

**A COMPARATIVE INVESTIGATION OF METHODS USED  
TO DOCUMENT SEIZURES FOR PEOPLE WITH  
EPILEPSY AND LEARNING DISABILITIES**

**AND RESEARCH PORTFOLIO**

**PART ONE**

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**1<sup>st</sup> August 2000**

Submitted in partial fulfilment of the degree of Doctor of Clinical Psychology within the  
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# **1. Small Scale Service Evaluation Project**

## **The Evaluation of a Self-Help Emotion Regulation Leaflet for use with Anxious and Depressed Patients**

Small - scale project submitted in partial fulfilment of the requirements  
for the degree of Doctor of Clinical Psychology

Prepared in accordance with the guidelines for contributions to the  
Clinical Psychology Forum; Division of Clinical Psychology of the  
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## INTRODUCTION

Recent research findings by Wilson et al. (1998) have demonstrated that patient information leaflets affect health outcomes. However, the provision of patient leaflets is an under-utilised resource by health professionals and many are inadequately written. The literature in this area reveals that there is very little research which goes beyond the application of readability formulae to written information. This paper aims to address factors that affect readability and comprehensibility by involving patients in the evaluation process of patient information.

Written material has been extensively used with patients to provide instruction for self-help, manual-guided therapy or simply to provide information (Glasgow & Rosen, 1978). Based on the concept of self-efficacy (Bandura, 1977), results of a study by Tyrer et al. (1993) suggested that the 'personal control of therapy that is intrinsic to self-help is of major therapeutic benefit.' This is in accordance with a study by Borkovec & Mathews (1988) who suggest that faith in an approach, in addition to an ability to conceptualise one's own problem in a different manner, is important. A self-help approach can lead to information being transmitted more effectively than therapist input alone (White, 1995).

Readability formulae are commonly used by researchers to examine information leaflets given to patients in health-care settings (Reed et al. 1993). For example, Cole (1979) found that the readability of a selection of fifteen health education leaflets ranged from an estimated readability of 25% or less to 75% or more of the target population. Although a low readability score indicates that revisions need to be made, understanding of information may not necessarily become easier (Ley, 1982). Comprehensibility of written self-help materials is still largely assessed in terms of readability measures only (Turvey, 1985). Several factors

in addition to readability affect user comprehension, text processing and satisfaction (Sturmev, 1990). This could be further assessed by asking readers to relate what they have read (Wilson et al. 1998) or by asking them to rate how much of the information they understood.

### **Self- help Materials For Depression and Anxiety**

The co-morbidity of anxiety and depression is increasingly accepted as a common phenomenon (Stavraki & Vargo, 1986 & Paykel & Priest, 1992). The literature has mentioned that there is a need for the development and evaluation of self-help materials directed at both anxiety and depression (Holdsworth et al. 1994).

The Clinical Psychology department at Dykebar Hospital, Paisley have formulated 'Emotion Regulation' leaflets based on the work of Marsha Linehan (1993) with a view to implementing them as self-help materials in conjunction with therapist input. There are eight separate steps that comprise the complete programme of learning for the development of emotion regulation skills. These skills can be applied to a range of emotions experienced in many adult mental health problems. It is the department's aim to distribute the leaflets for such frequently referred problems as depression and anxiety. A leaflet for each step has been developed to help the patient with proper mastery of the strategies. However the leaflets have not been assessed by users of the service.

## **METHOD**

### **Aims**

This study is specifically investigating *content* of information as opposed to the effects of information on treatment outcome. Thus the aims of the study are:

- (1) To evaluate aspects of readability in terms of factors such as comprehensibility, relevance and usefulness of one of the leaflets in the series.
- (2) To determine whether the leaflets can be used with patients with either anxiety, depression or co-morbidity of anxiety and depression as opposed to being specific to one disorder only.

### **Subjects**

Inclusion criteria for the study sample were a) out-patient b) referred to the Psychology Department at Dykebar hospital by the General Practitioner or Psychiatrist c) adults in the age range 16-65 years d) formulated by the Psychologist as having anxiety or depression or co-morbidity of both e) attending for an initial assessment interview. Exclusion criteria were a) current alcohol or drug abuse b) psychosis or c) dementia.

### **Response**

The original aim was to sample approximately 90 subjects with either anxiety only, depression only or co-morbidity of anxiety and depression. This was to determine whether or not the leaflet was disorder specific. The sampling rate was in accordance with the approximate number of referrals in the department during the course of the project. Eighty-eight questionnaires were distributed and 45 were returned (response rate was approximately 50%). The patients all met diagnostic criteria for anxiety, depression or co-morbidity of both,

which were validated by scores on the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). There were only 3 patients presenting with depression only and so they were excluded from the study as the numbers were too low. The total number of subjects included in the study was 42.

### **Procedure**

Nine Psychologists within the Psychology department were given ten questionnaire packages each and a set of instructions at the outset of the study. Patients who were presenting with symptoms of Anxiety or Depression at the initial assessment interview were asked by the Psychologist to complete the questionnaires and return them to the department by post. Completed questionnaires were anonymous and confidential. This took place during a six month period.

### **Measures**

A questionnaire package was compiled by the author to address the main aims of the study. This consisted of (i) the leaflet on the nature of emotions (appendix 1.0), (ii) the questionnaire booklet referring to the leaflet which was devised by the author (appendix 1.1) and (iii) the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

#### *i. The Leaflet on the Nature of Emotions:*

One of the leaflets from the series was selected to be included in the package. It provided a broad overview of the nature of emotions and was representative of the other leaflets in the series.

*ii. The Questionnaire Booklet:*

This consisted of a consecutive series of questions relating to various aspects of the content of the leaflet. They were divided into 3 sections.

a. The first section comprised 3 closed questions addressing the amount of information in the leaflet, the patient's ability to read it and ability to attend to it. There were also opportunities to provide qualitative information pertaining to these aspects.

b. The second section comprised 9 questions measured on visual analogue scales from 0 - 100. Questions relating to the information included; ease of reading, usefulness, understandability, relevance to experiences, amount of new information, whether it helped the patient make sense of their emotions, level of interest, expectations of therapy before reading the leaflet and expectations of therapy after reading the leaflet.

c. The third section comprised 2 questions requiring qualitative information. The patient was required to state (i) the main points understood from the leaflet and (ii) the most useful parts of the leaflet.

*iii. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983):*

This is a 14-item self-report scale consisting of 7 items relating to anxiety and 7 relating to depression. It is easy to use and score and is used to gain a diagnostic impression of levels of anxiety and depression.

*Flesch Reading Formula (Flesch, 1948):*

The text of the leaflet was analysed for readability and human interest using the Flesch Formulae (Flesch, 1948). This is an objective measure of readability which was used in addition to the above measures.

## **RESULTS**

*Descriptive Summary of the Sample*

Eighty-eight questionnaires were distributed and 45 were returned (response rate was approximately 50%). The sample consisted of 15 males (35.7%) and 27 females (64.3%). The age groups were divided into three categories for statistical purposes as the sample was evenly distributed across the range of ages. Groups were categorised between the age ranges of 16-35 years (Group 1 - n = 15, 35.7%), 36-45 years (Group 2 - n = 13, 30.9%) and 46-65 years (Group 3 - n = 14, 33.3%). There were 18 patients with anxiety only (42.9%) and 24 with anxiety and depression (57.1%). The depression only group were excluded as n = 3.

*Readability According to the Flesch Formula*

The leaflet had a 'fairly difficult' level of reading ease (56.3) which predicts that the information will be accessible to approximately 40 % of the population. The Flesch score for interest was 40, with 15% personal sentences and 8% personal words. The qualitative rating was 'interesting'.

The following section presents an analysis of the results. They were analysed according to the layout of the questionnaire:

*1. Readability, Appropriateness of Length and Ability to Attend to the Information*

*(Closed Questions)*

The initial analysis referred to the first three questions which measured the readability of the leaflet, appropriateness of the length and ability to attend to the information (ie: the closed questions). Of the total sample, 97.6% read the whole leaflet, 85.7% thought the length was appropriate and 73.6% managed to attend to the information.

Chi-squared tests were computed to determine any differences between the two diagnostic groups on the three variables. There were no significant differences evident which suggests the leaflet is not specific to one diagnostic group in particular. Chi-squared tests were then computed for gender and age groups. The only significant difference evident was between males and females on the 'ability to attend' variable. Ninety-three percent of males attended to all the information compared to 62.9% females ( $\chi^2 = 4.601$ ;  $df = 1$ ;  $p = .05$ ).

*2. Factors Assessing Readability - e.g. interest, usefulness (measured on visual analogue scales)*

The second part of the analysis referred to the questions measuring the various readability aspects of the leaflet which are outlined in figures and tables 1-3.

(i) Mean Scores and Comparisons between Means for the Different Groups:

*a. The Two Diagnostic Groups (Anxiety only and Anxiety and Depression)*

Means for the principal comparison of anxiety only and anxiety and depression are presented in Figure 1. The mean scores were greater than 50% for most variables. Exceptions included the amount of new information for both groups; the mean score for the anxiety only group was 39.33 (sd = 26.75) and for the anxiety and depression group it was 38.92 (sd = 33.08). The mean score for the extent to which the information helped the anxiety and depression group to make sense of their emotions was 43.63 (sd = 28.44). The standard deviations ranged from 21 to 33 and the range in scores were from 0 to 100, suggesting that the ratings were widely distributed around the mean.

A Mann-Whitney U Test was computed to determine any differences between diagnostic groups on the mean scores. No significant differences were evident suggesting no specific disorder effect.

**INSERT FIGURE 1 HERE**

*b. Gender*

Mean scores for males and females on aspects of the leaflet are presented in Figure 2. The majority of mean scores were above 50%. The exceptions were for females on the 'New Information' variable (mean = 30.11, sd = 26.15) and 'sense' (mean = 42.33, sd = 25.91). The standard deviations ranged from 21 to 31 and the range in scores was from 0 to 92, again suggesting that the ratings were widely distributed around the mean.

A Mann-Whitney U Test was computed to determine any gender differences on aspects of the leaflet. The only significant gender difference evident was that males gained significantly more information than females from the leaflet ( $U = 107, p < .02$ ).

**INSERT FIGURE 2 HERE**

*c. Age Groups*

Mean scores for the three age groups are presented in Figure 3. The majority of mean scores were again above 50%. However, expectations before reading the leaflet were rated less favourably for Age Group 3 (mean = 47.14, sd = 28.48). Mean scores for the amount of new information gained was slightly lower for all age groups (Group 1 - mean = 34.8, sd = 26.61; Group 2 - mean = 41.46, sd = 28.41; Group 3 - mean = 41.50; sd = 36.50). The extent to which the information helped them to make sense of their emotions was rated in accordance with the diagnostic groups and gender (Group 1 - mean = 42.20, sd = 21.25; Group 2 - mean = 52.15, sd = 32.40; Group 3 - mean = 49.47, sd = 27.25). The standard deviations ranged from 16 to 32 and the range in scores was from 0 to 100, which is a similar finding to the previous groups.

A Kruskal-Wallis test was computed to determine any significant differences between the age groups on the mean scores. There were no differences highlighted suggesting there was no specific age effect.

**INSERT FIGURE 3 HERE**

## (ii) Correlational Analysis of Aspects of the Leaflet

Spearman's Rho Correlation Co-efficient was computed to assess the extent of correlation between aspects of the leaflet. There were several significant correlations at  $p = .01$ . These ranged from 0.463 to 0.601 (appendix 1.2). The most important findings are as follows:

The variables 'easy', 'perceived usefulness', 'understand' and 'relevance' were all inter-correlated. 'Expectations after' was correlated with 'relevance' ( $r_s = 0.517$ ) and 'usefulness' ( $r_s = 0.449$ ) whereas 'expectations before' was not correlated with any of the variables. Ability to 'make sense' of the information was correlated with 'usefulness' ( $r_s = 0.500$ ), 'interest' ( $r_s = 0.557$ ) and 'relevance' ( $r_s = 0.464$ ). 'Interest' in the information was correlated with 'usefulness' ( $r_s = 0.463$ ), 'new information' ( $r_s = 0.451$ ) and 'sense of the information' ( $r_s = 0.557$ ). These correlations suggest that several variables were related to each other.

Cronbach's  $\alpha$  was computed to determine the overall level of correlation amongst the variables. For the 9 items  $\alpha = 0.706$  and for item deletion  $\alpha$  ranged from 0.621 - 0.757 indicating that the items were closely linked.

### *3. The Main Points Understood and the Most Useful Parts of the Leaflet as rated by Patients (Qualitative Section)*

The two qualitative questions at the end of the leaflet were grouped into general categories according to frequencies of responses by the patients. The main points of the leaflet understood by the patients are presented in Table 1 which indicates several commonalities between responses. Figure 4 presents the most useful parts of the leaflet as rated by the

patients in the final question. Visual inspection of the comments did not primarily highlight any effects of diagnostic group, gender or age.

### **INSERT TABLE 1 & FIGURE 4 HERE**

## **DISCUSSION**

The main aim of the study was to evaluate factors that affect comprehensibility of one of a series of self-help leaflets. A further aim was to determine whether the leaflet was disorder specific or could be used by individuals with co-morbidity of anxiety and depression. Initially readability factors will be discussed, followed by related aspects such as comprehensibility and relevance of information.

### *Readability Factors*

The reading ease of the leaflet, as measured by the Flesch Formula, indicated that it is fairly difficult to read by a large proportion of the population. This paper replicates findings of previous studies that suggest leaflets are written in a language that is too difficult for people to understand (Ley, 1982). Readability can be enhanced by shortening sentence length and reducing the number of syllables per 100 words (Flesch, 1948). However, readability alone is not necessarily the most effective measure of assessment of the leaflets. Therefore questions including both qualitative and quantitative information were used to gain more detailed information about readability.

Of the total sample, most patients read the leaflet. Interestingly the two patients who thought that it could have been shorter had high levels of depression. Diminished concentration is a feature of depression and may have affected their ability to read the whole leaflet. In contrast to this three patients said that it could have been longer. These patients were not depressed and evidently some people do prefer lengthier explanations (Reed et al. 1993). However, this is one leaflet in a series of eight and perhaps some questions were answered further on in the series, such as *how* to control emotions, as was suggested by two patients. One person said that more emphasis on gender and cultural differences should have been included and this could be considered for future revision of the leaflets.

Patients who had difficulty keeping their attention on the information in the leaflet mainly had problems with concentration. There were significantly more females than males who had problems attending to the information. Depressive thoughts may have been masking the females' ability to attend to the information in the co-morbidity group. A depression only group would have been valuable to further assess this issue to determine if problems with concentration were significantly greater in this group.

Ratings on the visual analogue scales indicated that the mean scores for most aspects were above 50%. However, there was a large range of values with standard deviation values ranging from 21 to 35 on all aspects. This suggests that not all patients rated these aspects positively and many may have difficulty with readability, as reflected by the Flesch score. The amount of new information was rated as being relatively low in all groups. Perhaps readers were already familiar with the information as many of them had had previous therapy involvement. However without the complete series of leaflets, the information may have

been perceived as being difficult to actually implement. This may account for the lower ratings by all groups on the extent to which it helped them make sense of their emotions.

There were no significant differences between mean scores on the visual analogue scales for the two groups. The implications of this are that the leaflet is not specific to one group only. It would have been interesting to assess the leaflet with patients with depression only.

### *Comprehensibility of Information*

Comprehensibility was assessed both quantitatively and qualitatively. The quantitative responses suggested that understanding of the information was rated positively although there was a large range in responses. However, the qualitative information regarding the main points of the leaflet understood was varied and it is unclear how the questions were interpreted. For example, they may have understood several 'main' points but only stated one. Alternatively, they may have misunderstood the points but selected and copied parts of the text into their answer. Understanding could perhaps have been assessed more effectively by follow-up interviews. This is a possibility for further studies.

### *Relevance & Usefulness of Information*

It is plausible to suggest that information such as that contained in a self-help leaflet which is understandable and personally relevant, may help to provide a framework for perceiving and coping with problems. Significant correlations were evident between comprehensibility and relevance. Future analysis could involve regression analysis to determine which variables are predicted from each other. This would require a significantly larger sample to provide

enough power in each cell. Factor analysis could also have been conducted had time and sample size permitted.

It was evident in this study that the information in the leaflet was relevant to most individuals, as rated on the visual analogue scales. It is important for information to relate to the reader's existing knowledge in order for it to be meaningful. This is similar to the cognitive model (Fennell & Teasdale, 1987) whereby individuals do not accept it if they fail to recognise its usefulness or personal relevance.

There was much variance amongst the qualitative comments on the most useful aspects of the leaflet. Patients found different parts of the leaflet useful that may have been internalised according to their own personal experiences. It is possible they may have read the leaflet differently without the demand characteristics of knowing they were being assessed. Expectations of therapy before and after reading the leaflet were assessed and mean score ratings did increase, although not significantly. This may help the patient take on responsibility for change and prompt self-efficacy beliefs.

In conclusion, it is evident from the study that although the leaflet was assessed as being fairly difficult using the Readability Formula, responses were generally positive on individual aspects of readability. However there was a large range in values and so the responses cannot be too conclusive. Qualitative information identified that some parts of the leaflet are more able to be understood than others and similarly some are more useful than others. This identified various aspects that could be revised and simplified before distribution amongst patients.

The findings of the study could be further validated by follow-up interviews. This would provide a clearer impression of how the questions were interpreted. It would also enable aspects such as comprehensibility and relevance to be further explored. This is a preliminary study which has identified various factors to be considered when evaluating a self-help leaflet. Future research should address the final stage of evaluation - the effect the leaflets have on therapy and whether they do in fact help reduce the amount of therapist contact, whilst achieving greater therapeutic gains (White, 1995).

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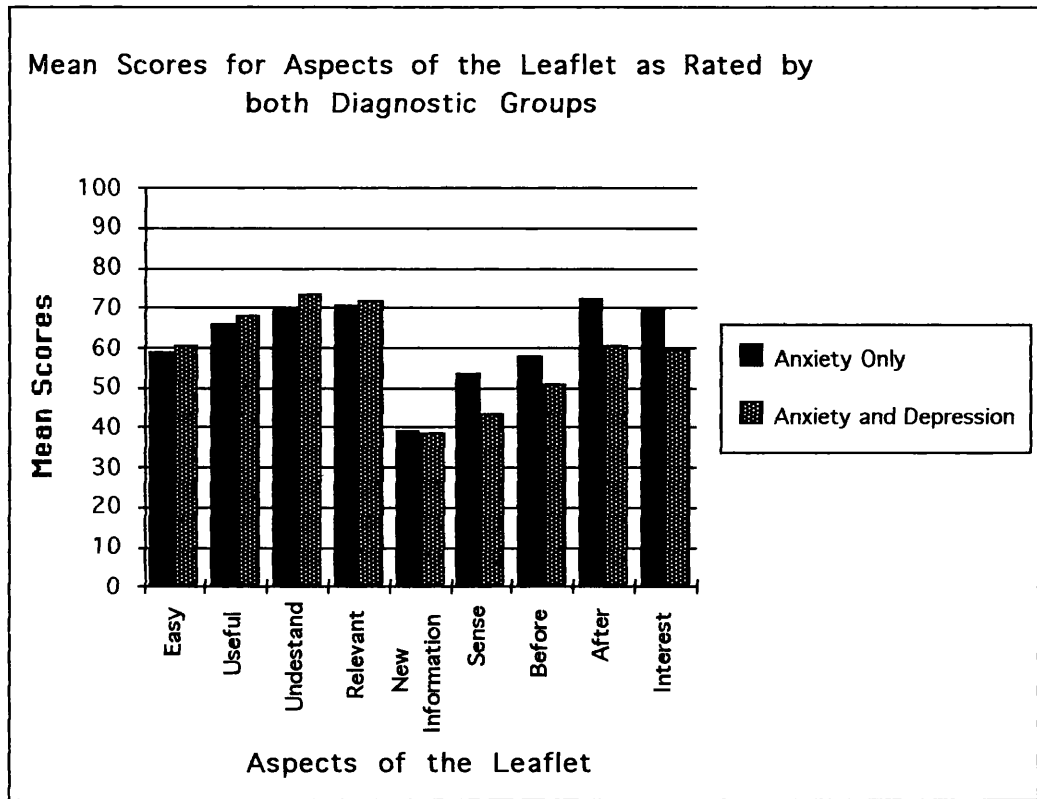
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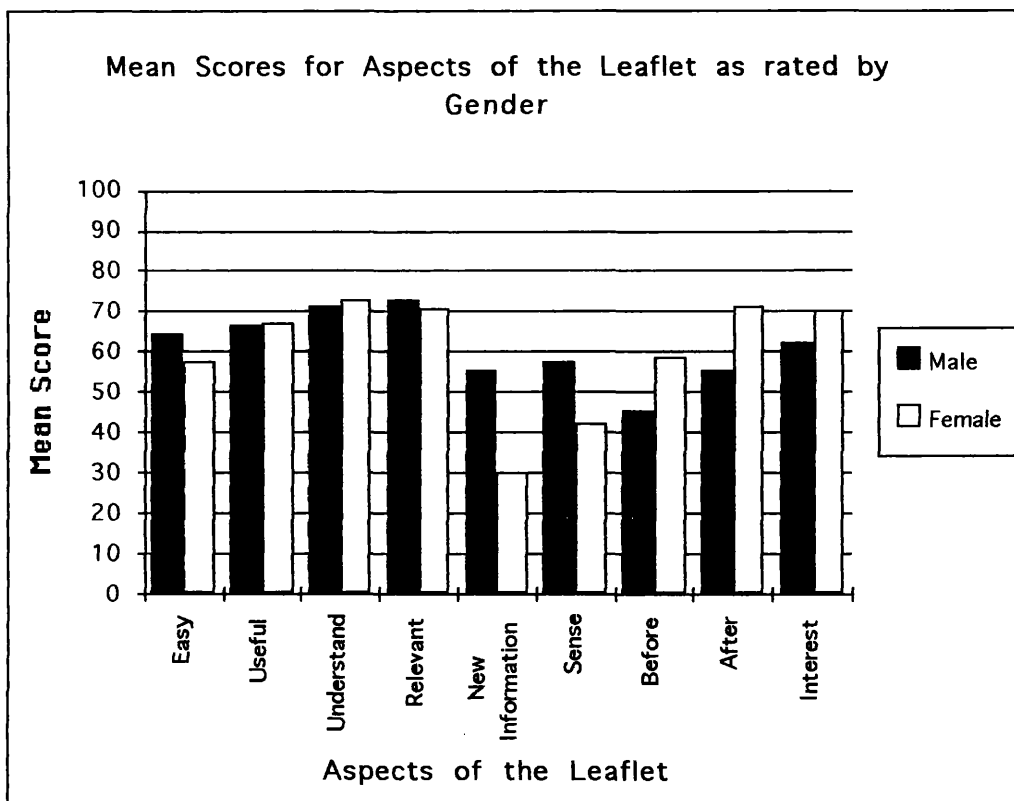
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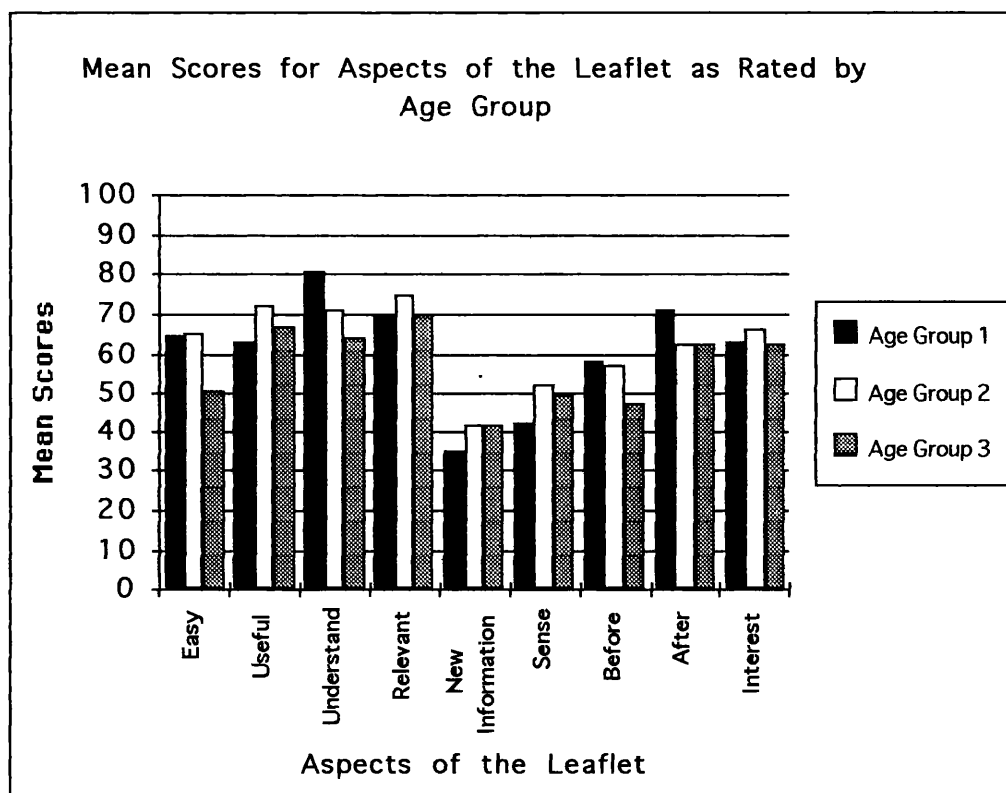
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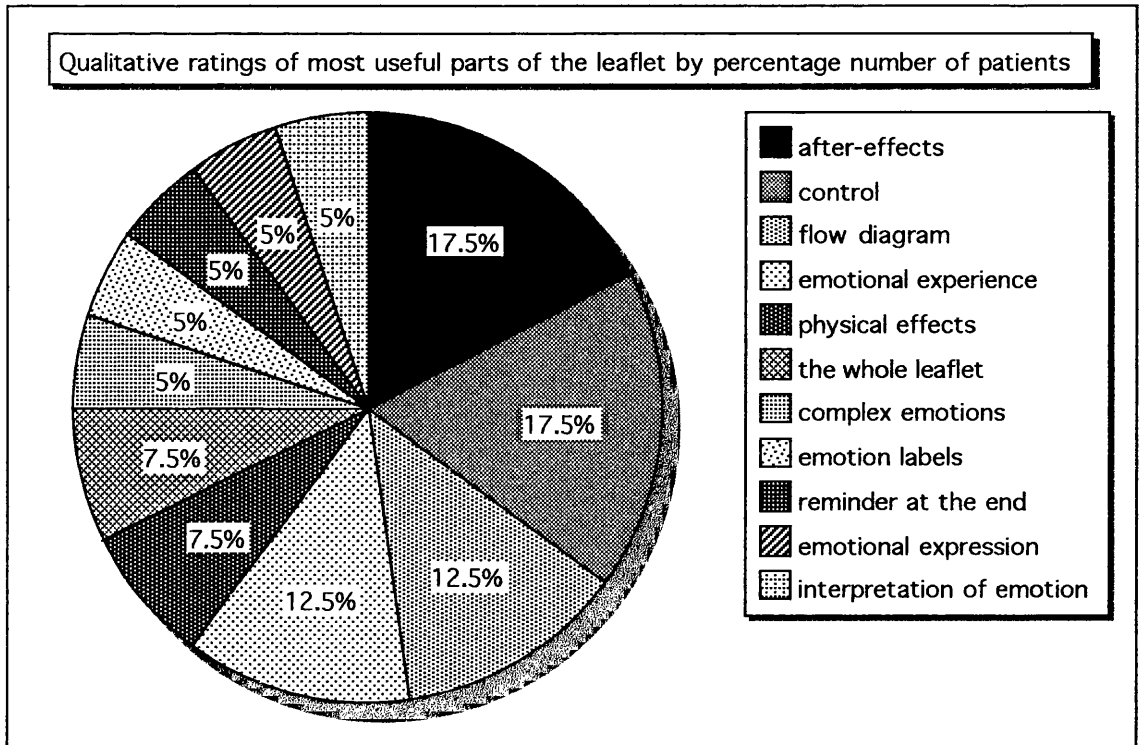
**Figure 1: Mean Scores for aspects of the Leaflet as Rated by both diagnostic groups**



**Figure 2: Mean scores for Aspects of the Leaflet as rated by Gender**



**Figure 3: Mean Scores for Aspects of the Leaflet as Rated by Age Group**



**Figure 4: Qualitative Ratings of the Most Useful Parts of the Leaflet**

<b>The Main points Understood</b>	<b>No. of patients</b>	<b>Percentage</b>
• control over emotions	8	17.8
• emotions are complex	8	17.8
• emotions can be triggered by events outside oneself	7	15.6
• understanding the nature of emotions	6	13.3
• one emotion can affect another one	4	8.9
• emotions are associated with an urge to act	3	6.7
• after-effects	3	6.7
• several ways of expressing emotions	2	4.4
• to feel different emotions is normal	2	4.4
• emotions can affect how you act and express yourself	2	4.4
• emotions follow a sequence	2	4.4
• emotions are a reaction to the interpretation of events	2	4.4
• emotions can be triggered within the self	2	4.4
• emotions are linked to biology	2	4.4
• explanation about emotional expression	2	4.4
• emotions are associated with physical changes	2	4.4
• achievement of emotional regulation	1	2.2
• emotions can affect thinking	1	2.2
• knowing how to regulate emotions	1	2.2
• explanation about emotional experience	1	2.2

**Table 1: The Main points of the Leaflet understood by Patients**

## **2. Major Research Project Literature Review**

### **Epilepsy and Learning Disabilities: A Review of the Literature**

#### **Addressing Methods Used to Document Seizures**

Prepared in accordance with the notes for contributors to the journal

‘Epilepsia’

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## **Abstract**

Accurate seizure diagnosis is important for appropriate epilepsy management. This paper aims to address the issues of seizure diagnosis and classification in the learning disabled population. A review of the literature reveals that methods used by carers to document seizure information include behavioural descriptions and both formal and informal classification methods of describing seizures. Differential decisions between epileptic and non-epileptic events is relevant to this process. To date, studies have examined the reliability of the ILAE classification system used by physicians and trained lay reviewers with child and adult populations. Studies indicated that reliability was lowest when classification was not based on standardised methods of collection or interpretation of data on seizure symptoms. Reliability was higher when standardised methods were used and interpreted by experienced physicians. Reliability was also higher when trained lay reviewers interpreted information collected in standardised interviews. However the findings were not consistent for all seizure types in the studies with some types producing lower levels of reliability when classified. Evidence also suggests that the ILAE system cannot reliably be used to classify infantile seizures. This information emphasises the importance of determining the reliability of the methods for accurate seizure diagnosis and classification and their suitability for use by carers in the learning disabled population.

## INTRODUCTION

It is important for clinicians working in services for people with learning disabilities or epilepsy to be aware of the issues involved in the assessment and treatment of those with a dual disability. The prevalence rates for people with learning disabilities and epilepsy are high; it is 20 per cent for those with mild or moderate learning disabilities and increases to 50 per cent when learning disabilities are severe or profound (1). In the general population prevalence rates range from 0.5 to 1 per cent, with a lifetime prevalence of 2 to 5 per cent (2,3). The aims are the same for patients with learning disabilities as those with epilepsy alone which are achieving maximum health gain, reducing morbidity and preventing avoidable mortality (4).

Appropriate medication and subsequent care relies on an accurate diagnosis of epilepsy. There is evidence that approximately 40 per cent of people with learning disabilities are on polytherapy, although using a particular drug of choice is usually the recommended approach (5,6). Individuals who have been seizure free for at least two years and may benefit from a reduction or withdrawal of antiepileptic medication are often not identified. This could affect medical, social and psychological aspects of Quality of Life (7).

With the move of patient care into the community, there is greater opportunity for staff and family carers to provide for learning disabled people in hospitals, clinics and other community settings. The following issues are relevant to both staff and family carers, who play a key role in the assessment and management of the individual's epilepsy.

## **THE DIAGNOSIS OF EPILEPSY**

The diagnosis of epilepsy is mainly a clinical one, as there is no definitive test for the condition. In order to provide the best care possible it is vital that adequate information be acquired so that clinical judgements can be made. Where there are verbal comprehension and expressive language difficulties in people with learning disabilities, information derived from carers observations is central to the diagnostic process.

The episodic nature of seizures mean that quite often physicians or nurses do not witness a patient actually having a seizure during a clinic visit. Diagnosis and treatment may often be based on the history and observations of eye witnesses who are usually carers. Without seizure information the clinician can have problems with diagnosis, evaluation of seizure frequency, or adverse side effects of medication. It is important that documented information is standardised and valid when given to the clinician in order to ensure diagnostic accuracy. Informants responsible for providing this information may know little, if anything, about seizures and errors can occur. Electroencephalographic (EEG) may be used to assist the process. Seizures are then classified and an epileptic syndrome diagnosis is usually made by the clinician according to the International League Against Epilepsy Classification System (ILAE; 8) which is a uniform scheme developed for the categorisation and naming of specific types of seizures.

It has been recognised that the valid and reliable measurement of therapeutic outcomes in people with learning disabilities is very important (9). In particular, measures relating to

seizures have not been systematically studied in this population and interobserver agreement studies using seizure documentation is a neglected area.

## **TYPES OF INFORMATION DOCUMENTED BY CARERS**

### **INSERT TABLE 1**

A review of the literature of seizure documentation methods revealed that several types of information may be documented in seizure charts and diaries by the observers, who are usually staff or family carers (see table 1).

#### **1. Behavioural Descriptions**

Behavioural descriptions (10,11) of seizure events may be documented by carers. Behavioural descriptions are written for each seizure presentation exhibited by an individual which then requires carers to only enter a code letter and time at each seizure presentation. For example, W suddenly collapses, his whole body jerks quite violently, his eyes may appear to 'roll' and he will vocalise quite loudly. This could then be coded as 'A' at each presentation (11). The system is often used but its reliability and level of accuracy has not been formally assessed.

#### **2. 'Major' or 'Minor' Classification**

Carers may classify the seizure as being major or minor (9). This is a lay interpretation of seizure type which is often documented in seizure diaries and may be used in addition to or instead of behavioural descriptions of seizure events. Inferences are required to be made

without any standardised criteria that have been developed systematically. It can be hypothesised that this system will lack reliability or validity between observers as they are potentially using different criteria amongst them to aid their decision-making process. Again the reliability of this method has not been formally assessed.

### **3. Classification Using The Carers' Own Knowledge Base**

A classification decision may also be based on terminology relating to the carers' own knowledge base. The terminology may have been acquired using standardised classification systems such as the International League Against Epilepsy Classification System (ILAE) or non-standardised systems developed by the carers' own organisation or care setting (12).

### **4. 'International League Against Epilepsy' Classification**

The International League Against Epilepsy (ILAE) Classification System is accepted as the standard system of classification and terminology. A classification scheme (13) was first proposed in 1970 by the International League Against Epilepsy (ILAE) which was revised in 1981 (14) and again in 1989 (8). The current ILAE classification system is an important advance for epilepsy research, but is often used by carers without adequate experience or substantial information to guide their decision. The label assigned to the observed seizure is directly based on the revised ILAE classification system.

## **DIFFERENTIAL DIAGNOSIS**

The diagnosis of a condition such as epilepsy is fraught with difficulties as external phenomena associated with a variety of origins can often be mistaken for epileptic events (10). There are various conditions which confuse and sometimes completely mislead the

clinician. Genuine epileptic seizures should initially be differentiated from non-epileptic seizures.

For example, there are difficulties in differentiating at the behavioural level between stereotypies, non-epileptic seizures, movement disorders, self-injurious behaviour and genuine seizures (see Table 2) which can result in confusion. This is complicated by the fact that individuals are unable to express their experiences such as an aura or déjà-vu at the beginning of a simple partial seizure or verbalise sensations such as dizziness.

In the learning disabled population identification of the above conditions follows a similar procedure to that in the general population i.e.: particular attention is paid to gathering a detailed history including an account of behavioural events and where necessary an EEG may be requested (15).

## **INSERT TABLE 2**

### **RELIABILITY OF THE METHODS**

The information documented by carers and assessed by clinicians should be reliable and valid. This will help ensure that the information is a true representation of what is actually occurring. The most common way of demonstrating the acceptability of observational data is to report inter - observer agreement. This is assessed by arranging for two or more observers to conduct observations on the same individual simultaneously. However observer agreement does not by itself assess observer accuracy unless it is compared with some previously established standard. It is possible to obtain high observer agreement with close to zero reliability in terms of accuracy and stability (19).

Behavioural analysis is widely used in clinical psychology (20) and entails direct observational methods to describe the behaviour of individuals. As epilepsy is characterised by behavioural manifestations, behavioural assessment should be central to the diagnostic and classification process. In an adequate description, the behaviour of the individual must be adequately described in reliable operationalised terms (20). The adequacy of direct observational data will depend on its ability to reflect accurately and reliably the behaviours of individuals. The amount of inference required by the observer is important to try and minimise variability in responses. If the units of behaviour are comparatively unambiguous, then reliability of the method should be substantial (21).

Behavioural assessment has been previously used to aid diagnosis (22) and the following studies suggest it may be useful in the diagnostic process of epilepsy.

Studies documented in the literature assessing the reliability and validity of the classification process use the ILAE Classification system which are based on adult and child populations rather than the learning disabled population. However, findings from these studies can be considered relevant when determining its properties. Recognised difficulties are evident even when the standard criteria of the ILAE Classification System are applied (11). Factors such as observer characteristics, type and amount of information upon which the classification is based are all relevant when considering reliability issues.

The following studies used kappa ( $k$ ) statistics to measure interobserver agreement. This is a flexible index that discounts expected chance agreements between two or more observers (23). Interpretation of values of  $k$  above zero are based on an analysis by Landis

& Koch (24). They suggested that values up to 0.4 should be interpreted as 'poor'; those from 0.4-0.75 as 'fair to good' and those greater than 0.75 as 'excellent'.

A study by Bodensteiner et al. (25) examined interobserver agreement of seizure classifications by pairs of neurologists. This was based on information regarding descriptions of children's seizures in medical records. The overall level of agreement was only slightly better than would have been expected from chance (k ranged from 0.26 to 0.38) and was described as being 'less than desired'. When comparisons of classifications were then restricted to those based on descriptions with some degree of detail, fair agreement was concluded, as measured by the weighted k (k values ranged from 0.24 to 0.58).

The classification of specific seizure types was fair to excellent ( $k = 0.45 - 0.90$ ) for the more common seizure types, such as complex partial which were more easily identifiable. However, agreement was lower for the less common types such as atypical absence seizures ( $k = 0.11 - 0.28$ ) which may be misclassified. It was suggested that the findings could be related to a lack of standardised criteria on which the neurologists could base their decisions. Levels of agreement were hypothesised to improve with classifications based on videotapes of seizures or interviews with observers of the seizures, in addition to specific ILAE criteria for the categorisation of symptoms.

Such problems with reliable and valid seizure classification raises serious questions about strategies for accurate diagnosis and classification. The issue of standardised data collection was addressed in a further study by Ottman et al. (26). A semi-structured

interview was developed to investigate the reliability and validity of the ILAE classification system with non-learning disabled adults, mainly from voluntary organisations. Agreement between diagnoses by a research assistant using information from the interview and physician-based diagnoses was assessed.

The study showed that the interview produced excellent agreement with physicians for diagnosis of any partial onset, secondarily generalised and primary generalised tonic-clonic seizures as well as fair-to-good agreement for all of the remaining types assessed (such as generalised and simple partial seizures). K values overall ranged from 0.54 to 0.83 and it was suggested that levels of agreement compared well to studies of clinical diagnoses of other disorders. For example, k values ranged from 0.29 to 0.59 with normal clinical assessments for diagnosis of Hodgkin's disease and from 0.75 to 0.93 when specific criteria were used (27).

Values within this range, however, were in fact only evident in secondarily generalised ( $k=0.81$ ), any partial ( $k=0.83$ ) and tonic-clonic seizures ( $k=0.76$ ). For the other seizure types, specifically absence, myoclonic, and atonic, k values were lower and it was recommended that medical records should also be used for these seizure types as diagnosis could not be made accurately on questionnaires alone. This suggests that as much detailed information as possible is often needed for diagnosis of certain seizure types.

In a further study by Reutens et al. (28) a group comprising adults and children with epilepsy was selected from a community-based study of epilepsy in twins. A seizure

questionnaire, similar in form to a clinical history, was designed for use by trained interviewers. Diagnoses made by a neurologist based on data from the semistructured interviews were compared with clinical diagnoses made by a different neurologist trained in epileptology. Levels of agreement overall were significantly higher when data from the interview was gained from an informant only ( $k=0.76$ ) rather than from the patient only ( $k=0.41$ ).

This finding emphasises the importance of an observer's account in clinical seizure diagnosis. It is particularly relevant to the learning disabled population as individuals are usually unable to report the information due to limited communication skills. However, biased sampling was evident as patients were only selected if the patient or observer was able to comply with the questionnaire.

Specifically K values ranged from 0.78, 0.70 and 1 for absence, myoclonic and atonic seizures respectively. Stratified random sampling was used to ensure an adequate number of patients with generalised seizures was included. The values were lower in the Ottman et al. (26) study which grouped absence, myoclonic and atonic seizures together as nonconvulsive generalised seizures ( $k=0.56$ ) due to the small number included. K is affected positively by the prevalence of the diagnostic category under consideration (23) and so the values are not comparable with previous studies. The study concluded that a questionnaire enabling trained interviewers to gather data is a reliable method for classifying data. However, these sampling biases should be accounted for when considering the properties of a questionnaire for diagnosis of seizure type.

A semistructured interview was developed by Ottman et al.(29) and assessed with non-learning disabled adults as part of a university based epilepsy family study. The study addressed the consistency of different lay reviewers in interpreting interview data and the similarity of their interpretation to that of an expert neurologist. Reviewers were three nonphysician research assistants trained to use the ILAE classification system. Agreement between lay reviewers ranged from  $k= 0.67 - 0.89$  and between the neurologist and lay reviewers it ranged from  $k= 0.71 - 0.97$  for all seizure types with the exception of simple partial.

Agreement was better between reviewers one and two than the other two pairs. Although they all received the same amount of training, reviewers one and two worked together for a longer period of time and reviewed a larger number of subjects than did reviewer three. It was suspected that participation in the consensus meetings provided continual training and improved reliability. It would be interesting to assess whether the length of time and number of individuals observed would affect reliability of diagnoses. Similarly participation in training may also affect levels of accuracy and reliability. Agreement however was substantially lower for myoclonic and atonic seizures. For myoclonic seizures,  $k=0.26$  for both pairs of reviewers and for atonic,  $k = 0.19$  between the lay reviewers and  $k= 0.13$  between the neurologist and lay reviewer. Again a majority of subjects in the sample had partial onset seizures and less than one fourth had generalised-onset seizures. As a result the number of patients with generalised nonconvulsive seizures was small which affected  $k$  values.

The above study suggested that using a trained, nonexpert research assistant to interpret data can be reliable. For certain seizure types, however, reliability was much lower than the acceptable level for diagnosing other disorders when specific criteria are used (27). This may have been affected by the proportion of seizure types included. Also unfamiliarity with myoclonic and atonic seizures could result in less accurate classification compared to the more familiar types. Additional information to the interview may have produced higher levels of agreement for all seizure types.

A study by Berg et al. (30) demonstrated a high level of agreement between three independent paediatric neurologists in the classification of epilepsy syndromes in children. This was a prospective, community-based study and recruited children with newly diagnosed epilepsy. It was based on information from initial diagnostic evaluation and clinical history. K values ranged from 0.82 to 0.85 for agreement of seizure types. This was attributed to the fact that in this study classifications were based on a number of factors which aided the process. Factors included were age, seizure descriptions, EEG, underlying aetiology and diurnal seizure pattern. Disagreement of seizure type was associated with a tendency for less seizure information.

Finally, the ILAE Classification system is sometimes inappropriate for use with certain populations. It was demonstrated by Nordli et al. (31) that with clinical observations and interictal EEGs, seizures in infants cannot be reliably classified by current ILAE classification criteria. For example, two epileptology clinicians experienced in infantile seizures, seldom agreed when they tried to classify seizure onsets as partial or generalised, using only clinical indications, even when they could view a seizure several times.

This can be attributed to the fact that the clinical features of infantile seizures are too non-specific to allow accurate classification based on clinical observations alone by the ILAE Classification System. It was apparent when trying to classify seizures that there were major limitations in the attempt to apply ILAE criteria to infants. These limitations included the inability to assess consciousness reliably and to distinguish partial from generalised seizures on the basis of clinical observations and interictal EEG. These observations indicate that it is difficult to classify infantile seizures reliably using ILAE criteria derived from older children and adults. However, a few discrete clinical features were repeatedly observed in infantile seizures, such as loss of muscle tone and subtle changes in behaviour. These descriptive features became the basis of a new classification scheme in which seizures are categorised by their most overt clinical manifestations. As a result, they developed their own classification system based on observed behavioural features.

It would be interesting to determine whether the ILAE criteria used with older children and adults can be generalised to the learning disabled population. It is important to determine whether observers can describe seizures accurately and classify them using ILAE classifications.

### **Relevance of the Current Study**

It is evident from the above studies that there is a need to address the issue of accurate seizure description and classification. In order for this to be achieved it is important that the information upon which clinicians are formulating their classification decision is

reliable and valid. Often the information presented to them is in the form of a behavioural description or it has been classified into categories by the carers themselves.

The current study aims to address the question of the reliability and validity of the methods currently used by carers to document seizures in hospital and community settings. An experimental procedure will be devised involving both staff and family carers and an expert consensus panel of clinicians viewing video clips of seizure events. Documentation of their responses according to the methods currently used in care settings will then proceed this.

The study is concerned with looking at which method of documenting seizures produces the greatest level of accuracy and hence reliability when compared to clinicians' descriptions and classification labels. The extent to which the carers responses agree with the experts external criteria and the known clinical diagnosis will demonstrate this. It is hypothesised that the behavioural descriptions will produce the highest levels of accuracy as this requires a simple description of the events seen by the observer. Sources of disagreement will also be considered which will aim to include factors such as knowledge of epilepsy and training experience.

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MEASURE	OBSERVER REQUIREMENTS	DECISION-MAKING PROCESS
Seizure diary requiring behavioural description of seizure event.	Observer (usually staff or family carer) documents behavioural descriptions corresponding to the individual's seizure presentation.	The carer documents all the observed behavioural manifestations. For example, R stares straight ahead, appears to lose consciousness and face twitches. A simple coding system is often used to simplify subsequent recording but carers are not involved in making a classification decision.
Major or minor classification.	Carers assign a label of major or minor to the seizure following their observation.	It is unclear whether set criteria are used to aid the decision. For example, carers may think that when there is an alteration of consciousness such as in a complex partial seizure, this has 'big' implications and they subsequently rate it as being 'major'. The converse may be true for a simple partial seizure which is classed as 'minor'. Alternatively, the term 'major' may be assigned to a seizure where there are large body movements e.g. tonic clonic seizure. 'Minor' may be assigned to an absence seizure. Different criteria may be used to aid the carers' decisions, resulting in variation.
Classification system using carers terminology.	Carers assign a label to the seizure following their observation. This is based on terminology learnt from previous experiences or familiar classification systems.	Terminology may not correspond to the correct seizure type. For example, carers may apply the term 'grand mal' to every convulsive seizure and 'petit mal' for every other type (12). Different criteria may be used again.
International League Against Epilepsy Classification System. (9)	Carers assign a label to the seizure following their observation. This is based on the standardised ILAE classification criteria (9).	The system is standardised and broadly divides seizures into partial, generalised and unclassified epileptic seizures. Although there are standardised descriptions, carers with limited experience or training of the system may have difficulty accurately using the criteria to guide their classification decision.

**Table 1 - Properties of the Current Methods Used to Document Seizures**

<b>Seizure Type</b>	<b>ILAE Classification Description</b>	<b>Possible Misdiagnosis</b>	<b>Reference</b>
Myoclonic seizure	Type of generalised seizure; takes the form of jerky movements that may be generalised to the face, body and limbs.	Spasms & tremors - often resulting from neurological impairments.	10
Absence seizure	Type of generalised seizure; there is an abrupt onset and activity stops. Person may appear vacant as stares blankly.	Attention deficit - for example, lapses in concentration may be confusing.	12
Complex partial	Type of partial seizure where there is an alteration of consciousness. Person engages in involuntary activity during or after the seizure. It is usually preceded by amnesia.	Behavioural problems/ self-injurious behaviour - e.g. approximately 55% of people with learning disabilities in a group of 300 were found to have behavioural problems.	16,17, 18
Temporal lobe epilepsy	Characterised by partial seizures. Motor manifestations easily confuse the diagnostic process. Frequently a family history of febrile seizures and possibility of memory deficits.	Stereotyped behaviours - 57% of this population found to have stereotyped behaviours in a study on individuals living in institutions. Behaviours include body rocking and pacing.	11

**Table 2 - Possible Sources of Misdiagnosis in the Classification of Seizure Types**

### **3. Major Research Project Proposal**

## **A Comparative Investigation of the Methods Used to Document Seizures For People with Epilepsy and Learning Disabilities**

Prepared in accordance with guidelines detailed within the Doctorate in Clinical Psychology Handbook. Guidelines based on the application for a mini-project grant in Health Services Research (Appendix 3.0).

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## SUMMARY

Epilepsy is the most prevalent neurological problem which people with learning disabilities experience. Approximately twenty per cent of people with learning disabilities have epilepsy and it has been recognised as an area of research priority. Both descriptive accounts of seizures and EEG recordings are important for diagnosis, and information on seizure frequency is essential for monitoring the effectiveness of anti-epileptic medication. However, limited communication often hinders accurate reporting and thus the provision of such information becomes the responsibility of the family or staff carers. A particular issue that arises in this population is that stereotypical behaviours and non-epileptic events may be misinterpreted and misdiagnosed as epileptic seizures.

There is considerable variation in types of seizure documentation tools in use across settings. These are normally in the form of charts and diaries. A survey of these tools has indicated that the type of information carers are required to enter falls into one of four principal methods. These are; (1) A full behavioural description of the seizure; (2) A decision as to major or minor classification; (3) Classification using the carer's own knowledge base; (4) A diagnostic label according to a checklist of the International Classification of Epileptic Seizures (The Commission on Classification and Terminology for the International League Against Epilepsy, 1981).

The study will systematically compare inter-observer concordance rates for each of the four reporting methods between the carers and expert panels. An experimental model will be adopted and a videotape comprising twenty epileptic and non-epileptic seizure extracts will be presented to carers. They will then be required to record information according to the four methods outlined above. Comparisons will be made between family and staff carers,

evaluating performance against external criterion scores derived from consensus panels. The amount of agreement within and between groups on the various categories of information will be statistically evaluated. Effects of knowledge of epilepsy on inter-observer concordance rates will also be assessed.

\* **ILAE** will be used to refer to the International Classification of Epileptic Seizures (The Commission on Classification and Terminology for the International League Against Epilepsy, 1981)

## **INTRODUCTION:**

Epilepsy is highly prevalent in the learning disabled population and research has indicated that accurate assessments which result in appropriate care enable the person to operate at the optimum level of functioning (Lannon,1990). The use of valid and reliable measures which are capable of describing and quantifying the range of seizure types and related behaviours are important for diagnosis and treatment.

The diagnosis of epilepsy is based on a detailed history as the clinician rarely witnesses a seizure. Observation and written documentation of seizures is usually the responsibility of the carer due to poor communication skills of this population and is often supplemented by an electroencephalogram recording (Jenkins & Brown,1992).

### ***Methods Used To Document Seizure Information***

The literature reveals that there are several methods used to document written seizure information which have varying levels of validity and reliability in the diagnostic process (Espie et al. 1997). Information is usually written by the carer in a seizure chart or diary produced by the pharmaceutical industry or by clinical settings. Firstly, behavioural descriptions of a seizure may be documented in addition to or instead of a classification label. The description is an account of the observed seizure behaviour, similar to the written description of 'B' in the ABC three-term contingency of behavioural assessment.

Following a detailed behavioural description, the carer subsequently enters a code letter and time corresponding to an observation of each seizure event, rather than making a classification decision (Espie & Paul,1997). This method does not require carers to make a clinical judgement and may be more reliable than a classification procedure. Behaviour analytical methods may also be incorporated into seizure diaries (Baker et al. 1994), using behavioural descriptions as outlined above. This allows more information about seizure events, such as antecedent triggers and environmental contexts to be documented. It can be useful for differentiating genuine epileptic seizures from non-epileptic seizures and stereotyped behaviours (also known as stereotypes).

Secondly, the International League Against Epilepsy (ILAE) is the standard system of classification and terminology (Commission,1981). Seizure information using the ILAE system is often documented in addition to or instead of a behavioural description. However, there are recognised difficulties in interobserver agreement, even when the standard criteria are applied (Espie & Paul,1997). Inexperienced carers have to differentiate between seizure types, which is a difficult distinction even amongst experienced clinicians (Espie et al. 1997).

Thirdly, carers may also classify seizures as being ‘major’ or ‘minor’. This could be unreliable as the decision is not based on standardised criteria. Alternatively, carers often use terminology developed by their organisation or from their own knowledge about seizures. For example, many carers continue to use the term ‘grand mal’ for any convulsive seizure and ‘petit mal’ for every other type (Lannon, 1990).

Previous studies have assessed the inter-observer reliability of reviewers assigning diagnostic labels according to the ILAE classification criteria. Seizure information contained in medical records (Bodensteiner et al. 1988) and information generated in semi-structured interviews (Reutens et al. 1992) was classified by neurologists. The level of agreement between pairs of neurologists was then assessed using unweighted and weighted Kappa Statistics. Reliability was higher in the latter study which was attributed to the use of standardised methods for collection and interpretation of data on seizure symptoms. Training by participation in consensus meetings was also seen to improve reliability (Ottman et al. 1993) and produced consistent responses between lay reviewers.

### ***Differentiation of Genuine Epileptic Seizures from Non-Epileptic Events***

The differentiation of genuine epileptic seizures from non-epileptic seizures and stereotyped behaviours can further complicate the classification procedure. Non-epileptic seizures refer to behaviours which have another physical, emotional or psychological origin. For example, migraines produce similar symptomatology to simple partial seizures (Vossler, 1995) and may be difficult to differentiate.

Stereotyped behaviours (also known as stereotypies) have been reported present in approximately two thirds of institutionalised people with severe learning disabilities (Repp & Barton, 1990) and are often confused with epileptic seizures. For example, myoclonic seizures may be difficult to differentiate from habits and stereotyped behaviours (Espie & Paul, 1997).

Psychologists frequently use functional behavioural analysis and should be involved in refining programmes which enable staff and family carers to test hypotheses based on differentiating epileptic from non-epileptic seizures. For example, based on one hypothesis that stereotypy is due to hypoarousal (Repp et al. 1990), a functional analysis could involve determining whether an increase in overall stimulation produces a decrease in the stereotyped behaviour. It would be useful to also determine the reliability of behavioural documentation methods for the process of differentiating genuine epileptic from non-epileptic seizure events.

***Current Documentation Methods Used in Practice:***

A survey of the seizure documentation methods that are actually used by carers across settings was conducted by the author. This involved gathering a sample of charts and diaries used in hospital, residential and family settings across the West of Scotland and Edinburgh. The type of information documented falls into one of four principal categories and often more than one category is specified, as outlined below:

1. A detailed behavioural description of the observed seizure event.
2. A categorical decision by the carer as to whether a seizure can be classified as ‘major’ or ‘minor’.
3. The provision of a diagnostic label according to the carers’ own terminology and knowledge base regarding seizure classification. For example, carers may use terminology which they have acquired from contact with professionals, organisations or from their own experiences. They often use the term ‘grand mal’ for any convulsive seizure and ‘petit mal’ for every other type.

4. The provision of a diagnostic label by the carers according to the International League Against Epilepsy Classification Criteria (Commission,1981) corresponding to the observed seizure event.

In spite of common usage, to date there has been no formal evaluation of the various types of documentation methods. It is clearly important to assess their comparative reliability and validity and to determine their value in diagnosis and monitoring of epileptic seizures as well as their value in differentiating between seizure types. The current study aims to address these needs.

## **AIMS & HYPOTHESES**

The aim of this project is to evaluate, systematically and comparatively, the measurement accuracy of the four methodologies in current use to gather seizure information. It is hoped that this will lead to a standardised approach with demonstrated validity and reliability.

The specific hypotheses that this study will address are:

1. It is predicted that the behavioural description of a seizure event will produce the greatest amount of agreement within the carers groups and between the staff and family carers sub-groups and the expert panel in comparison with the other methods of recording.
2. It is predicted that 'General Knowledge of Epilepsy', measured by the Epilepsy Knowledge Questionnaire (Jarvie et al. 1993) will be positively associated with accuracy of documentation methods.

3. It is also predicted that measured 'General Knowledge of Epilepsy' will be positively associated with the ability to discriminate non-epileptic seizures and stereotyped behaviours from genuine seizures.

## **PLAN OF INVESTIGATION**

### **Recruitment and Consent of Subjects**

A database has been set up of individuals with Epilepsy and Learning Disabilities and their principal carers, identified from an audit of active caseloads from hospital and community based settings across Central Scotland. It has provided a subject pool for the ongoing Scottish Office Funded project (Grant No:98/55(2)), 'Epilepsy in People with Learning Disabilities: A Comparative Investigation of Perceived Needs and Priorities for Treatment Outcome'. This is based at the Department of Psychological Medicine, Gartnavel Royal Hospital and is supervised by Professor Colin Espie. As the current study is associated with the larger ongoing project, sampling will be taken from the database. The research team has selected 200 subjects from within stratified samples reflecting clinic location, residence and degree of learning disability. Of the sample, 100 carers will then be selected for this study at random from within stratified samples reflecting care setting. This will be from hospital, residential or home settings. There will be 25 carers selected from both hospital and residential settings respectively and 50 carers from home settings, which will provide an even representation of staff and family carers.

### ***Inclusion Criteria for Patients***

- a) Adults in the age range 18 to 60 years.
- b) Mild, moderate or severe learning disability according to the standard definitions.

- c) Epilepsy confirmed by clinical history and diagnosis and having a minimum of one seizure per month on average.

#### ***Exclusion Criteria for Patients***

- a) Deteriorating health, particularly neurological disorder.
- b) Established non-epileptic seizure disorder as the principal problem.

#### ***Inclusion Criteria for Carers***

- a) Adults over 18 years of age.
- b) The principal family or staff carer of a person with a dual diagnosis of epilepsy and learning disabilities who meet the inclusion criteria for patients, as outlined above.

#### ***Inclusion Criteria for the Expert Panel***

- a) Previous or current involvement in the diagnostic process of people with learning disabilities and epilepsy.
- b) Previous or current involvement in the interpretation of written seizure documentation.
- c) Healthcare professionals with an expertise in epilepsy - including neurologists, clinical psychologists, physicians and epilepsy nurse specialists.

#### **Power Calculation**

There are no directly comparable studies on which to make a power calculation. The minimum number of subjects required to demonstrate a significant difference has been calculated as 19. This would be for a paired sample t-test ( $p < 0.05$ ) with 0.9 level of power.

It is based on the principal prediction that the behavioural descriptions will produce the greatest number of correct responses relating to the Psychologists' scores within and between groups. The prediction also assumes that an expected 80% correct response rate on behavioural descriptions will compare with a 30% correct response rate on the categorisation of the seizure types relating to the expert panel and the actual ILAE classification as the external criteria. However, 40 subjects will be selected because comparisons will also be made within sub-groups of carers (n=20 in each group) and this will ensure demonstration of any significant differences.

## **MEASURES**

### **Workbook to Assess Methods of Documenting Seizure Information**

A workbook devised by the author will be used to assess each method of documenting information about the seizures following the presentation of each video clip. This comprises 4 sections as outlined below:

#### ***Section 1 - Structured Interview Schedule***

A Structured Interview Schedule (appendix 3.1) has been devised to record both demographic information about the carer and information relating to the patient. This will take approximately five minutes to complete and will be administered at the beginning of the workshop; prior to the video presentation. The schedule consists of questions relating to sex, age, marital status, carer type, care setting, years of experience, training experience and the number of people cared for with epilepsy. In addition to this, information regarding the patient will include seizure frequency and severity of learning disability.

## ***Section 2 - Information based on Observation of Seizure Clips***

The carer will provide information on the worksheet according to the following four sections which correspond to the existing methods identified in the charts and diaries.

1a. Provision of a detailed description of the observed behaviour viewed on the video clip.

1b. The carer will then decide whether or not the seizure is genuinely epileptic and tick the appropriate box.

2. Decision as to whether the clip represents a major or minor seizure and then provision of a response by ticking the appropriate box.

3. Assignment of a classification label to the seizure according to the carers' own diagnostic terminology depending on their personal experience of classification systems.

The three sections above will be completed consecutively on a worksheet corresponding to each clip (appendix 3.2).

4. The final section consists of a list of ILAE classification labels used to describe seizure types. The carer will be required to tick the correct classification label corresponding to each video clip. Again there will be an individual worksheet corresponding to each video clip (appendix 3.3).

## ***Section 3 - Information on Seizure Documentation Methods***

A short schedule has been devised by the author to gain information regarding the carers' current practice of recording information about seizures (appendix 3.4). This includes questions about the carers' current practice of seizure documentation, the consistency of the procedures involved in recording seizures and carers' descriptions of major and minor seizures. This will take approximately ten minutes to complete.

#### ***Section 4 - Epilepsy Knowledge Profile***

The Epilepsy Knowledge Profile (Jarvie et al. 1993) assesses knowledge of the medical and social aspects of epilepsy (Appendix 3.5). It comprises 45 questions in a true/false format. The scale takes approximately ten minutes to complete and will follow the section outlined above.

### **EXPERIMENTAL DESIGN AND PROCEDURE**

#### ***Experimental Procedure (Figure 1)***

##### **Phase I**

**Stage 1:** It is proposed that a video will be prepared of twenty clips of different pre-recorded seizure types according to the ILAE classification system, including two examples of stereotypies and two non-epileptic seizures. There will be two clips of each seizure type, including examples of generalised seizures such as tonic clonic and simple absence as well as examples of partial seizures. Two different randomised versions of the video will be presented to counteract any order effects.

**Stage 2:** A pilot study will determine whether the experimental procedures are acceptable. This will involve a group of assistant psychologists watching the video and writing information according to the format of the workbook.

**Stage 3: Validation Procedure** - experienced Psychologists, familiar with behavioural observation will form a consensus panel (n = 8). They will watch the video and provide a behavioural description for each seizure clip observed. The behavioural features of the description will be divided into segments and each one granted a score of one point. A composite score will then be determined for each behavioural description. This information

will be used as the external criteria against which the carers' behavioural descriptions will be assessed.

A consensus panel of clinicians with epilepsy expertise ( $n = 4$ ) will then view the video. They will provide behavioural descriptions, major or minor classification labels and their own diagnostic labels according to the procedure outlined in phase II.

## **Phase II**

**Stage 1:** For procedural reasons, the family and staff carers will be divided into separate carer groups and each one will be invited to attend for one of two sessions at a central location. The carers will initially be requested to complete section 1 of the workbook; the Structured Interview Schedule.

**Stage 2:** Carers will view the video and be asked to rate each clip according to the information requested in section 2 of the workbook. That is, they will provide a behavioural description of the seizure, decide whether or not the clip represents an epileptic event, provide a classification of a 'major' or 'minor' label and then a diagnostic label according to their own knowledge of classification systems.

**Stage 3:** The video will be replayed and the carers asked to assign a diagnostic label according to ILAE classification for each seizure clip in section 2a of the workbook. This is to ensure that the carers will not have been exposed to the ILAE classification terminology when required to provide a label based on their own knowledge of the classification system in Stage 2.

**Stage 4:** Carers will then complete section 3 of the workbook regarding their own practice of seizure recording methods. This will be preceded by a debriefing session and discussion regarding current individual practice of seizure recording.

**Stage 5:** Carers then complete section 4 of the workbook, the Epilepsy Knowledge Profile - General (Jarvie et al. 1993).

### Time-scales corresponding to Figure 1

Phase	Time-scale
Phase I	January 1999 - May 1999
Phase II	June 1999- February 2000

## DATA ANALYSIS

The data will be analysed in two parts. The first part will consist of descriptive statistics which will be presented in tables and charts.

The second part will consist of statistical procedures according to whether the data are interval or nominal:

### *1. Comparison of the Amount of Agreement Within and Between Groups on the Behavioural Descriptors (Interval Data):*

The behavioural descriptors will be assumed to be interval scale data. They will be scored according to checklist criteria generated from the behavioural descriptors by the consensus panel.

### *2. Comparison of the Amount of Agreement For Diagnostic Measures (Nominal Data):*

Kappa statistics will be used to determine the level of agreement on the categories of 1. A major or minor classification 2. A diagnostic label using carers' own terminology and 3. A diagnostic label according to the ILAE classification. This will be calculated both within and between the groups of family and staff carers and within the expert panel. Agreement between the carers and the expert panel will also be assessed.

### ***3. Effects of Knowledge on the Accuracy of Recording Seizures (Interval data):***

The following analysis will be based on the confirmation of the principal prediction that the behavioural description will generate the highest level of agreement between and within carers groups:

Taking into account that the dependent variable is the accuracy of recording behavioural descriptions of seizure events and the independent variable is the level of knowledge, then:

a) A coefficient of Multiple Correlation will be computed to determine the level of correlation between the independent and dependent variable.

If the data is linearly related, then a stepwise linear regression will be calculated to determine the factors affecting the dependent variable. Otherwise, a factorial Analysis of Variance (ANOVA) will determine whether the level of knowledge is positively associated with accuracy of documenting a behavioural description of a seizure.

### ***4. Effects of Knowledge on ability to Differentiate Between Epileptic and Non-Epileptic Seizures (Categorical Data):***

Analyses will either comprise between group T-tests or Chi-square Analyses, depending on the distribution of the data. Level of knowledge will be the independent variable and ability to discriminate between epileptic and non-epileptic seizures (including stereotypies) the dependent variable.

## **SETTINGS AND EQUIPMENT**

The seizure clips will be edited onto two videos at the Media Services Department at the University of Glasgow. The experimental procedure will take place in a central location in Glasgow that is reasonably accessible to carers. A television and a videotape player will be used.

## **PRACTICAL APPLICATIONS**

The research findings will hopefully assist with the determination of the most accurate measure of recording seizures. There is evidently variation in the current practices and this study aims to help standardise these. This will also identify training needs for carers and help provide clearer guidelines for documentation of information to aid differentiation between seizure types.

## **ETHICAL APPROVAL**

Ethical approval has been granted as part of the three year ongoing Scottish Office funded project (Grant code: K/RED/4/C357), 'Epilepsy in People with Learning Disabilities : A Comparative Investigation of Perceived Needs and Priorities for Treatment Outcome.' This is based at the Department of Psychological Medicine, Gartnavel Royal Hospital, Glasgow, U.K.

## **ADDENDUM TO PROPOSAL**

It was anticipated that Kappa statistics would be used to determine the level of agreement with the expert panel for the major/minor classifications, classifications using carers' own knowledge base and classifications using the ILAE classification system. However statistical advice was sought and it was decided that this measure of agreement would not be suitable for the nature of the data. Kappa statistics are typically used to assess inter-observer agreement between two individuals or more using categorical data. This would have been appropriate if there had been greater numbers of individual seizure types sampled. However it was more appropriate to convert the data into an interval scale and calculate carers' percentage mean scores. This allowed concordance with the expert panel to be assessed as well as direct comparison between methodologies.

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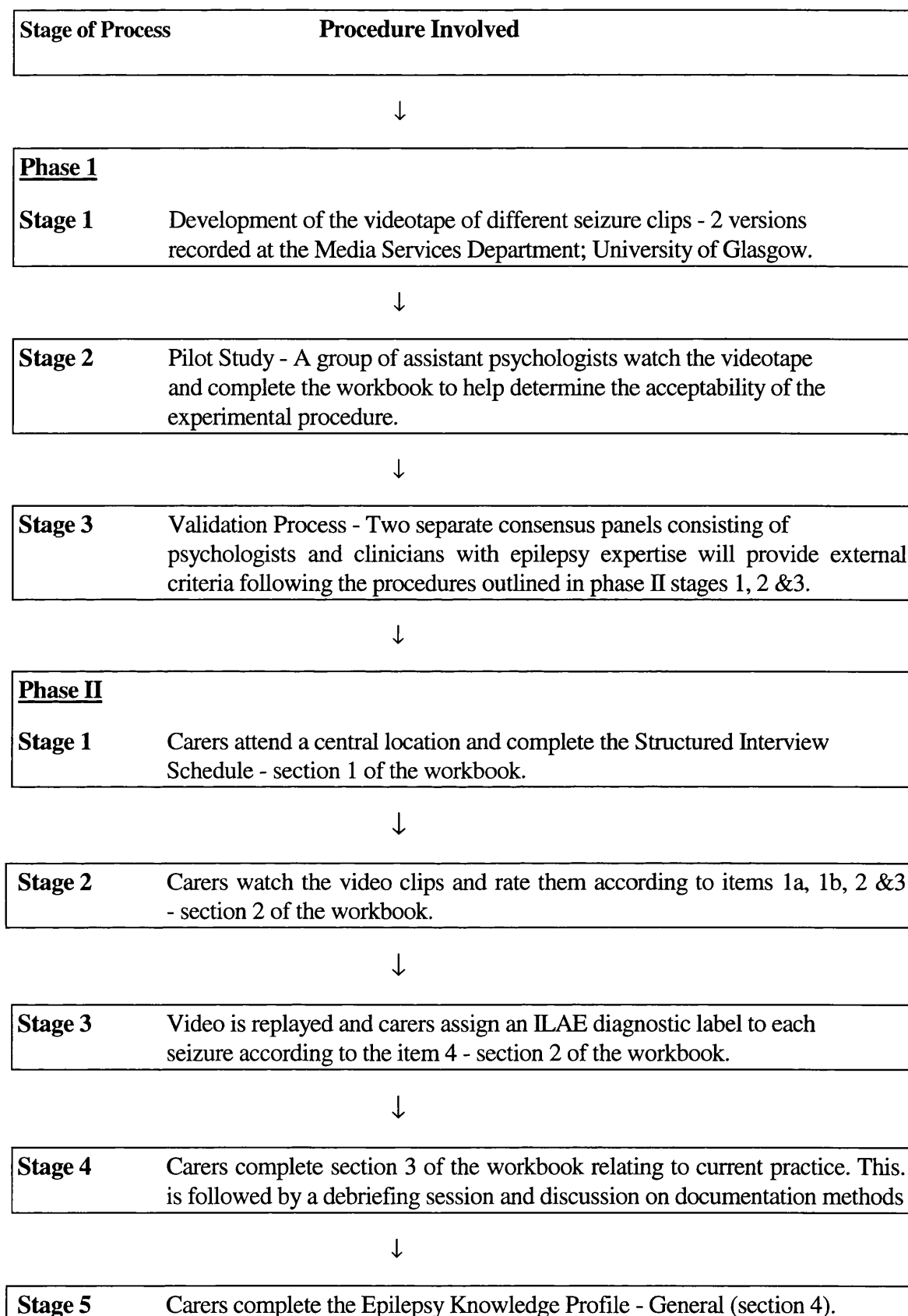
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**Figure 1. Experimental Procedure**

## **4. Major Research Paper**

# **A Comparative Investigation of the Methods Used to Document Seizures for People with Epilepsy and Learning Disabilities**

**Major Project submitted in fulfilment of the requirements for the degree  
of Doctor of Clinical Psychology**

Prepared in accordance with the guidelines for contributors to 'Epilepsia'

(Appendix 2.0)

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## ABSTRACT

**Purpose:** The aim of the study is to determine the accuracy, and compare where possible, the accuracy of four methods commonly used to document seizure information by carers of individuals with epilepsy and learning disabilities. These methods comprise a) a behavioural description, b) major or minor classification, c) classification using the carer's own knowledge base and d) a diagnostic label using the ILAE Classification System. It is hypothesised that the behavioural descriptions will generate the highest level of accuracy with no differences between groups. Epilepsy knowledge is predicted to be positively associated with accuracy of the methods.

**Method:** The study was approached experimentally by presentation of a videotape comprising twenty seizure extracts to groups of staff and family carers. Following observation they documented information using the methods outlined above for each seizure type. The procedure was validated by expert panels to produce external criteria. Levels of accuracy were determined by comparing carers' responses against the external criteria.

**Results:** Concordance with the external criteria was compared using percentage mean scores for the behavioural descriptions, classifications using the carers' own knowledge base and the ILAE classifications. Kappa statistics were used for the major/minor descriptions. The behavioural descriptions were the most accurate methodology with no differences between carer groups (percentage mean range: 30 - 40). Between group differences were only evident using the ILAE classification system with staff being more accurate than family (percentage means:  $32.5 \pm 8.5$  vs  $18.66 \pm 7.8$ ;  $p < .005$ ). Knowledge accounted for 15.5% of the variance in accuracy of the behavioural descriptions.

**Conclusions:** The research findings indicate that behavioural descriptions are more reliable than the use of formal or informal classification methods. Training programmes and guidelines for carers should incorporate this approach.

## **INTRODUCTION**

Epilepsy is highly prevalent in the learning disabled population particularly where the learning disability is severe or profound (1,2). Research in this area remains limited, notably the investigation of methods used to document seizure information. As clinicians rarely observe seizures, epilepsy diagnosis is based on the individual's seizure information which is often supplemented by an EEG recording (3). Within the learning disabled population, where individuals have communication problems, carers' observations and subsequent documentation of seizure events are important in the clinicians' diagnostic process. Incorrect diagnoses result in inappropriate treatment and management (4). Variability in the methods of documenting information is a recognised problem in clinical practice although their comparative reliability has not been formally assessed (5). Methods include behavioural descriptions of seizure events and the application of diagnostic labels using classification systems. Such information is usually documented in seizure charts or diaries.

### **Methodologies Used To Document Information**

#### *Behavioural Descriptions*

Carers may write a behavioural description of the observed seizure event. This is a similar concept to the ABC three-term contingency which is used in behavioural assessment to determine the relationship between the target behaviour and environmental events (6). The observed seizure event is classified as 'B' which is the description documented. For example, following observation of a seizure, the carer documents the sequence of events such as 'W suddenly collapses, his whole body jerks quite violently, his eyes may appear to

‘roll’ and he will vocalise quite loudly’. This method does not require a classification to be made (7). It could be hypothesised that it would be reliable as few inferences are required (8).

### *Major/Minor Classification*

In addition to or instead of the behavioural description, carers may classify seizures as ‘major’ or ‘minor’. These are lay interpretations that are not based on standardised criteria (5). For example, falling and convulsive movements observed in a tonic-clonic seizure may be perceived as being ‘major’ owing to large motor manifestations. Similarly ‘minor’ seizures may be defined by smaller movements, including cessation of activity and automatisms as observed in absence or complex partial seizures. The criteria upon which carers base these definitions have not been assessed and there is likely to be variability between carers’ perceptions, making them less reliable than behavioural descriptions.

### *Classification Using Carers Own Knowledge Base*

Carers may classify seizures using terminology derived from personal knowledge of classification systems. Terminology may be non-standardised if it is not based on a recognised system such as the International League Against Epilepsy (ILAE) Classification System outlined below. For example terms such as ‘grand mal’ for any convulsive seizure and ‘petit mal’ for every other type may be used (9) which are old and possibly inaccurate classifications.

*International League Against Epilepsy Classification System (ILAE)*

Carers may use the 'International League Against Epilepsy Classification System' (ILAE; 10) in addition to or instead of the other methods. It is a uniform scheme developed for the categorisation of specific seizure types whereby seizures are divided into partial (simple and partial), generalised and unclassified. A review of studies indicates variable inter-observer agreement and accuracy using this system (11). Variability amongst the accuracy of various seizure types was evident with certain types being classified more accurately. This depended on familiarity of the seizure by the individual or the nature of the data on which the classification was made (12,13). Lay reviewers classifications produced more agreement with experienced clinicians when reviewers had more training experience gained through participation in consensus meetings (14). However variability again existed for certain seizure types. It could therefore be hypothesised that reliability of classification may vary depending on seizure type. Reliability may also be associated with individual characteristics of the reviewer, who in this study is the carer. It may vary depending on knowledge gained through training or experience of observing seizures.

The differentiation of epileptic from non-epileptic events is a further issue and the individual with learning disabilities may experience both (15). Non-epileptic events comprise non-epileptic seizures, stereotypies and movement disorders and are common in people with learning disabilities (16). It has been estimated that approximately 20% of patients attending specialist epilepsy outpatient clinics do not have epileptic seizures (17). Scheepers et al. (18) found 35% of 'epileptics' to have a misdiagnosis of epilepsy. This figure is likely to be much higher in the learning disabled population where added difficulties including poor communication and confusing behavioural features exist. A decision as to whether

behavioural manifestations represent epileptic or non-epileptic events may depend on similar characteristics of the carer as outlined above for the ILAE classification system.

Decisions on diagnosis and management of seizures may be more appropriately assessed based on behavioural descriptions in contrast to classifications. Previous studies have only assessed inter-observer agreement using the ILAE classification system and have indicated the factors most important for improved seizure classification and reduced variability. To date, there have been no comparative reliability and validity studies of the documentation methods in use.

## **AIMS**

This study aims to evaluate systematically the measurement accuracy of the four methodologies currently used to gather seizure information in care settings. Where possible the accuracy of the methodologies will be compared. It is hoped that this will lead to a standardised approach with demonstrable validity and reliability.

## **METHODS**

Prior to the development of the final protocol the author conducted a preliminary survey of seizure documentation methods. Samples of seizure diaries and charts used in hospital, residential and family care settings across the West of Scotland and Edinburgh were gathered through contact by telephone or letter. Four main methods were identified. These comprised: (1) behavioural description of the seizure; (2) classification of major/minor; (3) classification using the carer's own knowledge base; (4) diagnostic classification according to the ILAE classification system.

## **Hypotheses**

The following hypotheses underpinned the study:

- 1a. Behavioural descriptions of a seizure event will produce the greatest concordance with the psychologists' external criteria when compared to other methodologies.
- 1b. Behavioural descriptions of a seizure event will produce the greatest concordance between the staff and family carers sub-groups when compared to other methodologies.
- 1c. There will be greater concordance with the expert panel for certain seizure types using the classification methodologies (major/minor, carers' classifications using own knowledge base and ILAE classification).
2. 'General Knowledge of Epilepsy' as measured by the Epilepsy Knowledge Profile will be positively associated with accuracy of documentation methods.
3. 'General Knowledge of Epilepsy' will be positively associated with the ability to decide whether a seizure represents an epileptic or non-epileptic event.

## **Design**

A between groups experimental design involving staff and family carers was devised utilising a workshop format. Both carer types were included as they may have different levels of knowledge and epilepsy experience and are involved in the process of documenting seizure information. The workshop format enabled groups of carers to follow the same procedure in a controlled environment. As the practicalities of live seizure observation are difficult the author compiled a videotape of a random selection of seizure types corresponding to the ILAE classification system (Appendix 4.0). This ensured standardisation of the reference material.

Staff and family carers workshops were run separately to allow group differences to be systematically compared. The study was validated against external criteria developed during workshops by two expert panels comprising physicians and psychologists. The same standardised procedure was followed throughout each workshop.

## **Participants**

There are no directly comparable studies on which to make a power calculation. Therefore the power calculation was derived following discussions with a Psychologist with epilepsy expertise. Based on clinical experience, it was estimated that an 80% correct response rate on the behavioural descriptions would compare with a 30% correct response rate on the categorisation of the seizure types.

A power calculation based on this estimation indicated that groups of 19 individuals would be adequate to test the principal hypothesis with 0.9 level of power at  $p < .05$  (2-tailed). The aim was to sample at least 40 carers ( $n = 20$  in each group) to allow comparisons to be made between the groups.

One hundred carers of individuals with epilepsy and learning disabilities were initially randomly selected from within stratified samples reflecting care setting. Twenty - five staff carers were targeted from hospital, 25 staff carers from community residential settings and 50 family carers from home settings.

Inclusion criteria for the individuals with epilepsy and learning disabilities were: 1) age range between 18 - 60 years; 2) at least a mild learning disability and 3) epilepsy confirmed by

clinical history and diagnosis, with a minimum of one seizure per month on average. Exclusion criteria were: 1) deteriorating health (particularly neurological disorder) and/or 2) established non-epileptic seizure disorder as the main clinical problem.

The principal carers of the individuals outlined above were identified and selected if they: (1) had participated in care decisions for at least three preceding months and (2) were over 18 years of age.

A database of individuals with epilepsy and learning disabilities and their principal carers was set up for the Scottish Office Funded project (Grant Code: K/RED/4/C357), 'Epilepsy in People with Learning Disabilities: A Comparative Investigation of Perceived Needs and Priorities for Treatment Outcome', based at the Department of Psychological Medicine, Gartnavel Royal Hospital, Glasgow, U.K. The sample was drawn from a random selection of 250 participants. It was originally selected from a database of 685 individuals by the research team from within stratified samples reflecting clinic location, residence and degree of learning disability. The clinical sources used were two Glasgow epilepsy clinics: 1) the Western Infirmary Epilepsy Unit and 2) the Southern General Hospital, and the four Community Learning Disability Teams covering the Greater Glasgow area. Participants in Edinburgh were selected from both the community and Gogarburn Hospital via specialist clinics for those with epilepsy and learning disabilities. Ethical approval was granted for the study as part of the Scottish Office Funded Project. Recruitment began in June 1999 until February 2000.

## **Response Rate**

Four workshops took place, including 1 staff carer and 3 family carer workshops. The overall response rate was 43%.

### *Staff Carer Workshop*

Fifty staff carer invitations were distributed and 34 staff carers replied (68%). Twenty-three staff carers subsequently attended representing 46% of the sample initially contacted. Of those who replied but did not attend, 5 had work and 6 had personal commitments. Ten expressed future interest.

### *Family Carer Workshop*

Fifty family carer invitations were distributed and 38 family carers replied (76%). Nineteen carers overall subsequently attended which was 38% of the sample initially contacted. Of those carers who replied but did not attend, 5 said the time of day was inconvenient, 10 had problems with alternative care arrangements and 4 had difficulty with transport. Four expressed future interest.

## **Development of Materials**

### a) Preparation of The Videotape:

A selection of seizure clips was obtained from pre-recorded video material of individuals with epilepsy and learning disabilities at the Quarriers Epilepsy Centre, Bridge of Weir, Renfrewshire. Individuals had previously given consent to be recorded. The video clips had been pre-classified by clinicians using the ILAE Classification System Terminology. A selection of seizure clips were selected to represent the main seizure types seen in clinical

practice according to the ILAE classification system. The video clips were initially reviewed by the author and then by a clinical psychologist with epilepsy expertise to identify the clips most representative of seizures seen in clinical practice. The aim was to provide a standardised range of seizure clips. A total of 20 clips was selected comprising the main types outlined in the ILAE classification system. These clips included 3 complex partial seizures, 3 absence seizures, 2 stereotypies, 2 myoclonic seizures, 2 non-epileptic seizures, 1 tonic-atonic, 2 simple partial seizures, 2 tonic clonic seizures, 2 tonic seizures and 1 clonic seizure. Individual video clips were edited at the Glasgow University Media Services department onto two different videotapes. Each one consisted of a randomised version of the clips to counterbalance order effects. The clips varied in duration from 25 seconds to 100 seconds with a total duration of 19 minutes and 14 seconds.

b) Preparation of the Workbook:

A workbook was developed by the author consisting of 4 sections which are outlined below:

*Section 1* - A structured interview schedule was developed to obtain demographic information (Appendix 3.1)

*Section 2a* - This included one worksheet for each seizure clip. Every worksheet comprised 4 parts corresponding to the seizure documentation methods (Appendix 3.2), including a question referring to a decision as to whether each clip represents an epileptic or non - epileptic event.

*Section 2b* - This included one worksheet for each clip. Every worksheet consisted of a checklist of 10 seizure types corresponding to the ILAE classification system. The carer was

required to tick their response according to the most appropriate classification label (Appendix 3.3).

*Section 3* - This assessed the carers' personal seizure documentation method. Questions related to the carers' current practice of seizure documentation and definitions of major and minor seizures (Appendix 3.4).

*Section 4* - The Epilepsy Knowledge Profile - General (19). The EKP - G comprises 45 questions in a true/false format. It has two sub-scales designed to measure knowledge of the medical and social aspects of epilepsy. It was included to gain an objective measure of carers' knowledge of issues relating to epilepsy (Appendix 3.5).

In order to conduct the study validation of the procedure with expert panels, development of a scoring system and workshops for data collection were necessary. The validation procedure and scoring system is outlined in Table 1. A brief pilot study of the workshop procedure was conducted at the outset with 3 assistant psychologists in order to assess the viability of the planned procedure. No significant problems were identified.

### **INSERT TABLE 1 HERE**

#### **Procedure**

##### *Validation Process*

The validation process (Table 1) involved the development of external criteria against which the carers' responses were compared. They followed the same procedure as the carers within the workshop format outlined below. The Psychologists initially viewed the behavioural

descriptions and individually documented their own behavioural description. Following this they discussed their responses and consensus decisions regarding the individual behavioural features corresponding to each clip was compiled. These were the external criteria used by author against which the carers' responses were compared.

The expert panel then viewed the video clips and individually documented their responses for the classification decisions. Following this the experts discussed their responses and consensus decisions were made regarding whether or not the seizure was major or minor, as well as an appropriate classification label for the seizure type. These responses were used by the author as the external criteria against which the carers' responses were compared.

### *Workshop Process*

Following validation, information letters, booking forms and programmes for the workshops were sent to carers (Appendix 4.1). The standardised procedure outlined below was followed within a workshop format. The workshops were run by the author (workshop facilitator) and an epilepsy nurse specialist who was present for the discussion session. Carers were introduced and given an outline of the workshop format. They were provided with a workbook and asked to read the instructions on the first page which corresponded to each section. Following this, they were asked to complete section 1, which took ten minutes approximately.

Carers then turned to section 2a and were given a detailed explanation about writing behavioural descriptions. Each video clip was played once and the carer was asked to write a behavioural description in the worksheet corresponding to the clip. They were also required

to complete the other 3 parts of the worksheet referring to seizure information. This procedure was followed for every clip.

Carers then turned to section 2b and the seizure clips were replayed. There was 1 worksheet per seizure clip and they were required to tick the most appropriate seizure classification label according to the ILAE classification system. The procedure was repeated for each of the 20 seizure clips.

Carers were then asked to complete Section 3 of the workbook which took approximately ten minutes. This was followed by a forum with the workshop facilitator and epilepsy nurse specialist to discuss current individual practice and issues concerning documenting seizures. The workshop facilitator distributed fact-sheets about epilepsy and seizure descriptions. Finally carers completed section 4 (the Epilepsy Knowledge Profile - General) which also took 10 minutes to complete.

### **Statistical Analysis**

Scores for each carer were converted to percentage values for the behavioural descriptions, classifications according to the carers' own knowledge base and the ILAE classification system using the scoring system outlined in Table 1. Mean percentage scores were then calculated for both groups. The kappa statistic ( $k$ ) was used for the major/minor categorisation methodology as this assesses agreement beyond chance.

Values of  $k$  were interpreted based on an analysis by Landis & Koch (20). They proposed that values of  $k \geq 0.81$  should be considered as 'almost perfect', substantial when  $0.80 \geq k \geq$

0.61, 'moderate' when  $0.60 \geq k \geq 0.41$ , 'fair' when  $0.40 \geq k \geq 0.21$ , 'slight' when  $0.20 \geq k \geq 0$ , and 'poor' when  $k < 0$ .

## RESULTS

Table 2 presents summary demographic information for the sample. Chi-square analyses indicated a significant ( $\chi^2 = 31.15$ ;  $df = 2$ ;  $p < .001$ ) mean age difference between family and staff carers (56.3 years vs 36 years). There were more females ( $n = 32$ ) than males ( $n = 10$ ) within the two groups overall but no differences between groups. The groups differed in terms of marital status with there being significantly more married individuals in the family than staff carer group ( $\chi^2 = 7.1$ ;  $df = 2$ ;  $p = .028$ ). There were no differences between groups regarding years of care experience ( $\chi^2 = 5.014$ ;  $df = 3$ ; n.s.). However, staff had significantly greater levels of training experience than family carers ( $\chi^2 = 13.8$ ;  $df = 2$ ;  $p = .001$ ) and they had also cared for significantly more individuals with epilepsy than family carers ( $\chi^2 = 27.44$ ;  $df = 2$ ;  $p = .001$ ).

**INSERT TABLE 2 HERE**

### **Hypothesis 1a - Accuracy of the Four Methodologies**

According to the hypothesis it would be expected that the behavioural descriptions would produce the highest level of concordance with the external criteria. Figures 1a - 1c offer a visual inspection of the accuracy levels of the 9 seizure types according to the behavioural descriptions and classification methodologies using the carers' own knowledge base and ILAE classification terminology. Visually the behavioural descriptions (mean range: 30 -

40%) appear more accurate than the other methodologies with no difference between carer groups. Staff carers appear slightly more accurate (mean range: 10 - 40%) than family carers (mean range: 10 - 35%) using the carers' own knowledge base and similarly for the ILAE classification system terminology (mean range: staff 20 - 40% vs family 10 - 20%).

### **INSERT FIGURES 1a - 1c HERE**

Kappas for the major/minor classifications for both carer groups are compared in figure 2. Kappa scores ranged overall from 0.14 (slight agreement) - 0.68 (substantial agreement) with  $k \leq 0.4$  on 5 seizure types for both carer groups. Kappas for staff carers ranged from 0.14 - 0.68 and for family carers they ranged from 0.16 - 0.67.

### **INSERT FIGURE 2 HERE**

#### **Hypothesis 1b - Comparison of Methodologies Between Groups**

According to the hypothesis it is expected that concordance would be greatest between carers groups for the behavioural descriptions. Due to the parametric nature of the data demonstrated by Kolmogorov-Smirnov Tests, independent sample t-tests were used to assess differences between groups for each methodology. There were no significant differences overall between percentage mean scores for staff and family carer groups for behavioural descriptions ( $37.2 \pm 14.6$  vs  $34.5 \pm 17.3$ ; n.s.) and carers' own knowledge base classifications ( $24.5 \pm 6.3$  vs  $23.3 \pm 4.8$ ; n.s.). However, staff were more accurate than family carers on their ability to classify seizures using the ILAE classification system terminology ( $32.5 \pm 8.5$  vs  $18.66 \pm 7.8$ ;  $p < .005$ ).

Overall there did not appear to be significant differences for the major/minor classifications between carer groups using kappa statistics. However there were differences between groups on individual seizure types, which is outlined below.

### **Hypothesis 1c - Comparative Accuracy of Individual Seizure Types**

According to the hypothesis it is expected that concordance with the expert panel would be greater for certain seizure types using the classification methodologies. Visual inspection of figure 1a indicates that the level of accuracy for the seizure types are broadly similar. Percentage mean scores were within a 10 point range (31 - 41) except for absence seizures ( $25 \pm 8.4$ ). Percentage mean scores for carers' own knowledge base classifications (figure 1b) indicates a 10 point range (21-33) for most seizure types except for non-epileptic ( $15 \pm 6.4$ ) and tonic seizures ( $11 \pm 3.2$ ). The ILAE classification system (figure 1c) indicates that staff carers' percentage mean scores were mainly within a 12 point range (20.5 - 32) except for complex partial seizures ( $15.5 \pm 4.3$ ).

Figure 2 indicates that kappa scores for major/minor classifications were quite variable. Specifically kappas for complex partial, absence and simple partial seizures were 0.68, 0.61 and 0.6 respectively which are all classified as substantial agreement. Kappas were 0.47 for the stereotypies and 0.56 for the tonic clonic seizures which are classified as moderate agreement. Finally Kappas were 0.33, 0.3, 0.22 and 0.24 for myoclonic, non-epileptic, tonic atonic and tonic seizures respectively which can all be classified as 'fair' agreement.

Between group differences in figures 1a -1c were assessed for individual seizure types by independent t-tests. Using a Bonferroni (alpha - splitting) correction for multiple comparisons, a  $p$  value of  $< .006$  was set. These analyses revealed no significant difference between carer groups for individual seizure types in figure 1a. In figure 1b, staff were significantly more accurate than family carers in classifying the simple partial seizures ( $t = 3.61$ ;  $df = 40$ ;  $p = .001$ ). In figure 1c, there were significant differences between 7 seizure types with the exception of complex partial seizures and stereotypies. These were absence ( $t = 3.28$ ;  $df = 40$ ;  $p = .001$ ); myoclonic jerks ( $t = 3.14$ ;  $df = 40$ ;  $p = .005$ ); non-epileptic seizures ( $t = 3.12$ ;  $df = 40$ ;  $p = .001$ ); tonic atonic ( $t = 3.62$ ;  $df = 40$ ;  $p = .004$ ); simple partial ( $t = 3.41$ ;  $df = 40$ ;  $p = .001$ ); tonic clonic ( $t = 3.18$ ;  $df = 40$ ;  $p = .001$ ) and tonic ( $t = 3.37$ ;  $df = 40$ ;  $p = .001$ ).

In figure 2, Kappas for major/minor were similar between groups for most seizure types. Exceptions were for complex partial, absence and myoclonic seizures. Specifically, kappas for staff carers were 0.59 (moderate) and 0.67 (substantial) for family carers on the complex partial seizures. The reverse was evident for absence seizures whereby kappas for staff carers were 0.68 (substantial) and 0.55 (moderate) for family carers. Kappas for staff carers were 0.39 for staff carers (fair) and 0.28 (slight) for family carers for the myoclonic jerks.

Confirmation of hypothesis 1 indicated the importance of looking at the features of seizures documented by carers. Due to the large amount of information gathered a sample of carers' behavioural descriptions was generated from a table of random numbers ( $n = 14$ ). The descriptions obtained were then categorised according to the ILAE classification system as outlined in table 3 and further in Appendix 4.3.

Examples of frequencies of behavioural features which can be interpreted from the table are falling over (100%) compared to loss of consciousness (33.3%) during a tonic-clonic seizure; and jerking movements (91.6%) compared to eyes blinking (10.5%) during a myoclonic seizure.

### **INSERT TABLE 3 HERE**

#### **Features of Major & Minor Descriptions**

Descriptions of major and minor seizures documented in the workbook were similarly collated from the above sample. 'Falling over' (staff - 38%; family - 26.3%), body jerking (staff - 38%; family - 31.5%) and loss of consciousness (staff - 28.5%; family - 21%) were most frequently used to describe major seizures. 'Absence' (25%) or loss of consciousness (17.3%) were most frequently used to describe minor seizures by staff and strange eye movements (10.5%) by family carers. These movements were not mutually exclusive and several were expressed as co-occurring (Appendix 4.4).

#### **Carers Abilities To Decide Between Epileptic and Non-epileptic Events**

Carers were also required to decide whether each seizure clip represented an epileptic or non-epileptic event. As staff carers classified seizures more accurately than family using ILAE diagnostic labels it was of interest to determine carers' accuracy on this task (figure 2). Mean percentage scores ranged from 6.5 to 21.5 for 8 seizure types except for the complex partial seizure ( $29.5 \pm 5.6$ ), with no significant difference between groups. Carers mean

percentage scores were least accurate for absence seizures ( $6.5 \pm 3.4$ ) and non-epileptic seizures ( $7.5 \pm 2.8$ ).

Independent t-tests were used to assess differences between groups on individual seizure types. Again using a Bonferroni (alpha - splitting) correction for multiple comparisons a  $p$  value of  $< .006$  was set. Staff carers were significantly more accurate in identifying absence seizures as epileptic ( $t = 3.12$ ;  $df = 40$ ;  $p < .004$ ) and non-epileptic seizures as non-epileptic ( $t = 3.82$ ;  $df = 40$ ;  $p < .000$ ) than family carers. Staff carers were significantly better at identifying stereotypies as non-epileptic than family carers ( $t = 3.49$ ;  $df = 40$ ;  $p < .001$ ).

### **INSERT FIGURE 3 HERE**

#### **Hypotheses 2 & 3 - Effects of Knowledge on Accuracy Levels of the 4 Methodologies & Decision between Epileptic & Non-epileptic Events**

There were no significant differences ( $t = 0.293$ ;  $df = 40$ ; n.s.) on the Epilepsy Knowledge Profile-total between mean scores for staff and family groups ( $44.21 \pm 4.26$  vs  $43.84 \pm 4.26$ ; n.s.). Similarly there were no significant differences between groups on the 'medical' and 'social' sub-scales. According to hypotheses 2 and 3 it was expected that level of knowledge would affect the accuracy of the methodologies and the ability to decide between epileptic and non-epileptic events. Rather than look at knowledge within a bivariate model, it was decided to use a regression model as knowledge may be related to other variables such as training and number of years experience.

Stepwise Linear Regression was used to investigate predictors of accuracy in using each of the 4 methodologies outlined above, and the epileptic and non-epileptic decision process. Five variables were entered into the equations, namely knowledge, carer type, training, number of people cared for and number of years experience. The results of these findings are presented in table 4.

Findings indicated that knowledge accounts for 15.5% of the variance in behavioural description scores (Adjusted  $R^2$  square - table 4). All variables were excluded from the major/minor regression analysis and were not considered significant. Type of carer accounted for 42.7% and training accounted for 7.3% of the variance in carers' classifications using their own knowledge base. Training experience accounted for 28% of the variance in the ILAE classification system. The variables were all associated with higher mean percentage scores. All variables were also excluded from the regression analysis for the differentiation process between epileptic and non-epileptic events in spite of the significant difference indicated using a bivariate model as outlined below.

**INSERT TABLE 4 HERE**

## **DISCUSSION**

This study aimed to determine the accuracy of methods used to document seizures. Where possible accuracy was compared between methodologies. Consistent with the principal hypothesis, behavioural descriptions emerged as the most accurate methodology, with no significant difference between the carer groups or seizure types. Visual inspection indicated varying levels of accuracy between seizure types with the other three methodologies. Knowledge accounted for 15.5% of the variance in behavioural descriptions but did not affect carers abilities to decide between epileptic and non-epileptic events. These findings will be discussed systematically with reference to clinical implications, methodological issues and future work.

### **Accuracy of the 4 Methodologies**

The results indicate that percentage mean scores were highest for the behavioural descriptions. However there are recognised difficulties when comparing different types of methodologies. Although the four methodologies are often documented sequentially in clinical practice, it is difficult to make direct comparisons as there are different sources of variance involved in behavioural descriptions and the use of classification systems, which involve inferential decisions. It is important to control confounding sources of measurement variability when comparing methodologies (21). Accuracy of each methodology will be considered successively, and comparative sources of variance discussed.

#### *Behavioural Descriptions*

This methodology was found to be the most accurate which is expected as behavioural descriptions do not involve making diagnostic decisions or having classification knowledge.

No significant differences existed between carer groups, suggesting the method was independent of carer status and that findings may be extrapolated to all care settings.

Knowledge accounted for 15.5% of variance whereby it was associated with higher percentage mean scores. This suggests that having some knowledge of the issues associated with epilepsy may affect the carers' abilities to recognise behavioural features. Knowledge of epilepsy may be associated with intelligence and perhaps it has some influence on the accuracy of carers' descriptions. Further assessment may identify the association between knowledge and intelligence. Individual factors on the Epilepsy Knowledge Profile that affect accuracy could also be assessed.

Approximately one third of the information was documented accurately for each seizure type (Figure 1a). Closer analysis of the descriptions demonstrated a wide range in the frequencies of documented features (0-100%). Large motor manifestations, including 'falling over' and jerking movements were more frequently documented than subtle aspects such as blinking and a 'vacant look'. Memory issues are relevant as primacy effects may have contributed to some seizures. For example, all carers documented the fall in the tonic-clonic seizure but only 50% documented clonic details and 33.3% reported loss of consciousness. This could be assessed in further detail.

Visual inspection of Figure 1a indicates that accuracy levels were similar for all seizure types except for absence seizures. It may be attributed to the more subtle defining behavioural features which were less frequently documented. For example, carers failed to document lack of responsiveness and only 16.7% documented eyes rolling. Carers of children

diagnosed with absence seizures reported a clear pattern of behaviours associated with an absence seizure including cessation of speech and failure to respond (22). Using open-ended questions in this study to describe seizures would have been useful to determine carers' perceptions of defining features. This would identify the carers' implicit knowledge base, upon which training programmes could be developed.

It would be expected that this methodology would have the least amount of variance when comparing it to the other methodologies. The seizure clips were standardised to represent a range of seizure types seen in clinical practice and it could be assumed that the task of writing behavioural descriptions would be similar for each clip. Thus, variance resulting from the clips was probably minimal for this methodology. It could also be assumed that carer variance would be lower than the other methodologies as the task of writing behavioural descriptions does not involve making inferential decisions based on experience of observing knowledge of various seizure types, or training experience. However it was evident that general knowledge of epilepsy accounted for some variance and greater levels of knowledge predicted increased accuracy as discussed above. This was independent of whether the carer was staff or family as there was no significant difference between knowledge levels for both groups. Finally variance due to chance agreement was considered but it is unlikely that the responses would be affected by chance as there are numerous combinations of behavioural features that could be documented. Also this involves a different task to the classification decisions as there are no responses provided in the workbook which the carer could select from.

### *Major/Minor Classifications*

This methodology was found to be highly subjective and unreliable. Following corrections for chance agreement using Kappa statistics it was found that kappa scores ranged from 0.14 - 0.68 when considering the staff and carer groups separately. According to the qualitative descriptions (20) these ratings range from poor to substantial. However, kappas for six seizure types were lower than 0.56 (moderate agreement) which suggests that it is not particularly reliable. This decision-making process has previously been said to be arbitrary and is confirmed by these inconsistent findings (5). Responses to open-ended questions suggested some agreement amongst staff carers and the on the behavioural features that constitute a major or minor seizure. However there was little agreement amongst family carers. Loss of consciousness was a feature used to describe both classifications but represents a poor discriminating factor as it can occur during tonic - clonic and absence seizures. This aspect merits further investigation as expert panels' behavioural definitions of major and minor were not ascertained in the study.

This methodology may have had greater sources of variance compared to the behavioural descriptions. Specifically this could be attributed to sources of rater variance, variance based on chance agreement as well as some variance from the clips. Firstly, carers were more accurate in classifying certain seizure types which suggests that the clips may not be standardised when using this categorisation methodology. This decision-making process may depend on characteristics of the observer such as previous experience of using this system in their care setting. This suggests that this methodology may be affected by more rater variance than behavioural descriptions. Secondly there may be more error variance on this methodology than the other three methodologies as carers may generate correct

responses based on chance. However this was accounted for using kappa statistics which assess agreement beyond chance. Thirdly the clips varied in length and number of behavioural features. This suggests that some clips may have been easier to identify correctly compared to others and may contribute to further variance.

### *Classification Labels Using Carers' Own Knowledge Base*

This methodology was also found to be unreliable although carer type and training were associated with higher levels of accuracy. Regression analysis indicated that carer type and training accounted for 42.7% and 7.3% of the variance respectively. This may be explained by carers having a broader spectrum of epilepsy experience which may contribute to increased knowledge of accurate ILAE classification system terminology. Participation in training programmes may also contribute to the increased accuracy, which would be expected based on previous findings (14). However the assessment of training experience was ambiguous as discussed below. The terms 'grand mal' and 'petit mal' are commonly used to describe tonic-clonic seizures and absence seizures respectively (9). In this study they were used by approximately 10% of carers (all family) in reference to all seizure types which suggests that some family carers continue to use this terminology.

Again it would be expected that there would be different sources of variance when using this methodology. These could be attributed mainly to variance from the seizure clips, and rater variance. Again as the clips varied in length and number of behavioural features it may be easier to identify and classify certain seizures than others. Rater variance may depend on experience in care settings and carer type as indicated above. Some seizure types may be

easier to identify and classify than others. For example, a carer may be most familiar with complex partial seizures only and more able to classify this particular type. It is expected that this would occur more frequently with family carers who have experience of only one or two seizure types, in comparison to staff carers who have experience of working with more individuals and subsequently a wider range of seizure types. Training experience also contributes to the accuracy levels of using this methodology. As staff carers have more training experience than family this further suggests that rater variance may affect this methodology. Variance due to chance agreement may be slightly lower for this methodology compared to the major/minor and ILAE classifications as it was more difficult for carers to guess the responses. Carers were not involved in selecting labels and so the level of chance agreement would probably be lower than in the following methodology.

#### *ILAE Classification System*

Accuracy levels for staff carers responses were significantly more accurate than that of family carers. This may be explained by staff having more training experience which accounted for 28% of the variance. Knowledge of the terminology may have been gained from training and accuracy may be dependent on this knowledge base. Additional possibilities include family carers being significantly older and perhaps less familiar with the ILAE classification originally devised in 1981. Also staff had cared for more individuals than family carers and may be more familiar with a wider range of seizure types. Tonic-clonic and tonic seizures were most accurately classified by staff and family carers respectively which has been previously reported (14). Complex partial seizures were less likely to be accurately classified by staff carers and confusion between complex partial and absence seizures may underlie this finding (15). Training may reduce this variability,

although inconsistencies between seizure types suggests that it is not a particularly reliable diagnostic tool.

It should be noted that the data obtained may have been affected by several sources of variance. Again as discussed above, some variance may be attributed to the clips. For example, the tonic-clonic and tonic seizures had the highest accuracy levels in the staff carers group. It may be that these seizure types are more easily identifiable than others from the clips as the behavioural features are more explicit than other seizure types. Alternatively these seizures may be the most commonly observed seizures by this particular group.

Variance could also be attributed to training experience and type of carer. There were significant differences between carer groups on 7 seizure types in favour of staff carers. This may be due to their higher levels of training experience, which is discussed above. Variance due to chance agreement may also have affected this methodology. There was a 10% chance rate that the carers may have guessed the seizure types correctly as the task involved selecting one ILAE classification from a list of ten. In retrospect it may have been useful to have used Kappa statistics to account for chance agreement. This statistical correction for chance should be considered in future studies. However this is what happens in clinical practice whereby carers are given a list of ILAE classifications from which they are to select the appropriate label for the seizure type. It could be argued that it is obvious that this methodology is less accurate than behavioural descriptions even before correcting for chance.

### **Decision - Making Process Between Epileptic and Non-Epileptic Events**

Low accuracy levels suggest that this decision-making process is not an appropriate task for carers. Knowledge was not associated with increased levels of accuracy. However this finding could be attributed to the generality of the epilepsy knowledge scale which is a potentially poor assessor of this information. Both staff and family carers were most accurate at differentiating complex partial seizures from non-epileptic events. These seizures may have been the most frequently observed but this was not assessed. The findings suggest that detailed descriptions of seizures may be more reliable. Further evidence can be gained in Figure 1a which indicates that carers' behavioural descriptions of non-epileptic seizures and stereotypies were of a similar standard to the other seizure types. Detailed descriptions are said to assist in differentiating between non-epileptic and epileptic seizure incidents (23, 24).

### **Methodological Strengths & Weaknesses**

Although observation of pre-recorded seizures was important for behavioural assessment purposes, there are some flaws compared to live seizure observation. Changes in face colour were difficult to detect on the videotape and were not even documented by the psychologists. Videotapes were muted, making characteristic noises of seizures, such as screaming, difficult to detect. Carers were sometimes unable to detect pre-ictal behaviours owing to certain seizure clips being recorded from seizure onset. It could be postulated that with live seizure observations more information may have been generated. Perhaps future studies should ensure clips contain a full pre-ictal to post-ictal progression.

Assessment of the aspects affecting methodology variance could be improved upon. The workbook question on training referred to 'identification and recording of seizures' which,

with hindsight, was potentially ambiguous. This does not specify what the training involved and may have been educational rather than training on the use of a specific methodology. The category 'other' would have allowed carers to specify this information but this response was not completed. Knowledge assessment may be improved using a scale specifically addressing knowledge of seizure types and their defining features. The EKP is general with only 7 questions referring to seizure symptomatology. Carers' individual documentation method may have affected accuracy of methods and further assessment of this association would be useful.

The workshop duration may have influenced responses whereby carers may have become tired and lost concentration. However this is unlikely as clips were arranged to counterbalance fatigue and sequencing effects. The workshop format enabled carers to follow the documentation procedure in a controlled environment. It also allowed contact with other carers which was reported to be useful.

As discussed above it is important to account for sources of variance when determining accuracy of the methodologies and making comparisons between them. Although issues of error variance due to chance agreements and rater variance due to differences in carer experience and training were addressed in this study, they should be further considered in future comparison studies.

### **Clinical and Scientific Implications of Findings**

As behavioural descriptions produced greatest concordance both with the expert panel and between groups, their use by carers should be encouraged as previously recommended for

epilepsy management (25,26). The behavioural descriptions will be valuable as part of an epilepsy care plan and allows carers to recognise when there is a deviation from the norm. As several different carers may observe the same individual with learning disabilities it is important that the information is consistent and reliable rather than using variable terminology. Psychologists should be involved in developing epilepsy programmes based on concepts of behavioural analysis. Carers could then be trained to express behaviours in reliable operationalised terms corresponding to their observations of the various seizure types, paying attention to both peri-ictal and post-ictal behaviours. Accurate seizure evaluation and subsequent management to reduce seizure severity will hopefully be achieved. This may reduce the risk of misdiagnoses and its accompanying social and economic implications (27).

### **Future Work/Implications For Practice**

Individual behavioural features documented by carers are clinically important and preliminary analysis of this information was undertaken in the study. Future research should determine variables such as carer type or experience that contribute to the range of individual features documented. The current study could be expanded upon by clinicians with epilepsy expertise assigning diagnostic labels to behavioural descriptions of seizures. Concordance of clinicians' classifications could be compared to the reference standard, that is, the known diagnosis. The approach is similar to that used in previous studies (13,14,28) although classification labels were assigned to information generated from semi-structured interviews. A further possibility is the development of checklists based on behavioural descriptors common to seizure types to help generate more detail and address memory issues outlined above.

## **Conclusion**

In conclusion, behavioural descriptions produced the highest level of concordance with the expert panel. Compared to the other methodologies the findings were considered to be least influenced by different sources of variance. This suggests that it is the most accurate method and should be used by carers. As there were no differences between groups it can be developed for use in both family and staff care settings. It is important for carers to play a role in the classification process but more appropriately at an early stage; using behavioural descriptions without attempting classification.

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**Table 1****Validation Method of the Four Methodologies with the Consensus Panel**

<b>Documentation Methodology</b>	<b>Recruitment Method</b>	<b>Workshop Task</b>	<b>Scoring Criteria &amp; Analysis</b>
<b>Behavioural Descriptions</b>	<p>Consensus panel of psychologists with experience of behavioural assessment was recruited for production of the behavioural descriptions. This comprised 4 clinical psychologists, 2 trainee psychologists and 2 assistant psychologists.</p>	<p>The psychologists viewed the video clips and completed sections 1 &amp; 2a of the workbook. Their behavioural descriptions were discussed and features were included in the finalised description if there was consensus agreement upon their presence in the seizure.</p>	<p>Descriptions were divided into segments according to individual behavioural features. Carers' responses were calculated by determining the number of segments documented in their description corresponding to those in the consensus description. Each segment was given a score of 1. The total number of segments in each clip ranged from 4 to 11. Carers' scores were divided by the total generated by the consensus panel for each clip and converted to percentage values.</p>
<b>Major/Minor Classifications &amp; Differentiation Between Epileptic &amp; Non-epileptic Events</b>	<p>Expert panel was recruited comprising health care professionals with epilepsy expertise - specifically a consultant neurologist, general practitioner, epilepsy nurse specialist and consultant psychiatrist.</p>	<p>On a separate occasion the expert panel followed the above procedure and independently completed sections 1 and 2a of the workbook. Their responses were discussed and consensus opinions were used as the external criteria.</p>	<p>Responses were compared to the experts responses and a score of 1 given to each response that agreed with the panel. Kappa statistics were then calculated for major/minor classifications.</p>
<b>Carers Classification Labels Using Their Own Knowledge Base</b>	<p>Same expert panel as outlined above involved in the validation process.</p>	<p>The panel followed the procedure above independently. Consensus opinions of the classification labels were used as the external criteria.</p>	<p>Responses were compared to the expert panel and the known diagnosis (Appendix 4.2). Responses were reviewed by two clinicians with epilepsy expertise using a scoring system based on a scale of 0-2 (0 = incorrect; 1 = partially correct - e.g.: partial instead of simple partial; 2 = correct).</p>
<b>ILAE Classification labels</b>	<p>Same expert panel as outlined above involved in the validation process.</p>	<p>The panel followed the same procedure outlined above and independently completed section 2b of the workbook. Again consensus opinions were used.</p>	<p>Carers' diagnostic labels were compared to the expert panel and known diagnostic label. A score of 1 was given for complete agreement.</p>

**Table 2****Summary of Demographic Information on the Staff Carer (n= 23) and Family****Carer (n= 19) Samples**

	Staff Carers		Family Carers	
	n	%	n	%
<b>Age Range of Carers</b>				
16 - 30 years	6	26.1		
31 - 45 years	15	65.2	1	5.3
46 - 60 years	2	8.7	13	68.4
61 - 75 years			5	26.3
<b>Gender</b>				
Male	5	21.7	5	26.3
Female	18	78.3	14	73.7
<b>Marital Status</b>				
Single	10	43.5	2	10.5
Married	13	56.5	15	78.9
Separated				
Divorced			2	10.5
<b>Care Setting</b>				
Hospital	8	34.8		
Supported group community	10	43.5		
Family Home	1	4.3	17	89.5
Own Home	4	17.4	2	10.5
<b>Years of Care Experience</b>				
♣ 1 year	1	4.3		
1-5 years	6	26.1	2	10.5
5-10 years	3	13	1	5.3
† 10 years	13	56.5	16	84.2
<b>Training Experience</b>				
No Training	2	8.7	9	47.4
Informal Training	9	39.1	10	52.6
Intensive Training	3	13		
Other	9	39.1		
<b>People Cared For</b>				
1 person	2	8.7	17	89.5
2-5 people	7	30.4	1	5.3
6-10 people	1	4.3		
<10 people	13	56.5	1	5.3

**Table 3**

**Percentage Frequencies of Behaviours Documented by a Sample of Staff & Family Carers For Individual Seizure Types; Categorised According to the ILAE Classification System.**



**Table 4**

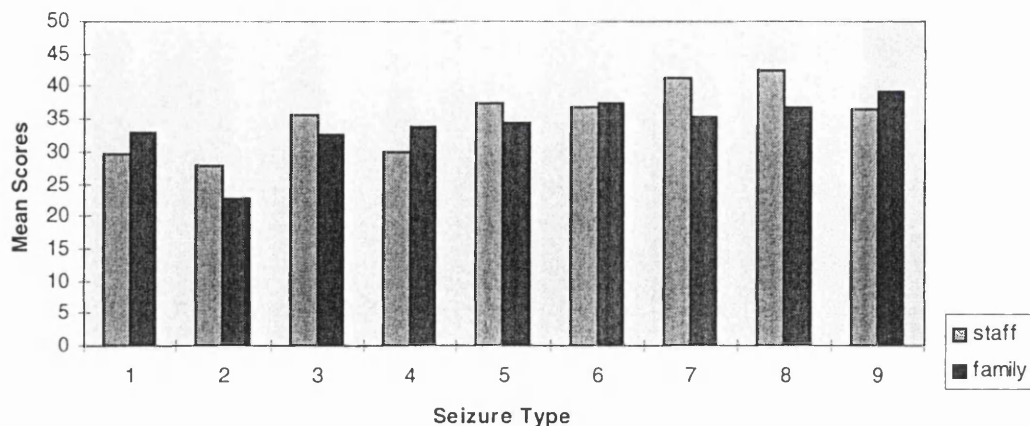
**Stepwise Linear Regression Analyses of Five Predictor Variables (Knowledge, Training, No. of People Cared For, No. of Years Experience and Carer Type) For Dependent Variables Consisting of the Four Seizure Recording Methodologies and Decision between Epileptic and Non-epileptic Events.**

<b>Dependent Variable</b>	<b>Predictor Variables Entered in Equation</b>	<b>Multiple R Square</b>	<b>Adjusted R Square</b>	<b>Beta</b>	<b>t</b>	<b>Sig</b>
<b>Behavioural Description</b>	Knowledge	.177	.155	.421	2.86	.007
<b>Major/Minor</b>	No variables entered					
<b>Classification Using Carers Knowledge Base</b>	Type of carer	.441	.427	.415	2.82	.008
	Training	.525	.500	.383	2.6	.013
<b>ILAE Classification System</b>	Training	.298	.280	.546	4.072	0.001
<b>Epileptic/non-epileptic Decision</b>	No variables entered					

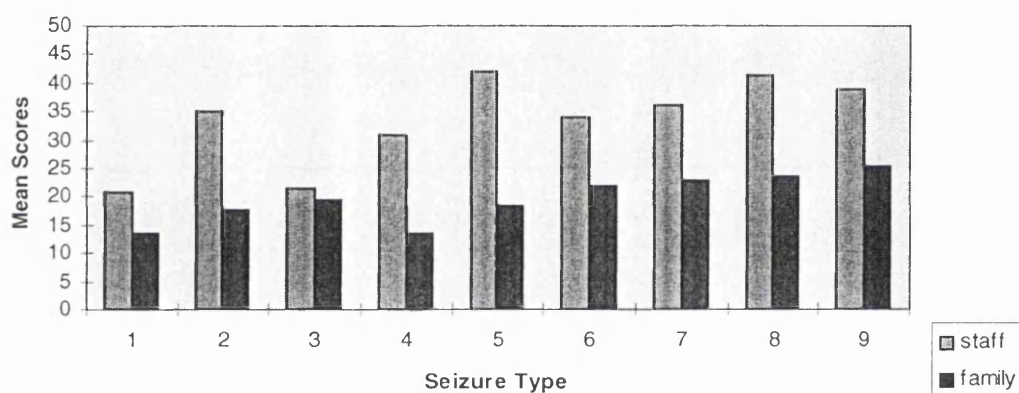
**Figure Legend**

**Figures 1a-1c: Comparison of Percentage Mean Scores for Behavioural Descriptions, Carers' Diagnostic Labels and the ILAE Classifications**

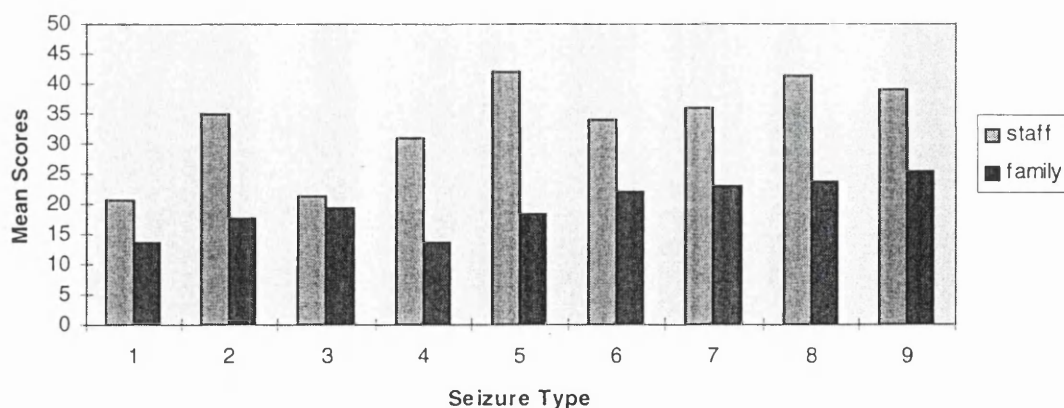
Comparison of Mean Scores for Behavioural Descriptions Between Seizure Types - Both Carer Groups - figure 1a



Comparison of Mean Scores for Carers' Diagnostic Labels Between Seizure Types - Both Carer Groups - figure 1b



Comparison of Mean Scores For the ILAE Classifications Between Seizure Types - Both Carer Groups - figure 1c

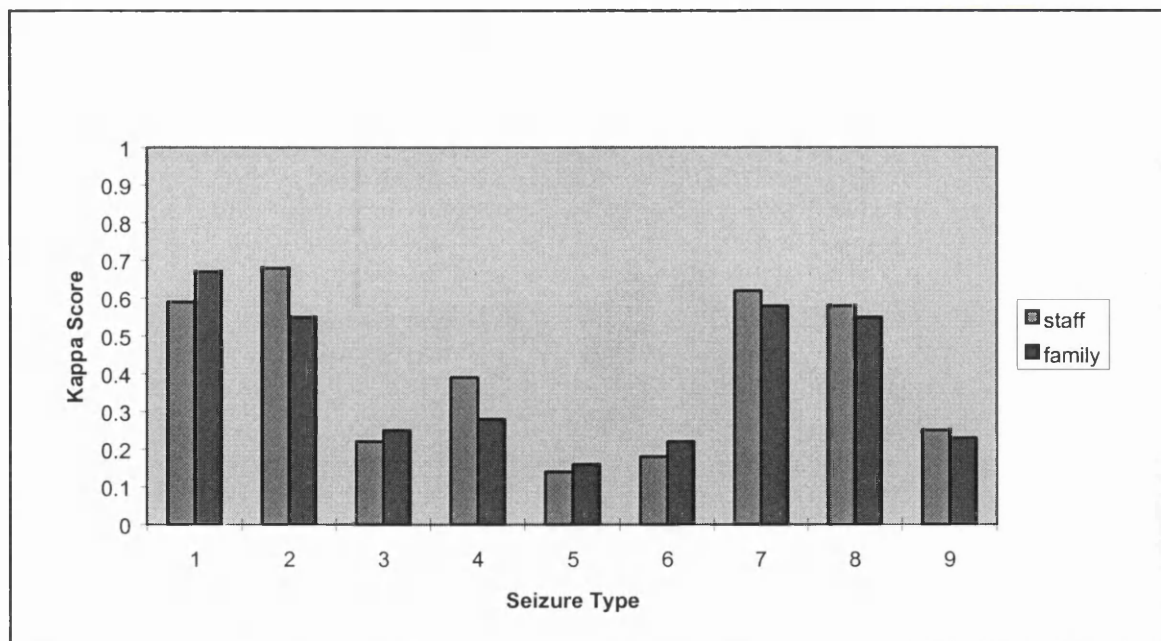


**KEY FOR SEIZURE TYPES:**

1. Complex Partial 2. Absence 3. Stereotypy 4. Myoclonic Jerks 5. Non - epileptic seizure 6. Tonic Atonic 7. Simple Partial 8. Tonic Clonic 9. Tonic

**Figure Legend**

**Figure 2: Comparison of Kappa Scores for Major/Minor Classifications Between Seizure Types - Both Carer Groups**

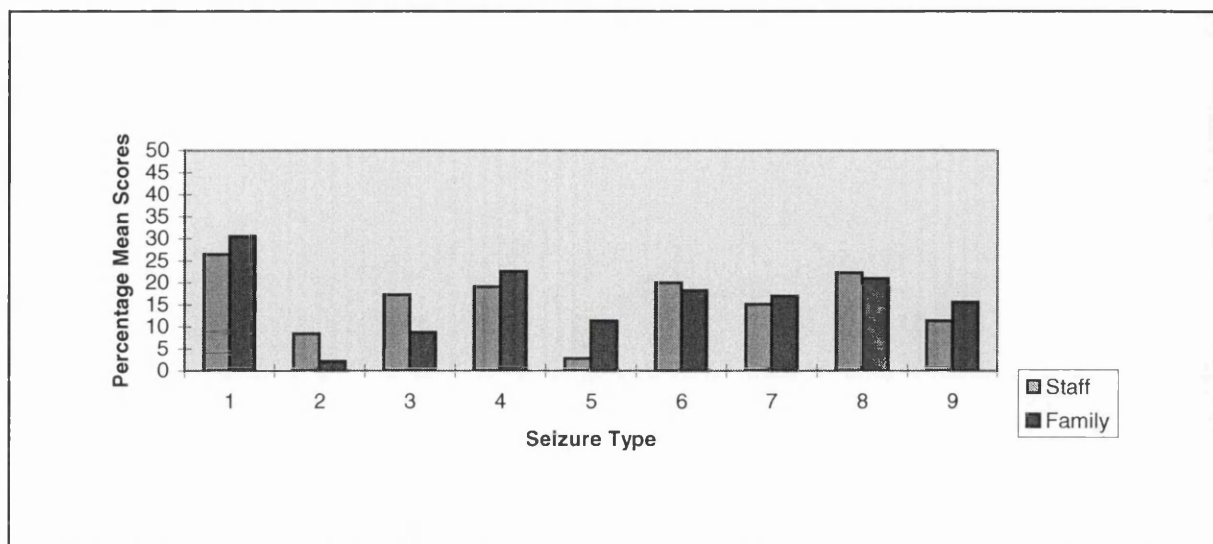


**KEY FOR SEIZURE TYPES:**

1. Complex Partial 2. Absence 3. Stereotypy 4. Myoclonic Jerks 5. Non-epileptic Seizure 6. Tonic Atonic 7. Simple Partial 8. Tonic Clonic 9. Tonic

**Figure Legend**

**Figure 3 - Comparison of Carers' Abilities on the Decision-Making Process  
Between Epileptic & Non-epileptic Events**



**KEY FOR SEIZURE TYPES:**

**1. Complex Partial 2. Absence 3. Stereotypy 4. Myoclonic Jerks 5. Non-epileptic Seizure 6. Tonic Atonic 7. Simple Partial 8. Tonic Clonic 9. Tonic**

## **5. Clinical Case Research Study**

### **An Experimental Investigation of the Role of Attention in the Maintenance of Self-Reported Anxiety and Pain**

Prepared in accordance with the notes for contributors to the journal 'Behavioural and Cognitive  
Psychotherapy'

**\* Address for correspondence**

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Trainee Clinical Psychologist  
University Department of Psychological Medicine  
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## **Abstract**

By means of a single case study, the role of attention in subjective levels of pain and anxiety was assessed using two different types of focusing procedures. An alternating treatments reversal design was used with a chronic pain patient with post-traumatic stress disorder who acted as his own control. Treatment consisted of two trials, replicating procedures within session controlling for treatment order (ABACA, ACABA). 'A' represented the baseline phase, 'B' the external focusing procedure, and 'C' the internal focusing procedure. External focusing consisted of attention training and internal focusing consisted of autogenic training. During home practice external and internal focusing procedures were also followed in a sequential design and again the order of presentation was alternated at each session to counterbalance order effects (ABAC, ACAB). Subjective measures of pain and anxiety were recorded using an analogue scale (0-100) rated at two minute intervals for every ten minute phase during each session. Visual analysis of the data concentrated mainly on sessions within the clinic. Analysis of the findings indicated that there was minimal change in levels of pain and anxiety using both treatment approaches. There was no difference between the effects of the treatment approaches. Suggestions for future methodological approaches and implications of the findings are discussed.

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## UNDERSTANDING THE NATURE OF EMOTIONS

We all experience a wide range of emotions. Some of these are basic, such as anger, sorrow, joy and fear. All human beings are biologically wired up for these emotions. Other, often more subtle emotions (e.g. resentment, apprehension or delight) are learned from combining the basic emotions in various ways.

Emotions are complex reactions to events and have a number of parts to them. They are constantly coming and going in our lives ; like waves in the sea. Most last no more than a few seconds or a few minutes. However, once started, they can often keep restarting themselves. When an emotion stays around, it is called a mood.

Emotions are prompted or triggered by events outside of ourselves, in our environments (e.g. anger at being criticised), or by events within ourselves. Possible internal prompts include a person's own thoughts, behaviours and physical reactions (eg: anger at forgetting something). One emotion can also set off another emotion (eg : guilt about feeling angry). While some emotions are started automatically by events (eg: fear on looking down from a high place), most are started by a person's view or interpretation of events. For instance, we learn over time to regard a gun pointed at us as meaning danger, and it is this interpretation of danger which gives rise to fears in us.

Although each emotional state is experienced by us as a single whole, which we identify by one name such as anger or joy, every emotion is actually made up of many parts. In other words, what feels like one reaction is, in actuality, many reactions which interact with or influence each other. These may be described under several headings:

### a) Emotional Experience:

This is closely associated with bodily changes such as tensing or relaxing of muscle, changes in blood vessels, fluctuations in heart rate, skin temperature etcetera. The most important of these changes are in facial muscles since experts now believe that these play a very important role in actually causing emotions, even when these are not all outwardly obvious.

Changes in brain chemistry are also an important part of emotions. When people have emotional feelings, they are actually sensing their bodily changes, including changes in brain chemistry. This is usually what is meant by an emotional experience. This helps to explain why it is so difficult to simply switch emotions off. The only way it can be achieved slightly is by diverting your attention, which is often no easy matter. The bodily aspects of our feelings take time to die down once stirred up, and they may start again before they have 'settled down'

Each emotion is associated with an urge to act in certain ways. For instance there is an urge to fight when angry or flee when fearful. The action urge that is present in depression is to withdraw or shut down, and when joyous to approach or to repeat activities. Although such urges may not always be acted upon, they are always part of the emotional experience.

Interpretations and beliefs are often also part of the emotion, especially when it is a complex emotion. For instance, despair is sadness combined with a belief that things are terrible and will not get better.

### **Emotional Expression:**

Emotions are not only experienced, they are also expressed. Emotional expression has a vital role to play in communicating with others. Not surprisingly it is facial expression which plays the most crucial role in this type of communication. (eg: furrowed brows when anxious). Emotions can, of course, be expressed in ways other than through facial expressions. These include bodily postures (eg: stooped posture in depression), words (eg: "I am sad", "I hate you") and actions (hitting, running, hugging etc.)

These various forms of emotional expression can have a significant effect on the experience of emotions. Learning to change our manner of expressing our emotions can, therefore, greatly contribute to the development of skill in emotion regulation.

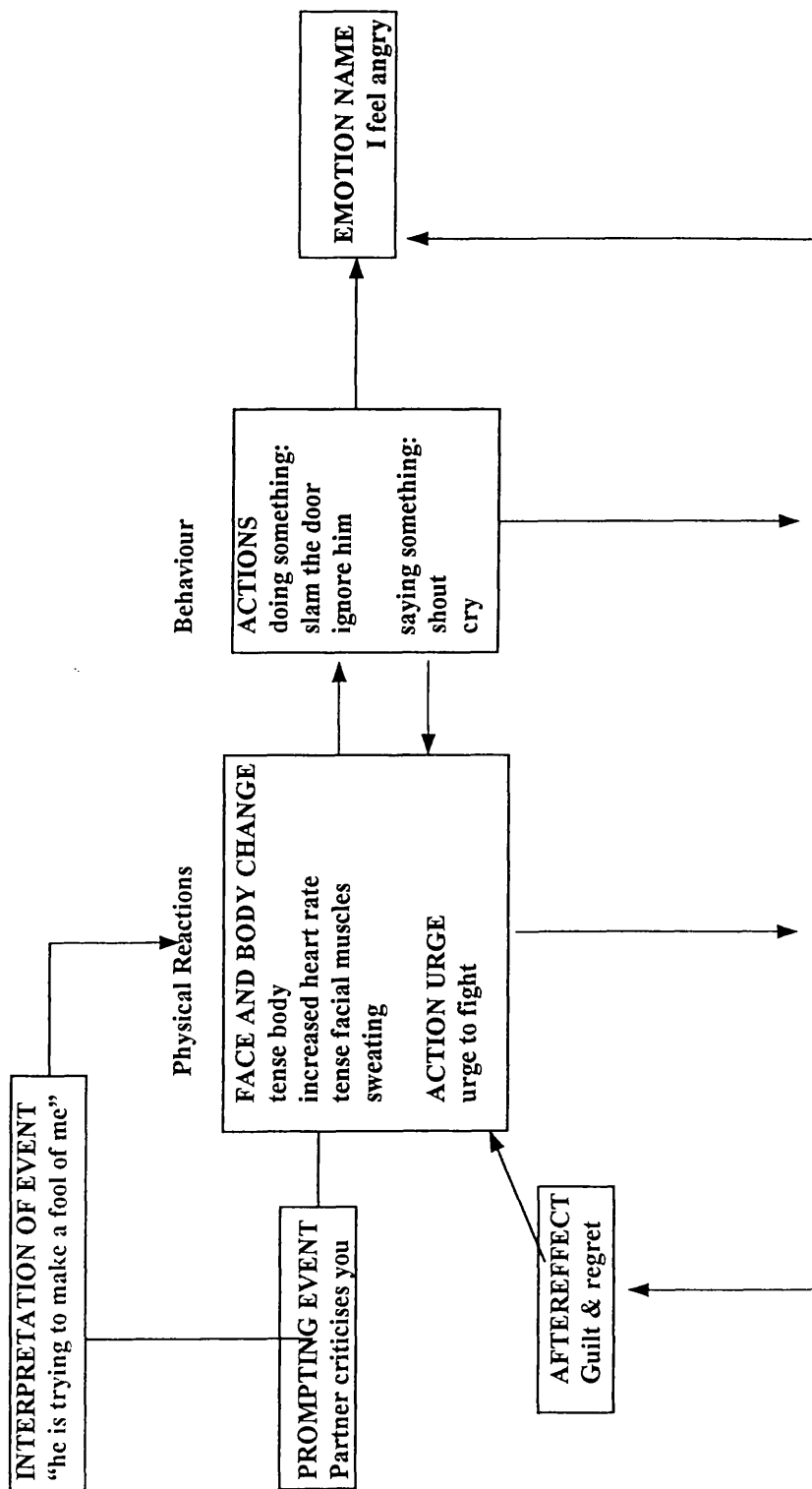
Emotions also have after-effects. Intense emotions have powerful after-effects on memory and thought. They can also affect the ability to think, physical function and behaviour. These after-effects can act as further prompts to cause additional emotional reactions which may make the initial reaction worse. Depression or fear, for example, may interfere with the person's ability to think clearly and the recognition of this may be interpreted by the person so as to cause further feelings of depression or fear.

Another way in which emotions can be influenced for the better or the worse, is through the names or labels we give to them. There is evidence that people who can give a name to an emotion are better able to control the emotion. The actual names which we each apply to emotions is learned through contact with important people in our lives and through our particular cultures.

It is generally the case that emotional states decrease relatively quickly if they are not further fired-up by a person's reactions to an emotional label or an after-effect. When this does happen, however, emotions can be re-fired over and over and leads to a spiralling of emotions. This is when we say that 'emotions love themselves.'

All these parts of the emotional response complex contribute in their various ways to the onset (beginning), experience, maintenance and resolution of emotions. Altering any one of these parts can potentially influence the whole complex. Developing the skills of emotion regulation involves learning how to change these parts so that our emotions cease to simply have a life of their own but come more under our own control or influence.

## MODEL FOR DESCRIBING EMOTIONS (EXAMPLE: anger)



Please tick the appropriate box:

Are you? Male  Female

What age are you? 16-25  26-35  36-45  46-55  56-65

1. Did you read all the information in the leaflet?

Yes  No

If No please state the reasons:

2. Did you think the length of the leaflet was appropriate?

Yes  No

If No please state the reasons:

3. Did you manage to keep your attention on the information throughout reading the leaflet?

Yes  No

If No please state the reasons:

Example:

0 \_\_\_\_\_ X \_\_\_\_\_ 100

4. The information in the leaflet was easy to read:

0 \_\_\_\_\_ 100  
Not at all Very

5. The information in the leaflet was useful:

0 \_\_\_\_\_ 100  
Not at all Very

6. I was able to understand the information:

0 \_\_\_\_\_ 100  
Not at all All of it

7. The information was relevant to my experiences:

0 \_\_\_\_\_ 100  
Not at all Very

8. The information in the leaflet was new to me:

0 \_\_\_\_\_ 100  
Not at all All of it

9. The information helped me to make sense of my emotions:

0 \_\_\_\_\_ 100  
Not at all completely

# Questionnaire

## Booklet on

# 'Emotions'

10. My expectations of therapy before reading the leaflet were:

0 \_\_\_\_\_ 100  
Negative Positive

11. My expectations of therapy after reading the leaflet are now:

0 \_\_\_\_\_ 100  
Negative Positive

12. The information in the leaflet was interesting:

0 \_\_\_\_\_ 100  
Not at all very

13. Please state the *main points* that you understood from the leaflet:

### INSTRUCTIONS:

It is our intention to use the enclosed leaflet on "Understanding the Nature of Emotions" within the department. However we are interested to know about certain aspects concerning the information given in the leaflet before distributing it to patients.

It would be very helpful if you could:

1. Read the leaflet carefully
2. Mark your answers to the questions referring to the leaflet which are in Questionnaire 1
3. Underline the answers to the questions referring to your own emotions in Questionnaire 2

14. Please state what the *most useful parts* of the leaflet were for you:

Thankyou for your time and co-operation. Your responses to the questions are both anonymous and confidential. They will be extremely valuable to this study and the future development of the leaflets.

Please return the completed booklet to the department as soon as possible.

### Correlations Between Aspects of the Emotion Regulation Leaflet

Content Variables	Easy	Useful	Under- stand	Relev- ant	New Info	Sense	Expec- tation Before	Expec- tation After	Interest
<b>Easy</b>		0.545**	0.594**	0.446**	-0.072	0.180	0.229	0.311*	0.168
<b>Usefulness</b>	0.545 **		0.317*	0.601**	0.079	0.500 **	.0406	0.449 **	0.463 **
<b>Understand</b>	0.594 **	0.317 *		0.455 **	-0.288	-0.13	0.215	0.300	-0.090
<b>Relevant</b>	0.446**	0.601 **			-0.213	0.464 **	0.180	0.517 **	0.108
<b>New Information</b>	-0.072	0.079	-0.288	-0.213		0.277	-0.320*	-0.087	0.451 **
<b>Sense</b>	0.180	0.500 **	-0.13	0.464**	0.277		-0.232	0.320	0.557 **
<b>Expectations Before</b>	0.229	0.0406	0.215	0.180	-0.320 *	-0.232		0.381*	-0.180
<b>Expectations After</b>	0.311	0.449 **	0.300	0.517**	-0.087	0.320	0.381*		0.230
<b>Interest</b>	0.168	0.463 **	-0.090	0.108	0.451 **	0.557 **	-0.180	0.212	

\*Correlation is significant at the 0.05 level (2-tailed)\*\* Correlation is significant at the 0.01 level (2-tailed)

# Clinical Psychology Forum

Clinical Psychology Forum is produced by the Division of Clinical Psychology of The British Psychological Society. It is edited by Steve Baldwin, Lorraine Bell, Jonathan Calder, Lesley Cohen, Simon Gelsthorpe, Laura Golding, Helen Jones, Craig Newnes, Mark Rapley and Arlene Vetere, and circulated to all members of the Division monthly. It is designed to serve as a discussion forum for any issues of relevance to clinical psychologists. The editorial collective welcomes brief articles, reports of events, correspondence, book reviews and announcements.

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#### Sample References:

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Lancman ME, Asconapé JJ, Penry JK. Clinical and EEG asymmetries in juvenile myoclonic epilepsy. *Epilepsia* 1994;35:302---6.

##### Book:

Kessler JA, Apse S. *The epilepsy handbook: the practical management of seizures*. 2nd edition. New York: Raven Press, 1994.

##### Chapter in a book:

Fisher RS, Uthman BM, Ramsay RE, et al. Alternative surgical techniques for epilepsy. In: Engel J Jr, ed. *Surgical treatment of the epilepsies*. New York: Raven Press, 1993:549---64.

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Barrow Neurological Institute  
350 west Thomas Road  
Phoenix, Arizona 85013-4496, U.S.A.

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- 1.1 Applicants - names and addresses including the names of co-workers and supervisor(s) if known.
- 1.2 Title - no more than 15 words.
- 1.3 Summary - No more than 300 words, including a reference to where the study will be carried out.
- 1.4 Introduction - of less than 600 words summarising previous work in the field, drawing attention to gaps in present knowledge and stating how the project will add to knowledge and understanding.
- 1.5 Aims and hypothesis to be tested - these should wherever possible be stated as a list of questions to which answers will be sought.
- 1.6 Plan of investigation - consisting of a statement of the practical details of how it is proposed to obtain answers to the questions posed. The proposal should contain information on Research Methods and Design i.e.
  - 1.6.1 Subjects - a brief statement of inclusion and exclusion criteria and anticipated number of participants.
  - 1.6.2 Measures - a brief explanation of interviews/observations/ rating scales etc. to be employed, including references where appropriate.
  - 1.6.3 Design and Procedure - a brief explanation of the overall experimental design with reference to comparisons to be made, control populations, timing of measurements, etc. A summary chart may be helpful to explain the research process.
  - 1.6.4 Settings and equipment - a statement on the location(s) to be used and resources or equipment which will be employed (if any).
  - 1.6.5 Data analysis - a brief explanation of how data will be collated, stored and analysed.
- 1.7 Practical applications - the applicants should state the practical use to which the research findings could be put.
- 1.8 Timescales - the proposed starting date and duration of the project.
- 1.9 Ethical approval - stating whether this is necessary and, if so, whether it has been obtained.

Please complete the following questions as accurately as possible. The responses are confidential and are for the purposes of the study only. Please tick the appropriate box:

Sex:  Male:  Female:

Date of Birth:

Marital Status:

- Single
- Married
- Separated
- Divorced

Type of Carer:

- Family carer
- Staff carer (e.g. keyworker)
- Other (please specify):

Care Setting:

- Hospital
- Supported group community accommodation
- Family home
- Own home (with minimal support)
- Other (please specify):

**Number of Years Experience of Caring for people with Epilepsy and Learning Disabilities:**

- up to 1 year
- 1-5 years
- 5-10 years
- more than 10 years

**Training Experience of identifying and recording seizures:**

- No training
- Informal training (e.g. of own recording method)
- Intensive training: e.g. day course
- Other (please specify):

**Number of people with epilepsy that you have cared for:**

- 1 person
- 2-5 people
- 6-10 people
- more than 10 people

**The following questions refer to a person with epilepsy in your care. Please tick the appropriate box:**

**Number of seizures per month that the person experiences:**

- less than 5
- between 6 and 10
- between 11 and 15
- more than 16

**Severity of Learning Disability of the person:**

- Mild
- Moderate
- Severe
- Profound



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**CLIP 8**

PLEASE TICK THE SEIZURE TYPE CORRESPONDING TO  
THE VIDEO CLIP:

SEIZURE TYPES:

ABSENCE:

MYOCLONIC:

CLONIC:

TONIC:

TONIC-CLONIC:

TONIC ATONIC:

SIMPLE PARTIAL:

COMPLEX PARTIAL:

NON-EPILEPTIC SEIZURE:

MOTOR STEREOTYPED BEHAVIOUR:

Following questions relate to various aspects of documenting seizure  
Please tick the appropriate box:

Indicate what type(s) of information you usually document after observing a seizure:

Behavioural Description

Coding procedure corresponding to behavioural descriptions

Major/Minor label

Own label

Diagnostic Label

Other, please describe:

Is the same person who observes and then records the seizures?

Yes  No

If No, please explain the procedure for documenting the seizures:

Please indicate the length of time that passes between observing and recording seizures:

less than 1 hour

between 1 and 3 hours

between 3 and 5 hours

more than 5 hours

Please give a brief description of a major seizure:

Please give a brief description of a minor seizure:

## EPILEPSY KNOWLEDGE PROFILE - GENERAL (E.K.P.- G)

S. Jarvie, C.A. Espie, M.J. Brodie, J.M.B. Gray

Your help with the following questionnaire would be much appreciated.

In the first 2 sections there are a number of statements about epilepsy, some of which are true, some false. Beside each statement is a box. If you think the statement is true put a tick in the box in the "true" column. If you think it is false put a tick in the box in the "false" column.

If you are not sure whether an item is true or false answer what you think is most likely to be the case. Please answer all questions.

There are many names used to describe an epileptic attack, e.g "fit", "turn", "seizure", or you may have your own name. In the following statements the term "seizure" is used to describe an epileptic attack.

### SECTION 1 - MEDICAL ASPECTS OF EPILEPSY

- 1) Epilepsy is always caused by brain damage
- 2) Epilepsy is not infectious
- 3) Epilepsy is a symptom of mental illness
- 4) All people with epilepsy have similar symptoms
- 5) Almost anyone can have a seizure given the appropriate circumstances
- 6) An E.E.G can be used to help diagnose epilepsy
- 7) If an E.E.G is abnormal, this is a definite sign of epilepsy
- 8) An E.E.G is designed to detect electrical activity from the brain
- 9) All people with epilepsy lose consciousness during seizures
- 10) An epileptic seizure can be described as a temporary lack of oxygen to the brain

	True	False

(P.T.O.)





# EPILEPSY ASSOCIATION OF SCOTLAND

NATIONAL HEADQUARTERS

48 GOVAN ROAD, GLASGOW G51 1JL Telephone: 0141-427 4911

Registered Charity Number SC000067



FACT  
SHEET

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## Epilepsy . . . do you know?

### WHAT IS EPILEPSY?

Epilepsy is a condition which affects one person in every 200 and means that a person has a tendency to have recurring seizures. It occurs in people of both sexes, cuts across all racial, social and age groups and affects people of all levels of intelligence. The spectrum of epilepsy is very wide. It includes people whose seizures have been completely controlled and who experience no adverse side effects from their treatment, people who have occasional seizures, and people who have very difficult to control epilepsy, whose seizures are frequent and severe and who sometimes have other disabling conditions. It is diagnosed most commonly in childhood and adolescence but can develop in anyone at any age. It can also develop in the older person as a consequence of such factors as strokes, heart attacks, diminishing supplies of blood to the brain etc.

Epilepsy is generally divided into two main categories called **generalised** and **partial**.

**Generalised epilepsy** involves a disturbance in the brain's normal electrical activity affecting the whole brain and during which there will always be some loss of consciousness. However there are several different kinds of seizure patterns in this generalised category with distinct features.

**Partial epilepsy** involves a disturbance in the brain's normal electrical activity confined to a local area of the brain which causes either simple partial seizures or complex partial seizures.

N.B. In some cases partial epilepsy may develop into generalised epilepsy if the disturbance spreads from the localised area to affect the whole brain.

### WHAT IS A SEIZURE?

A seizure indicates that a disturbance is occurring in the usual electrical activity of certain brain cells. It can vary from person to person e.g. in frequency and length, in what the person having the seizure experiences before, during and after the seizure, and in how long it takes the person to feel back to their usual self. Seizure symptoms also vary greatly. The seizure pattern may be very obvious to a person who is nearby or may pass almost unnoticed except to a trained observer. There are over 20 different kinds of seizure, the majority of which are shortlived and self-righting.

The pattern a seizure takes depends on where in the brain the disturbance first starts and where and how quickly that disturbance spreads. Some people experience an 'aura' (e.g. a strange taste, smell, noise sensation) which indicates a seizure is already taking place and warns that a further seizure is likely to occur.

### SOME SEIZURE TYPES

#### Generalised seizures

- i) **Absence seizures:** involve a momentary loss of consciousness which can look like a very brief daydream and often happen so quickly that an onlooker may note nothing different.
- ii) **Tonic seizures:** involve muscles of the body developing exaggerated tone so that arms, back, legs and sometimes the whole body itself can go rigid, consciousness is lost and the person, if they are standing, can fall very heavily to the ground.
- iii) **Atonic seizures:** involve loss of muscle tone in which the body goes limp, consciousness is lost and again a person who is standing can fall very heavily to the ground.
- iv) **Clonic seizures:** involve loss of consciousness followed by jerking of legs, arms or sometimes of the whole body.
- v) **Myoclonic seizures:** involve a brief loss of consciousness and sudden muscle spasms which if severe, particularly in young children, can throw the person to the ground.
- vi) **Major convulsive (tonic clonic seizures):** most of us would recognise this form of seizure during which the person loses consciousness and falls to the ground. They first stiffen, which is the tonic phase, and then start to convulse or jerk - this is known as the clonic phase. They may make strange noises and there may be saliva around the mouth in the process of the seizure. They may also be incontinent.
- vii) **Infantile spasms:** sometimes called West's Syndrome or salaam seizures because there is a brief, sudden flexion of the head, body and limbs as if the baby is making a "salaam". Consciousness is lost during the seizure.

**BOOKING FORM**

**Family Carers Epilepsy Workshop**

**Tuesday 25<sup>th</sup> January 2000**

**10a.m.-12.30pm**

**NAME:.....**

**ADDRESS: .....**  
.....  
.....  
.....

**POST CODE: .....**

**TELEPHONE NO: .....**  
.....

**IF YOU ARE UNABLE TO ATTEND, PLEASE  
STATE IF THERE IS A MORE CONVENIENT  
DAY OR TIME: .....**

.....

Division of Clinical Psychology

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## Invitation to Epilepsy and Learning Disabilities Workshop

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**Workshop for Carers of People with Epilepsy and Learning Disabilities**  
**Lecture Theatre 1**  
**Academic Centre**  
**Gartnavel Royal Hospital**  
**1055 Great Western Road**  
**on Tuesday 29<sup>th</sup> June at 6.00pm.**

*a buffet will be provided.*

This workshop aims to look at issues relating to the recognition and documentation of the various seizure types. There will be short talks from some of the professionals who work in the epilepsy field and also opportunities for discussion with other carers.

We do hope that you will accept this invitation to attend the workshop as it will provide both valuable information for the purpose of the study and will enable staff to share their experiences with other carers.

We have enclosed some booking forms for yourself and any other staff carers you know who may be interested in attending and we would be grateful if these could be returned to the Department in the FREEPOST envelopes provided.

We look forward to seeing you at the Workshop.

**JESSAMY WATKINS**  
Research Fellow

**JOANNA LIVINGSTONE**  
Trainee Clinical Psychologist

### EPILEPSY AND LEARNING DISABILITY PROJECT

*Principal Researcher: Jessamy Watkins, Research Assistant: Kalli Mantala, Research Secretary: Marian Kenny*

### DEPARTMENT OF PSYCHOLOGICAL MEDICINE

Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH

*Head of Department: Professor C A Espie*

Direct Line: 0141-211 3943  
 Fax: 0141-357 4899  
 Email: J.Watkins@clinmed.gla.ac.uk



UNIVERSITY  
 of  
 GLASGOW

Mrs Guy  
 69 Eastwoodmains Road  
 Clarkston  
 Glasgow

11 January 2000

Dear Mrs Guy

*Invitation to a Family Carer Epilepsy Workshop  
 Tuesday 25<sup>th</sup> January at the Department of Psychological Medicine,  
 Lecture Theatre 1, Academic Centre, Gartnavel Royal Hospital.*

You may recall taking part in the 'Epilepsy Project' recently, by agreeing to see Jessamy Watkins or Jennifer Ryan. Your help with this project was greatly appreciated. Another part of the Epilepsy Project (which Jessamy or Jennifer may have mentioned) is about the ways that people record information about seizures.

I would like to invite you to attend a Family Carers Workshop about seizure recording. At the workshop we will show a video of different seizures and people will write down what they see. You are then invited to discuss, with other family carers, the issues of using the various ways of recording seizures. People seem to record seizures in lots of different ways. For example, some carers may write down a description of what they see or sometimes they name the type of seizure instead.

We are trying to find out the way of recording seizures that is the best for family carers, so that doctors can tell what is happening even when they don't actually see the seizures themselves.

At the workshop, there will be opportunity to share information and discuss issues about epilepsy in general with other carers and epilepsy professionals.

If you wish to attend the workshop, please complete the enclosed booking form (a FREEPOST envelope is provided so no stamp is needed).

I look forward to seeing you at the workshop.

Yours sincerely,

Ms Joanna Livingstone  
**Trainee Clinical Psychologist**

DEPARTMENT OF PSYCHOLOGICAL MEDICINE  
 Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH

*Head of Department: Professor C A Espie*

*Family Carer Epilepsy Workshop*

*10.00 a.m. to 12.30 p.m.*

*Tuesday 25<sup>th</sup> January 2000*

*Lecture Theatre 1, Department of Psychological Medicine, Academic Centre, Gartnavel  
Royal Hospital.*

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WORKSHOP PROGRAMME

- *Welcome*
- *Viewing of video clips*
- *Refreshments*
- *Discussion with other carers*

Clip	1	2	3	4	5	6	7	8	9	10
Actual Diagnostic Label	COMPLEX PARTIAL	ABSENCE	STEREOTYPY	MYO-CLONIC	COMPLEX PARTIAL	NON-EPILEPTIC SEIZURE	TONIC ATONIC	SIMPLE PARTIAL	TONIC CLONIC	TONIC
Carer										
1	complex partial	complex partial	missing	missing	missing	missing	missing	missing	tonic clonic	missing
2	myoclonic	missing	simple partial	motor stereotyped behaviour	tonic	non-ep.seizure	clonic	partial	tonic	tonic
3	absence	absence	non-ep.seizure	simple partial	tonic-clonic	absence	tonic clonic	tonic clonic	tonic clonic	absence
4	absence	non-ep.seizure	non-ep.seizure	non-ep.seizure	tonic-clonic	missing	missing	tonic clonic	complex partial	absence
5	myoclonic	absence	motor stereotyped	myoclonic	tonic-clonic	myoclonic	atonic	motor stereotyped	tonic clonic	tonic-clonic
6	complex partial	absence	myoclonic	tonic myoclonic	complex partial	complex partial	complex partial	simple partial	tonic clonic	complex partial
7	myoclonic	absence	motor stereotyped	myoclonic jerks	tonic	myoclonic jerks	atonic	complex partial	tonic clonic	simple partial
8	non-ep.seizure	non-ep.seizure	myoclonic	myoclonic	tonic	simple partial	complex partial	atonic	complex partial	don't know
9	absence	absence	non-ep.seizure	myoclonic	tonic	tonic clonic	atonic	non-ep.seizure	tonic clonic	tonic
10	missing	absence	non-ep.seizure	missing	tonic	missing	complex partial	missing	tonic clonic	partial
11	non-ep.seizure	absence	missing	Jacksonian	partial complex	missing	missing	missing	tonic clonic	complex partial
12	non-ep.seizure	non-ep.seizure	non-ep.seizure	not applicable	complex partial	complex partial	clonic	missing	complex partial	simple partial

Clip	1	2	3	4	5	6	7	8	9	10
Actual Diagnostic Label	COMPLEX PARTIAL	ABSENCE	STEREO-TYPY	MYO-CLONIC	COMPLEX PARTIAL	NON-EPILEPTIC SEIZURE	TONIC ATONIC	SIMPLE PARTIAL	TONIC CLONIC	TONIC
Carer										
13	simple partial tonic clonic	absence	simple partial myoclonic	myoclonic	tonic	simple partial missing	absence	simple partial missing	complex partial tonic clonic	missing
14	non-ep.seizure	absence	non-ep.seizure	tonic	clonic	simple partial	tonic atonic	tonic	tonic clonic	myoclonic
15	myoclonic	absence	tonic	tonic	tonic-clonic	absence	complex partial	atonic	tonic clonic	tonic
16	non-ep.seizure	absence	missing	complex partial	tonic	absence	tonic	non-ep.seizure	complex partial	generalised-absence
17	myoclonic	non-ep.seizure	stereotyped behaviour	myoclonic	tonic	absence	tonic	myoclonic	tonic clonic	myoclonic
18	complex partial	absence	missing	missing	tonic	missing	tonic atonic	non-ep.seizure	complex partial	partial
19	myoclonic	absence	non-ep.seizure	myoclonic	tonic	very mild	non-ep.seizure	non-ep.seizure	tonic clonic	tonic clonic
20	absence	absence	non-ep.seizure	complex partial	complex partial	missing	non-ep.seizure	non-ep.seizure	myoclonic	complex partial
21	missing	non-ep.seizure	non-ep.seizure	complex partial	tonic	missing	myoclonic	tonic clonic	tonic clonic	myoclonic
22	minor	absence	motor stereotyped behaviour	don't know	missing	loss of concentration	atonic	non-ep.seizure	tonic clonic	missing
23	missing	absence	missing	don't know	tonic-clonic	boredom	missing	absence	missing	minor tremor
24	petit mal	absence	minor	petit mal	missing	none	atonic	missing	major mal	tonic
25	missing	petit mal	non-ep.seizure	tonic	grand mal/myoclonic	missing	missing	non-ep.seizure	clonic-tonic	petit mal
26	petit mal	absence	non-ep.seiz	missing	rigid seizure	missing	minor	non-ep.seiz	grand mal	partial
27										

Clip	1	2	3	4	5	6	7	8	9	10
Actual Diagnostic Label	COMPLEX PARTIAL	ABSENCE	STEREO-TYPY	MYO-CLONIC	COMPLEX PARTIAL	NON-EPILEPTIC SEIZURE	TONIC ATONIC	SIMPLE PARTIAL	TONIC CLONIC	TONIC
Carer										
28	missing	petit mal	missing	partial	missing	tonic	clonic	petit mal	tonic clonic	petit mal
29	missing	absence	non-ep.seizure	petit mal	missing	complex partial	grand mal	missing	grand mal	petit mal
31	missing	non-ep.seizure	myoclonic	petit mal	don't know	absence	fall	absence	grand mal	absence
32	missing	petit mal	non-e.s.	missing	missing	missing	petit mal	non-e.s.	missing	missing
33	myoclonic jerks	absence	motor stereotyped behaviour	infantile spasm	tonic seizure	missing	minor	missing	tonic clonic	missing
34	missing	non-ep.seizure	non-ep.seizure	myoclonic	complex partial	myoclonic jerks	missing	missing	grand mal	minor tremor
35	missing	absence	petit mal	mild seizure	complex partial	no seizure	missing	missing	grand mal	tonic
36	missing	non-ep.seizure	missing	non-ep.seizure	tonic clonic	non-ep.seizure	grand mal	spontaneous recovery	tonic clonic	myoclonic
37	missing	missing	non-ep.seizure	missing	tonic clonic	usual behaviour	drop seizure	non-ep.seizure	missing	petit mal
38	missing	missing	missing	missing	complex partial	missing	very mild	non-ep.seizure	don't know	partial
39	mild	absence	non-ep.seizure	don't know	tonic clonic	non-ep.seizure	missing	missing	missing	tonic-clonic
40	absence	missing	non-ep.seizure	missing	complex partial	missing	missing	non-ep.seizure	tonic clonic	petit mal
41	missing	don't know	non ep-seizure	myoclonic	complex partial	complex partial	non-ep.seizure	missing	grand mal	minor
42	missing	non-ep.seiz	missing	missing	partial	missing	grand mal	simple	grand mal	absence

Clip	11	12	13	14	15	16	17	18	19	20
Known Diagnostic Label	TONIC-CLONIC	MYO-CLONIC	COMPLEX PARTIAL	ABSENCE	TONIC	STEREO-TYPY	SIMPLE PARTIAL	CLONIC	NON-EPILEPTIC SEIZURE	ABSENCE
Carer										
1	tonic clonic	tonic	missing	myoclonic	tonic atonic	brain injury	missing	missing	non-epileptic seizure	absence
2	tonic atonic	partial	motor stereotyped behaviour	no seizure activity	motor type behaviour	partial complex	simple partial	myoclonic	complex partial	absence
3	tonic clonic	simple partial	absence	non-ep.seizure	simple partial	normal behaviour	simple partial	tonic clonic	non-epileptic seizure	non-epileptic seizure
4	tonic clonic	tonic clonic	absence	absence	motor stereotyped	missing	missing	tonic clonic	missing	non-epileptic seizure
5	complex partial	non-ep. seizure	complex partial	non-ep.seizure	tonic	motor stereotyped	simple partial	non-epileptic seizure	complex partial	absence
6	clonic	complex partial	complex partial	non-ep.seizure	motor stereotyped	motor stereotyped	simple partial	non-epileptic	tonic	absence
7	tonic clonic	non-seizure	complex partial	simple partial	myoclonic	motor stereotyped	non-ep/partial	non-epileptic	complex partial	absence
8	complex partial	tonic atonic	myoclonic	motor stereotyped behaviour	myoclonic	motor stereotyped	tonic	tonic	absence	absence
9	complex partial	don't know	missing	myoclonic	tonic	motor stereotyped	complex partial	clonic	simple partial	non-epileptic seizure
10	tonic clonic	don't know	missing	missing	non-ep.seizure	non-ep.seizure	don't know	tonic-clonic	clonic	absence
11	tonic clonic	don't know	partial complex	don't know	myoclonic	absence	complex partial	spinal damage	absence	self-stimulation
12	complex partial	tonic clonic	tonic clonic	don't know	myoclonic	partial	simple partial	complex partial	complex partial	tonic clonic
13	clonic	simple partial	myoclonic	missing	missing	stereotyped	simple partial	tonic	myoclonic	absence

Clip	11	12	13	14	15	16	17	18	19	20
Known Diagnostic Label	TONIC-CLONIC	MYO-CLONIC	COMPLEX PARTIAL	ABSENCE	TONIC	STEREOTYPY	SIMPLE PARTIAL	CLONIC	NON-EPILEPTIC SEIZURE	ABSENCE
Carer										
14	tonic clonic	tonic-clonic	tonic-clonic	missing	missing	partial	partial	tonic	myoclonic	absence
15	tonic clonic	non-ep.seizure	partial complex	missing	myoclonic	non-ep.seizure	myoclonic	tonic-clonic	absence	absence
16	tonic clonic	non-ep.seizure	non-ep.seizure	tonic clonic	complex partial	non-ep.seizure	myoclonic	generalised	long absence	absence
17	tonic clonic	simple partial	complex partial	myoclonic	myoclonic jerks	myoclonic	generalised	non-epileptic	complex partial	absence
18	tonic clonic	non-ep.seizure	complex partial	partial seizure	myoclonic	complex partial	myoclonic jerks	stereotypical movement	complex partial	absence
19	tonic clonic	partial	absence	stereotypical movement	tonic	stereotypical behaviour	non-ep.seizure	tonic	partial	non-epileptic seizure
20	tonic/atonic clonic	simple partial	complex partial	missing	complex partial	motor stereotyped	simple partial	clonic	complex partial	absence
21	clonic	myoclonic	complex partial	absence	simple partial	stereotyped	complex partial	myoclonic	complex partial	absence
22	tonic clonic	myoclonic	complex partial	absence	missing	stimulation	non-ep.seizure	tonic clonic	complex partial	absence
23	tonic clonic	absence	complex partial	simple partial	petit mal	motor stereotyped behaviour	missing	missing	complex partial	absence
24	missing	missing	complex partial	absence	non-ep.seizure	non-ep.seizure	minor	major	non-epileptic seizure	non-epileptic seizure
25	major	none	missing	missing	uncontrolled movement	poor concentration	clonic	clonic-tonic	non-epileptic seizure	non-epileptic seizure
26	clonic-tonic	missing	petit mal	continuous minor seizures	missing	mental handicap	partial	grand mal	missing	non-epileptic seizure

Clip	11	12	13	14	15	16	17	18	19	20
Known Diagnostic Label	TONIC-CLONIC	MYO-CLONIC	COMPLEX PARTIAL	ABSENCE	TONIC	STEREOTYPY	SIMPLE PARTIAL	CLONIC	NON-EPILEPTIC SEIZURE	ABSENCE
Carer										
27	complex partial	missing	petit mal	minor	non-ep.seizure	non-ep.seizure	partial	clonic	missing	non-epileptic seizure
28	tonic-clonic	non-ep.seizure	lapse of concentration	blackouts	petit mal	non-ep.seizure	petit mal	missing	non-epileptic seizure	non-epileptic seizure
29	missing	missing	partial	non-ep.seizure	petit mal	behaviour pattern	non-ep.seizure	grand mal	missing	don't know
30	grand mal	petit mal	petit mal	absence	missing	motor stereotyped behaviour	very mild	grand mal	non-epileptic seizure	non-epileptic seizure
31	grand mal	petit mal	petit mal	absence	missing	non-epileptic seizure	missing	missing	petit mal	non-epileptic seizure
32	missing	missing	absence	petit mal	missing	non-epileptic missing	partial seizure	tonic clonic	absence	non-epileptic seizure
33	partial	partial	missing	non-ep.seizure	non-ep.seizure	missing	missing	missing	missing	absence
34	missing	missing	missing	missing	very minor	non-epileptic seizure	absence/partial	partial	missing	non-epileptic seizure
35	myoclonic	myoclonic jerks	missing	missing	non-ep.seizure	non-epileptic seizure	minor	mental problem	missing	non-epileptic seizure
36	grand mal	minor	grand mal	non-ep.seizure	non-ep.seizure	mental handicap	non-ep.seizure	missing	absence	mental handicap
37	missing	non-ep.seizure	minor	very mild	non-ep.seizure	missing	missing	tonic clonic	non-epileptic seizure	non-epileptic seizure
38	tonic clonic	non-ep.seizure	missing	non-ep. Seizure	non-ep.seizure	usual behaviour	partial	missing	diabetic seizure	missing
39	missing	missing	missing	missing	non-ep.seizure	don't know	missing	missing	non-epileptic seizure	don't know

Clip	11	12	13	14	15	16	17	18	19	20
Known Diagnostic Label	TONIC-CLONIC	MYO-CLONIC	COMPLEX PARTIAL	ABSENCE	TONIC	STEREO-TYPY	SIMPLE PARTIAL	CLONIC	NON-EPILEPTIC SEIZURE	ABSENCE
..... Carer										
40	don't know	non-ep.seizure	missing	missing	non-ep.seizure	missing	missing	missing	non-epileptic seizure	non-epileptic seizure
41	missing	non-ep.seizure	don't know	non-ep	localised seizure	non-ep.seizure	missing	clonic	missing	missing
42	tonic-clonic	myoclonic	missing	missing	tonic	absence stereotypy	clonic	tonic-clonic	absence	absence

**Frequencies of Behaviours Documented By a Sample of Carers (n = 14) for Partial and Generalised Seizures, and Non-epileptic Events**

	<b>Partial</b>	<b>Generalised</b>	<b>Non-epileptic event</b>
BITING FINGERS	45.8%		
BECOMES STILL/ VACANT	20.5%	8.3%	41.6%
PLAYING WITH OBJECT		33.3%	
AGITATED	50%		
JERKING MOVEMENT	70.8%	41.6%	33.3%
SMILING	16.7%		
EYES BLINKING	44.4%	8.3%	
HEAD SHAKING		33.3%	
HANDS SHAKING IN THE AIR		33.3%	
‘C’ STEREOTYPED BEHAVIOUR			
BODY SHAKING		33.3%	
MAINTAINS CONSCIOUSNESS		8.3%	
BODY RIGID	58.3%	75%	
ARMS STRAIGHT OUT	33.3%		
CONFUSION/ DISORIENTATION	12.48%	8.3%	25%
MOUTH TWITCHING	29.18%		16.7%
MUSCLES LIMP		12.5%	
FALLS OVER SUDDENLY		79.1%	
LONG RECOVERY PERIOD		25%	
TWITCHING HEAD		8.3%	
HEAD FLOPS BACK	45.8%		

	<b>Partial</b>	<b>Generalised</b>	<b>Non-epileptic event</b>
EXPLORATORY BEHAVIOUR			8.3%
LOOKING AROUND		10.3%	16.7%
WALKING AROUND			25%
STARING AT CEILING			16.7%
FLICKING FINGERS			25%
LYING IN FOETAL POSITION	25%		

Behavioural Features	Major (Staff carers)	Major (Family Carers)	Minor (Staff Carers)	Minor (Family Carers)
Body jerking	38	31.5	9.5	5.2
Falls over	38	26.3		
Loss of Consciousness	28.5	21	14.2	5.26
Rigidity	21.7	10.5	13	5.2
Difficulty breathing	21.7			
Tonic-Clonic	8.6	10.5		
Colour change	19	5.2		5.2
Absence			25	5.2
Incontinent	4.3			
Facial movements	8.6	5.2		
Strange eye movements	11.9	15.7	13	10.5
Salivation	9.5	10.5		

Percentage Frequencies of Behavioural Features used to define Major & Minor Seizures by a Sample of Staff and Family Carers (n = 14)