinical Psychologist,  
Department of Psychological Medicine  
Academic Centre  
Gartnavel Royal Hospital  
Glasgow  
Email: k.bruce.1@research.gla.ac.uk  
Telephone number: 07902293700

Dr. Andrew Jahoda  
Clinical Psychologist  
Department of Psychological Medicine  
Academic Centre  
Gartnavel Royal Hospital  
Glasgow  
Email : aj26r@clinmed.gla.ac.uk  
Telephone number: 0141 211 0693

*Thank you for taking the  
time to read this information sheet!*

# PARENT INFORMATION SHEET

**Study title: A qualitative investigation into the social experiences of young people with epilepsy; perceived impact and sense of self**

Thank you for reading this information sheet. My name is Katherine Bruce, and I am a psychologist at the University of Glasgow. I am doing a study which is looking at how epilepsy affects young people in their daily lives, by speaking with young people themselves.

Your child is being invited to take part in this research study. Before they decide whether to take part, it is important for them to understand why the research is being done and what they will be asked to do. Please take time to read the following information carefully and discuss it with your child. You can contact myself if there is anything that is not clear or if you have any questions.

## **What is the study for?**

This study is looking at young people's experiences of living with epilepsy, and how they feel this impacts on their life. We want to know about young people's experiences at school and in their social life, so people have a better understanding of what it is like to live with epilepsy. Sometimes studies ask parents and teacher what their views are, but we are interested in speaking to young people themselves. The results of this study should help medical staff provide better care, and would be useful in informing future public information campaigns.

## **Why has my child been chosen?**

All young people aged between 12 and 18 years old who have epilepsy and attend either the Fraser of Allander Unit or the Epilepsy Unit, could be invited to take part in the study. This is to get a really good understanding of what it's like to have epilepsy as a young person, by talking to young people themselves.

## **Does my child have to take part?**

It is up to you and your child to decide whether or not they should take part. If you and your child do decide to take part you will both be asked to sign a consent form. If your child does decide to take part they are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care they receive.

## **What will happen to my child if they take part?**

If they decide to take part in the study, then your child will be invited to the {*Fraser of Allander Neurosciences Unit/the Epilepsy Unit*} where we will use a room there to sit and talk. This should take approximately one hour. There will be no physical examination, just a chance for them to talk about some of their experiences of living with epilepsy. Our conversation will be audio-taped, so that I can remember what was said, but only my research supervisor and myself will be allowed to listen

to these tapes. A contribution towards your travel expenses will be provided for any visits to the clinic required for the purpose of the research.

### **What are the possible disadvantages of taking part?**

There are no real risks of taking part. Your child will not be asked to do anything other than talk about their experiences of living with epilepsy. If during our meeting there are any things they are particularly worried about, I will arrange an appointment for them to talk to a clinician at the Fraser of Allander Unit.

### **What are the possible benefits of taking part?**

The information your child gives us will help people better understand what it is like for young people living with epilepsy. The results of this study should help medical staff provide better care, and would be useful in informing future public information campaigns.

### **Will my child taking part in this study be kept confidential (private)?**

All information which is collected about your child will be kept strictly confidential. Any information about them will have their name and address removed so that they cannot be identified. Only my supervisor and myself will be able to listen to the audio-tape recordings of the interview. The tapes and any other information will be stored in locked cabinets and will be destroyed after 10 years of the study being completed. The only reason I would have to break confidentiality, is if I was worried about your child's or someone else's safety. If this were to happen I would have to tell the appropriate people.

### **What will happen to the results of the research study?**

This research is being carried out as part of the Doctorate in Clinical Psychology. It is intended that the results be published in a journal specialising in epilepsy research. Quotations from the interviews may be used within the write-up of the study, but there will be no way of identifying your child, as all names and personal information will be removed. You will be able to get a copy of the article from me once it is published.

### **Contact for Further Information**

If you have any questions you would like to ask, you can contact my supervisor or me:

Katherine Bruce,  
Trainee Clinical Psychologist,  
Department of Psychological Medicine  
Academic Centre  
Gartnavel Royal Hospital  
Glasgow  
Email: k.bruce.1@research.gla.ac.uk  
Telephone number: 07902293700

Dr. Andrew Jahoda  
Clinical Psychologist  
Department of Psychological Medicine  
Academic Centre  
Gartnavel Royal Hospital  
Glasgow  
Email : aj26r@clinmed.gla.ac.uk  
Telephone number: 0141 211 0693

*Thank you for taking the  
time to read this information sheet*

### **Appendix 3.1.3: Opt-in Forms**

*(Opt-in form when only participant consent required)*



Centre No:  
Study No:  
Participant Identification No:



## **OPT-IN FORM**

### **Title of Study**

A qualitative investigation into the social experiences of young people with epilepsy;  
perceived impact and sense of self

If you would like to take part in this study, please complete the following and return it in  
the stamped addressed envelope:

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Contact telephone number:** \_\_\_\_\_

Once I have received this form I will contact you by telephone to arrange a time for us to  
meet.

Yours Sincerely

Katherine Bruce  
Trainee Clinical Psychologist

*(Opt-in form when parental consent required)*



Centre No:  
Study No:  
Participant Identification No:

### **OPT-IN FORM**

#### **Title of Study**

A qualitative investigation into the social experiences of young people with epilepsy;  
perceived impact and sense of self

If you are happy for your child to take part in this study, and your child also agrees, please  
complete the following and return it in the stamped addressed envelope:

**Name of parent/guardian** \_\_\_\_\_

**Name of child:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Contact telephone number:** \_\_\_\_\_

Once I have received this form I will contact you by telephone to arrange a time for the  
interview.

Yours Sincerely

Katherine Bruce  
Trainee Clinical Psychologist

## **Appendix 3.2: Consent Forms**

***(Only participant consent required)***

### **CONSENT FORM**

#### **Title of Study**

A qualitative investigation into the social experiences of young people with epilepsy; perceived impact and sense of self

#### **Researcher**

Katherine Bruce, Trainee Clinical Psychologist

Address for Correspondence:

Department of Psychological Medicine  
Academic Centre  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow  
G12 OXH

#### **Please tick as appropriate**

I have read and understood the information sheet

☐

I have been given the opportunity to ask questions

☐

I understand that I am free to withdraw from the study at any time without giving any reason and without my medical care or legal rights being affected and that on withdrawal from the study all information about me will be destroyed.

☐

I understand that that I shall be audio-taped during the interview, and that the recording will be kept in a locked filing cabinet and only listened to by the researcher and their supervisor.

☐

I understand that some quotations from the interview may be used in the write-up and future publication of this study, but that there will be no way of identifying me, as all names and personal information will be removed.

☐

I give permission for the researcher to obtain the following information from my clinician: 1) the age I was diagnosed with epilepsy 2) the type of seizures I experience 3) the frequency of my seizures 4) details of any current medication.

☐

I agree to take part in the above study

☐

**Name of Participant.....**

**Date.....Signature.....**

**Name of Researcher.....**

**Date.....Signature.....**

## CONSENT FORM

### Title Study

A qualitative investigation into the social experiences of young people with epilepsy; perceived impact and sense of self

### Researcher

Katherine Bruce, Trainee Clinical Psychologist

Address for Correspondence:

Department of Psychological Medicine  
Academic Centre  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow  
G12 OXH

### Please tick as appropriate

My child and myself have read and understood the information sheet

☐

My child and myself have been given the opportunity to ask questions

☐

I understand that my child is free to withdraw from the study at any time without giving any reason and without their medical care or legal rights being affected and that on withdrawal from the study all information about them will be destroyed.

☐

I understand that that my child shall be audio-taped during the interview, and that the recording will be kept in a locked filing cabinet and only listened to by the researcher and their supervisor.

☐

I understand that some quotations from the interview may be used in the write-up and future publication of this study, but that there will be no way of identifying my child, as all names and personal information will be removed.

☐

I give permission for the researcher to obtain the following information from my child's clinician: 1) the age they were diagnosed with epilepsy 2) the type of seizures they experience 3) the frequency of their seizures 4) details of current medication, if any.

☐

I agree to my child taking part in the above study

☐

Name of Parent/Guardian.....

Date.....Signature.....

Name of Participant.....

Date.....Signature.....

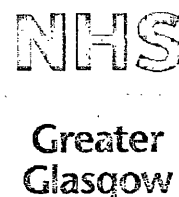
Name of Researcher.....

Date.....Signature.....

## Appendix 3.3: Ethical Approval

### Primary Care Division

Divisional Headquarters  
Gartnavel Royal Hospital  
1055 Great Western Road  
GLASGOW G12 0XH  
Telephone 0141 211 3600  
www.nhs.uk



Miss Katherine L Bruce  
Trainee Clinical Psychologist  
Greater Glasgow and Clyde University of  
Glasgow  
Department of Psychological Medicine  
Academic Centre  
Gartnavel Royal Hospital  
G12 0XH

Date 31 October 2006

Your Ref

Our Ref

Direct line 0141 211 3324

Fax 0141 211 3314

E-mail [L.L.Bruce@glasgow.ac.uk](mailto:L.L.Bruce@glasgow.ac.uk)  
[g.ac.uk](mailto:g.ac.uk)

Dear Miss Bruce

**Full title of study:** A qualitative investigation into the social experiences of young people with epilepsy; perceived impact and sense of self.

**REC reference number:** 06/S0701/83

Thank you for your letter of 28 August 2006 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 26 October 2006. A list of the members who were present at the meeting is attached.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

#### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	1	
Investigator CV	1	



INVESTOR IN PEOPLE



Covering Letter	1	
Participant Information Sheet: Young Person Information Sheet	Three	28 October 2006
Participant Information Sheet:	1	
Participant Information Sheet:	1	
Participant Information Sheet: Parent Information Sheet	Two	29 August 2006
Participant Information Sheet: Young Person Information Sheet	Two	28 August 2006
Participant Consent Form: Participant Consent Form - only participant consent required	Two	28 August 2006
Participant Consent Form: Participant Consent Form - parental consent required	Two	28 August 2006
Participant Consent Form	-	
Participant Consent Form	-	
Response to Request for Further Information	Letter	28 August 2006
Response to Request for Further Information	Letter	
Participation Note - only participant consent required	Two	28 August 2006
Participation Note - parental consent required	Two	28 August 2006
Opt-in Form only participant consent required	Two	28 August 2006
Opt-in Form parental consent required	Two	28 August 2006

### Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001), and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**06/S0701/83**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



**Liz Jamieson**

Research Ethics Committee Co-ordinator on behalf of Dr Paul Fleming, Chair

Enclosures:      List of names and professions of members who were present at the meeting  
                          Standard approval conditions  
                          Site approval form

Greater Glasgow  
and Clyde

Miss Katherine Bruce  
Trainee Clinical Psychologist  
Department of Psychological Medicine  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow  
G12 0XH

Date 02 November 2006  
Your Ref  
Our Ref BR/AW/approve  
Direct Line 0141 211 3661  
Fax 0141 211 3814  
Email annette.watt@  
gartnavel.gla.ac.uk

Dear Miss Bruce

**Project Reference Number: PN06CP016****Project Title: A qualitative investigation into the social experiences of young people with epilepsy: perceived impact and sense of self**

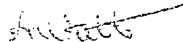
Thank you for your application for (R&D) Management Approval Application for the above study. I am pleased to inform you that R&D management approval has been granted by NHS Greater Glasgow & Clyde Community and Mental Health Partnership subject to the following requirements:

- You should notify me of any changes to the original submission and send regular, brief, interim reports including recruitment numbers where applicable. You must also notify me of any changes to the original research staff and send CVs of any new researchers.
- Your research must be conducted in accordance with the National Research Governance standards. (see CSO website: [www.show.scot.nhs.uk/cso](http://www.show.scot.nhs.uk/cso)) Local Research Governance monitoring requirements are presently being developed. This may involve audit of your research at some time in the future.
- You must comply with any regulations regarding data handling (Data Protection Act).
- Brief details of your study will be entered on the National Research Register (NRR). You will be notified prior to the next submission date and asked to check the details being submitted.
- A final report, with an abstract which can be disseminated widely within the NHS, should be submitted when the project has been completed.

Do not hesitate to contact the R & D office if you need any assistance.

Thank you again for your co-operation.

Yours sincerely



**Brian Rae**  
**Research Manager**



D370787

## Appendix 3.4: Interview Guide

### Consent

Before the interview commences I will have introduced myself and the consent forms will have been discussed and signed.

### Introduction to interview

- So, before we start, I will explain a bit about what we will be doing.
- I am doing research at the University of Glasgow. I am interested in hearing the views of young people who have epilepsy, which is why I am meeting with you today.
- I'd like to hear about some of your experiences of living with epilepsy, as well as your thoughts and feelings about it. You are the expert in this, and I am here to learn from you. I am meeting with a number of young people and I aim to gather all the information and look at what issues come out.
- I have some points written down here, which are just to remind me of the information I am interested in hearing about. So it's not about getting through a list of questions, and there are no right or wrong answers.
- I may take some notes as we go along, but I will also be taping the interview, so that I can give you my full attention without missing anything.
- Just to remind you, the things that we talk about are private and will not be discussed with anybody who is not involved in this research. Any details that are discussed will be anonymised, which means your personal details will have been removed so you can't be recognised.
- The only reason I could not keep what you say as private is if I was worried about your safety or someone else's safety. If this were to happen, I would have to tell the appropriate people, but I would let you know before I did this.
- So, this will take approximately one hour. If you would like a drink, or need the toilet, just let me know. Have you any questions?

### Ice-breaker/Engagement

"So, it would be good to start by finding out a bit about you and your life. I have a poster her, which I thought would be helpful to fill in. So if we put your name and age in the middle, and fill in these other boxes." *{{Using informal chat to facilitate engagement, participant can choose whether they write on the poster themselves and can choose from a variety of brightly coloured pens}}*

Family		School/Work
Hobbies/Interests		Friends

**Family:** So who lives at home, names, ages and jobs? Are there other members of your family who you see regularly?

**School/Work:** Primary and Secondary school name? What school? What year? Good/bad? Favourite bits? What lessons are you missing today, what year are you in, how's school? What are teachers like? Member of clubs? Saturday job?

**Hobbies/Interests:** what do you like to do outside of school? Clubs, interests, hobbies?

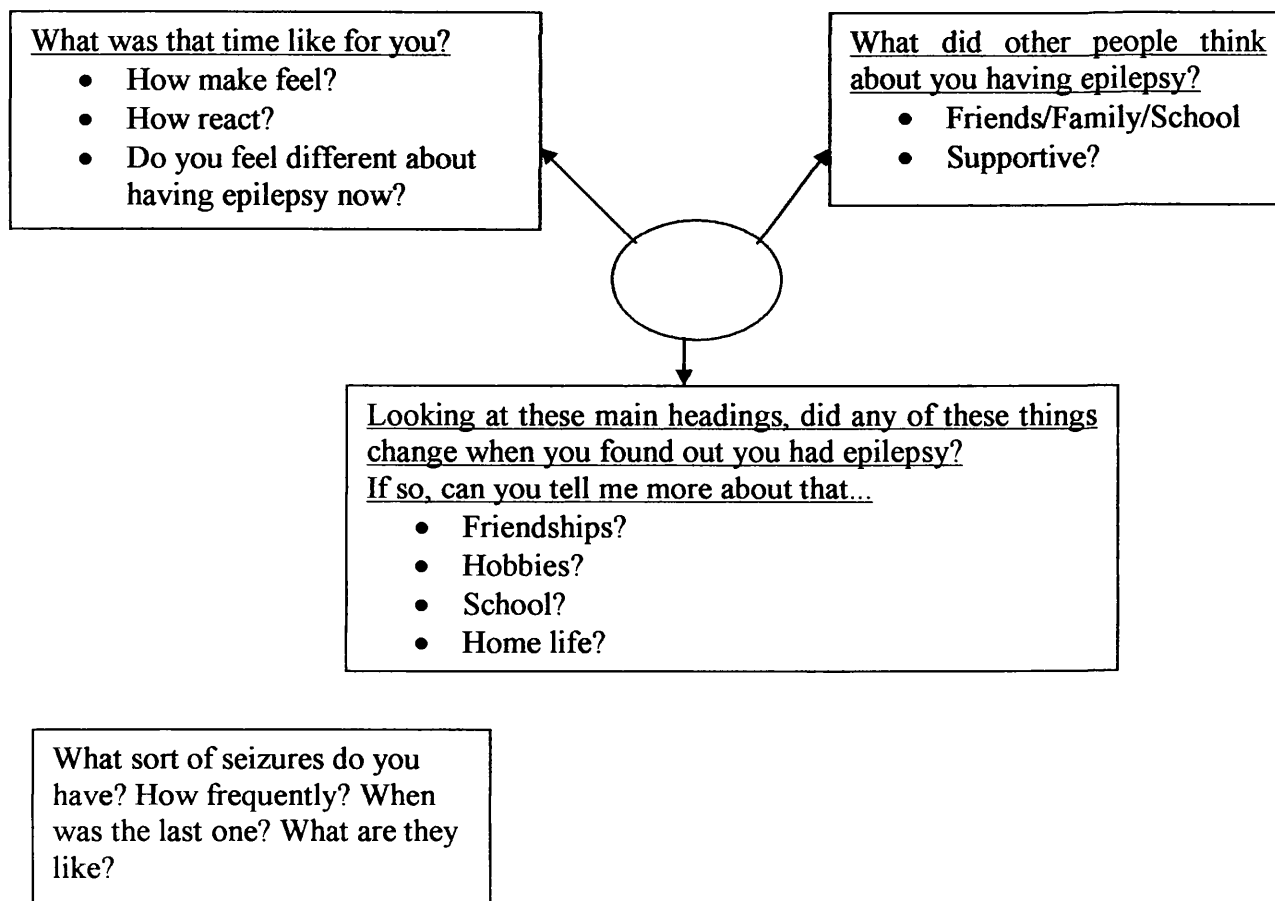
**Friends:** who are your close friends? different groups of friends?

"Great, this is very helpful, because I feel I know a bit more about you now. I will also be helpful when I am asking you about what it is like living with epilepsy, because I am interested in hearing what it is like in all these different areas of your life."

**1) So can you start by telling me a bit about how you first found out you had epilepsy?**

If had epilepsy all their life:

**Can you remember the first person you ever talked to about epilepsy?**



**Potential Prompts:**

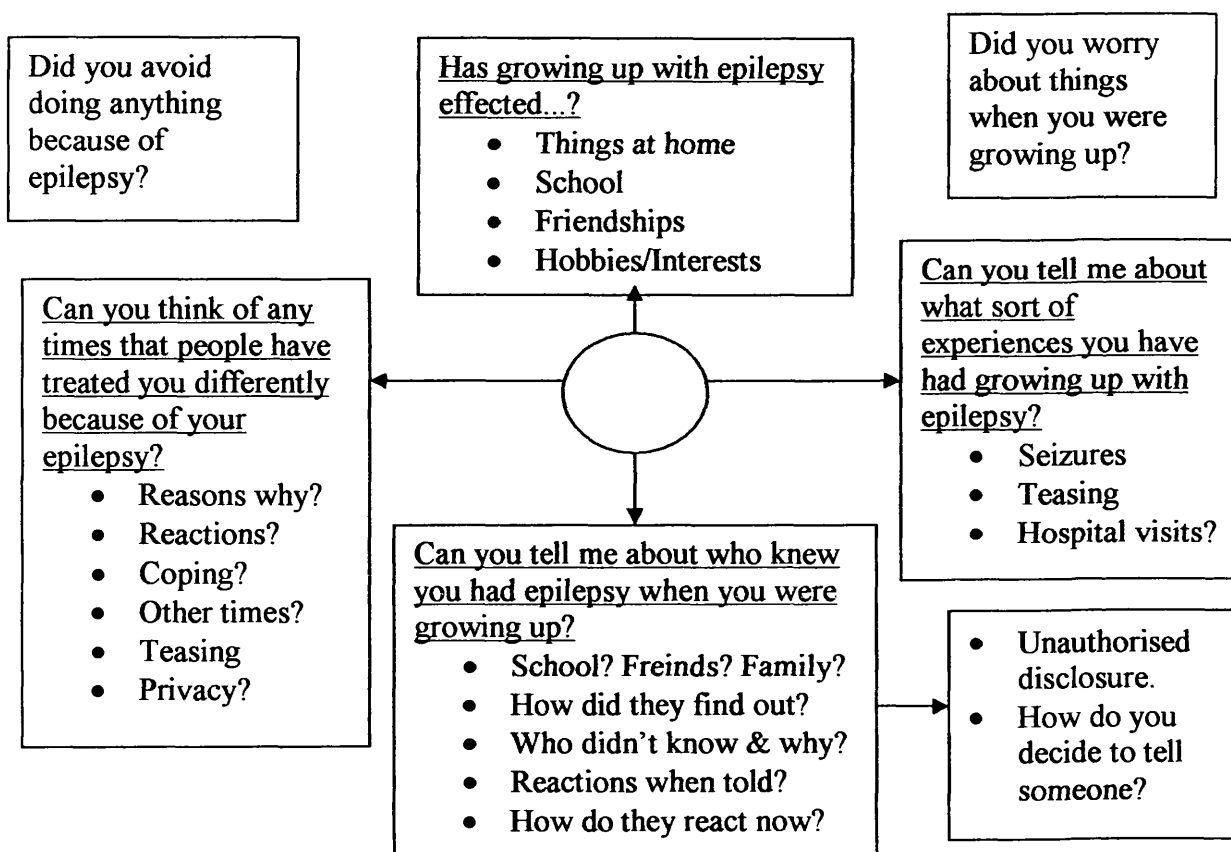
Impact: How did that feel / How did that effect you / did that change the way you behave now / Has that incident stopped you from doing anything

Coping: How did you react / What did you say / What did you do / How did other people react / What did other people say / What did other people do / What advice would you give to someone else in that position

**Potential Comments:**

That must have been difficult / Tell me more about that / That's interesting / How did that make you feel / How did you react / Can you tell me a bit more about what that was like / That sounds like a difficult experience / That sounds like fun.

## 2) Can you tell me about what it was like growing up with epilepsy?



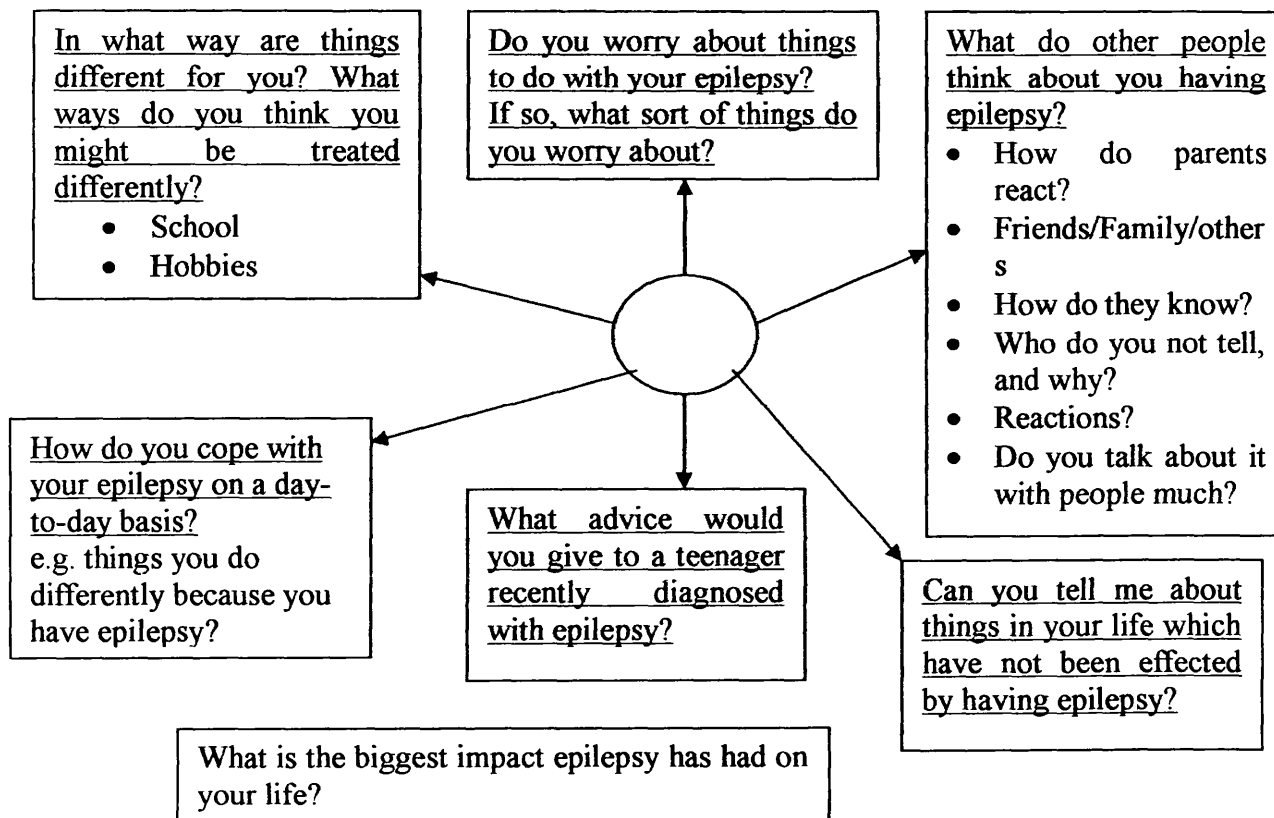
### **Potential Prompts:**

Impact: How did that feel / How did that effect you / did that change the way you behave now / Has that incident stopped you from doing anything

Coping: How did you react / What did you say / What did you do / How did other people react / What did other people say / What did other people do / What advice would you give to someone else in that position

**Potential Comments:** That must have been difficult / Tell me more about that / That's interesting / How did that make you feel / How did you react / Can you tell me a bit more about what that was like / That sounds like a difficult experience / That sounds like fun.

### 3) How has having epilepsy effected your life now? (Friends, home-life, school, hobbies)



#### **Potential Prompts:**

Impact: How did that feel / How did that effect you / did that change the way you behave now / Has that incident stopped you from doing anything

Coping: How did you react / What did you say / What did you do / How did other people react / What did other people say / What did other people do / What advice would you give to someone else in that position

#### **Potential Comments:**

That must have been difficult / Tell me more about that / That's interesting / How did that make you feel / How did you react / Can you tell me a bit more about what that was like / That sounds like a difficult experience / That sounds like fun.

**4) How do you feel your epilepsy will effect your life in the future?**

- Do you know what you want to do when you leave school? Do you think your epilepsy will effect that in any way?
- Do you have any worries about the future?

**End of Interview**

Is there anything else that you think is important that we haven't talked about?

How did it feel talking about things with me today?

Thank you for taking the time to talk to me. Do you have any questions you want to ask about the study, or what we have talked about today?

Thank you.

## **APPENDIX 3.5 : Themes and Illustrative Quotes**

Quotations followed by ⇒ *Participant number: (sex, age)*

<b>Limitations on Activities</b>
<p><b>Restricted independence</b></p> <ul style="list-style-type: none"> <li>• "I am fed up that I cannot go out because I need someone beside me cos I get epilepsy and I just drop down" "So you've not been able to go to the cinema, as you've been growing up, on your own without an adult. What else haven't you been able to do on your own?" "Basically everything" "Can you give me some examples...of err things that other people do your age that you..." "Swimming, because you can drown, and I'm, you know, someone who wants to go in the deep end. So if I go and if there's no adult there..." P01:(M,12)</li> <li>• "When I was at the {2nd School}, they had, because I have epilepsy, they had a bag with my tablets in with them, so I couldn't go... say at lunchtime...everyone was allowed to leave out to the playground, I couldn't because {teacher 2} had to stay with me, cos she had my tablets. So, I'd have to stay to the very end, and then go out to the playground." P01:(M,12)</li> <li>• "so before were you spending a lot of time with adults?" "Yes" "Can you tell me what wasn't good about that?" "Ummm - erm, what wasn't good about that? - - My sister {sister's name} could just clear off and go with her pal {pal's name}. I'd have to stay behind with an adult." "How did that make you feel?" "Err, sad and unhappy - - And I'd feel angry aswell" P01:(M,12)</li> <li>• "So what are the biggest things in your life that have changed because of it?" "Erm...Can't do certain things with my niece, can't baby-sit her. I can't go and take her to the shops and that by myself. Just like daft things, but its quite a lot to you....." P02:(F,17)</li> <li>• "Like when I was in the class and I wanted to go to the toilet, you'd to wait for somebody to come with you, and like...I can go myself...just things like that...I didn't have any more privacy any more." P02:(F,17)</li> <li>• "My mum is my carer." " - - How does she care for you?" "She looks after me all the time." P04 (F,17)</li> <li>• "my mum says never to leave me in the pool on my own just in case that I have one," P06:(F,15)</li> <li>• "I love swimming (yeh) but you know I have to make sure I've got someone with me." P06:(F,15)</li> <li>• "I'm getting older and, when you're going swimming with your dad, you're like "oh poor little baby, I've got to go with someone" so...it's really go with no-one or go with dad, basically." P06:(F,17)</li> <li>• "How would life be better? What is the big thing that would be better?" " - - Erm...I don't know...well any hour off a school is like forbidden, so I have to go to an appointment during the week, they seem to think "oh my god!" I think "yes!" An hour off school or something like that. Erm... but erm...not having to go to appointments, erm...being allowed to be on my own in a swimming pool, being allowed to drive, you know...stuff like that." P06:(F,15)</li> </ul> <p><b>Restricted activities</b></p> <ul style="list-style-type: none"> <li>• "So are there things you avoid doing to try and avoid having a fit then?" "Erm...like going to discos...err...going to places that might bring on stress, like...dunno...I cannot remember {{participant laughs}} ...err, what else..." P02:(F,17)</li> <li>• "Discos...do your pals...do they go to (uh huh) when do they go?" "The weekends, and I feel left out..." P02:(F,17)</li> <li>• "Have you ever been a member of any groups, or clubs at any of your schools?" "I've asked my mum but she won't let me." "Will she not? (no) Why's that?" "Cos she thinks that I won't fit in." "What do you think?" "Dunno?" "What sort of clubs have you wanted to join?" " - - Can't remember there's - - there's lots, the last time that I had in my mind - - I can't remember now." "Cos I guess schools often have, sports clubs don't they...or music clubs... games clubs. Why do you think she thinks you wouldn't fit in?" "Cos of my epilepsy - -" "What do you think that's about? Why does she think your epilepsy would stop you fitting in?" "I won't fit in with some of the people." "Ok. What bit of your epilepsy?" "Seizures." P04:(F,17)</li> <li>• "I just stay in all the time (ok) I'm not allowed out." P04:(F,17)</li> <li>• "Why aren't you allowed to go out?" "Cos of my epilepsy (ok) I'm just allowed to take the dog for a walk and that's it." P04:(F,17)</li> <li>• "Are there stuff outside you can't do because you've got epilepsy? (yeh) What sort of stuff?" " - - Going to the shop when it gets dark - - Cos last time I went to the shop when it was dark I took a seizure - - I had one and then an ambulance came, and I burst my lip" P04:(F,17)</li> <li>• "Did that change anything after that incident? I don't know whether it changed the way you acted or the way you felt or..?" "No not really I've just not done a swimming gala since. {{Participant and interviewer laugh}} "So do you still swim, but you just don't..?" "Yes, I just don't do competitive swimming." P05:(F,15)</li> <li>• "Is there anything else you can't do or you're kind of restricted from doing because of your epilepsy?" "Well, my...if you were talking to my teachers they would probably say...oh we don't let her in the swimming pool because of her seizures, but that was really because I asked my mum to write a note about that. I don't like swimming with the school. I can swim anywhere else, but not with the school. Erm..." "So is that...was that your choice?" "Yeh, it was a made up thing really" P06: (F,15)</li> <li>• "Actually one thing that really, really annoyed me...at the time I was playing for a football team and I was a striker, and I wasn't too bad and I was getting better and better and then they told me I had to take a while out to see if headering the ball was effecting it, and it was about a good few months after that they told me I could maybe go back, but I never really cottoned on again, and I wasn't quite the same, and was really err....well, there's a few words I could</li> </ul>



come up with to describe how I felt, but...I won't say it on this." P07:(M,15)

- **"Was he saying that you couldn't play football at all? Or was he..."** "He said err.. he wanted to see what I was like without playing football, see if it effected my seizures, but I mean, I didn't really agree to it, but my mum said, "well come on see if it helps", see if football was effecting it, so you don't diss your mum, I had to." P07:(M,15)
- **"Right. And who's decision was that? Who decided that?"** "The doctor. (*Oh was it?*) I could have knocked him out. Oh well, as I say you've got to get on with it haven't you?" **"Yeh. So err... how did you react to that when he said that?"** "Pretty angry. Yeh, one of the things I love was being taken away from me. I was a bit hacked off." (M,15)
- **"I had to miss out on some things that didn't really want epileptics... kind of joining in...erm, like parties for instance. Erm, one of my friends {{Name of friend}}, he particularly likes paintballing and err... I really wanted to do it, but I couldn't do it because... err... it has instructions, the rules, for the people that like do the paintballing, that say epileptics can't come...so that annoyed me as well... when all my friends went for a birthday party and I couldn't join them, because of my epilepsy."** P07:(M,15)
- **"the things that I do are limited, like the paintballing, but I mean I'd love to do that, but I can't"** P07:(M,15)
- **"I used to do sports but I had to stop because of the epilepsy."** P08:(M,16)
- **"So how come you...why did your epilepsy stop you doing basketball?"** "Just with a lot of things like exercise it kind of got worse, so I had to stop, cos I had seizures." P08:(M,16)
- **"Is there anything else, any other sports or activities or trips or..."** "Nothing that I'm really interested in no. I am sure that there are things that I couldn't have done, but nothing I was interested in." **"Ok. What sort of things might they have been? Are there things you are aware of that you..."** "Just other sports, other really active sports, and that's about it actually" P08:(M,16)
- **"Like Laserquest, sometimes it says no people with epilepsy on this (*right*)....and once she took that a wee bit, kind of...she told me not to go on it,"** P09:(M,14)

#### Disruption of activities

- **"I'm wondering about when you first found out you had epilepsy. Did ...any of your hobbies or interests get affected, by that?"** "No -- err dancing, if I get too hot, but I still do the dancing, I just don't...when I get too hot I just go and sit down and cool down a bit (*ok*) that's all." P02:(F,17)
- **"Do you remember the last time you had a seizure?"** "Yes. I was at hockey camp and I was really like warm and I was really dehydrated, so I had a seizure in the middle of the warm-up." P05:(F,15)
- **"But then I had a seizure in the middle of the pool (*gosh*) so that put me off a little bit {{Participant laughs}}"** **"Wow. Can you tell me a bit about what happened."** "Well we were just doing the warm up and I don't know, it just suddenly came on and." P05:(F, 15)
- **"Well, when I went in to see Harry Potter with my mum and dad I had a big one just before we got in and err mum started really panicking and I was like "I'm fine, I'm fine, it will be over in a minute, lets just go inside, and err I think I remember holding on to mum, I think I saw this woman above me and I'm like who are you? I like walked away and dad pure pulled my away and I'm like "ok, Hi there" and mum started really panicking going "We've got to get her out of here" and I'm like "what?"** P06:(F,15)
- **"Yeh, ok, so how did that effect you then, having to go to the hospital and stuff..."** "Well I was missing classes. -- Missing stuff I should be learning." P07:(M,15)
- **"There's not really much I can't do. It's just that when I have it I can't do it at the time....whatever I happened to be doing, (*ok*) I just have to go away and do my own thing...at home."** P08:(M,16)
- **"Ok, so what sort of stuff, does it get in the way of then...if say you're having a bad day?"** "Anything...anything I happen to be doing at the time. I'm always dead distracted at the time, because I'm always thinking... am I going to be ok without having to go home, or am I going to have to go home and take some tablets or whatever." P08:(M,16)
- **"What is the thing that makes the big impact...what is the impact?"** "Just the -- erm -- I don't get to do as much I suppose -- and I don't go to school as much as I could do if I didn't have epilepsy." **"How much are you missing school then?"** "Oh, it used to be, last year, the year before it was one/two days a week and this year it's got better, cos its only a couple of periods a week now. (*ok*) at most." P:12(M,16)
- **"have you had experiences of having a seizure when you've been out with your friends in town and stuff... Yeh, but it's never really been a problem. Just take the tablets when I need to, or either go home."** P08:(M,16)
- **"I think, in a way everything has probably been effected by epilepsy -- there's nothing that hasn't especially been effected by it. Just, whatever I do is always effected by it, depending on how I feel I suppose."** **"Ok. So when you are having a really bad day... what you described as a bad day what gets disrupted with that?"** "Everything. That becomes a day when I sit about doing nothing. -- And whatever I try to do, its always hard to do because I've got no concentration" P08:(M,16)
- **"I was really good at football when I was before that, cos I did goalkeeper and I thought I could make it (*yeh*) I was really good I think. Well...all I can remember I was good. But then just after it I forgot how to do it really, so when I got back...it kind of supports the clumsiness thing"** P09:(M,14)
- **"Just cos I was so bad at it, cos I was losing 16 mill and that, cos I just kept...the ball just kept going past me. Just couldn't save anything, so I tried to go outfield and I was even worse, then I just kind of...was fed-up with it...cos they kept putting me in goals, I don't know why, because I was so bad at it...couldn't save anything really."** P09:(M,14)

#### Minimal Limitations

- **"Are there things that you don't do that you maybe would have done because you have epilepsy now?"** "-- erm -- I've never really thought of that -- no." P03:(M,16)
- **"what's it been like for you growing up with epilepsy, through your teenage years?"** "Urm...nothing really, cos basically, err I don't worry about it a lot. (*no*) no. Like I said but, everything's just stayed the same." P:07(M,16)
- **"Do you think your life has ended up much different that if you hadn't had epilepsy?"** "No. Not at all." P05:(F, 15)

child then?" "I pretty much went to school and went and saw friends so I don't think there was much my mum and dad didn't let me do." P08:(M,16)

- "I didn't think anything of it. I didn't think anything of it at all. It didn't really effect my life at all. Just think nothing of it. Just forget about it completely. -- It doesn't effect me in the day, so I just get on with it." P09: (M,14)

#### **Response to Epilepsy from Others**

##### **Teasing/Bullying**

- "I get treated sometimes differently at college. Cos, a lot of the people they do say to me wee jokes about my epilepsy and they think its funny but I don't, so...its pretty annoying." "Can you tell me what sort of things they say?" "Like they imitate me taking a fit and just like things like that...one falls on the ground and that and start shouting, 'oh I'm taking a fit, I'm taking a fit', but its not really that funny...." P02:(F,17)
- "What was it like having epilepsy at {{name of primary school}}?" "I got bullied." "Did you?" "Uh huh" "What sort of things happened, in {{name of primary school}}?" "Just like what bullies say." "Was it to do with your epilepsy?" "Yeh." P04:(F,17)
- "I guess what I'm wondering is, there's different types of bullying, sometimes people say things, sometimes people do things, what sort of things..." "Well they didn't want to hang about with me (ok) They didn't want to sit near me..." P04:(F,17)
- "So after they'd seen you have the seizure, how did they react?" "They didn't speak to me." P04:(F,17)
- "When the class found out that you had epilepsy, do you think you were treated differently in any way... after that?" "Yes." "Can you tell me a bit about in what sort of ways?" "Cos, they wouldn't speak to me and that." P04:(F,17)
- "I ended up telling one of my teachers about it...one of these stupid guys in my class heard me and since then he's been trying to find something wrong with it. I'm like "You're just sick, it's just wrong" and he's...and my tablets fell out my bag one time and he went "Ah that says retard on them, you're a retard" P06:(F,15)

##### **Support**

- "They actually take care of me. Ask me if I'm all right." P01:(M,12)
- "How are they helpful?" "They'd go and get someone, as quick as they can" P01: (M,12)
- "That sounds quite difficult having to do that, at school (Uh hum). -- Does it worry you about having a seizure when you are at school?" "No. Because its {name of special needs school} and I know there's people there." "And who's helpful? Who's there for you?" "All, everyone." P01:(M,12)
- "Where do you get the most support from?" "My friends." "In what way?" "They do loads of stuff with me, and they don't put my epilepsy as an excuse all the time...like they kid on that I don't have it...so...that's what I like" P02:(F,17)
- "I was with my friends...so they helped me up and took me home...so that was that {{participant laughed}}"
- "But when I fell and I had all my lip was burst in {{name of town}}, everyone was...erm...caring for me when I went back, because they knew that I was in hospital, and they were sad." "What sort of stuff did they say to you then?" "They gave me hugs...and things like that...and said "what did you do to yourself"...slagging me off, like just for a laugh." "Oh, that's good. So how did you feel that they reacted like that?" "I was laughing." P04:(F,17)
- "one of the girls went and got the teachers and helped me." P04:(F,17)
- "they were great to me...being epileptic and all that." "Yeh? How were they great?" "Err well, best mates, and they knew exactly what to do if I had a fit, and they'd help." P07:(M, 15)
- "they all helped me, whenever I had a fit." "How did they help you, what does help you mean?" "Errm. Make sure I don't hurt myself. Make sure, like I'm safe and... stand by me till the fits over." P07:(M,15)
- "but some people I'm quite close to, they'll know exactly what to do and help." P07:(M,15)
- "most of the time someone will come and help." P07:(M,15)
- "It lasted 15 minutes. Erm, yeh...but my brothers were with me and a few people pulled over at the side of the road to help. One person called an ambulance. My younger brother went to the police to try and find my mum." P07:(M,15)
- "how did they react?" "Well {{Name of friend}} is the best. He'll shove his jumper under my head and just stand by and help me whilst other people just stand round and watch -- well actually until the teachers come...yeh." P07:(M,15)
- "{{Name of previous school}}... when I'd had a few fits, in the medical room, they bought a new bed and it had a side... a kinda of cushion side which hung down and you just bring it up around and push it into place so its nice and firm, so that I wouldn't fall out of the bed and the medical room was right beside the office... and they had a part of the wall replaced with a window, so that if I felt a fit coming on I would just knock on the window and they would come through" P07:(M,15)
- "Yeh, yeh, if I have a fit, either him or {{Name of name of father's partner}} will come help me, come and take me home and look after me. So they'll come home from work and help me...yeh, look after me (sounds good) Or if they need to go back to work, they will make sure there is someone there to look after me" P07:(M,15)
- "Teachers have always been really good about it. Always offered to help when I needed it and just always try to help me." "What's helpful to you? How do they help?" "Just by going over the stuff that I've missed and asking them whenever I need help and I don't understand it because I wasn't there beforehand." P08:(M,16)
- "How about, erm -- family? What do they... what are they like around your epilepsy." "They just...ah, they try to help as much as they can obviously, but again, they can't really do anything either...I mean, because... there's not really much anyone can do. I just have to take tablets and hope for the best. They've always been as supportive as they need to...just with whatever comes up." P08:(M,16)
- "My friends just take me home". P08:(M,16)
- "Then I had all the letters and that, from all the people at school...like in school they were all writing letters"

**Not a Significant Issue***(Descriptions where epilepsy is not perceived as being a significant issue to other people)*

- “Back three years ago when you found out you had epilepsy, how did your friends react to that?” “They didn’t treat me any different than I used to be. They just spoke to me as normal, so...{{participant laughs}}” P02:(F,17)
- “They do loads of stuff with me, and they don’t put my epilepsy as an excuse all the time...like they kid on that I don’t have it...so...that’s what I like...{{participant laughs}}” “when you say ‘an excuse’ what do you mean by that? What sort of things would it be an excuse for?” “Erm -- basically, when we want to go and do something...I can’t think of anything but {{participant laughs}} -- if they want to do something, and I say but I can’t do that because of my epilepsy, they say ‘stuff the epilepsy, kid on you don’t have it’, stuff like that {{participant laughs}}.” “So how does that make you feel that they react like that?” “-- Funny -- {{participant laughed}}” P02:(F,17)
- “Right ok. So err with the two friends that do know you’ve got epilepsy, do you ever talk with them about it?” “Not about it nah.” “No. Are they.. would you say they are quite supportive....or?” “I just say its basically like the usual, its no like anything that comes up all the time. Its only maybe been brought up once.” P03:(M,16)
- “They knew...I had epilepsy.” “And how did they...” “They didn’t mind.” P04:(F,17)
- “I was just wondering what your friends and your classmates kind of made of you having epilepsy as you were growing up?” “Erm. -- They don’t really take much notice of it actually. It doesn’t really affect any things -- it doesn’t really have much relevance to be honest.” P05:(F,15)
- “Like, do you think of it in a different way than you maybe did when you did when you were younger or not?” “No not really I just think other people probably view it in a different way. Like it doesn’t really bother them.” P05:(F,15)
- “People in school don’t really care about my epilepsy so...” P06:(F,15)
- “Everyone else is like, ‘Oh, Ok she’s having a seizure, leave her to it!’” P06:(F,15)
- “did your epilepsy get in the way of your friendships at all...in any other way?” “Not really no...no...they all accepted I had epilepsy and they all helped me, whenever I had a fit.” P07:(M,15)
- “are there other things in your life, that haven’t been effected by epilepsy at all?” “Erm...well my friends...still are great pals with them down there.” P07:(M,15)
- “they probably said one day, why have you been off and I said cos I’ve got epilepsy, so its fine. They’ve never had a problem with it either.” P08:(M,16)
- “what do you think they think about you having the seizures?” “Honestly have no idea. I am sure they just find it fine and don’t really have any problems with it. They’ve certainly never brought anything up” P08:(M,16)
- “what do your friends think about you having epilepsy, you’ve talked about how they react when you tell them...” “I think it’s all right. Nobody says anything about it -- no-one thinks about it...about anything. I don’t think.” P09:(M,14)

**Anxiety**

- And how did she react at the time?” “She was shocked. Shocked and terrified -- so...” P02:(F,17)
- “my dad he’s hardly around to see them, so...sometimes he feels bad that he misses me taking a fit, and he’s not there...and I’d rather he just...he doesn’t know what to do...he’s always...I don’t know.” “He doesn’t know what to do? -- if you’re having a fit?” “He does know, but he’s in a panic, so...that’s that {{participant laughs}}” P02:(F,17)
- “Did other people start acting differently? (No). No, just the teachers, and what sort of things did they do?” “They were dead clingy and dead protective, and...” P02:(F,17)
- “what do you think your mum thinks about your epilepsy?” “She’s worried.” “What does she worry about?” “-- Me.” P04:(F,17)
- “did you ever have a seizure in front of them?” “Uh hum.” “And how did they react to that?” “They were shocked and scared.” “Ok.” “But they got used to it after a while.” P04:(F,17)
- “Did you have any seizures when you were at {{name of special needs secondary school}}?” “Erm -- I think so? -- Yeh, I did.” “And how did they react when...” “Erm, one of the girls panicked...” P04:(F,17)
- “Ok. So you were out on the hockey pitch (yeh, uh huh) So that was quite busy, everyone was around (uh huh) What was that like? Can you tell me a bit about that?” “Erm -- It was quite embarrassing actually, cos everyone was just like ‘What the hell!’” P05:(F,15)
- “What sort of stuff, erm is she cautious about?” “I don’t know, she just...I don’t know, she just gets really worried and is like don’t do this, don’t do that, and be careful with this --” P05:(F,15)
- “What are things like at school? I don’t know maybe in terms of how the teachers reacted to you?” “Ummm. They were always a bit, sort of too cautious. They kind of... I don’t know exaggerated a little bit, which is kind of a bit annoying, but I don’t know, that’s it really...” “Can you give me an example of what sort of stuff...” “I don’t know -- like if we went on school trips or anything everyone was always just constantly asking me like if I was alright and everything? Which was quite annoying, but?” P05:(F,15)
- “What about what...how other people reacted, like...I don’t know...your friends for example?” “Well they were really freaked out. I took one on the way home from school, one time and was like “{{name of friend}} you’re going to have to help me out, yeh I’m having a seizure” she was like “What! What! Oh my god!” and she was “Ok, hold onto my shoulders, hold on” I’m like “{{name of friend}}, I’m all right ok” she’s like “just keep walking! Keep walking!” P06:(F,15)
- “Well, when I went in to see Harry Potter with my mum and dad I had a big one just before we got in and err mum started really panicking and I was like “I’m fine, I’m fine, it will be over in a minute, lets just go inside, and err I think I remember holding on to mum, I think I saw this woman above me and I’m like who are you? I like walked away and dad pure pulled my away and I’m like “ok, Hi there” and mum started really panicking going “We’ve got to get her out of here” and I’m like “what?” P06:(F,15)

- "One time on MSN I like put I'm not feeling too good I'm going to go off-line for a bit, she wrote "WHAT!" in big capital letters "What! Are you ok, are you really ok?" and she's like "I'm coming over!" I'm like BB I'm fine!" "And what's that reaction like?" "It's really funny when they start screaming! {{participant laughs}} pure like "What! What!" erm..." P06:(F,15)
- "...she worries a lot actually." P06:(F,15)
- "Well during a sleep over I forgot to take my tablets and err I was fine I wasn't having any seizures, I was sound asleep and got woken up by my pal going "{{participant's name}}, {{participant's name}}"" "What, what is it?" "If someone wakes me up, oh my god you are going to get the wrath of {{participant's name}}.{{Participant laughs}} {{participant's name}}, {{participant's name}} wake up" I was like "what is it?" "You haven't taken your tablets." I'm like "is that it? I thought the house was on fire." She's like, "well go and take your tablets", and I was like, "no I'm fine, go back to sleep. If I've not had anything I'll be fine." She was like "no I want you to take your tablets." "But I'll be fine." "I want you to take your tablets. For me, it will put my mind at rest," I'm like, "ok then. Right. Now go to sleep." "Take your tablets!" "Ok, ok then." "Did you give in?" "Yeh, "oh god I'm going to kill you in the morning" she's like, "yeh I know, I know. But you'll be ok now". I was like "I was ok anyway!" P06:(F,15)
- "What do you think they thing about you having epilepsy." "They worry. They worry a lot. Erm..." P06:(F,15)
- "So does she worry about your epilepsy?" "Yeh. Usually if I have to stay over at hers I come down, take my tablets and before I've got them to my mouth "Have you taken your tablets?!" Like "Yeh, I've just taken them, like a second ago!" P06:(F,15)
- "how do people react when you have them?" "Like I had a wee come and go one in the pool and...that's just like when it started and went away...like immediately. I went "oh, dad...I just had a wee one there a wee seizure." He was like "what! Get out here!" I'm like "dad its over now! It was over like five minutes ago." P06:(F, 15)
- "It depends who it is. I mean some people think, what's going on? What is this? Just not have a clue what to do." P07:(M,15)
- "The people that don't understand. How do they react then? The people that don't really..." "Err -- scream for help... and just like before I go completely into the fit, I'll maybe ask them to do something, maybe hold my head or something, make sure I don't hit it off the ground, but they'll just stand there looking at me -- and I'd think to myself... if I was that guy over there I'd punch him. But, err -- yeh it can be frustrating when I ask them to do something which can help me from hurting myself too much and they just stand there watching me (yeh) rather than do anything about it." P07:(M,15)
- "My headteacher at primary...he really liked me, but I think he was just scared." "Was he? What was he scared about?" "Well just in case anything happened, he just treated me good. Just treated me pretty good, so." "What do you think he was scared would happen?" "If I had a seizure, he would have to deal with it. (ok) So he treated me well...he treated me diff...everyone else he didn't treat well, it was only me." P09:(M,14)
- "were there other people you maybe think were scared of...." "Yeh. One time in primary five my teacher....she went and said...one time...there was a nutter in the class, he punched me in the face once... well he punched everyone anyway...cos he's a nutter, but she just shouted it out, "He's got epilepsy you know" and all this....I think she might have been a wee bit..." P09:(M,14)

#### Potential Negative Impacts

##### Discrimination

- "... and was that, erm...a difficult decision to make? Whether to tell them."
- "Yeh, cos...for example, for my work, I didn't know if I told them they would fire me, cos...and then...but they didn't, so it doesn't matter. {{participant laughs}} P02:(F,12)
- "...so why would you not have a quiet life if people knew, do you think?" "I don't know...err...basically because I'd get the piss took out of me... for it all the time." "Yeh? (uh huh) Who would that be? Would that be your friends or....at school...?" "Well if I get bullied...well if I told one person in school and it started spreading around -- and then I'd get the piss took out of me." P03:(M,16)
- "...everyone takes the piss out of everyone for the slightest reason." "Right ok, so epilepsy would be..." "Err...something that I'd never be able to live down." P03:(M,16)
- "See erm, your friends. Do you think they'd take the piss out of you if they knew?" "Well -- some of them. See of them I've already told, like the people I can trust, I've already told (oh right). Aye, they'd take the piss out of me." P03:(M,16)
- "so you feel embarrassed about other people knowing that you have epilepsy?" "Yeh -- if they don't have a disability." "Ok -- do you feel anything else about it?" "No." "What are you embarrassed about? Do you know?" "Just if they laugh at me." P04:(F,17)
- Last time I got a like a wee questionnaire on this, my dad kept saying "oh but she's very bright, she's great at school!" and afterwards he was like, I just didn't want her to think that because you've got epilepsy that you're dumb. I'm like "no, would she actually think that?" cos...I do get on pretty well at school, or so my dad and mum keep saying. I keep thinking "Oh it's too hard, this is too hard". P06:(F,15)
- "I never thought of it until dad like mentioned it, but that's people that don't really know me. People at school know I am pretty bright. I've had quite a few pretty good praise like from teachers, so I don't really...so I don't really care if people I don't know think I'm dumb, again erm...just people in school know I'm not dumb and people in school don't really care about my epilepsy so... they think "oh she's smart" -- epilepsy is nothing to do with it anyway." P06:(F, 15)
- "I'm not actually sure if like I apply for a job it will effect it sometimes." "How might it effect..." "I don't know...I think I've seen a programme it happens, like they don't want to do it in case anything happens....(ok) they don't like employ someone in case anything happens (ok) don't get any risks." P09:(M,14)

##### Risk of seizure-related death

- "- - Can you give me some examples...of err things that other people do your age that you..." "Swimming,

because you can drown, and I'm, you know, someone who wants to go in the deep end. So if I go and if there's no adult there..." P01:(M,12)

- "I just wondered whether there's anything you worry about to do with your epilepsy?" "Erm - - I don't know? My heart goes fast, maybe it will pop." P01:(M,12)
- "And then, one of my pals, he died. He had epilepsy. He and err...we were at swimming and he drowned. Cos everybody thought he was playing hide and seek, and then 10 minutes later we couldn't find him, and then err, they grabbed him out of the pool, and we saw his body down at the bottom of the pool...so...and that was showing me that err...people should like worry about me {{participant laughs}} "That sounds like an awful thing to witness...go through..." "It was...and then at that time when my pal died I had God knows how many fits because...stress came on...so..." "So how did things change for you after...so you were saying you had more fits..." "I lost a lot...I kept worrying that it might happen to me next, and my mum keeps telling me not to think that...and err...what else {{participant laughs}} err...that's it..." P02:(F,17)
- "What did you used to worry about...what were your biggest worries?" "That I was going to take a fit when I cross the road" P02:(F,17)
- "...and I had one...a quite scary one in the bath...my mum said if I was any shorter I would have drowned...I was like 'thanks!' {{participant laughs}} (oh gosh)...erm...so..." P02:(F,17)
- "I just wonder, do you worry about anything to do with your epilepsy at all?" "Erm - -well yeh sometimes I do worry about finding myself in sticky situations, but not really to a great extent." "What would be your description of a sticky situation?" "Erm - - just having a seizure somewhere where - - like I - - just actually in general having a seizure somewhere like where I would be in any kind of danger, like." P05:(F,15)
- "What do you worry might happen?" "Erm - - I don't know, just like if I have a seizure half way down and kill myself or something like that. Like, cos. It could be quite dangerous because you go so fast. (yeh) I could like fall off a cliff or something like that." P05:(F,15)

#### Future limitations

- "So if you want to be an actor and a singer, do you think your epilepsy will affect that in anyway?" "Staying up late, jumping about the stage, filming movies maybe - - late at night? I don't know, maybe yes, it probably would." {{the participant has a high frequency of night-time seizures}} P01:(M,12)
- "Do you have any worries about the future?" "Aye, about my kids, if my medication will affect my kids, err...I hope it doesn't, but the doctor said they don't really know (ok) so...I hope not..." P02:(F,12)
- "Do you have any worries for the future, I mean as an adult? Growing up into adulthood? Anything about how it will be like living with epilepsy?" "Well if I'm not allowed to drive I would be really pissed off." P05:(F,17)
- "How about, does epilepsy get in the way of any of these other interests or hobbies." "Well my mum said I may not be able to drive if I'm not free from a seizure for a year..." P06:(F,15)
- "Guess the driving thing is quite a big impact, because you know it would be quite handy to drive" P06:(F,15)
- "Do you think having epilepsy is going to interfere with your plan to be a PE teacher at all? Oh, I mean it shouldn't do, I don't think...I mean, I've asked a few teachers, but I mean...I doubt a school would like a teacher wriggling about on the floor in front of his class.... But I mean, hopefully it will pass through my teenage years...fingers crossed..." P07:(M,15)
- "Erm, I don't know...if I've still got it and I'm living on my own and something... then god knows what will happen." P07:(M,15)
- "Well I am just worried...well, that it will get better so I can go to college and get a job and that...erm... I never really worry about much else than that." "Ok. So your plan is to go to uni and then do {name of course}. So how do you think epilepsy might get in the way with that? What is your worry there?" "That I'm not going to get enough...either time next year to get the highers I need next year to go to uni...Or when I'm at uni I'm going to be off and not going to be there enough to get what I need...for a good job." P08:(M,16)

#### Disclosure of Epilepsy to Others

##### Selective disclosure

- "So who does know?" "Well basically my family and that's it." "Ok. How about. School?" "Aye. Yeh my teachers know." P03:(M,16)
- "Ok - - Just thinking about your friends...you've not given me their names, but the small group of friends you hang around with. Do they know that you've got epilepsy?" "No." "They don't." "Uh hum." "So erm. Why is that? (what?) How come they don't know you've got epilepsy." "I don't know. I just decided not to tell them." "Can you tell me a bit about why you decided...why did you decide that?" "Err...cos I probably thought that it was none of their business." P03:(M,16)
- "Some of them I've already told, like the people I can trust, I've already told" P03:(M,16)
- "How many people is that that you've told then, that are close?" "Two." "And what makes them trustworthy? What makes you be able to trust them?" "Well erm...one of them I've known since primary and erm... another one, basically, she stays far away, so she'll never get to see my friends." P03:(M,16)
- "Some of the girls knew." "Did you tell them, or?" "I told them." "Ok. Were they... why did you...I guess you can choose to tell someone you have epilepsy, or you can choose not to tell someone (Hum) Why did you decide to tell..." "The lecturer asked me to choose, who I wanted to tell, cos it was my first day, so I had someone to hang about with - - so they would know." P04:(F,17)
- "So why did you decide not to tell anyone at {{name of mainstream secondary school}}?" "Because in our class there were only two girls - - and the rest boys." P04:(F,17)
- "Do people at {{name of college}} know that you've got epilepsy?" "Just a couple." "Yeh? Erm - - how do they know?" "Cos I told them." "And why did you decide to tell them?" "Because they came up to me, something - - talking about disabled things their selves - - their own disabled problems, so (ok) I got into a wee conversation with a

girl and I told her." P04:(F,17)

- "Do you have friends that don't know you have epilepsy?" "Some, yeh." "And why did you decide not to tell them?" "I don't know -- I don't know them really well." "Ok -- So -- knowing someone really well would be a reason why you would tell them?" "Yeh -- and of their personality....if they're like...if they tell...if they pass on things...can't keep a secret (ok) Do you know what I mean?" "Yes I do. So you are more likely to tell someone if they can keep secrets (yeh)" P04:(F,17)
- "Why would you want them to keep it a secret?" "Cos it's embarrassing, everyone knowing." "Ok -- so you feel embarrassed about other people knowing that you have epilepsy?" "Yeh -- if they don't have a disability." P04:(F,17)
- "So what happened at {{name of mainstream secondary school}}?" "I didn't tell." "You didn't tell? So people didn't know at {{name of mainstream secondary school}}. Ok -- erm. Did anybody know at {{name of mainstream secondary school}} School at all?" "I didn't have any friends at {{name of mainstream secondary school}}." P04:(F, 17)
- "I wonder, like growing up, whether -- who knew you had epilepsy?" "Erm -- not many people actually. Cos I just really... I think my mum was like, make sure you tell this person and make sure you tell this person. But I didn't really, I didn't tend to tell many people, just a few people." "Who were the few people that you..?" "Erm -- like my friend {{name of friend}} she's been my best friend since I was about three, so --" P05:(F,15)
- "Why did you decide not to tell them?" "Erm -- I don't know, I think I just found it quite embarrassing to be honest, like. Erm -- I don't even know, like -- I couldn't actually tell you the answer to that." P05:(F,15)
- "I don't tell anyone that don't think...know me really. I only tell anyone that's good friends." "Ok. Is there a reason why you wouldn't?" "Well...no, I just wouldn't tell them. It was only... remember I said like.... it was only in conversation I said I had epilepsy (yeh) like that...between friends and that....then I would say it...but I mean the people I don't know....I wouldn't say it to." P09:(M,14)

#### Comfortable with Disclosure

- "And did you tell him that you had epilepsy, or did someone else tell him." "Well they know. There is a reason for why they do these schools you know. {1st School}'s a special needs school, the {2nd School}'s a mixture and {current school}'s a special needs school. So, I'd be in the section of special needs in the {2nd School}, so {friend 3} would have known yes, or he would have found out. Somebody told him. Or maybe I would have told him. I probably told him." "If you were to make a new friend, would you probably tell them you have epilepsy (yes) -- Would that be easy to do?" "Erm, -- yes. I'd just tell them" P01:(M,12)
- "...are there any times that you've kind of made a conscious decision that I'm not going to tell... such a body that I've..." "No...cos there's no point hiding it cos they'll find out sooner or later. Just in case you take a fit in front of them. So. Might as well just tell them..." P02:(F,17)
- "who knows that you have epilepsy? So I know that your family knows and your best pals know..." "Everybody knows." "Everybody knows, ok. And how has everybody found out?" "I either tell them, or one of my friends tell them." P02:(F,17)
- "So how come you came to that decision? Why did you..." "Cos its right to tell them. Tell your boss that you've got epilepsy...so..." P02:(F,17)
- "And I am just wondering what your view is on telling people that you meet that you've got epilepsy." "Well if it comes up in conversation, fine, but I am not going to go out of my way and announce it." P05: (F,15)
- So how about all your friends written here, do they know?" "Yeh they do cos they are sort of more recent friends so... it doesn't really bother me anymore like." "So you are saying it doesn't really bother you any more, does that mean...I'm not sure...are you saying that you are not as embarrassed?" "Uh huh yeh." P05:(F,15)
- "I'm wondering whether you told your friends...cos I guess with epilepsy you can choose to tell people you've got it or sometimes choose not to. Did you..." "Tell people....well I'm not really embarrassed of it, so...err....ended up telling them anyway, so...well it wasn't like a formal thing "by the way, sit down I've got epilepsy" It was just a "I'm not feeling too good" "do you want a glass of water" "No hang on a sec. I am just having a seizure" they're like "What's that" and I'm like "Ok, I'm going to have to tell you now!" (ok) Yeh, I am not really embarrassed about it, so...it came naturally really." P06:(F,15)
- "well it wasn't like a formal thing "by the way, sit down I've got epilepsy" It was just a "I'm not feeling too good" "do you want a glass of water" "No hang on a sec. I am just having a seizure" they're like "What's that" and I'm like "Ok, I'm going to have to tell you now!" (ok) Yeh, I am not really embarrassed about it, so...it came naturally really." P06:(F,15)
- "And did you actually tell them that you'd got epilepsy or..." "Yes...I just told them what they had to do and they did it." "Ok. I guess people can choose whether to tell people or not tell people..." "Oh yeh, well its hard to keep secret isn't it...when I'm rolling about on my back." "Ok, so was that not a difficult decision to make then, whether to tell people?" "No, no!" P07:(M,15)
- "in moving to a new place, you again had to tell people -- what was that like?" "It was fine, just had to tell them what it was like." P07:(M,15)
- "Ok, so when you first met your group of friends, how did that come up then?" "Oh, I don't remember it was so long ago... they probably said one day, why have you been off and I said cos I've got epilepsy, so its fine. They've never had a problem with it either." P08:(M, 16)
- "I've got no problem hiding it, I mean I don't need to hide it. I've never hidden it from anybody actually...erm...its always something I can admit to... Not really a problem." (M,16)
- "Anyone that spoke to me about it. I don't feel the need to go around telling everyone. Just when anyone asked about it I would tell them." (M,16)
- "I just told....I don't tell them like, I don't tell them, but sometimes they ask. (ok) when it gets around a wee bit....but I

don't tell them in conversation... I just talk about other things normally." "Yeh ok. But if someone were to ask you then..." "Yeh, I'd say yeh, just casually." P09(M,14).

- "How many people do you think do know then?" "Well I think all my class in primary, yeh." "They all knew?" "Yeh... Most people in high school and mo...some people at golf." P09(M,14)
- "They were saying like he had epilepsy and then I said I'd got it as well." P09(M,14)

#### **Pro-active Responses to Impact**

##### **Getting on with Life**

- "Although I have started, you know {cousin 1}? (*cousin 1*? *That cousin there? yeh?*) I started, I've been to see two movies now, I've just started going to the cinema with her, with no adults, so that's something." P01:(M,12)
- "Did ...any of your hobbies or interests get affected, by that?" "No - - err dancing, if I get too hot, but I still do the dancing, I just don't...when I get too hot I just go and sit down and cool down a bit.(*ok*) that's all." P02:(M,17)
- "I told my dance teacher and then she said 'don't let it effect your dancing', so I just didn't...I just got on with my dancing as usual." P02:(F,17)
- "If you were to meet someone who had just been diagnosed, today with epilepsy, what advice would you give them? If you could think of some really good advice that would kind of help them cope and get them through?" "Don't put your epilepsy in the way of everything else. P02:(F,17)
- "I love skiing." "And your epilepsy, does that limit that in any way?" "No - - well I do - - I sometimes do get quite worried, but I would rather ski than not ski, so... (*ok*) - - So I just sort of forget about it." P05:(F,15)
- "Erm...so I can't really say that's a big effect cos nothing's going to keep me out the pool, I love swimming (*yeh*) but you know I have to make sure I've got someone with me." P06:(F,15)
- "Well it hasn't been too nice, but - - fine. Just had to get on with it. I mean, just let the fits pass and then carry on with what I'm normally doing." P07:(M,15)
- "Well I just take my medicine and try to carry on with my life. Just go ahead with whatever I've got planned for the day." P07:(M,15)
- "And now you know a bit more about it, how do you feel?" "Well I'd prefer if I didn't have it, but I've got it and I've got to get on with it." P07:(M,15)
- "I was kind of gutted about football, erm, but then I tried to think, tried to find other sports I was good at...(*ok*) I found skateboarding for a while, but then...I couldn't improve and I hit myself in the face with a skateboard once (*oh dear*) But then I found golf and that was pretty good." P09:(M,14)
- "I forgot all the things to do, all the skills and that. I kind of got fed up with it.- - But everything else...when I got new skills I was ok. Just got to try to forget about it." P09:(M,14)
- "Are there things you avoid?" "No. I just try and have a normal life." P09:(M,14)

##### **Confront teasing**

- "And how do you cope with that? How do you react?" "I keep telling them to stop it, and if they don't stop I'll go and tell err the head of the college...and...but they don't listen, but I'll still go and tell the head...even though...I don't care what they think...if I'm a wee grass bag, but...its to make them stop, so..." "Do you think you will end up telling?" "Yeh { {participant laughs} } " P02 : (F,17)
- "I ended up telling one of my teachers about it...one of these stupid guys in my class heard me and since then he's been trying to find something wrong with it. I'm like "You're just sick, it's just wrong" and he's...and my tablets fell out my bag one time and he went "Ah that says retard on them, you're a retard" that's just stupid. I'm like "I don't know why it says retard on them, you're just being stupid, you're just finding anything wrong with this" P06:(F,15)
- "Erm...and so since then he was making fun of me and I just called him on it an was "You're just sick if you are just making fun of someone because they've got a problem with an illness or something like that, so you're just being sicko" he's like "I don't care, bye" and he hasn't said anything since, so..." P06:(F,15)
- "But no, no-one's teased me (*that's great*) - - I'd have them if they did (*yeh?*) Yeh - - I mean I don't often get in fights and that, but if someone were to tease me about something that I have to put up with, and I've got to put up with, like throughout my life, or so it has been for four years, I wouldn't be so happy." P07:(M,15)