ADULTS WITH LEARNING DISABILITIES AND EPILEPSY: KNOWLEDGE ABOUT EPILEPSY BEFORE AND AFTER A PSYCHOEDUCATIONAL PACKAGE (EPILEPSY AND YOU)

and

RESEARCH PORTFOLIO

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Small Scale Service Evaluation Project

Do Clinical Psychologists Know Why Patients Do Not Attend Initial Appointments?

Prepared in accordance with guidelines for submission to "Clinical Psychology Forum" (Appendix 1.1)

Do Clinical Psychologists Know Why Patients Do Not Attend Initial Appointments?

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INTRODUCTION

A well documented problem for Clinical Psychology Departments is that approximately twenty per cent of people do not attend initial appointments (Philip, 1983; Weighill, Hodge and Peck, 1983; Crawford, Blakey and Gullion, 1987; Munro and Blakey, 1988). This phenomenon has far reaching consequences. Waiting list times are longer than necessary for other patients, therapist time is wasted and there is financial expense for the Trust involved. It is therefore, advantageous to be able to predict patients likely not to attend initial appointments so management strategies can be developed.

Previous studies investigating this issue reveal we do not know why patients choose not to attend initial appointments. Weighill et al. (1983) suggest females are more likely not to attend initial appointments whereas Marks (1984) finds no difference between the genders. Weighill et al. (1983) propose anxious clients are more likely not to attend, Marks (1984) suggests the nature of the problem does not affect attendance and Simons (1980) states non-attendance at a sex-therapy clinic is significantly higher than the norm (32%). Trepka (1986) proposes initial appointment non-attendees are more likely to have had previous contact with psychiatric services, contrary to the finding by Carpenter, Morrow, Del Gaudio and Ritzler (1981) in an American sample. Philip (1983) and Crawford et al. (1987) disagree whether the venue of the appointment affects attendance, the former suggesting Health Centre appointments more likely to be not attended than those in a psychiatric hospital, the latter arguing there is no difference.

Other studies require replication. Carpenter et al. (1981) propose younger patients are more likely not to attend initial appointments. Weighill et al. (1983) propose patients with families, of lower socio-economic status and who use public transport, are more likely not to attend appointments. Munro and Blakey (1988) argue patients who suggest the referral themselves, and who discussed this twice with their GP, are *more likely to attend* initial appointments.

Studies agree on one finding. In general health care there is a relationship between the length of waiting list time and future attendance (Becker, Drachman and Kirscht, 1974). Weighill et al. (1983) and Marks (1984) do not find this relationship for clinical psychology patients.

Unfortunately, conclusions from these studies are hampered by sampling methods. Weighill et al. (1983) examine non-attendance in a group of new and current patients. However, Trepka (1986) argues patient attrition should not be regarded as a unitary phenomenon. He recommends distinguishing between patients who do not attend initial appointments from those who do, but drop out of treatment later.

Therefore, factors affecting patient initial appointment non-attendance to be investigated in this study are;

1. Gender.
2. Nature of the problem.
3. Previous contact with psychiatric services.
4. The venue of the appointment.

5. Age.
6. Whether the patient has a family to care for.
7. Socio-economic status.
8. Reliance on public transport.
9. Who suggested the referral.
10. How many times the referral was discussed with the GP.
11. Waiting list time.

Following recommendations by Weighill et al. (1983) there will also be investigation into the patient's preconception of treatment, the lack of anticipated benefit, improvements in their psychological state and inhibiting aspects of the venue.

This study investigates initial appointment non-attendance rates at a Clinical Psychology Department that utilises an "opt-in" procedure to manage its waiting list. This procedure, argued by Startup (1994) as the most appropriate waiting list management measure, requires referred patients to re-register their desire for an appointment approximately four to six weeks before one is offered.

This study divides initial appointment non-attendees into two groups. Reference to a later-attendee refers to patients who although not attending the first initial appointment "opted into" attend subsequently. The Department being investigated requires non-attendees to request a second initial appointment. Reference to a DNA describes an individual who, after "opting into" the initial appointment, does not attend the appointment and has no further contact with the psychology service.

Research questions to be addressed are:

1. What is the initial appointment non-attendance rate within the patient group studied?
2. How does the non-attendance rate break down into later-attendees and DNAs?
3. How much therapist time is lost and what is the financial expense to the Trust from DNAs?
4. What factors are indicative of DNAs within this sample?
5. What reasons do DNAs give for their non-attendance?

DNAs are highlighted in this investigation because their failed contact with the service is contrary to their recent "opting into" an initial appointment.

SAMPLE

GP referrals who did not attend an initial appointment within a one year period were studied. For the DNAs a control group of patients who entered treatment at the first appointment (attendees) within the same time span were studied.

METHOD

The clinical files of all patients who did not attend an initial appointment were retrieved. The demographic information of DNAs and attendees was collected from the GP referral letter. Clinical files of attendees were randomly selected. Data was collected a minimum of three months after the initial appointment offered. For the

DNAs and the attendee group an estimate of the classification for the residential area of each subject, from very affluent to severely deprived, was determined using guidelines proposed by Carstairs and Morris (1991). The GP's proposed reason for referral was categorised using the American Psychiatric Association DSM-IV (1994) major diagnostic classes.

To gather additional data a questionnaire and a covering letter for the DNA and the attendee groups were developed (Appendices 1.2 and 1.3). After piloting the materials on three colleagues, recommendations were corrected. It was investigated whether any subjects had died. This was conducted by gaining information from the Hospital database which is updated by information from GPs and the local Council. A questionnaire, covering letter and a prepaid return envelope were forwarded to each subject in a hand written envelope after the materials were re-piloted on another colleague. The Flesch Reading Ease of all materials was equivalent to standard writing.

RESULTS

The initial appointment non-attendance rate divided into later-attendees and DNA groupings

GP referrals formed the largest proportion of referrals to the Department investigated. Of 1,106 initial appointments offered within the time span 950 (85.9%) were for Outpatients. Within this Outpatient group 44% (418) were GP referrals, 35.4% (336) were neuropsychological or spinal injury referrals and 20.6% (196) were other agency

referrals, such as Hospital Consultants or Lawyers. When the GP referral initial appointment non-attendance rate was compared with the non-attendance rate of the other Outpatient groupings combined the results were 22.7% and 10.5% respectively.

Within the time studied 282 (67.5%) GP referrals attended the initial appointment, 95 (22.7%) did not and 41 (9.8%) cancelled. Of the 95 original non-attendees 54 (56.8%) were later-attendees and 41 (43.2%) were DNAs. Thus, of 418 GP referrals 9.8% (41) did not attend for an appointment at any point in time.

Therapist time lost and financial expense for the Trust by DNAs

Approximately forty-one therapist hours were not utilised by DNAs (n=41). The financial expense was approximately £1,087 using guidelines calculated by Webster and Thornhill (1993) but adjusted for current salary ranges.

Factors suggestive of DNAs

GP referral letter data revealed DNAs (n=41) and the control group of attendees (n=41) did not differ on gender, level of deprivation/affluence of their residential area, reason for referral, location of the appointment (whether in a Hospital or Health Centre) or previous attendance with the service. The groups differed significantly on age (x^2=13.75, df=3, $p<0.004$) with DNAs tending to be younger (Table 1), and on waiting list time (x^2=8.62, df=3, $p<0.035$) with DNAs tending to wait longer for an appointment (Table 2).

	Age			
	18 - 27 years	28 - 37 years	38 - 47 years	>48 years
DNAs	16	18	6	1
Attendees	10	9	12	10

Table 1. Age groupings for DNAs and attendees, n=82

	Waiting list time			
	1 - 6 weeks	7 - 12 weeks	13 - 18 weeks	>18 weeks
DNAs	9	10	10	12
Attendees	11	19	8	3

Table 2. Waiting list time for DNAs and attendees, n=82

Other suggestive factors could not be investigated because of the poor questionnaire response rate. As it was discovered that one subject in each group had died after the date of the appointments offered forty questionnaires were sent out for each group. Fourteen attendees (35.0%) and seven DNAs (17.5%) responded.

Reasons given for attendance/DNAs

Due to the poor questionnaire response rate the replies received are not representative of the groups. Therefore, reasons for attendance/DNAs cannot be investigated.

DISCUSSION

Of five research questions, three are answered clearly and one answered to some degree.

The non-attendance rate for initial appointments, approximately twenty per cent, is similar to that noted by other researchers (Philip 1983; Weighill et al. 1983; Crawford et al. 1987; Munro and Blakey, 1988).

However, analysis of this group reveals over half return later for an initial appointment. Thus, the proportion of DNAs is only 9.8% for the sample. This suggests that even when patients do not attend an initial appointment "opted into", they are likely to request and attend another initial appointment at a later date. This finding is contrary to Weighill et al. (1983) who propose that if a patient does not attend an initial appointment their non-compliance is doubled for the next appointment.

For DNAs the therapist time lost was slightly more than one therapist's working week. The associated cost was just over one thousand pounds. Although there appears to be a substantial loss of time and expense incurred, therapists utilise the time to conduct other clinical or administrative business.

DNAs in this sample tend to be younger individuals. They also tend to wait longer for appointments. Despite adopting some recommendations by Fox, Crask and Kim (1988) and Duncan (1979) to increase the questionnaire reply rate, the poor response meant some suggestive factors could not be examined.

The poor questionnaire response meant reasons for attendance/DNA could not be investigated. This is partly unsurprising given that the DNAs had already rejected an appointment. However, one would have expected more attendees to respond. Reminder letters were not forwarded to non-respondents; one must acknowledge the ethics of twice approaching individuals who have chosen not to return the first questionnaire and/or have not attended an agreed appointment.

In conclusion, this study highlights some indicators why there are initial appointment DNAs. It reveals that younger patients and those waiting longer for an appointment are more likely to DNA. The difficulty of reliably questioning DNAs is demonstrated by the poor questionnaire response rate. Limited recommendations on how to manage initial appointment DNAs are proposed.

RECOMMENDATIONS TO MANAGE INITIAL APPOINTMENT DNAs

1. **Prepare written information for patients detailing the psychology service.** As DNAs tend to be younger the leaflet should be designed to attract this population. Startup (1994) suggests this simple and inexpensive addition to practice appears to increase consumer satisfaction even though there appears to be little evidence that information leaflets independent of "opt-in" systems are effective in reducing non-attendance rates (Balfour, 1986; Green and Giblin, 1988; Spector, 1988; Markman and Beeney, 1990; Webster, 1992).

2. **For the sample group studied inform GPs that DNAs tend to be younger and tend to have been on the waiting list longer.** GPs can then emphasise to these patients the importance of attending or cancelling the arranged appointment.

3. **Prompt patients near the time of their appointment.** Burgoyne, Acosta and Yamamoto (1983) demonstrate in a psychiatric outpatient clinic, that a telephone prompt nearer the time of an appointment helps to reduce non-attendance rates.

4. **If a patient does not attend an initial appointment Clinical Psychology Departments need not automatically offer another.** This study finds over half the sample are later-attendees rather than DNAs. Since the Department investigated does not automatically send out second initial appointments, it appears that patients take on the responsibility of arranging another appointment should they desire one.

Future research needs to re-address suggestive factors and reasons for DNAs. In addition, it would be interesting to investigate the suggestive factors and reasons for later-attendees. More information may be gained by questioning patients when they "opt-into" the appointment. When tailored management strategies are developed for non-attendance groupings a future audit could analyse the strategies' effectiveness.

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Major Research Project Literature Review

Adults with a Learning Disability and Epilepsy: a review

Prepared in accordance with guidelines for submission to "Seizure" (Appendix 2.1)

Adults with a Learning Disability and Epilepsy: a review

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ABSTRACT

The article presents an overview of epilepsy in adults with a learning disability. However, due to limited research, investigations focusing on non-learning disabled adults will also be presented. The terms 'epilepsy' and 'learning disability' will initially be defined. After which, the prevalence and presentation of epilepsy in adults with a learning disability will be discussed and issues of differential diagnosis examined. Psychological adjustment reactions to having epilepsy will be discussed, particularly whether having epilepsy results in an increased risk for psychiatric disturbance, behaviour disturbance or personality disorder in adults with a learning disability. How epilepsy affects the learning potential of adults with a learning disability will be presented prior to a discussion of professional approaches to epilepsy. Recent advances in professional care in relation to the psychological adjustment of adults with a learning disability, will be presented and recommendations for future research made.

Key Words

Adult Learning disability Epilepsy Psychological adjustment Professional approaches

A DEFINITION OF 'EPILEPSY'

Epilepsy is "... an abnormal and excessive discharge of a set of neurones in the brain. The clinical manifestation consists of sudden and transitory abnormal phenomena, which may include alterations of consciousness, motor, sensory, autonomic or psychic events, perceived by the patient or an observer." [1] (p. 1).

An individual is usually diagnosed as having epilepsy only if that person has had two or more epileptic seizures. A diagnosis and classification of epilepsy follows guidelines established by the International League Against Epilepsy (ILAE) in 1981 [2]. However, as electroencephalography (EEG) can be unavailable or impracticable, a classification based predominately on clinical criteria has also been suggested by the ILAE [3].

A DEFINITION OF 'LEARNING DISABILITY'

The American Psychiatric Association [4] states an individual has a learning disability if they have an intelligence quotient (IQ) of approximately 70 or below, as measured by standardised, individually administered intelligence tests. The person must also have significant limitations in their adaptive functioning in at least two skill areas, for example; communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. Adaptive functioning is defined as how effectively individuals cope with life demands and how they meet standards of personal independence expected of someone in their particular age and cultural group [4]. The onset of a learning

disability occurs before the age of eighteen years. A learning disability can be categorised into four levels of increasing severity; mild, moderate, severe, profound.

EPILEPSY IN ADULTS WITH A LEARNING DISABILITY

Epilepsy is reported to affect approximately one per cent of the general population with a lifetime prevalence of approximately three per cent [5].

However, around twenty per cent of people with learning disabilities have epilepsy, in that they present with at least one epileptic seizure per year, and prevalence rates appear to be correlated with the level of learning disability; approximately fifty per cent of individuals with a severe or profound learning disability have epilepsy [6-8]. The more severe levels of learning disability can also be associated with comparatively more mixed seizure presentation [9, 10].

Epileptic seizures are more common in chromosomal abnormality syndromes such as Angelman's and Fragile X syndrome rather than in Down's or Prader Willi Syndrome [11]. A review of previous studies into the frequency of epilepsy in people with Trisomy 21 (Down's Syndrome) concluded that, although epilepsy is not as common as the frequency of epilepsy in other individuals with a learning disability due to other causes, the frequency of epilepsy in Trisomy 21 is still above that of non-learning disabled individuals, at five to ten per cent [12]. Epilepsy also presents as a part of other conditions, for example, tuberous sclerosis.

Singh and Towle have proposed there is no relation between IQ and seizure control in adults with learning disabilities living in the community [10]. However, within the study subjects with epileptic syndromes (such as Lennox-Gastaut syndrome) that can be difficult to control were excluded.

- ***Differential diagnosis of epilepsy***

Non-epileptic seizures (NES) can present. NES are seizures that look like epilepsy but have entirely different mechanisms. Stephenson [13] has proposed four major categories of NES. First, anoxic seizures, a fainting or simple syncope, where there is a short, sudden loss of oxygen supply to the brain that leads to loss of consciousness and loss of postural tone, and, if longer lasting, to a convulsion. Second, psychic seizures, of psychological origin. Helpful diagnostic criteria for NES of a psychic origin have been proposed [14, 15]. Third, toxic seizures, primarily motor reactions as a sequelae to an increasing number of drugs. Fourth, hypnic seizures, which are primarily disorders of sleep. In cases of differential diagnosis video EEG telemetry can be useful in distinguishing seizures from NES.

There is little research into NES in adults with a learning disability; the majority of investigations have been limited to children and non learning disabled adults [13]. Espie and Paul [16] provide a review of NES in adults with a learning disability. A single case report documents the use of behavioural interventions to effectively reduce the frequency of a learning disabled individual's NES [17]. In addition, Paul [18] has recently demonstrated the application of EEG telemetry for the differential diagnosis of epileptic seizures versus stereotypy.

It is unclear what the estimated prevalence of NES is in learning disabled adults. It has been suggested that twenty to thirty per cent of children who are diagnosed with epilepsy have NES [13] and that between five to thirty per cent of adults diagnosed with epilepsy have NES [19, 20]. Although previously stated that NES often co-exists with true epileptic seizures [21], recently researchers [22, 23] have argued that few individuals have both.

PSYCHOLOGICAL ADJUSTMENT REACTIONS TO HAVING EPILEPSY

To make a positive adjustment to epilepsy an individual must deal with various psychological factors. As a condition, epilepsy has features peculiar to it. It is episodic, unpredictable and potentially dangerous which can lead to heightened anxiety. In addition, it can cause behaviours that others may perceive as 'abnormal' which can lead to a sufferer's perception of 'felt' or enacted stigma [24].

There is little research into the psychological adjustment of the learning disabled to epilepsy. Therefore, this section will first, review studies for non learning disabled adults and second, examine the evidence for adults with a learning disability.

- ***Non learning disabled adults***

Antonak and Livneh [25] give a review of adjustment reactions to epilepsy in adults. Some adjustment reactions they quote are anger, dependency, fear, helplessness, low self-esteem and worry. There is not a parallel review for adults with a learning

disability. Is there any reason why similar reactions should not be expected in the adult with a learning disability and epilepsy?

The Commission for the Control of Epilepsy and its Consequences [26] has asserted *"The understanding that an individual has about any disability is directly related to the success the individual has in coping with the disability."* (p. 133). In addition, beliefs and perceptions are believed to have a significant relationship to the psychological and social adjustment of the individual independent of seizure frequency [27].

Considerable patient ignorance has been demonstrated regarding the purpose and results of diagnosis [28, 29], the causes and consequences of seizures [28] and the purpose and possible side effects of medications [28, 30]. The medical significance of such ignorance should not be under estimated. It has been proposed one third of patients do not achieve seizure control because of medication non compliance [26] - the foremost cause of seizure exacerbation [31].

- ***Adults with a learning disability***

Although any psychological condition can occur in people with epilepsy and a learning disability [6], there is little research into the specific types of conditions that occur. To date, three avenues of enquiry have been documented.

I. Is there an increased risk of psychiatric disturbance?

Lund [32] suggested psychiatric illness was more prevalent in individuals with epilepsy than those without. In the sample studied, fifty two per cent of persons (with seizures in the past year) suffered from a psychiatric diagnosis as compared to twenty six per cent without seizures. However, there have been criticisms of this study. A matched control group was not used [33]. In addition, researchers noted that autism [33] and behaviour disorder [33-35] were included in the classification of psychiatric diagnosis. It has been suggested that thirty nine per cent of those classed as psychiatric cases were misclassified [34].

Deb and Hunter [33] studied matched subjects from hospital and community settings and discovered the non epileptic group had a higher rate of psychiatric illness than the epileptic group. It was discovered that where "... the epileptic factor is stronger (i.e. active epilepsy, an earlier age of onset, a longer duration of epilepsy and frequent fits)" (p. 829) subjects presented with less psychiatric illness than those whose epilepsy was 'weaker'. The authors warned this latter result could be due to small sample sizes.

In conclusion, it seems there may not be a link between having epilepsy and psychiatric disorder in this population.

On a different slant, Pary [36] studied whether epilepsy either significantly prolongs hospital psychiatric inpatient treatment or causes a transfer to a state psychiatric hospital. Epilepsy did not affect the treatment or outcome for patients. Thus, an additional diagnosis of epilepsy should not preclude an individual with a learning

disability and a psychiatric disorder gaining equal access to the same psychiatric services as those who do not have epilepsy.

II. Is there an increased risk of behaviour disturbance?

There has been debate regarding this issue [37-39].

However, a study by Espie *et al.* [34] of adults with learning disabilities in a hospital concluded that "... Disturbed behaviour was not, however, associated with epilepsy *per se*," but that "... the relatively small sub-group of subjects who have poorly controlled epilepsy do present greater behavioural management problems," (p. 135). Gillies *et al.* [35] supported these findings for adults with learning disabilities who lived in the community and attended Adult Training Centres. Deb and Hunter [40] also discovered there were no statistically significant differences regarding behaviour problems between a group of hospital and community persons with epilepsy and a matched control group. In addition, their research supported Espie *et al's.* previous findings [34] that subjects with (what was defined as) 'strong' epileptic factors (i.e. mild learning disability, multiple type of fits, frequent fits, generalised activity in the EEG) showed more problem behaviour than those who did not have epilepsy.

In conclusion, an association between behaviour disturbance and epilepsy in this population appears to be weak unless epilepsy factors are 'strong'.

III. Is there an increased risk of personality disorder?

Deb and Hunter [41] studied matched subjects in hospital and community settings. Statistical differences were not found.

In a study that encompasses the three subsections above Deb [42] studied the psychopathological correlates (maladaptive behaviour, psychiatric illness and personality disorder) of EEG results in adults from the hospital and community. No significant differences emerged when psychopathology was compared between those with generalised epileptiform EEG changes and those with focal EEG changes.

To summarise, there is little evidence for psychopathological adjustment reactions to epilepsy in adults with a learning disability unless epilepsy factors are 'strong'. However, epilepsy can affect the learning potential of a learning disabled individual.

HOW EPILEPSY AFFECTS LEARNING POTENTIAL

Epilepsy frequently results in changes in consciousness (both ictal and inter-ictal) [43]. Inter-ictal changes are sub-clinical activity that occurs between seizures. Espie and Paul [16], drawing their rationale from information processing models [44-47], illustrate how learning potential is dependant on a satisfactory allocation of attention which can be adversely influenced by these changes in consciousness both during epileptic episodes, post-ictal recovery and inter-ictal activity.

PROFESSIONAL APPROACHES TO EPILEPSY IN INDIVIDUALS WITH A LEARNING DISABILITY

Betts [5] has noted that services for people with epilepsy are patchy, inconsistent and usually fall short of the ideal. He has proposed that the prevention of secondary consequences of epilepsy are as important as medical care.

Coulter [6] has stated the comprehensive management of epilepsy in people with a learning disability requires four aspects of care: diagnosis and classification, AED treatment, safety and protection from injury and psychological functioning. Each of these aspects will be examined.

- ***Diagnosis and classification***

Related research was described in the previous section entitled "Epilepsy in adults with a learning disability".

- ***AED treatment***

Recently, there have been two important trends regarding medication use for adults with a learning disability. First, the increased use of newer drugs such as Lamotrigine and Topiramate. Second, the emphasis on using a single drug wherever possible (monotherapy).

Fischbacher [48] demonstrated a positive relationship between a reduction in polypharmacy, a reduction of seizure frequency and an improvement in behaviour. A more recent study [49] of adults in large residential facilities found an increased use of monotherapy was feasible; it did not result in significant deterioration in seizure control. In addition, the reduction of barbiturates (e.g. Phenobarbitone, Primidone and Mephobarbital) was often accompanied by significant improvement in behaviour. Singh and Towle [10] have shown that virtually all of the community based subjects they studied could be managed successfully on one (sixty per cent) or two (thirty eight per cent) drugs. The importance of these findings should not be underestimated as it has been stated that in the past, for patients with learning disabilities, maintenance on six or seven AEDs was not atypical [10].

Deb and Hunter [50] studied the particular effect of AED factors (e.g. type, dose, serum level etc.) on the psychopathology of subjects. Monotherapy, Carbamazepine in particular, seemed to have some protective effect against aggressive behaviour. The authors acknowledged this finding may be due to chance but noted that it concurred with previous research [51]. They observed there have been adverse psychopathological (e.g. behavioural) side effects of other AEDs used in the past, such as Phenobarbitone and Phenytoin [51].

- ***Safety and protection from injury***

Systematic epidemiological data regarding the types and frequencies of injuries in people with epilepsy is needed so rational procedures to assure safety and prevent

injury can be developed and assessed [6]. In a recent study of carers' concerns, risk of injury and sudden death emerged as important features of carer reports [52].

Litzinger *et al.* [53] suggested it is incorrect to believe that the risk of injury should prevent persons leaving institutionalised settings. They demonstrated that adults with a profound learning disability and complex epilepsy presentations could be moved safely to a community based setting. They attributed the success to the availability and the proper usage of new AEDs.

- ***Psychological adjustment and functioning***

Research studies evaluating psychological interventions addressing the adjustment and functioning of adults with a learning disability and epilepsy are practically non-existent. Therefore, related research with non-learning disabled adult populations will be examined.

I. Addressing the secondary consequences of epilepsy in the non learning disabled population

Research has worked towards addressing patient ignorance about epilepsy to help individuals psychologically adjust to having epilepsy. This is in accordance with The Commission for the Control of Epilepsy and its Consequences view (detailed earlier).

Helgeson *et al.* [54] criticised a study evaluating a two day psychoeducational programme 'Sepulveda Epilepsy Education' (SEE) [55] , as a control group or follow

up evaluations were not employed. Therefore, in a well thought out and thorough study, Helgeson *et al.* evaluated SEE again. A controlled outcome design entailing a treatment group and a waiting list control group was utilised. The programme was evaluated using paper and pencil inventories and objective measures of epilepsy such as number of prescribed AEDs, AED blood level and seizure frequency. Long term effects were assessed at four month follow up. Results revealed limited, but encouraging, support for the programme intervention. There was a decrease in levels of misinformation and misconceptions regarding epilepsy, a decrease in the fear of death and brain damage and a decrease in "hazardous medical self management practices" (p. 80). There was an associated significant and sustained improvement in AED blood level concentrations. At four month follow up AED levels remained at more therapeutic levels.

Oosterhuis [56] described results from the pilot study of a training course for adults who had stress induced seizures. The course, eight group sessions of two hours each, followed four principles; a symptomatic approach, emphasis on information, self-management and interventions based on behaviour therapeutic principles. Four patients had a decrease in seizure frequency which Oosterhuis concluded lent support for the psycho-educational approach used. There was no control group in this study. A more comprehensive follow up study is currently being conducted [57].

These are the only documented evaluations of psycho-educational approaches to epilepsy with adults. In order to measure a patient's knowledge about their own epilepsy and about epilepsy in general, two questionnaires have recently been developed [58, 59].

RECENT ADVANCES IN ADDRESSING THE SECONDARY CONSEQUENCES OF EPILEPSY IN THE LEARNING DISABLED POPULATION

One of the previous questionnaires mentioned above [59] has been adapted specifically for people with learning disabilities [60] and is being evaluated at present [61]. The questionnaire assesses knowledge regarding seizure presentation, assessment and treatment issues and epilepsy related precautions.

In addition, Paul [62] has produced a video-assisted training package (Epilepsy and You) to help people with learning disabilities understand their epilepsy. Currently, research investigating knowledge about epilepsy in a learning disabled population with epilepsy is being conducted with Paul's [62] package also being utilised to determine whether knowledge levels can be increased [63].

In conclusion, it is only very recently that psychological approaches to epilepsy in this population have commenced, despite authors noting the need for a more comprehensive approach to the care of individuals with epilepsy [5, 6].

RECOMMENDATIONS FOR FUTURE RESEARCH

Despite the increased prevalence of, and the often more serious presentation of epilepsy in the learning disabled population, it is notable that research within this area, (particularly regarding psychological issues) is limited. Although recent moves towards addressing this lack of research have commenced, further research is required.

Future research should elucidate the behavioural and social correlates of epilepsy within this population and clarify what psychological interventions benefit individuals. However, as any population of individuals with epilepsy and a learning disability is extremely heterogeneous, future research should investigate identifying population characteristics, so that clinical assessment and therapeutic decisions can be made effectively.

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Major Research Project Proposal

Adults with Learning Disabilities and Epilepsy: knowledge about epilepsy before and after a psychoeducational package

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 3.1)

Adults with Learning Disabilities and Epilepsy: knowledge about epilepsy before and after a psychoeducational package

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SUMMARY

A lack of knowledge regarding epilepsy issues has been demonstrated in adults with epilepsy. It is important to therapeutically address this lack of knowledge, as an individual's understanding about epilepsy has been suggested to effect the success with which they cope with epilepsy. A main reason for seizure exacerbation is medication non-compliance which in itself can be a consequence of lack of knowledge. There have been successful evaluations of psychoeducational approaches for adults with epilepsy. However, although epilepsy is more prevalent in adults with learning disabilities there are no published evaluations of a psychoeducational approach to epilepsy for this population. This study will be the first evaluation of a psychoeducational approach to epilepsy for adults with learning disabilities and epilepsy. Paul's (1996) package 'Epilepsy and You' will be utilised in a group format. Initially, the knowledge adults with learning disabilities and epilepsy have about epilepsy will be investigated. Their knowledge immediately after 'Epilepsy and You' and at one month follow up will then be investigated. The study will investigate if there are identifying characteristics of individuals who appear to benefit from 'Epilepsy and You'. Individuals' opinions about 'Epilepsy and You' will be investigated. The study will be conducted at Adult Training Centres and at residential establishments.

INTRODUCTION

> *The understanding that an individual has about any disability is directly related to the success the individual has in coping with the disability.*
>
> The Commission for the Control of Epilepsy and its Consequences (1978, p. 133).

Although nearly twenty years old the Commission's view is important to address today. Numerous articles have detailed psychosocial problems for adults with epilepsy (reviews by Hermann and Whitman, 1984 and Antonak and Livneh, 1992). Research has demonstrated patient ignorance about the purpose and results of diagnosis (Mittan, 1986; Schneider and Conrad, 1986), the causes and consequences of seizures (Mittan, 1986), and the purpose and possible side effects of medications (Mittan, 1986; Thompson and Oxley, 1989). Importantly, Barry (1982) has advised that medication non compliance is the foremost cause of seizure exacerbation.

Researchers have attempted to address the Commission's concern. Helgeson et al. (1990) utilised a controlled outcome design to evaluate a two day psychoeducational programme designed to provide medical education and psychosocial therapy for adult epilepsy outpatients. The programme led to a decrease in levels of misinformation and misconceptions regarding epilepsy, a decrease in the fear of death and brain damage and a decrease in "hazardous medical self-management practices" (p. 81). Oosterhuis (1994) in a pilot study of a psychoeducational programme in the Netherlands found that four out of five patients (who suffered from stress induced seizures) had a decrease in seizure frequency. Currently, a follow up study is being conducted (Oosterhuis, 1997).

These studies appear to be the only published evaluations of psychoeducational approaches to epilepsy with adults. Although epilepsy affects approximately one per cent of the general population it is more prevalent in adults with learning disabilities. Approximately twenty per cent of learning disabled adults have the 'dual disability' of

epilepsy, with prevalence rates correlated with the level of learning disability; approximately fifty per cent of people with a severe or profound learning disability have epilepsy (Corbett, 1981; Bicknell, 1985; Coulter, 1993). Although there is the increased prevalence of epilepsy in adults with learning disabilities there are no published evaluations of a psychoeducational approach to epilepsy for this population.

There has been debate about whether adults with learning disabilities present with adjustment problems to epilepsy (Capes and Moore, 1970 versus Corbett, 1981 and Deb et al., 1987). However, Espie et al. (1989); Gillies et al. (1989) and Deb and Hunter (1991) agree that although disturbed behaviour is not associated with epilepsy per se, a sub-group of people with poorly controlled epilepsy can present greater behavioural management problems.

Recently, progress has been made to help individuals with learning disabilities understand and deal with their epilepsy as efficiently as possible. Paul (1996), has produced 'Epilepsy and You' a video-assisted psychoeducational package designed specifically for this population. It is comprised of a ten minute video and discussion material. Paul's (1996) package will be utilised to address in part, the proposed study's research questions. This study will be, to the author's knowledge, the first evaluation of a psychoeducational approach to epilepsy for adults with learning disabilities and epilepsy.

Research Questions

1. What knowledge regarding epilepsy, and associated issues, do adults with learning disabilities and epilepsy present?

2. Does 'Epilepsy and You' increase their knowledge regarding epilepsy and associated issues?

- If yes, is an increase in knowledge durable over time?

3. Do some individuals appear to gain more knowledge from 'Epilepsy and You' than others?

- If yes, what are the identifying characteristics of individuals who appear to gain more knowledge from 'Epilepsy and You'?

4. What are individuals' opinions regarding 'Epilepsy and You'?

PLAN OF INVESTIGATION

SUBJECTS

Treatment Group (TG), n=10.	Two groups each containing five subjects.
Deferred Treatment Group (DTG), n=10.	Two groups each containing five subjects. These groups will have deferred entry to 'Epilepsy and You'.

Inclusion Criteria

Individuals will be invited to participate if they meet **all** the criteria:

1. a learning disability.
2. at least one documented epileptic seizure during the preceding twelve months.
3. prescribed anti-epileptic drugs (AED).
4. communicate verbally.

Exclusion Criteria

Individuals will not be invited to participate if they meet **any** of the criteria:

1. a vision or hearing impairment.
2. a diagnosis that further compromises cognitive processing, e.g. dementia or autism.
3. previous participation in an educational workshop addressing epilepsy.

Recruitment and Consent of Subjects

Subjects will be recruited from Adult Training Centres and residential establishments for adults with learning disabilities. The respective manager will highlight potential subjects, drawing on advice from staff. Subjects and the manager will receive written information about the study and complete a consent form (Appendices 3.2 and 3.3 respectively). Where required, keyworkers and relatives will receive written information about the study (Appendices 3.4 and 3.5 respectively). Individuals will be informed their participation (or lack of it) will not affect their placement, they may withdraw from the study at any time and all information will be treated with the strictest confidence.

MEASURES

1. **British Picture Vocabulary Scale** (BPVS) (Dunn et al., 1982), will provide an indication regarding the level of each subject's word knowledge.
2. **Raven's Coloured Progressive Matrices** (RCPM) (Raven, 1986), will provide an indication regarding the level of each subject's perceptual processing skills.
3. **The Epilepsy Knowledge Questionnaire - Learning Disabilities** (EKQ-LD) (Jarvie, 1995), which is being evaluated at present (Jarvie et al., 1997), will be administered by the experimenter. It investigates the subject's knowledge regarding seizure presentations, assessment and treatment issues and epilepsy related precautions.
4. **The Epilepsy and You - Checklist** (EY-C), administered by the experimenter, will be developed using facts contained within 'Epilepsy and You'. It will assess general knowledge regarding epilepsy and will include a structured set of prompts.
5. **Evaluation Questionnaire**. This questionnaire will be developed to investigate subjects' opinions about 'Epilepsy and You'. Forced choice questions will be supplemented by open-ended questions. The subject will where possible, complete the questionnaire him/herself. The experimenter will give appropriate assistance.

EXPERIMENTAL DESIGN AND PROCEDURE

The Development of the EY-C

Non-learning disabled adults (n=4, two females and two males) will watch the 'Epilepsy and You' video and list important facts it conveys. These facts will be used to develop the EY-C.

Pilot Study (n=5)

A pilot study (one group) will determine whether the experimental procedures are acceptable and collect the data required. If no changes are necessary, pilot study results will be included within the main study findings.

Experimental Procedure (Diagram 1)

Stage 1, subjects' cognitive abilities will be investigated.

Stage 2, Dyer's (1995) randomisation procedure will be utilised.

Stage 3, if clarification or further information is required about the subject's seizure presentation keyworkers or relatives will be approached. Epilepsy classification will utilise the International Classification of Epileptic Seizures (The Commission on Classification and Terminology for the International League Against Epilepsy, 1981).

For the TG stages 4 - 6, and for the DTG stages 8 - 10, a staff member will be invited to co-present the session. Between sessions the co-presenter and keyworkers will be asked to actively reinforce material presented and answer queries. The experimenter will address any outstanding queries.

The TG will participate for a maximum of seven hours; the DTG for a maximum of eight hours.

Following stages 3, 7, 11, 12, and 13 the experimenter will score subjects' knowledge. An independent rater, after signing a confidentiality declaration, will randomly select audio recordings of the above stages and repeat the scoring process.

Pre and post 'Epilepsy and You' levels of knowledge will be compared within groups, as will the level of knowledge at one month follow up. Levels of knowledge will also be compared between the TG and DTG.

Stage of Process	Procedure involved	
Stage 1 (day 1)	Subjects individually assessed using BPVS and RCPM. Demographic information collected.	
Stage 2	Subjects randomly allocated to the TG or DTG.	
	Treatment Group (TG).	**Deferred Treatment Group (DTG).**
Stage 3 (day 8)	Subjects individually complete EKQ-LD and EY-C. Interview audiorecorded.	Subjects individually complete EKQ-LD and EY-C. Interview audiorecorded.
Stage 4 (day 15)	Group session I of 'Epilepsy and You'. Video and discussion.	
Stage 5 (day 22)	Group session II of 'Epilepsy and You'. Video and discussion.	
Stage 6 (day 29)	Group session III of 'Epilepsy and You'. Discussion.	
Stage 7 (day 29)	Subjects individually complete EKQ-LD and EY-C and Evaluation Questionnaire. Interview audiorecorded.	Subjects individually complete EKQ-LD and EY-C. Interview audiorecorded.
Stage 8 (day 36)		Group session I of 'Epilepsy and You'. Video and discussion.
Stage 9 (day 43)		Group session II of 'Epilepsy and You'. Video and discussion.
Stage 10 (day 50)		Group session III of 'Epilepsy and You'. Discussion.
Stage 11 (day 50)		Subjects individually complete EKQ-LD and EY-C and Evaluation Questionnaire. Interview audiorecorded.
Stage 12 (day 57)	Subjects individually complete EKQ-LD and EY-C. Interview audiorecorded.	
Stage 13 (day 78)		Subjects individually complete EKQ-LD and EY-C. Interview audiorecorded.

Diagram 1. Experimental procedure

SETTINGS AND EQUIPMENT

Data collection will take place at the establishments. A television, videotape player and a tape recorder/player will be utilised.

DATA ANALYSIS

Data collation/storage/analysis will be conducted at the Department of Psychological Medicine. Written and computer entered information will be coded with a number from which subjects are unidentifiable. The independent audiotape rater will only have access to the number.

The experimenter and independent-rater scored data will be compared to determine inter-rater reliability.

The EKQ-LD and EY-C data

1. **Quantitative** - all EY-C data and some EKQ-LD data will be assumed to be interval scale data. Should the data demonstrate normal distributions and homogeneity of variance, parametric tests will be utilised in preference to non parametric tests.

   Descriptive statistics will document the subject's baseline knowledge.

   Standard knowledge 'change' scores will be calculated.

   T-tests (related) or Wilcoxon statistical tests will determine whether there has been a significant increase in knowledge following 'Epilepsy and You' within the groups and whether any knowledge increase is durable over time.

   A t-test (unrelated) or a Mann Whitney will investigate between the experimental and control group whether 'Epilepsy and You' was a contributory component to any change in knowledge.

2. **Qualitative** - the remaining data from the EKQ-LD will be qualitative. A qualitative data analysis software package may prove useful to determine whether there have been changes in knowledge pre and post 'Epilepsy and You', and at follow up.

Standard 'change' scores and characteristics will be examined to determine whether certain individuals appear to gain more knowledge from 'Epilepsy and You'.

Evaluation Questionnaire results will be described.

PRACTICAL APPLICATION

Results will determine whether 'Epilepsy and You' is a beneficial psychoeducational package for groups of learning disabled adults with epilepsy. Changes in knowledge about epilepsy and associated issues can give individuals more control over their health, encourage medication compliance and minimise secondary consequences of epilepsy.

In addition, a checklist will have been developed that will evaluate epilepsy knowledge in the population studied.

TIMESCALES

1. Subjects recruited, pilot study conducted and evaluated: January 1997 - February 1997.
2. Data collection for main experiment: February 1997 - April 1997.
3. Data analysis/writing up: May 1997 - July 1997.

ETHICAL APPROVAL

Ethical approval has been granted by Greater Glasgow Community and Mental Health Services NHS Trust, the Social Work Department (Glasgow South District Headquarters) and establishment managers/directors.

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Major Research Project Paper

Adults with Learning Disabilities and Epilepsy: knowledge about epilepsy before and after a psychoeducational package (Epilepsy and You)

SHORT RUNNING TITLE
Epilepsy and You: a beneficial psychoeducational package for adults with epilepsy

Prepared in accordance with guidelines for submission to "Journal of Intellectual Disability Research" (Appendix 4.1)

Adults with Learning Disabilities and Epilepsy: knowledge about epilepsy before and after a psychoeducational package (Epilepsy and You)

SHORT RUNNING TITLE
Epilepsy and You: a beneficial psychoeducational package for adults with epilepsy

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ABSTRACT

It has been asserted that the lack of understanding individuals have about their epilepsy can influence the success with which that individual copes with his/her epilepsy. This paper presents the first evaluation of a video-assisted psychoeducational package for adults with learning disabilities and epilepsy ('Epilepsy and You'). Utilising an experimental design, eighteen subjects participated in 'Epilepsy and You'. Their knowledge about epilepsy before and after was assessed using the Epilepsy and You Checklist and the Epilepsy Knowledge Questionnaire-Learning Disabilities. Although the adults with learning disabilities and epilepsy had deficits in their epilepsy knowledge, 'Epilepsy and You' beneficially addressed such deficits. In addition, knowledge increase was durable over a short term follow up (one month). 'Epilepsy and You' was suitable for use with a wide range of individuals and subjects' opinions demonstrated they enjoyed taking part. This study is a preliminary investigation from which other research can develop. Therefore, criticisms of this study and suggestions for further research have been made.

Key Words

Intellectual disability **Adult** **Epilepsy** **Knowledge** **Psychoeducational**

INTRODUCTION

This introduction briefly outlines the limited research involving adults with a learning disability and epilepsy. For more detailed literature reviews, the reader is directed towards Clark (1997) or Espie and Paul (1997).

Prevalence of epilepsy

Around twenty percent of people with a learning disability have at least one epileptic seizure per year, and the prevalence of epilepsy appears to be correlated with the level of learning disability, with approximately fifty per cent of individuals with a severe or profound learning disability having epilepsy (Corbett, 1981; Bicknell, 1985; Coulter, 1993). This is higher than the estimated one percent epilepsy prevalence in the general population. In addition, more severe levels of learning disability are associated with comparatively more mixed seizure presentation (Alvarez, 1989; Singh and Towle, 1993).

Psychological consequences of having epilepsy

Epilepsy is episodic, unpredictable and potentially dangerous which can lead to heightened anxiety. It can cause behaviours that others may perceive as 'abnormal', which can lead to a sufferer's perception of 'felt' or enacted stigma (Scambler and Hopkins, 1986). Although any psychological condition can occur in individuals with a learning disability (Coulter, 1993) there is little research investigating the psychological consequences of having epilepsy for this population.

Although Lund (1985) originally suggested psychiatric illness was more prevalent in individuals with epilepsy than those without the methodology of the study has since been criticised (Espie et al., 1989; Gillies et al., 1989; Deb and Hunter, 1991a). Furthermore, Deb and Hunter (1991a) found psychiatric illness was more prevalent in individuals who did not have epilepsy.

Following debate about whether there is an increased risk for behaviour disturbance (Capes and Moore, 1970; Corbett, 1981; Deb et al., 1987), Espie et al. (1989) concluded that "... Disturbed behaviour was not however, associated with epilepsy *per se*," but that "... the relatively small sub-group of subjects who have poorly controlled epilepsy do present greater behavioural management problems," (p. 135). Gillies et al. (1989) and Deb and Hunter (1991b) have supported Espie et al's. (1989) findings.

No evidence for an increased risk of personality disorder has been found (Deb and Hunter, 1991c).

However, the Commission for the Control of Epilepsy and its Consequences (1978) has asserted; *"The understanding that an individual has about any disability is directly related to the success the individual has in coping with the disability."* (p. 133). Although considerable ignorance about their epilepsy has been demonstrated in non-learning disabled individuals (Mittan, 1986; Schneider and Conrad, 1986; Thompson and Oxley, 1989) no studies have investigated the level of knowledge adults with a learning disability have regarding their epilepsy.

Therapeutic interventions to address the Commission's concern

Within the non-learning disabled population psychoeducational programmes have been effective (Helgeson et al., 1990; Oosterhuis, 1994). There are no comparative studies for the learning disabled population. However, Paul (1996) has produced a video-assisted training package ('Epilepsy and You') to help people with learning disabilities understand their epilepsy, and an epilepsy knowledge questionnaire for use with people with learning disabilities has been developed (Jarvie, 1995) and is being evaluated at present (Jarvie et al., 1997).

Conclusion

Despite the increased prevalence of epilepsy in the learning disabled population compared with the general population, there is no research investigating knowledge about epilepsy or how to preclude possible psychological consequences of epilepsy within the learning disabled population.

Aims of this study

This study will:

1. Assess what knowledge regarding epilepsy and associated issues, adults with learning disabilities and epilepsy present.
2. Determine whether 'Epilepsy and You' increases epilepsy knowledge, and whether any increase in knowledge is durable over time.
3. Examine whether any characteristics of those who benefit from 'Epilepsy and You' can be identified.
4. Investigate users' opinions of 'Epilepsy and You'.

PILOT STUDY

A pilot study was conducted to determine the experimental procedure was acceptable to participants and that required data was collected (n=4). Subjects reported they enjoyed the 'Epilepsy and You' package. Subjects' epilepsy knowledge following 'Epilepsy and You' increased by an average of 7.25 points using the Epilepsy and You-Checklist, and by 0.75 points using the Epilepsy Knowledge Questionnaire-Learning Disabilities. The results from the pilot study were incorporated into the main study results as no changes to the procedure were required.

MAIN STUDY

Subjects

Nineteen subjects consented to participate in the research. Subjects were from adult training centres (n=2), a residential village for adults with a learning disability (n=3), a residential hostel for adults with a learning disability and epilepsy (n=9) and an adult training centre for individuals with a learning disability and epilepsy (n=5).

Subjects were approached to inform them of the research and to request consent, after the manager of each establishment highlighted individuals who met the research criteria. Inclusion criteria were; a learning disability, at least one seizure during the preceding twelve months, prescribed anti-epileptic drugs, verbal communication. Exclusion criteria were; a vision or hearing impairment, a diagnosis that further compromised cognitive processing (for example, dementia or autism), previous participation in an epilepsy educational workshop.

Measures

1. **British Picture Vocabulary Scale** (BPVS) (Dunn et al., 1982). This assessment was used to gain an indication of each subject's vocabulary level.
2. **Raven's Coloured Progressive Matrices** (RCPM) (Raven, 1986). This assessment was used to provide an indication of each subject's perceptual processing skills.

3. **Epilepsy Knowledge Questionnaire - Learning Disabilities** (EKQ-LD) (Jarvie, 1995). This questionnaire was used to investigate subjects' knowledge regarding seizure presentations, assessment and treatment issues and epilepsy related precautions. Although the questionnaire mainly produces qualitative data some quantitative data can be gained. The questionnaire is being evaluated at present (Jarvie et al., 1997).
4. **'Epilepsy and You' - Checklist** (EY-C). It was thought that an epilepsy knowledge checklist based on information presented in the 'Epilepsy and You' video would be useful. This was developed by the author. Four non-learning disabled adults (two females and two males) watched the video and listed important facts it conveyed. Their lists were used to develop the checklist which has a structured set of prompts (Appendix 4.2). Structured scoring criteria were developed (Appendix 4.3).
5. **'Epilepsy and You'** (Paul, 1996). This video-assisted psychoeducational package was used as it has been specifically designed for adults with a learning disability and epilepsy. The package is comprised of a ten minute video and discussion material.
6. **Evaluation Questionnaire** was developed by the author to investigate subjects' opinions about 'Epilepsy and You' (Appendix 4.4). Forced choice questions were supplemented by open-ended questions.
7. **Independent rater scoring of EY-C and EKQ-LD.** To assess inter-rater reliability, all interviews during which the EY-C and the EKQ-LD were conducted were audiorecorded. An independent rater, after signing a confidentiality declaration, used Dyer's (1995) randomisation procedure to select a twenty five percent sample of audiorecordings for later re-scoring.

Procedure

As the 'Epilepsy and You' training programme was to be conducted in a group format subjects were allocated to either a treatment group (n=9) or a deferred treatment group (n=10), depending on clinical considerations about their epilepsy and the time of their entrance into the research project.

Prior to participating in 'Epilepsy and You' subjects completed the RCPM and BPVS. Demographic and epilepsy related information were collected (Tables 1 and 2). One subject who had been allocated into a treatment group did not participate in 'Epilepsy and You' after completing pre-'Epilepsy and You' assessments. Therefore, there were one, three and four subjects in each of three treatment groups (total n=8) and one, three and six subjects in each of three deferred treatment groups (total n=10) (Tables 1 and 2).

'Epilepsy and You' involved subjects participating in three, weekly sessions that lasted an hour each. At the first session discussion revolved around what epilepsy is and how it presents. Subjects also watched the 'Epilepsy and You' video. The second session involved discussion about medication and safety issues. The video was watched for a second time. The third session involved explanation about the importance of, and use of seizure diaries.

The Treatment Group (TG)

One week prior to commencing 'Epilepsy and You' subjects completed the EY-C and the EKQ-LD. Immediately after 'Epilepsy and You' subjects were re-assessed using the EY-C and the EKQ-LD. Subjects also completed the Evaluation Questionnaire. Four weeks later at follow up, subjects completed the EY-C and the EKQ-LD again.

The Deferred Treatment Group (DTG)

The DTG followed the same procedure as the TG, except they also completed the EY-C and the EKQ-LD **four weeks prior** to commencing 'Epilepsy and You'. The time period between their completion of EY-C and EKQ-LD at four weeks and one week prior to 'Epilepsy and You' was a baseline. The design of the study was such that the DTG completed one week pre- 'Epilepsy and You' assessments at the same time as the TG completed immediate post- 'Epilepsy and You' assessments.

RESULTS

Characteristics of the Subject Groups

In terms of demographic and cognitive functioning the groups which participated in 'Epilepsy and You' were similar (TG n=8, DTG n=10) (Table 1). Table 1 also details information for the 'original' treatment group prior to one subject dropping out (n=9). The DTG was significantly older than the TG ($z=-2.04$, $p=0.04$, two tailed significance).

Insert Table 1 here

In terms of presenting epilepsy the groups that participated in 'Epilepsy and You' were similar (Table 2). Table 2 also details information for the 'original' treatment group prior to one subject dropping out (n=9). The majority of subjects had tonic-clonic seizures although other seizure types were reported. Eight subjects had multiple seizure types. The majority of the subjects were on polytherapy. In each group some subjects had a large number of seizures per year.

Insert Table 2 here

The inter-rater reliability of the EY-C and the EKQ-LD

The independent rater scored seventeen EY-C and seventeen corresponding EKQ-LD. Inter-rater reliability was significant for the EY-C ($r=0.92$, $p=0.00$, one tailed significance) and for the EKQ-LD (quantitative data) ($r=0.80$, $p=0.00$, one tailed significance).

What knowledge regarding epilepsy and associated issues, do adults with learning disabilities and epilepsy present?

The number of correct responses to the EY-C prior to 'Epilepsy and You' are presented in Table 3 (n=19). In addition, Table 3 details information for the subjects that participated in 'Epilepsy and You' (n=18). Subjects in general, knew the presentation of different types of seizures, why they took medication, when it was important to take medication and how to help others having a seizure. Subjects were less knowledgeable about the mechanisms of epilepsy (why they happen, types of warnings, how to stop a seizure from happening when in its initial stages), how medication works through the body, some medical investigations for epilepsy and the importance of, and use of seizure diaries.

Does 'Epilepsy and You' increase epilepsy knowledge? If so, is an increase in knowledge durable over time?

The number of correct responses to the EY-C, for those who participated in 'Epilepsy and You', prior to and after 'Epilepsy and You' are presented in Table 3 (n=18). Inspection of the table shows epilepsy knowledge increased following 'Epilepsy and You'. Figures 1 and 2 summarise the TG and DTG average scores for each condition. Tables 4 and 5 detail the average score, in each condition, for the TG and DTG (Appendix 4.5). Figures 3 and 4 illustrate the change in scores for each subject using the EY-C and EKQ-LD (Appendix 4.6).

Insert Table 3 here

Insert Figures 1 and 2 here

For the DTG there was not a significant change in knowledge, using the EY-C and the EKQ-LD, during the baseline.

Change in knowledge for the DTG (n=10) over the baseline period was compared with the TG's (n=8) change in knowledge from one week before to immediately after 'Epilepsy and You'. The TG gained significantly more knowledge using the EY-C ($z=-2.02$, $p=0.04$, two tailed significance). There was not a significant difference using the EKQ-LD although the trend suggested an increase in knowledge for the TG.

As 'Epilepsy and You' had a significant positive effect on the TG's epilepsy knowledge, the TG and DTG were combined to determine whether, for the subjects as a whole (n=18), 'Epilepsy and You' had a significant effect on epilepsy knowledge throughout the three conditions. A Friedman test revealed a significant effect using the EY-C ($xr^2=18.75$, $df=2$, $p=0.00$) but not for the EKQ-LD.

To investigate further a Wilcoxon test was employed for the subject group as a whole (n=18). Comparing epilepsy knowledge immediately after 'Epilepsy and You' with

knowledge one week prior to 'Epilepsy and You' revealed there was a significant increase in scores, using both the EY-C and the EKQ-LD ($z=-3.03$, $p=0.00$, two tailed significance, and $z=-2.00$, $p=0.04$, two tailed significance, respectively). The average 'change' EY-C score was 5.50 points (SD=5.70). The average 'change' EKQ-LD score was 0.83 points (SD=1.58).

To determine whether knowledge increase was durable the level of knowledge at one month follow up was compared, using a Wilcoxon test, to knowledge one week before 'Epilepsy and You'. There was a significant increase at follow up, using the EY-C ($z=-3.62$, $p=0.00$, two tailed significance) but not using the EKQ-LD. There was not a statistical decrease in scores between those gained immediately after 'Epilepsy and You' and at one month follow up.

What are the characteristics of individuals who appear to gain more knowledge from 'Epilepsy and You'?

Those whose knowledge 'change' scores were in the upper or lower quartile for each questionnaire were identified. Their demographic and epilepsy characteristics were compared using percentiles, with the characteristics of the whole sample (n=18) (Table 6, Appendix 4.7). For the EY-C no characteristics appeared to be associated with those who scored higher or lower in the questionnaire. For the EKQ-LD a later age of onset for epilepsy appeared to characterise those who scored higher.

What are users' opinions of 'Epilepsy and You'?

All subjects completed the Evaluation Questionnaire. All responded they enjoyed 'Epilepsy and You' (n=18). When asked specifically if there was anything they did not like, one subject (5.6%) stated she preferred to talk about epilepsy in private. Following 'Epilepsy and You' sixteen subjects (88.9%) thought they knew more about their epilepsy and fifteen subjects (83.3%) thought they knew more about other people's epilepsy. Additional comments made were all positive.

DISCUSSION

Results suggest that adults with the 'dual disability' of epilepsy and a learning disability, although they know how epilepsy presents, are not likely to know the mechanisms behind epilepsy (why it happens, types of warnings, how to stop a seizure from happening in its initial stages). This lack of knowledge should be addressed to prevent the generation of false and distressing beliefs. Although knowledge about medication issues was not low, there were deficits in knowledge regarding; why it is important to visit doctors, what an EEG is and how medication works through the body in order to preclude seizures. It is important to target this lack of knowledge in order to preclude medication non-compliance - the foremost cause of seizure exacerbation (Barry, 1982). Some knowledge was exhibited about safety issues, such as how to help others who are having a seizure. However, there was little known about the use of, and importance of seizure diaries. This lack of knowledge should be addressed as medical intervention relies on the accuracy of seizure frequency reporting.

Utilising the EY-C, 'Epilepsy and You' increased the level of epilepsy knowledge in the sample studied. During a baseline period subjects' knowledge did not change. 'Epilepsy and You' continued to have a beneficial effect on the level of subjects' knowledge at short term follow up (one month). The reason for this sustained effect may be repetition of information within 'Epilepsy and You' helped subjects consolidate information. 'Epilepsy and You' offers individuals more control over health, it encourages medication compliance and may minimise secondary psychological consequences of epilepsy. Following 'Epilepsy and You' there were improvements in areas of knowledge that prior to 'Epilepsy and You' showed deficits.

EKQ-LD measured knowledge did not change significantly over several occasions. Although the EKQ-LD is an excellent instrument for gathering qualitative data the level of quantitative data that can be gained means there was little scope for change in 'knowledge' scores.

No characteristics (demographic or epilepsy) identified those who benefited more from 'Epilepsy and You', except a later age of epilepsy onset for EKQ-LD scores. This result is an anomaly. A similar effect was not observed for the EY-C which was the more thorough assessment of subjects' knowledge related to 'Epilepsy and You'. Results suggest variation in scores was not attributable to factors that it would be difficult to address, such as cognitive functioning level or seizure presentation. Variation in scores may have been due to subjects' attentiveness levels or investigator/subject interaction.

Subjects were extremely positive about 'Epilepsy and You'. This is important as people are more motivated to participate if they find the experience enjoyable and relevant.

Criticisms can be made of this study. Future research should study a larger sample size. However, as a population of individuals with epilepsy is heterogeneous it may prove difficult to match subjects on demographic or epilepsy variables. Future studies should investigate how durable knowledge increase is, and pinpoint why some individuals appear to benefit more from 'Epilepsy and You' than others. Within this study only individuals who communicated verbally were studied. However, as epilepsy prevalence appears to be correlated with the level of learning disability (Corbett, 1981; Bicknell, 1985; Coulter, 1993) it should be determined whether 'Epilepsy and You' is beneficial for individuals who do not communicate verbally. To explicitly demonstrate the beneficial effects of 'Epilepsy and You' a future study should examine objective measures such as behaviour disturbance ratings, seizure frequencies and blood anticonvulsant levels, before and after 'Epilepsy and You'. If appropriate, a standardised intelligence test to determine subjects' levels of learning disability, for example, the Wechsler Adult Intelligence Scale - Revised should be used (Wechsler, 1981).

The EY-C requires alterations before further use. Questions investigating how to keep the environment safe should be inserted. In addition, there is a preponderance of closed questions that can be correctly answered as 'yes'. As adults with a learning disability, when unsure of an answer to a closed question, tend to acquiesce and answer 'yes' in preference to 'no' (Sigelman et al., 1980; Sigelman et al., 1981),

present EY-C results may be slightly misleading. Balancing 'yes' and 'no' answered questions or rephrasing them into open questions will reduce acquiescence levels (Sigelman et al., 1982). Also, the EY-C scoring system requires standardising so all questions have an equivalent maximum score. Although the EY-C is valid, sensitive and practical, a larger pool of test-retest data and norms need to be gathered.

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TABLES AND FIGURES

	Treatment Group		Deferred Treatment Group
	'original group' (n=9)	(n=8)	(n=10)
Age:			
age range (years, months)	*23, 9 - 46, 5*	24, 0 - 46, 5	33, 4 - 68, 4
mean (years, months) ± SD (years, months)	*35, 0 ± 8, 3*	36, 5 ± 7, 8	45, 8 ± 9,11
Sex:			
male	*6*	5	5
female	*3*	3	5
Cognitive functioning:			
Raven's Progressive Matrices raw score			
range of raw scores	*9 - 23*	9 - 23	6 - 26
mean ± SD	*15.33 ± 5.48*	14.50 ± 5.21	15.20 ± 6.73
British Picture Vocabulary age score			
age range (years, months)	*2, 6 - 9, 10*	2, 6 - 9, 10	2, 0 - 13, 0
mean (years, months) ± SD (years, months)	*6, 4 ± 2, 10*	6, 0 ± 2, 11	5, 4 ± 3, 4

Table 1. **Distribution of subjects according to age, sex and cognitive functioning for TG and DTG.**

	Treatment Group		Deferred Treatment Group
	'original group' *(n=9)*	(n=8)	(n=10)
Seizure type:			
single seizure type (number of subjects)	*4*	3	7
multiple seizure type (number of subjects)	*5*	5	3
Number of subjects with specific type of seizure:			
tonic-clonic seizures	*8*	8	5
clonic seizures	*0*	0	2
tonic seizures	*0*	0	1
atonic seizures	*0*	0	1
myoclonic seizures	*0*	0	0
absence seizures	*4*	4	3
simple partial seizures	*1*	0	1
complex partial seizures	*2*	2	2
Approximate number of seizures per year:			
range of raw scores	*1 - 200*	1 - 200	2 - 200
mean ± SD	*41.22 ± 65.53*	46.00 ± 68.36	54.10 ± 68.38
median	*5*	18.50	22.5
Medication:			
monotherapy	*1*	1	3
polytherapy	*8*	7	7
Approximate age at onset of epilepsy:			
age range (years, months)	*birth - 12, 0*	birth - 12, 0	birth - 14, 0
mean ± SD (years, months)	*4, 6 ± 3, 9*	4, 7 ± 4, 1	3, 9 ± 4, 3
Approximate length of time participant had epilepsy:			
range of length of time (years, months)	*19, 1 - 43, 1*	20, 0 - 43, 1	30, 4 - 68, 4
mean ± SD (years, months)	*30, 5 ± 8, 8*	31, 10 ± 8, 1	41, 11 ± 3, 8

Table 2. Distribution of epilepsy variables for TG and DTG.

	Prior to 'Epilepsy and You'		**Immediately after 'Epilepsy and You'**
	Number (%) of subjects who gave a correct answer		Number (%) of subjects who gave a correct answer
	'original subjects' (n=19)	**(n=18)**	**(n=18)**
Why seizures happen	*6 (31.6)*	5 (27.8)	9 (50.0)
Whether seizures can go away completely	*9 (47.4)*	9 (50.0)	8 (44.4)
Whether some people remember events during seizures	*9 (47.4)*	8 (44.4)	10 (55.6)
Whether some people get warnings prior to seizures	*11 (57.9)*	10 (55.6)	13 (72.2)
A description of the types of warnings people get	*5 (26.3)*	4 (22.2)	7 (38.9)
Whether some seizures can be stopped while happening	*11 (57.9)*	11 (61.1)	12 (66.7)
A description of how to stop a seizure while it is happening	*1 (5.3)*	1 (5.6)	1 (5.6)
A description of how to tell another person has epilepsy	*16 (84.2)*	15 (83.3)	16 (88.9)
Whether there are different types of seizures	*16 (84.2)*	15 (83.3)	17 (94.4)
A description of the different types of seizures people can have:			
One seizure type described	*7 (36.8)*	7 (38.9)	4 (22.2)
Two seizure types described	*4 (21.1)*	4 (22.2)	7 (38.9)
Three seizure types described	*3 (15.8)*	3 (16.7)	3 (16.7)
Four seizure types described	*0 (0)*	0 (0)	1 (5.6)
Why medication is taken	*12 (63.2)*	11 (61.1)	13 (72.2)
When it is important to take medication	*15 (78.9)*	14 (77.8)	11 (61.1)
Whether there are different types of medication	*12 (63.2)*	12 (66.7)	14 (77.8)
Why there are different types of medication	*8 (42.1)*	7 (38.9)	8 (44.4)
How medication works	*0 (0)*	0 (0)	3 (16.7)
What professionals can help regarding epilepsy	*10 (52.6)*	10 (55.6)	10 (55.6)
What an EEG is	*6 (31.6)*	6 (33.3)	13 (72.2)
Why it is important to visit the Doctor	*9 (47.4)*	9 (50.0)	12 (66.7)
What to do if someone has a seizure	*14 (73.7)*	13 (72.2)	16 (88.9)
What to do if someone receives a warning of a seizure	*10 (52.6)*	10 (55.6)	11 (61.1)
When it is important to call for an ambulance	*11 (57.9)*	10 (55.6)	10 (55.6)
Why seizure diaries are important	*4 (21.1)*	4 (22.2)	10 (55.6)
What should be written in a seizure diary	*9 (47.4)*	8 (44.4)	12 (66.7)
When a seizure diary should be completed	*6 (31.6)*	5 (27.8)	9 (50.0)

Table 3. **Subjects who gave a correct answer to the following questions, using the EY-C.**

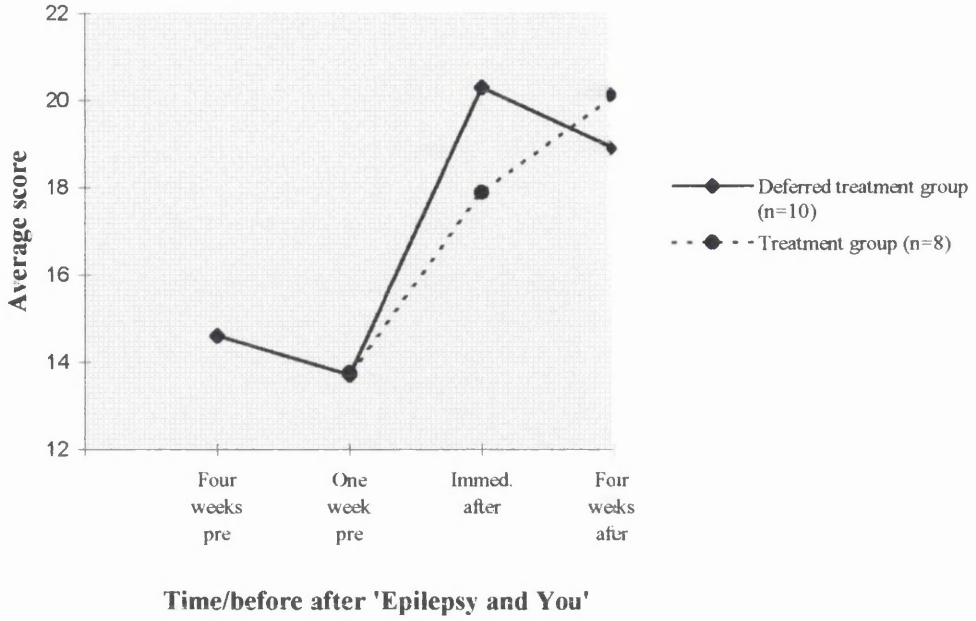

Figure 1. Average EY-C score, for the TG and DTG, relative to 'Epilepsy and You'

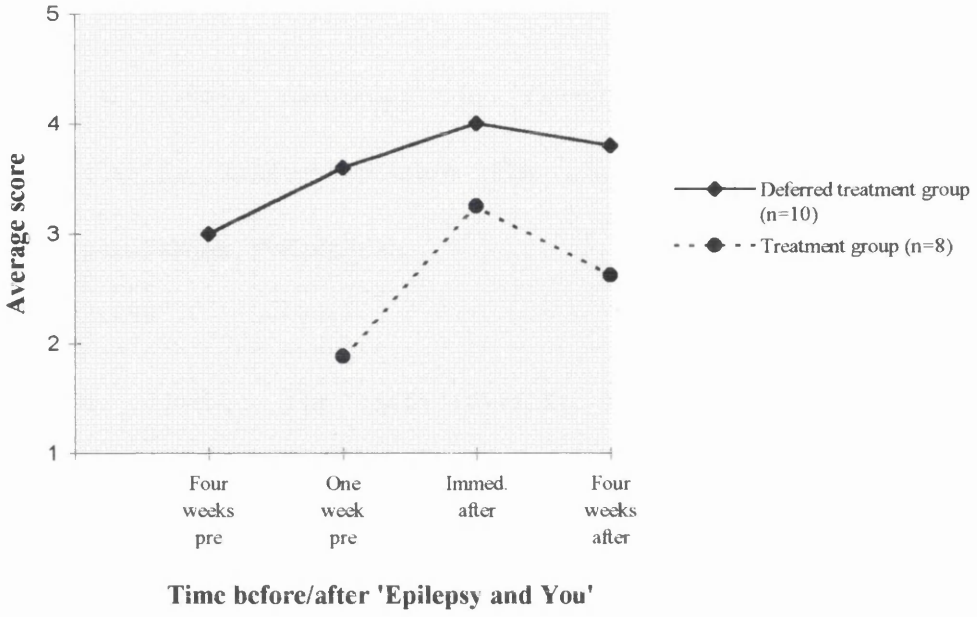

Figure 2. Average EKQ-LD score, for the TG and DTG, relative to 'Epilepsy and You'

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Single Clinical Case Research Study I

Intrusive Thoughts: a single case treatment failure

(Running head - Intrusive Thoughts: a treatment failure)

Prepared in accordance with guidelines for submission to "Behavioural and Cognitive Psychotherapy" (Appendix 5.1)

Intrusive Thoughts: a single case treatment failure

(Running head - Intrusive Thoughts: a treatment failure)

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SUMMARY

This single clinical case research study presents a treatment failure; clinical psychological intervention for a woman with intrusive thoughts (IT). Two therapeutic approaches were used; revised habituation and thought-stopping. The efficacy of each approach was monitored using daily diaries that recorded the frequency of the intrusive thoughts. Neither revised habituation nor thought-stopping had a beneficial clinical effect on the daily IT frequency. In addition, thought-stopping appeared to have a notable adverse effect. Hypotheses for the treatment failure are discussed in addition to methodological criticisms of the study. Finally, follow up information regarding her current presentation is provided.

INTRODUCTION

This single clinical case research study presents a treatment failure; clinical psychological intervention for a woman with intrusive thoughts. This case is presented for two reasons:

1. In the past, two interventions have been used to address intrusive thoughts; habituation and thought-stopping. Although there has been success for individual cases using each approach, neither has demonstrated either a general utility for treatment or strong evidence for its ineffectiveness. As both approaches are utilised within this case study the results can be added to efficacy information about each approach.
2. It is important to document, address and learn from treatment failures. Hypothesised reasons for failure can enhance therapeutic knowledge (Emmelkamp and Foa, 1983).

Intrusive thoughts

Intrusive thoughts (IT) are repetitive, unacceptable or unwanted thoughts, images or impulses that interrupt ongoing activity. They are of an internal origin and are difficult to control (Rachman, 1981).

I am grateful to Mrs Y for granting me permission to submit this case study. I am also grateful to Dr. Taylor for his advice.

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Approximately eighty to ninety percent of non-clinical subjects experience IT similar to clinical IT (Rachman and de Silva, 1978; Parkinson and Rachman, 1981; Freeston, Ladouceur, Thibodeau and Gagnon, 1991; Purdon and Clark, 1993). Researchers have hypothesised that due to a dysfunctional belief of controlling such thoughts, and a tendency to misinterpret thoughts as an indication that unacceptable or unwanted acts may be carried out, intrusions can escalate in frequency and severity so they become clinically significant (Clark and Purdon, 1993; Rachman, 1993).

Treatment approaches for IT

- ***Habituation***

The theoretical basis for this approach is that nearly every constant stimulus will produce habituation. It is hypothesised that in IT either avoidance or inconsistency of the thoughts has prevented habituation. The treatment aim is to deliberately elicit the IT repeatedly and predictably over a time period, so as to prevent covert avoidance and neutralising cognitions and promote habituation.

Treatment can be conducted using 'revised habituation'. This involves individuals recording their IT onto a loop cassette tape and then by playing back the tape, they self-administer habituation through exposure to their IT. There are successful reports for this technique's use (Salkovskis, 1983; Thyer, 1985; Headland and McDonald, 1987; Salkovskis and Westbrook, 1989; Martin and Tarrier, 1992; Simos and Dimitriou, 1994) with the lengths of time individuals have played back the tape varying from twenty minutes to one and a half hours daily. None of these studies has utilised

an experimental paradigm to investigate this technique, all reports are single case presentations, except for Salkovskis and Westbrook (1989) which is a series of four case studies.

- ***Thought-stopping***

Thought-stopping, the main alternative to habituation, is a strategy whereby individuals learn a technique to dismiss distressing thoughts. Individuals are hypothesised to gain a sense of control over their IT, so that in consequence their distress decreases. There is an inadequacy of supporting theoretical arguments for the use of thought-stopping in the treatment of IT versus the use of habituation. However, there are reports of success using this technique for single cases with IT (Stern, 1970; Yamagami, 1971; Lombardo and Turner, 1979).

- ***Studies comparing habituation and thought-stopping for IT***

There is a scarcity of controlled studies comparing habituation and thought-stopping for IT. Emmelkamp and Kwee (1977), in a cross-over design with five subjects, found that either approach could be effective, but that the effect tended to differ from patient to patient. The authors concluded however, habituation was the more valuable alternative as it rested on a theoretical basis. Stern (1978) found habituation to be effective for two out of seven subjects that had IT of a 'horror' type. To explain, one patient had an IT revolving around her embarrassment about an urge to touch another person on the knee. Thought stopping was not significantly effective for four patients studied. Likierman and Rachman (1982) compared six subjects in each condition

(habituation or thought stopping). They found weak and inconsistent support that habituation was more effective than thought-stopping.

Conclusions which can be drawn about the efficacy of either approach over the other are limited, given that only three studies have specifically compared habituation and thought stopping for IT. In addition, although Emmelkamp and Kwee (1977) and Stern (1978) specifically stated their subjects did not have accompanying compulsive rituals, Likierman and Rachman (1982) stated that the "primary problem" (p. 327) of their subjects was IT. They did not elucidate further what the other problems were. The three studies also contained low numbers of treatment sessions; either four (Stern, 1978; Likierman and Rachman, 1982) or five (Emmelkamp and Kwee, 1977). Further controlled studies are needed to determine which approach is the treatment of choice for IT.

The importance of addressing treatment failures

It has been suggested that the dominance of a 'success' ethos in our profession suppresses the reporting of treatment failures (Emmelkamp and Foa, 1983; Harper and Spellman, 1996). Treatment failures should be addressed so that discussion of, and exploration of failure in therapeutic practice is conducted (Harper and Spellman, 1996). Although psychology prides itself on a scientist-practitioner model, one can argue that it only follows a scientist-practitioner model if it is fed unbiased information. However, it has been stated that journals appear to favour the publication of treatment successes and discourage reports of negative results (Emmelkamp and Foa, 1983;

Harper and Spellman, 1996). One wonders how much treatment failure data is lying at the back of filing cabinets!

BRIEF CASE HISTORY

Mrs Y was thirty years old. She explained that for the previous five years she has been having IT about an ex-girlfriend of her husband, whom he had finished a relationship with prior to meeting his wife. Mrs Y's most frequent IT were of the ex-girlfriend's name repeated over and over again. Mrs Y specifically denied her IT were maintained by avoidance or overt/covert neutralisation. Previous informal attempts using distraction had been unsuccessful. Mrs Y reported no other additional worries, concerns or psychological problems. She did not work. She did not take alcohol or drugs and had no family history of psychological or psychiatric disorder.

TREATMENT PROCEDURE

- ***Prior to treatment (baseline 1)***

Mrs Y completed diaries recording the frequency of her IT (Appendix 5.2) for thirteen days. For investigative purposes she completed a personality questionnaire; Minnesota Multiphasic Personality Inventory (Hathaway and McKinley, 1951) and a psychiatric symptomatology questionnaire, Delusions, Symptoms, States Inventory - Revised (DSSI-R) (Foulds and Bedford, 1978).

Although there are self report questionnaires assessing IT (Distressing Thoughts Questionnaire, Clark and de Silva, 1985; Intrusive Thoughts and Impulses Survey, Niler and Beck, 1989; Obsessional Intrusions Inventory, Purdon and Clark, 1993) it was felt that due to the highly specific and idiosyncratic content of Mrs Y's IT, in addition to her lack of reported depressive or anxiety symptoms, these questionnaires were unnecessary.

- ***Revised habituation (3 sessions)***

As revised habituation has a rationale within psychological theory this technique was used initially. Mrs Y recorded her IT onto a looped tape which was then played within the session to determine she was not neutralising while listening to the tape. Mrs Y committed to listening to the tape for fifteen minutes twice a day. She kept diaries recording the frequency of her IT (Appendix 5.3). Mrs Y terminated the revised habituation after nineteen days as it was causing her distress.

- ***Thought-stopping (2 sessions)***

After Mrs Y had had another baseline period of thirteen days (baseline 2) during which she kept IT frequency diaries (Appendix 5.2) thought stopping was introduced. After practising thought-stopping in the initial session Mrs Y agreed to implement the technique initially for twenty minutes a day, starting with mildly difficult thoughts, and then once she became more skilled progressing onto thought-stopping more difficult IT. Mrs Y completed frequency diaries (Appendix 5.4). Mrs Y terminated thought-

stopping after sixteen days as the increased frequency of her IT was causing her distress.

- ***End of treatment (baseline 3)***

Prior to the cessation of input Mrs Y recorded more baseline IT frequencies over a period of nine days (Appendix 5.2) and re-completed the psychiatric symptomatology questionnaire, DSSI-R (Foulds and Bedford, 1978). At the end of input she was relieved that her IT frequency had fallen to (what she termed) "a manageable level".

RESULTS

Thus, clinical psychological input consisted of;

1. Baseline 1 (IT frequency recording and pre-treatment questionnaires)
2. Revised habituation (IT frequency recording)
3. Baseline 2 (IT frequency recording)
4. Thought-stopping (IT frequency recording)
5. Baseline 3 (IT frequency recording and post-treatment questionnaires)

Prior to treatment the results from the Minnesota Multiphasic Personality Inventory (Hathaway and McKinley, 1951) and the pre-treatment DSSI-R (Foulds and Bedford, 1978) were within normal limits. After clinical psychological intervention there was no significant change in scores for the DSSI-R (Foulds and Bedford, 1978).

Table 1 shows the average daily IT frequency recordings within each condition. Figure 1 illustrates baseline 1 daily IT frequencies and revised habituation daily IT frequencies. Figure 2, following on in time from Figure 1, illustrates baseline 2 daily IT frequencies, thought-stopping daily IT frequencies and baseline 3 daily IT frequencies.

Insert Table 1 here

Insert Figure 1 here

Insert Figure 2 here

- ***Data randomness***

Using the turning points test (Morley and Adams, 1989), baselines 1 and 2 data and the revised habituation and thought-stopping data were found not to be random, thus indicating trends within the data. Baseline 3 data was randomly distributed, possibly due to the small number of data points.

- ***Data trend***

Vertical line graphs revealed no indication of linear trend within the revised habituation and thought-stopping conditions. Thus, to compare data trends across conditions running medians of five were calculated for baseline 1 and revised habituation and for baseline 2 and thought-stopping (Figures 3 and 4, Appendices 5.5 and 5.6 respectively) (Morley and Adams, 1991). These figures show that neither the daily IT frequency baselines nor the treatment conditions were stable. Daily IT frequency reduced during the baselines whereas it tended to increase during both treatment conditions. Additionally, using visual analysis techniques (James, Smith and Milne, 1996) to investigate the 'mean shift' revealed there was an increase in the mean level of daily IT frequency within the revised habituation and thought-stopping conditions when compared to the mean level of daily IT frequency for the previous baselines.

- ***Data variation***

Using range lines (Morley and Adams, 1991) to investigate data variance revealed that there was similar variability within the baseline 1 and revised habituation conditions (Figure 1) and there was more variability in the thought-stopping condition than in the baseline 2 condition (Figure 2). When comparing data variability within baseline 1 with that of revised habituation there was a great deal of data overlap; only one point in the revised habituation condition was not contained within the range of baseline 1. This suggests revised habituation may not have adversely affected the overall daily IT frequency for the time span studied. However, due to the tendency for the daily IT frequency to increase in the revised habituation phase versus the observable decrease in

daily IT frequency for the previous baseline (as described in the subsection above) this suggests that had Mrs Y continued revised habituation for a longer time period a notable adverse effect may have been observed. Comparing the variability within baseline 2 with that of thought-stopping revealed there was little overlap of data; eleven of the sixteen points in the thought-stopping condition being outwith the upper range of the baseline 2 data. This suggests that thought-stopping did adversely affect daily IT frequency.

DISCUSSION

Neither revised habituation or thought-stopping had a beneficial clinical effect on Mrs Y's daily IT frequency. Thought-stopping appeared to have a notable adverse effect. It is noticeable that Mrs Y terminated both treatment techniques after a short period of time (nineteen days for revised habituation, sixteen days for thought-stopping). However, success for these techniques in shorter time intervals have been shown (Lombardo and Turner, 1979; Headland and McDonald, 1987; Salkovskis and Westbrook, 1989; Simos and Dimitriou, 1994). In addition, the presence of an 'extinction burst' following the introduction of these procedures does not appear to be documented in the literature. The above arguments however, detract from an important clinical issue. The techniques caused Mrs Y such distress that she refused to continue them. At the end of input she demonstrated no adverse additional psychological problems, as demonstrated by the use of self report questionnaires. In addition, her daily IT frequency had returned to (what she termed) "a manageable level".

Why did clinical psychological input fail?

Rachman (1983) proposed impediments to therapeutic success for IT; severe depression, the presence of over-valued ideas, whether the person is living under stressful conditions that give rise to anxiety. Mrs Y presented with none of the above.

- ***why did revised habituation fail?***

Presuming that Mrs Y adhered to the treatment protocol and was not utilising (previously undeclared) overt/covert neutralisation or avoidance it is unclear why the revised habituation technique was unsuccessful, especially when one considers its foundation in psychological theory. Perhaps the length of time Mrs Y listened to the loop tape was too short for her needs. However, she would not contemplate listening to the tape for longer periods. Salkovskis (1983) had success with an individual who initially listened to a tape for twenty minutes daily until following some improvement, the individual consented to listen to the tape for longer periods. In addition, Headland and McDonald (1987) successfully used a daily tape length of thirty minutes.

- ***why did thought-stopping fail?***

Presuming once again that Mrs Y adhered to the treatment protocol, one can hypothesise why thought-stopping adversely increased the daily IT frequency. Recent studies, using nonclinical subjects, have indicated that suppressing unwanted thoughts can increase their frequency (Salkovskis and Campbell, 1994; Trinder and Salkovskis, 1994).

Criticisms of this study

Clark (1988) has voiced concern that due to the internal private nature of IT, the sole evaluation of subject's self reports via diaries or interviews, can be problematic. Therefore, one has to acknowledge the additional criticism that Mrs Y may have withheld information (Clark and Purdon, 1995). However, clinical psychological intervention rests in the majority, on the strength of the therapeutic relationship and what individuals disclose. Throughout the input Mrs Y gave no indication that she was not totally committed to the procedures used.

FOLLOW UP

Recently, Mrs Y was contacted to investigate whether there had been any changes in her presentation. This was approximately eighteen months after her last appointment. Mrs Y advised that a year ago she had become depressed. She had visited a counsellor who practised cognitive therapy but felt this did not help. She then visited her Doctor who prescribed a course of anti-depressants ("Gamanil"). After this, she said she noticed the daily frequency of her IT decreasing. Prior to this, she hypothesised, the daily IT frequency had remained at a level similar to that recorded at the end of baseline 3. Mrs Y reported that since she finished the anti-depressants her daily IT frequency has remained at one to two per day. However, a complicating factor is that, following her anti-depressant medication she took part-time employment. Thus, it is unclear whether Gamanil helped her IT frequency or whether her IT decreased because she was no longer able to suppress her IT to the same extent.

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TABLES AND FIGURES

Condition	Number of days	Daily IT frequency Mean (SD)	
Baseline 1	13	120	(49)
Revised habituation	**19**	**140**	**(34)**
Baseline 2	13	113	(28)
Thought-stopping	**16**	**162**	**(36)**
Baseline 3	9	127	(25)

Table 1: Average daily IT frequency recordings within each condition

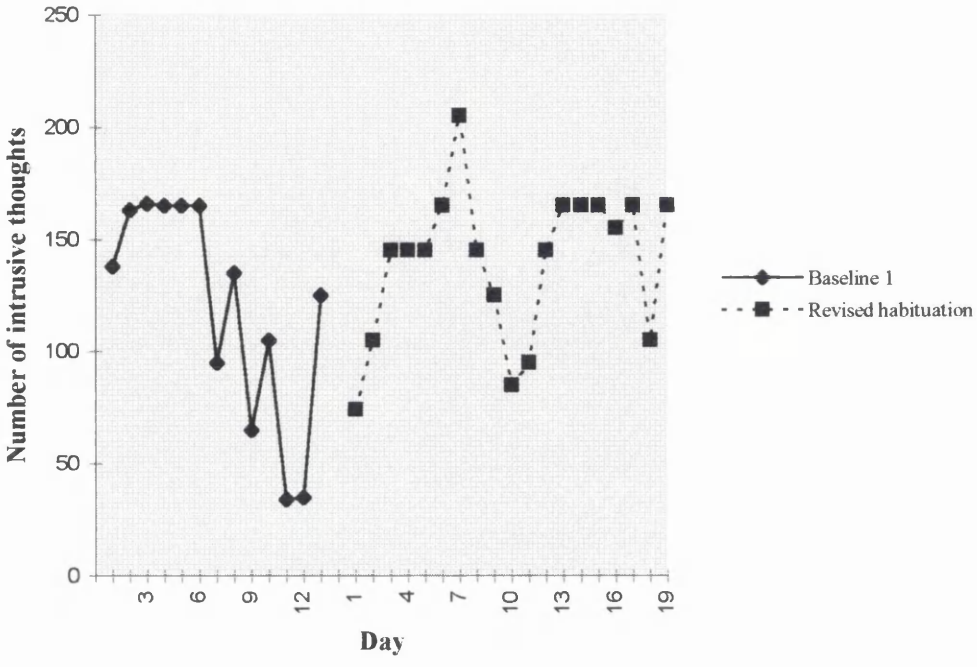

Figure 1. Daily frequency of intrusive thoughts during baseline 1 and revised habituation

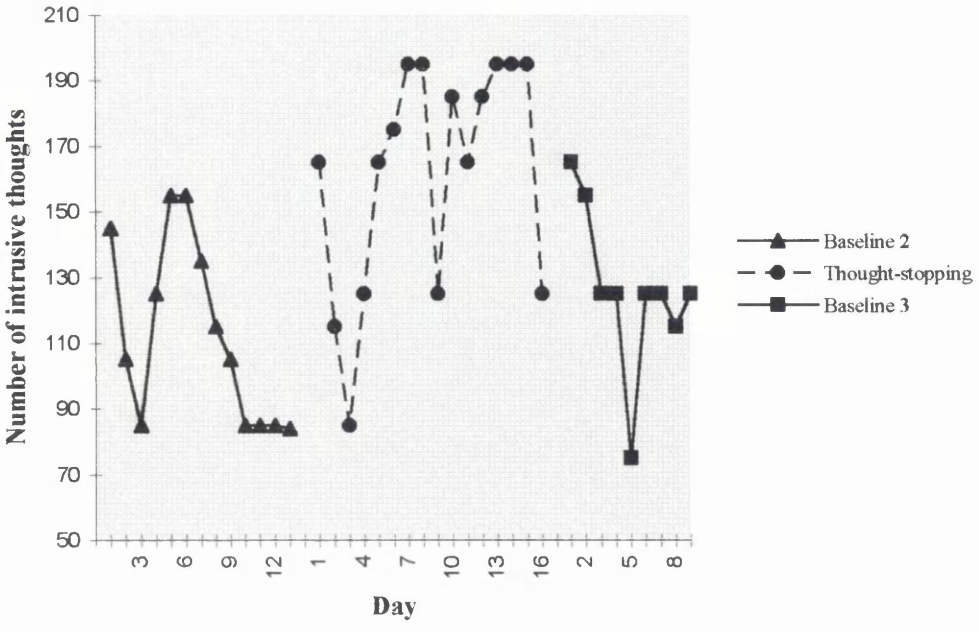

Figure 2. Daily frequency of intrusive thoughts during baseline 2, thought-stopping and baseline 3

Single Clinical Case Research Study II

Addressing Social Withdrawal in a Man With a Learning Disability

Prepared in accordance with guidelines for submission to the "British Journal of Learning Disabilities" (Appendix 6.1)

Addressing Social Withdrawal in a Man With a Learning Disability

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SUMMARY

This single clinical case research study documents clinical psychological input addressing social withdrawal in a gentleman with a learning disability, a sensory impairment and who was non-verbal. The gentleman's withdrawal was hypothesised to be because he found a lack of effective communication between himself and others anxiety provoking and confusing and would therefore avoid interactions in order to prevent distress. Following an assessment of his cognitive functioning, a tailored visual communication system utilising non-aversive behavioural principles was developed to enable the gentleman to have more choice, control and predictability during interactions. Beneficial effects were found. The level of initiation, the length of, and his motivation to re-establish interactions increased. Important issues arising from the case study are discussed. Criticisms of the study are presented.

INTRODUCTION

A large proportion of the clinical psychologist's time within the learning disability specialism involves assessing and providing management strategies regarding challenging behaviour. Challenging behaviour is "culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities." (Emerson, 1995, p. 4-5). Although challenging behaviour has many forms, there are three main types addressed within the research literature; self injury, aggression/destructiveness, stereotypy. A challenging behaviour infrequently addressed is 'social withdrawal'. Social withdrawal occurs when an individual voluntarily removes themselves from interactions with others, be it by physically leaving the environment or by using materials, such as clothing, to shield themselves.

There are serious consequences from withdrawal. Considering the normalisation philosophy for individuals with a learning disability (Wolfensberger, 1972), for which communication skills are necessary (Lindsay and Michie, 1991), along with the philosophy that each individual with a learning disability has the right to five necessary accomplishments for quality of life; community presence, choice, competence, respect, community participation (O'Brien, 1986), the importance of addressing withdrawal becomes paramount. In addition, research has documented that opportunities for social interactions play a part in a sense of personal identity and the feeling individuals belong somewhere (Condon, 1980; Jahoda et al., 1990).

Withdrawal can be negatively reinforced; by withdrawing from the environment an individual avoids interactions and communications with others they find distressing. For example, an individual's lack of expressive communication skills can lead to feelings of confusion and of having no control over their environment. Hastings and Remington (1994) stated staff behaviour also has an influence on challenging behaviour. Research has documented there is little interaction between individuals with a learning disability and staff, especially for individuals who reside within a hospital (Cullen et al., 1983; Felce and Repp, 1992; Markova et al., 1992) and, when approached by individuals to communicate, staff can be unresponsive (Cullen et al., 1983). Jahoda and Cattermole (1995) hypothesised that as a result individuals can withdraw into themselves and may use self stimulatory behaviour to pass time. Drawing from attribution theory (Kelley, 1973), staff can also seek to explain an individual's withdrawal in order to keep their own sense of control over the environment. Depending on whether staff determine withdrawal occurs because of factors within the person (internal attribution) or environmental factors (external attribution) affects their reactions. Staff would be less likely to interact with someone if they believe nothing can be done to change their withdrawal. Indeed, Fenwick (1995) hypothesised the perceived severity of a learning disability can be crucial in determining the cause ascribed to challenging behaviour. Although Bromley and Emerson (1995) have investigated the beliefs and emotional reactions of care staff working with people with challenging behaviour their study did not examine withdrawal.

This case study will detail clinical psychological intervention regarding a man with a learning disability who presented with withdrawal and was deaf and non-verbal. To

the author's knowledge there is no literature addressing withdrawal in an individual with a learning disability and a sensory impairment.

BRIEF CASE HISTORY

Mr M, who was a fifty nine year old gentleman, lived in a Learning Disability Hospital. He was referred for clinical psychological input as he had refused to attend Hospital Day Services for the previous thirteen months. His refusal to attend commenced after changes were made to the services.

Mr M was withdrawn on the ward. He initiated little interaction with other residents or staff. He would engage persons in an intricate 'greeting' ritual when he first met them. If individuals did not engage in this Mr M would become distressed and would follow them off ward (for about fifteen paces) until they completed the greeting. Mr M's communications with staff encompassed momentary interactions about food/drink, nursing or self care issues. He did not use Makaton but used his own small range of signs. Mr M would spend his day sitting in a chair (mostly outwith the eye contact of staff) or lying on his bed.

Staff initiated little interaction with Mr M and reported he would not participate with ward tasks. The perception of some professionals involved with Mr M's care was that, due to his age, his presentation and his level of functioning, it would be difficult to address his withdrawal and effect any change.

CLINICAL PSYCHOLOGICAL FORMULATION

Mr M did not display clinical indications of depression or agoraphobia. Mr M had become increasingly withdrawn as he had found the recent changes in his life extremely anxiety provoking and confusing, primarily due to the lack of effective communication between himself and others. Mr M's withdrawal behaviour on the ward was functionally adapted to avoid communications with others as he found these anxiety producing.

AIMS OF INPUT

The short term aim was to develop a visual aided communication system that would allow Mr M choice, control and predictability during interactions with the author. This case study details Mr M's progress regarding this aim.

Two long term aims (not detailed within this study) were also developed. One, to encourage Mr M to leave the ward using the visual aided communication system. Two, for Mr M and staff to interact with each other using the aided communication system.

METHOD

In order to gain an indication of the level of Mr M's adaptive functioning the Vineland Adaptive Behaviour Scales (Sparrow, Balla and Cicchetti, 1984) were utilised. His keyworker participated in a semi-structured interview to complete the scales. The

Vineland Adaptive Behaviour Scales were to be re-administered after the long term aims were implemented to evaluate Mr M's progress.

In order to develop an optimal, tailored visual communication system Mr M's cognitive functioning had to be evaluated (Jones and Cregan, 1986). A cut out version of the Coloured Progressive Matrices (Raven, 1986) was utilised to gain an clinical impression of Mr M's visual processing abilities. In addition, The Leiter International Performance Scale (Leiter, 1979), a non verbal means of assessing general intelligence was utilised to gain an indication about his cognitive functioning. Various 'informal' tests and observations also gave a clinical indication of Mr M's abilities.

The results suggested Mr M had difficulty with abstract reasoning, counting above two and with conducting three or more simultaneous concrete mental operations. He had no visual perception vulnerabilities.

An optimal aided communication system utilising symbols with high iconicity was indicated (Stansfield, 1991). Iconicity is the strength of the association between the visual sign or symbol and what it represents. There are three levels of iconicity with decreasing association strengths, transparent, translucent and abstract. A 'transparent' system, using photographs, was the optimal avenue as it required the least abstract reasoning for interpretation and hence, promoted optimal information acquisition and retention.

A structured hierarchy of increasing complex stages, utilising non-aversive behavioural techniques, was developed to teach Mr M the principles of the visual aided communication system (Table 1). It was utilised on a weekly basis by the author. The hierarchy was designed so Mr M did not negotiate more than two simultaneous mental operations without prior learning. Mr M's progress throughout the hierarchy was contingent on whether it was felt by the author that he understood what was happening.

Insert Table 1

During the hierarchy, Mr M learnt various interactional 'concepts', for example, the concept of choice and the concept of waiting.

RESULTS

The Vineland Adaptive Behaviour Scales revealed that, when compared with a learning disabled norm group, Mr M's adaptive behaviour composite, his socialisation skills and his daily living skills were average. However, his communication domain was below average. He had inconsistencies regarding receptive and expressive communication and with interpersonal relationships and play and leisure skills when compared to his overall profile (Appendix 6.2).

Prior to the hierarchy, i.e. the baseline, Mr M would tolerate approximately ten minutes of interaction, he would refuse to do tasks requested and would leave whenever ward routine interrupted.

Figure 1 presents Mr M's progress during increasing stages of the hierarchy. Mr M required gestural prompting during the first two sessions but thereafter required no further prompting. Due to his progress it was deemed unnecessary to conduct stage 6. Mr M was conducting stage 7 at the end of the author's input within the Hospital.

Insert Figure 1

At the end of the author's input Mr M would initiate participation in the communication system. He interacted and participated in tasks that lasted over an hour and returned to sessions after ward routine interrupted them. Additionally, he participated in domestic tasks related to input and would smile broadly while completing the tasks.

Mr M's keyworker, after observing progress made, requested a hierarchy be developed that would encourage Mr M to participate in ward activities.

DISCUSSION

This case study detailed clinical psychological intervention regarding a man (Mr M) with a learning disability who presented with withdrawal and was deaf and non-verbal. His withdrawal was hypothesised to be due to anxiety resulting from finding communications confusing. An visual aided communication system was developed to help him have choice, control and predictability over his interactions with, initially, the author.

This case study replicates research findings. There was little interaction between Mr M and staff (Cullen et al., 1983; Felce and Repp, 1992; Markova et al., 1992). In addition, it was observed that Mr M, whose challenging behaviour entailed little environmental disturbance, received less staff input than others who presented with more physically disruptive challenging behaviour (Hastings and Remington, 1994).

Mr M's visual aided communication system had a beneficial effect. The length of time he would interact with the author increased, he would seek out interactions, he would return to interactions that had been interrupted and he would engage alongside the author in ward based activities. These behaviours are all notably different from his presentation at referral. His eagerness to participate in the programme confirms his withdrawal was not attributable to a lack of motivation.

Mr M required less sessions to develop skills and knowledge associated with higher levels of the hierarchy (Figure 1). This demonstrated that although initial sessions involved him learning and registering relevant information, in further stages he used his

abilities to interpret information in the light of what had already been learnt. This process is further demonstrated by the slight increase in the number of sessions at stage 4. At that point Mr M was introduced to a new concept for him; waiting. However, once he understood the concept the number of further sessions again began to decrease. Figure 1 highlights Mr M's potential for learning; his knowledge did not reach a 'ceiling' effect.

Staff changed their attributions about Mr M, as demonstrated when a programme to encourage Mr M in ward activities was requested. Initially, some staff believed Mr M would not benefit from psychological input. This is a significant development as it would involve such staff modifying their pre-existing conceptual framework to accommodate the information regarding Mr M's progress.

Important issues arise from this case study. It highlights the necessity for staff working with individuals with a learning disability to be trained in communication methods. In addition, the potential for change and learning in an individual whose presentation caused some professionals to attribute erroneous beliefs to him has been demonstrated. Mr M's progress begs the question, what potential could he achieve if his communication needs are met within a more appropriate service?

Criticisms of this study

It would have been beneficial, for monitoring Mr M's progress, to collect more detailed information such as the exact length of time Mr M spent in each session and when exactly he initiated interactions. However, the limited quantitative and, more

importantly, the substantial difference within the qualitative measures described in this study demonstrate Mr M's significant progress.

ACKNOWLEDGEMENTS

The author is grateful to Mr K. Bowden, Mr K Tolland and Ms L Wanless for their guidance and assistance.

TABLES AND FIGURES

Stage of Programme	Procedure
1	To establish the link between his interactions and their effect Mr M was immediately reinforced, using primary and social reinforcement, when he pointed to one of two photographs of food. He was given the appropriate food while the photograph was still visible.
2	As stage 1, except the photograph of the primary reinforcer was removed before he received the food he had chosen.
3	As stage 2, except Mr M was given a choice of two alternative photographs of primary reinforcers (of drinks). This was implemented to prevent satiation and to increase his 'vocabulary'.
4	As stage 3, except Mr M waited a very short time for reinforcement. A sign for 'wait' was introduced to help him understand what was happening.
5	As stage 4, except he chose one of the four primary reinforcement photographs that he had learnt.
6	As stage 5, except the periods Mr M waited for reinforcement were increased in a systematic fashion.
7	As stage 6, except Mr M chose two of the four primary reinforcers. The waiting period continued to increase at systematic intervals.
Future Input	A hierarchy would then be developed to encourage Mr M to leave the ward to attain reinforcements that he had chosen.

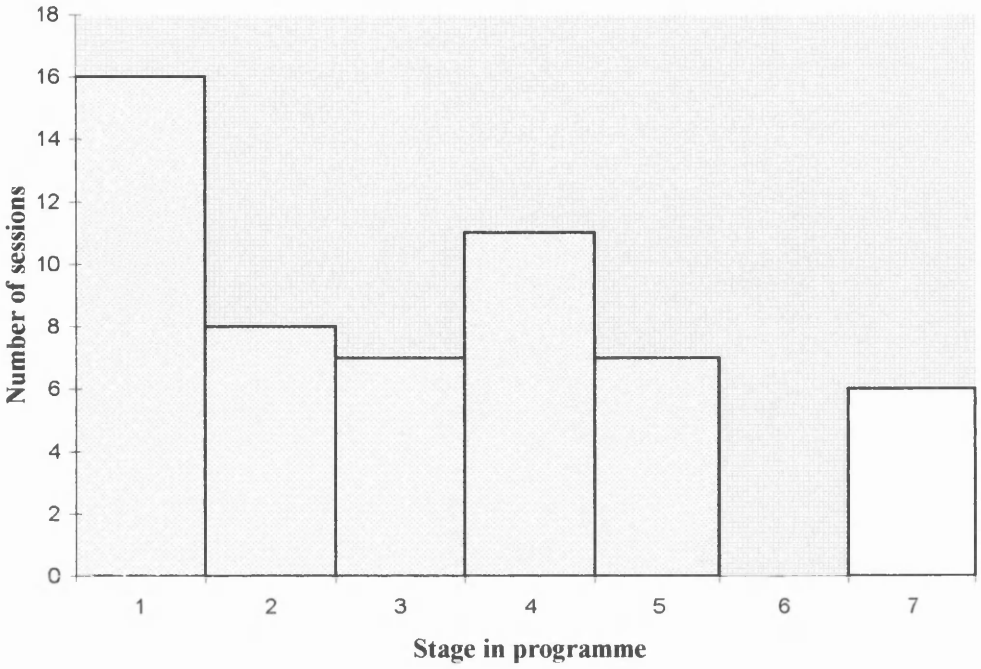

Figure 1. Number of sessions required for Mr M to complete each stage of the aided communication programme

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Single Clinical Case Research Study III

The Efficacy of CBT for Social Phobia: a single case study

(Running head - CBT for Social Phobia)

Prepared in accordance with guidelines for submission to "Behavioural and Cognitive Psychotherapy" (Appendix 7.1)

The Efficacy of CBT for Social Phobia: a single case study

(Running head - CBT for Social Phobia)

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SUMMARY

This single clinical case research study presents evidence for the successful use of cognitive behavioural therapy (CBT) for social phobia. An AB experimental design was utilised. Despite an initial setback during treatment both quantitative and qualitative measures revealed improvement in anxiety symptoms and associated low mood. In addition to CBT it became beneficial to address the individual's self esteem. The implications of this are discussed. This study does not indicate which part of the treatment procedure the individual benefited from more. Criticisms of this study are presented.

INTRODUCTION

This single clinical case research study documents the successful use of cognitive behavioural therapy (CBT) for social phobia.

Definition of social phobia

DSM-IV criteria state social phobia is characterised by a marked and persistent fear of social occasions (American Psychiatric Association, 1994). Social phobia is maintained by the avoidance of social situations that trigger anxiety responses. Individuals who have social phobia fear that they are being scrutinised by others and worry that they will do something in a social situation that is humiliating or embarrassing. Individuals with social phobia tend to be over compliant and have difficulty asserting themselves.

Treatment for social phobia

The conventional treatment for phobias, based upon work by Wolpe (1958, 1961) is to ask individuals with a phobia to approach and stay in the situation they fear. Consequently, individuals then re-learn how to deal with their fears effectively. Research has demonstrated that exposure to such feared situations can be effective but

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I am grateful to Dr. Taylor for advice during this case study.

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that it should be graduated, repeated and prolonged with practice tasks clearly specified for optimal effectiveness (Marks, 1981; Mathews, Gelder and Johnston, 1981; Emmelkamp, 1982; Butler, Cullington, Munby, Amies and Gelder, 1984). However, for individuals with a social phobia there are difficulties with putting these recommendations into practice. Social situations can be highly variable and unpredictable and difficult to control. Mattick and Peters (1988) and Butler (1989) have suggested additional procedures are used. For example, the rehearsal of social meetings and conversations, the controlling of anxiety symptoms using anxiety management and the recording and challenging of dysfunctional cognitions. It is important to focus on the dysfunctional cognitions of a individual with a social phobia as research has revealed they present with a selective attentional bias, for threat information, interpretation and the retrieval of related memories (Stopa and Clark, 1993). Hope, Gansler and Heimberg (1989) have also demonstrated that socially phobic individuals frequently apply standards to their own behaviour that they do not apply to others.

Does CBT work for social phobia?

Studies addressing the use of cognitive restructuring methods in social phobia have provided encouraging results (Kanter and Goldfried, 1979; Malkiewich and Merluzzi, 1980; Mattick, Peters and Clarke, 1989). However, McNally (1995) has argued that due to the involuntary and possibly unconscious nature of information processing in anxiety, verbal therapies such as cognitive therapy for anxiety (Beck, Emery and Greenberg, 1985) may be ineffective. McNally (1995) has stated that behavioural techniques should be solely used. This is in agreement with a finding by Chambless

and Gillis (1993) that CBT is not consistently superior to behavioural treatments. In response, Beck and Clark (1997) have argued that verbal techniques should be used (although not solely) for anxiety disorders because of the central role played by the assignation of threat to situations, and because the efficacy of verbal process on treatment outcomes has since been demonstrated (Feske and Chambless, 1995).

BRIEF CASE HISTORY

Ms W, who was twenty four years old, presented with social phobia of a generalised nature. Her phobia was maintained primarily by the fear of receiving negative evaluation from others. It was also maintained by the experience of extreme anxiety and panic in, and the deliberate avoidance of social situations. Her phobia, which had been present since seventeen years of age, had resurfaced two months previously when Ms W was informed she would be made redundant. Ms W was extremely fearful about having to initiate and maintain conversations with people unfamiliar to her when seeking alternative employment and was especially fearful what their opinions would be of her. Throughout her life Ms W had experienced little change. She lived with her family, she had the same friends she had at primary school and her close friends were also her work colleagues. Her job meant that she could avoid meeting strangers. Ms W also reported feelings of low mood stemming from her belief that her anxiety would never resolve. Although not fulfilling strict DSM-IV criteria for a major depressive episode her low mood was of clinical concern. Ms W did not misuse alcohol or drugs nor was she taking medication.

Based upon Ms W's presentation (social phobia of a generalised nature maintained by a central role of dysfunctional automatic anxiety thoughts) the aim of this single clinical case research study was to determine whether CBT for social phobia would be therapeutically effective for her. A basic AB experimental design was utilised.

TREATMENT PROCEDURE

- ***Prior to treatment (the baseline)***

Ms W completed;

1. Delusions, Symptoms, States Inventory - Revised (DSSI-R) (Foulds and Bedford, 1978). Gilleard (1983) and Morey (1985) have demonstrated the validity of Foulds and Bedford's (1975) hierarchical model of psychiatric illness.
2. Fear of Negative Evaluation Scale (FNE) and Social Avoidance and Distress Scale (SAD) (Watson and Friend, 1969). The FNE measures an individual's apprehension about others' evaluations of them, distress about negative evaluations, avoidance of evaluative situations and the expectation that others evaluate them negatively. The SAD measures social avoidance and social distress. Social avoidance is defined as avoiding being with, or escaping from, others for any reason. Social distress is defined as the experience of a negative emotion, for example being upset, distressed and anxious, in social interactions.
3. Excerpts from the Anxiety Disorders Interview Schedule - Revised (ADIS-R) (Di Nardo and Barlow, 1988). The ADIS-R measures the range of anxiety disorders.

4. Diaries recording daily anxiety and low mood level. Ms W rated her feelings along a range of 1-5 (little or no anxiety/low mood, to the most anxiety/low mood she could feel).

- ***Treatment***

Treatment focused primarily on addressing Ms W's social phobia. She stated her aim was to be able to initiate and maintain conversations with strangers. Although her low mood was monitored closely it was hypothesised to be a consequence of her social phobia. Following the discovery that people only retain a small proportion of information given during a consultation (Ley, 1979) Ms W was given, and encouraged to note other important therapeutic information for later reference.

Table 1 shows the content of each session.

Insert Table 1 here

Throughout treatment Ms W continued to complete anxiety and mood diaries daily, as described within the subsection above. Using diaries she also recorded her level of anxiety before, during and after exposure tasks; by noting the level of her anxiety along three horizontal ten centimetre lines. In addition, the percentage belief that Ms W had for dysfunctional automatic anxiety thoughts was calculated before and after cognitive evaluation.

RESULTS

Quantitative results

The pre-treatment DSSI-R revealed that Ms W recorded clinically significant anxiety, depression and rumination. Ms W did not return the post-treatment DSSI-R.

Table 2 details pre-treatment and mid treatment results for the FNE and the SAD. There was no improvement on these measures. Ms W did not return the post-treatment questionnaires.

Insert Table 2 here

Figure 1 demonstrates Ms W's average daily self report anxiety rating at baseline and throughout treatment. Figure 2 displays Ms W's average daily self report low mood rating for this time period also. Figure 3 shows her self reported anxiety level before, during and after exposure tasks.

Insert Figures 1, 2 and 3 here

Figures 4-6 illustrate positive therapeutic changes in Ms W's self reported fear of, and avoidance of social situations, and in the severity of anxiety symptoms she felt regarding social situations. For example, she recorded a decrease in her rating of fear associated with social situations when with friends and encouragingly, for some social situations associated with strangers. Ms W recorded beneficial effects regarding her fear of initiating and maintaining conversations with strangers; the treatment aim. Related to her decreased fear ratings Ms W also recorded decreased 'avoidance' ratings for social situations, either with friends or associated with strangers. Once again, she recorded a decrease in her rating for her avoidance of initiating and maintaining conversations with strangers; a treatment aim. Ms W recorded a decrease in all anxiety symptoms felt, with a maximum decrease recorded for derealisation, depersonalisation and the fear of doing something uncontrollable.

Insert Figures 4, 5 and 6 here

During cognitive restructuring, Ms W had an initial mean belief for dysfunctional automatic anxiety thoughts of 87%. After cognitive evaluation the mean belief for such thoughts decreased to 30%.

- ***Data randomness***

Figures 1 and 2 (the treatment phases) indicated a data trend (turning points test, T=2 for each figure, $p<0.002$, Morley and Adams, 1989). The null hypothesis, that the baseline data and the data within Figure 3 were random, could not be rejected.

- ***Data trend***

A resistant line, fitted by the three-group method, and two half lines (Morley and Adams, 1991) demonstrated that the treatment phase data in Figures 1 and 2 could not be described by a linear trend. This is due to the increase in self reported anxiety and low mood between weeks four to seven. To investigate the non-linear data trend running medians of five were calculated (Figures 7 and 8, Appendices 7.2 and 7.3 respectively). It was revealed that following weeks four to seven, there was a therapeutic beneficial decrease in the ratings for anxiety and low mood.

Qualitative results

Ms W reported that following input she was more able to initiate and maintain conversations with strangers. For example, she went out alone for a drink with a man; something she would not have considered before input. Near the end of input Ms W also recorded an interview for a national news programme. Furthermore, she reported stability in her phobia symptoms despite her job loss becoming more imminent. Ms W explained she felt the use of cognitive techniques were more beneficial for her than the exposure tasks.

DISCUSSION

Ms W presented with social phobia of a generalised nature. At assessment she presented with clinically significant anxiety, depression and rumination as measured with the DSSI-R. Although self report questionnaires assessing her social phobia did not show an improvement from baseline to the mid point of treatment other measures revealed improvement.

Improvement demonstrated by quantitative measures

Although Ms W had a setback between weeks four to seven of the treatment phase, when her anxiety and low mood self report ratings increased, this should not be taken as evidence that CBT did not help her social phobia. At that point in time Ms W had heard her job loss would be sooner than expected. Consequently, she had a severe anxiety reaction and became despondent about progress. The increase in anxiety and low mood ratings can be attributed to her not having had the opportunity to adequately learn and practise the appropriate CBT skills required. The data shows that once she had mastered the appropriate skills following weeks four to seven, Ms W demonstrated therapeutic progress, even when her job loss was becoming more imminent. Following on from this example, thus suggests patients may benefit from encouragement to persevere with CBT despite their perceived initial lack of progress.

Ms W had beneficial improvements regarding a decrease in her ratings for her fear of, and avoidance of the majority of social situations examined. She recorded improvements regarding her fear of, and her avoidance of initiating and maintaining a

conversation with a stranger; a treatment aim. Ms W recorded a decrease in the intensity of associated anxiety symptoms felt in social situations. A lack of improvement measured using the SAD and the FNE may be due to the structure of the questionnaires. Individuals are requested to response either 'true' or 'false' to statements provided. There is no opportunity for respondents to register gradations of self perceived improvement, whereas the excerpts used from the ADIS-R gave Ms W the opportunity to do just that.

As treatment addressed her social phobia, the close association between her self reported ratings of anxiety and low mood lends support to the hypothesis that Ms W's low mood was a consequence of her social phobia.

Qualitative improvement

Ms W reported stability in her phobia symptoms despite her job loss becoming more imminent. She advised she felt more confident about talking to strangers and that she had consequently, begun to increase her contact with them. A striking indication of Ms W's improvement was that she also recorded an interview for a television news programme, despite realising the interview would be seen by millions of television viewers!

At the beginning of the discussion it was noted that Ms W did not return post-treatment questionnaires. This can be regarded as a positive qualitative treatment outcome in itself. Individuals with social phobia are overly compliant and worry about being negatively evaluated. Thus, Ms W not returning the questionnaires may have

demonstrated a decrease in her compliance and with that an hypothesised decrease in her fear about being negatively evaluated.

In conclusion, CBT helped Ms W's social phobia. It is unclear which part of the procedure she benefited from more. Due to possible data randomisation for the exposure tasks it could not be concluded whether these helped or did not help Ms W. Ms W observed she felt the cognitive techniques were more beneficial for her. Indeed, there was a notable decrease in the percentage belief that she attributed to dysfunctional automatic anxiety thoughts following cognitive evaluation. An additional area addressed was Ms W's self esteem. This appears to be an issue that is beginning to be discussed within treatment approaches to social phobia. Wroblewska (1995) highlighted the beneficial effect that addressing an individual's self esteem can have on their social phobia.

Criticisms of this study

Although this study achieved it's aim; to determine that CBT for social phobia was therapeutically effective for Ms W, it would have been more useful to collect more quantitative baseline data in order to reinforce conclusions drawn. In addition, more data related to the exposure tasks would have possibly resulted in their efficacy being assessed. As discussed, addressing self esteem also formed part of the treatment package. However, no formal measures of self esteem were utilised to test the effectiveness of this approach.

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TABLES AND FIGURES

Session number	Week Number	Content of session
1	Baseline week 1	Assessment.
2	" 2	Assessment. ***DSSI-R, FNE, SAD, ADIS-R excerpts completed.***
3	Treatment week 1	Education regarding the mechanisms and manifestations of anxiety. Anxiety management techniques introduced.
4	" 2	Role plays utilised to highlight and address areas of verbal and non-verbal communication. Development of exposure hierarchy regarding initiating and maintaining conversations with strangers. Exposure homework tasks set.
5	" 3	Identification of dysfunctional automatic anxiety thoughts.
6	" 4	As a central aspect of Ms W's social phobia was a fear of negative evaluation, strategies addressing her self esteem were utilised. Information given to promote the normalisation of her response to change.
7	" 5	Crisis intervention requested by Ms W due to heightened anxiety and low mood resulting from imminent job loss.
8	" 6	Identification and evaluation of dysfunctional automatic thoughts.
9	" 7	Review of anxiety management techniques, evaluation of dysfunctional automatic thoughts. ***FNE, SAD, ADIS-R excerpts re-completed.***
10	" 8	Evaluation of dysfunctional automatic thoughts.
11	" 9	Evaluation of dysfunctional automatic thoughts.
12	" 11	Evaluation of dysfunctional automatic thoughts.
13	" 13	Evaluation of dysfunctional automatic thoughts.
14	" 15	Review of sessions. ***ADIS-R excerpts re-completed. DSSI-R, FNE and SAD to be re-completed and returned by post.***

Table 1. Session by session breakdown of clinical psychological input

	Pre-treatment score	Mid-treatment score
Fear of Negative Evaluation Scale	30	30
Social Avoidance and Distress Scale	27	28

Table 2. Scores, pre and mid treatment for the FNE and the SAD

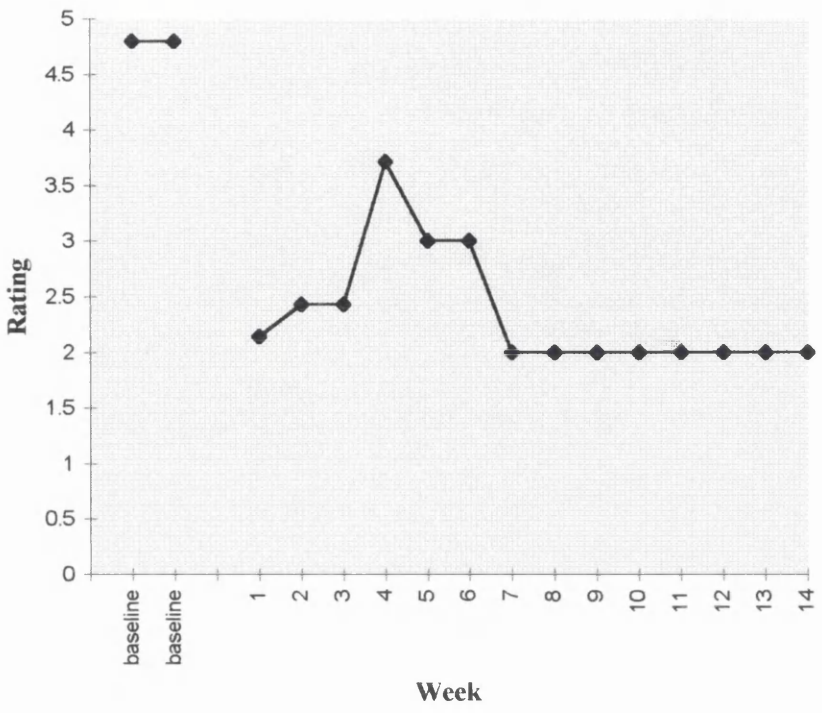

Figure 1. Average daily self report anxiety rating

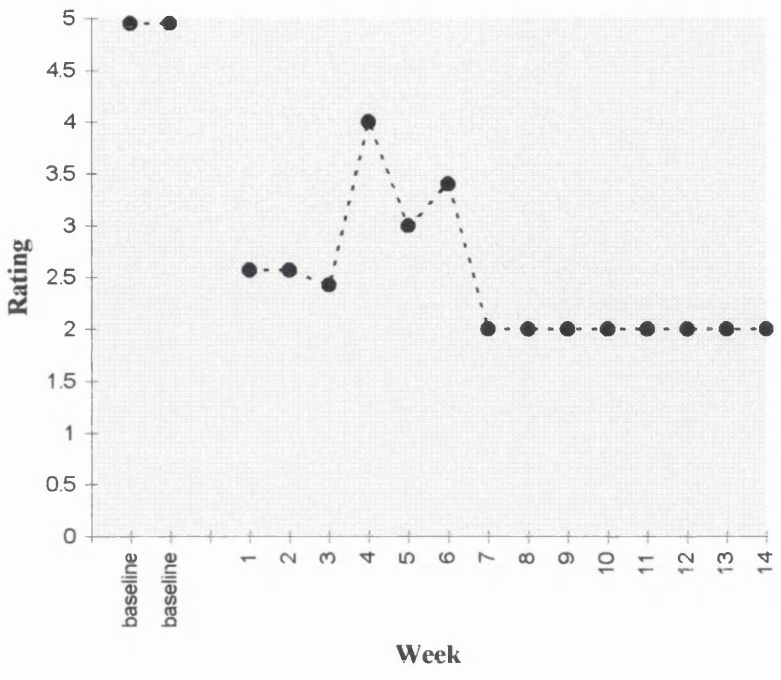

Figure 2. Average daily self report low mood rating

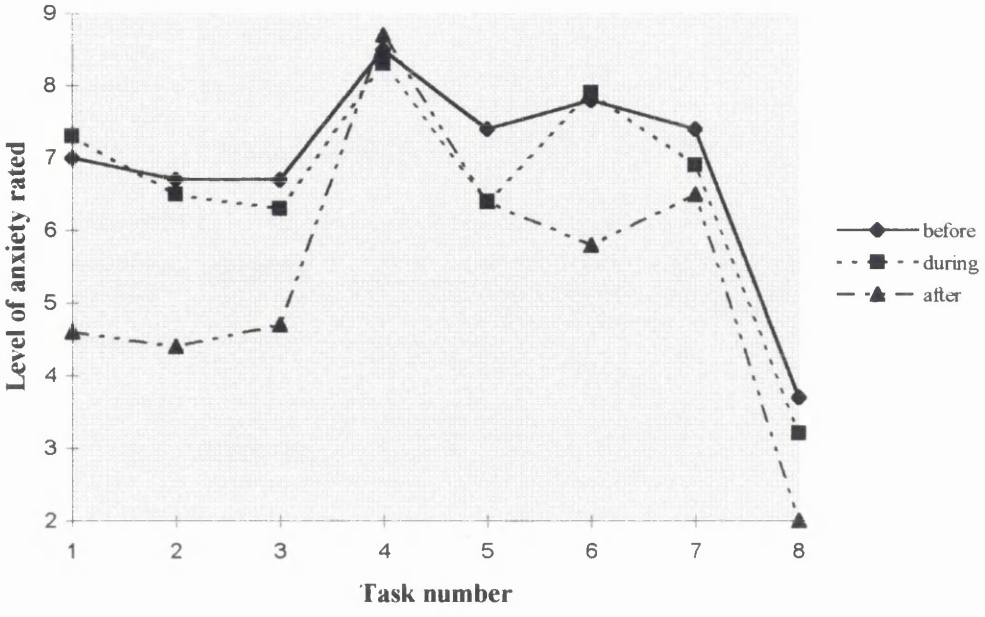

Figure 3. Rating of anxiety before, during and after an exposure task

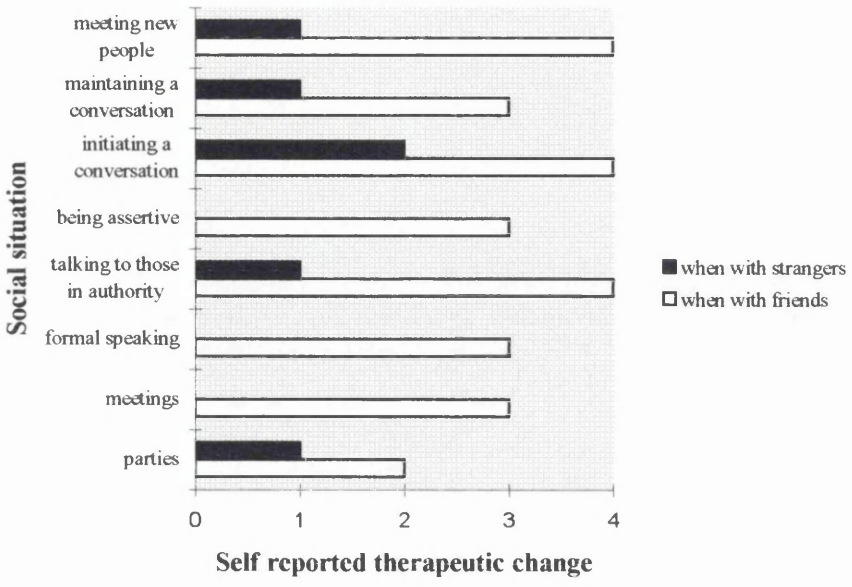

Figure 4. Overall therapeutic change in 'fear' score between baseline and end of treatment (maximum change-4 points)

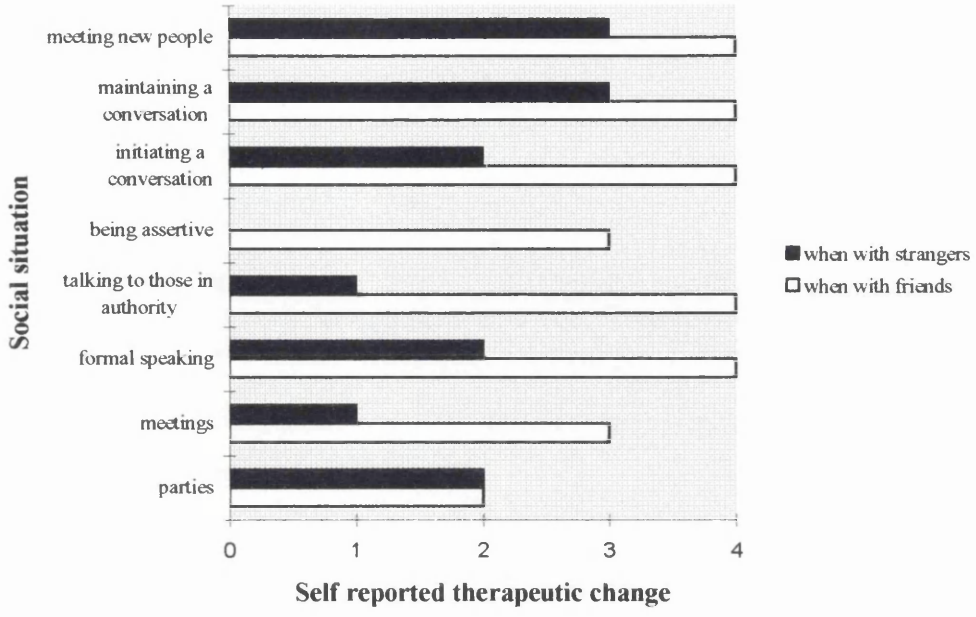

Figure 5. Overall therapeutic change in 'avoidance' score between baseline and end of treatment (maximum change- 4 points)

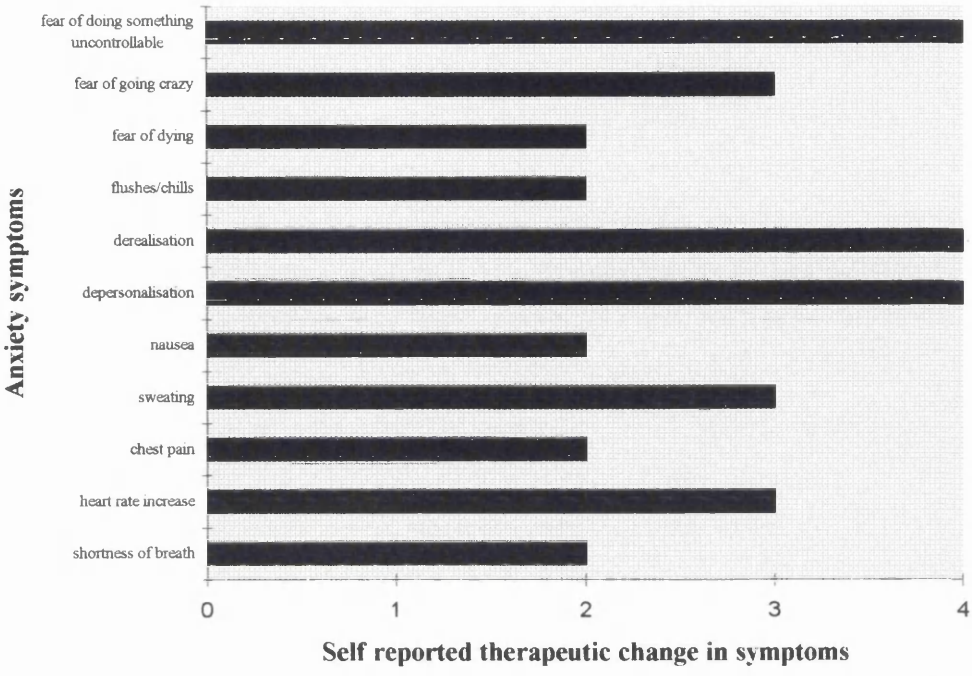

Figure 6. Overall therapeutic change in anxiety symptoms between baseline and end of treatment (maximum change-4 points)

APPENDIX 1

Do Clinical Psychologists Know Why Patients Do Not Attend Initial Appointments?

Appendix

1.1	Instructions to Authors "Clinical Psychology Forum"	156
1.2	Covering letter and questionnaire sent to DNAs	157
1.3	Covering letter and questionnaire sent to attendees	162

APPENDIX 1.1

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.

Notes for contributors

Articles of 1000-2000 words are welcomed. Shorter articles can be published sooner. Please check any references. Send two copies of your contribution, typed and double spaced. Contributors are asked to keep tables to a minimum; use text where possible.

News of Branches and Special Groups is especially welcome.

Language: contributors are asked to use language which is psychologically descriptive rather than medical and to avoid using devaluing terminology; i.e. avoid clustering terminology like "the elderly" or medical jargon like "schizophrenic".

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APPENDIX 1.2

Dear Sir/Madam,

Recently you were offered an appointment with a Clinical Psychologist who your Doctor had asked the to see you. The appointment you were offered would have been either at the Department of Clinical Psychology within the Southern General Hospital or at Govan Health Centre. This appointment would have been for a weekday between the beginning of April 1994 and the end of March 1995.

I am currently investigating why some people choose not to attend such appointments. I believe people often have very good reasons for not doing so. To discover these reasons I am currently sending questionnaires to people who did not attend the appointment offered with the Clinical Psychologist. I hope the information I gain will assist me to find ways in which the service offered to patients can be improved.

I would be very grateful indeed if you could complete the enclosed questionnaire and return it to me in the envelope provided. The envelope provided is a hospital standard envelope and will only be opened by myself. If you mislay the envelope provided I will be very grateful if you return the completed questionnaire to;

A. Clark
Clinical Psychology Department
Southern General Hospital
1345 Govan Road
Glasgow
G51 4TF

The information that you give will be **strictly confidential and used be only for the reason I have stated above. Neither your name nor your address will be entered onto a computer at any time nor will it be given to any other person.**

Thank you very much in advance for your co-operation

A. Clark
Clinical Psychology Department. Southern General Hospital.

APPENDIX 1.2 continued

INFORMATION ABOUT THE APPOINTMENT

Where required please tick the appropriate box. If there is a particular question you do not wish to answer please leave it blank.

1. There are many reasons why people miss appointments. Could you please tick any that applied to you?

I did not receive an appointment	☐1
I felt better	☐2
I had to wait too long for an appointment	☐3
Financial reasons	☐4
I forgot the appointment	☐5
I overslept	☐6
I got the date wrong	☐7
I knew what a psychologist did	☐8
I was not aware what a psychologist did	☐9
I felt a psychologist could help me	☐10
I was not sure whether a psychologist could help me	☐11
I could not get away from work/home	☐12
I was unable to get transport	☐13
I couldn't bring myself to attend	☐14
I do not like giving information about myself to others	☐15
I did not know who to contact to cancel the appointment	☐16
I did not know who to contact to change the appointment	☐17
I notified the Department I was unable to attend the appointment	☐18
Other (please explain)	

2. Did you seek help for your problem elsewhere?

No	☐1
Yes	☐2

If yes, when did you seek help? .....
What profession did you seek help from? .....
Where does that person work? .....
How long did you see this person for? .....
Did they help you with your problem?

No	☐1
Yes	☐2

APPENDIX 1.2 continued

3. Who suggested to you that you meet with a Clinical Psychologist?

I thought of it ☐1
My GP ☐2
My partner ☐3
A relative ☐4
A friend ☐5
A work colleague ☐6
Other (please specify) .....

4. What problem do you think your GP referred you to this Department for?

.....

5. How often did you discuss meeting a Clinical Psychologist with your GP?

Once ☐1
Twice ☐2
Three times ☐3
Other (please specify) .....

6. On the day of your appointment did you come to the hospital/clinic?

No ☐1
Yes ☐2

If yes, at what point did you decide to leave?

On way to appointment ☐3
Once outside the hospital/clinic ☐4
At the reception ☐5
Other (please explain) .....

7. Have you attended a Clinical Psychologist or a Psychiatrist before this referral?

No ☐1
Yes ☐2

If yes, who did you seek help from?

A Clinical Psychologist ☐1
A Psychiatrist ☐2

When did you seek help? .....
Why did you seek help? .....
Where does that person work? .....
How long did you see this person for? .....
Did they help you with your problem?

No ☐1
Yes ☐2

APPENDIX 1.2 continued

8. If you answered yes to Question 7 how do you rate the quality of the service you got from the Clinical Psychologist or the Psychiatrist?

excellent ☐1
good ☐2
adequate ☐3
poor ☐4
very poor ☐5

9. If you had attended the appointment how would you have travelled to it?

Walk ☐1
Car ☐2
Bus ☐3
Train ☐4
Taxi ☐5
Underground ☐6
Other (please specify) .....

10. How many miles would you have had to travel? .....

11. Do you have any thoughts on how we can improve the service we offer to patients?

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

Thank you for completing the section of the questionnaire. The information you have provided will be **strictly confidential and will only be used for the reason I have stated in the included letter. Neither your name nor your address will be entered onto a computer at any time nor will it be given to any other person.**

The next section of the questionnaire is asking for details about yourself. It would be very helpful if you could complete this also. It is necessary to have detailed information for further analysis of the results. However, if you do not wish to complete this second section I would be very grateful if you could return the questionnaire to me with the first part completed.

GENERAL DETAILS

Where required please tick the appropriate box. If there is a particular question you do not wish to answer please leave it blank.

1. What is your date of birth? .....

2. What sex are you?

Male ☐1
Female ☐2

APPENDIX 1.2 continued

3. What was your marital status when the appointment was offered?

Single	☐1
Single and living with a partner	☐2
Married and living with a partner	☐3
Separated	☐4
Divorced	☐5
Widow/Widower	☐6
Other (please specify)	

4. Who was living with you in your home at the time the appointment was offered?

Living alone	☐1
Partner	☐2
Partner and Children	☐3
Children only	☐4
Other relatives	☐5
Friends	☐6
Other (please specify)	

5. At what age did you leave full time education? .....

6. Were you in employment at the time of the appointment?

No	☐1
Yes	☐2

If yes, what job did you do? .....

7. Around the time of the appointment were you taking any medication prescribed by your Doctor?

No	☐1
Yes	☐2

If yes, can you tell me what the medication was? .....
How often did you take the medication? .....

As in the first section the information provided will be **strictly confidential and only used for the reason I have stated within the included letter. Neither your name nor your address will be entered onto a computer at any time nor will it be given to any other person.**

Thank you very much for your time and co-operation. If you would like to see a Clinical Psychologist in the future please ask your GP to refer you to a Clinical Psychology Department

APPENDIX 1.3

Dear Sir/Madam,

Recently you attended an initial appointment with a Clinical Psychologist who your Doctor had asked to see you. The appointment you attended would have taken place either at the Department of Clinical Psychology within the Southern General Hospital or at Govan Health Centre. This initial appointment would have been on a weekday between the beginning of April 1994 and the end of March 1995.

I am currently investigating why some people choose not to attend such initial appointments, believing that people often have very good reasons for not doing so. To discover these reasons I am currently sending questionnaires to people who have not attended the appointment offered with the Clinical Psychologist. However, it is also extremely valuable for me to know why some people do choose to attend their appointments. Therefore, I am also sending questionnaires to people who have chosen to meet the Clinical Psychologist. I hope the information I gain will assist me to find ways in which the service that is offered to patients can be improved.

I would be very grateful indeed if you could complete the enclosed questionnaire and return it to me in the envelope provided. The envelope provided is a hospital standard envelope and will only be opened by myself. If you mislay the envelope provided I will be very grateful if you return the completed questionnaire to;

A. Clark
Clinical Psychology Department
Southern General Hospital
1345 Govan Road
Glasgow
G51 4TF

The information that you give in the questionnaire will be **strictly confidential and will be used only for the reason I have stated above. Neither your name nor your address will be entered onto a computer at any time nor will it be given to any other person.**

Thank you very much in advance for your co-operation

A. Clark
Clinical Psychology Department. Southern General Hospital.

APPENDIX 1.3 continued

INFORMATION ABOUT THE APPOINTMENT

Where required please tick the appropriate box. If there is a particular question you do not wish to answer please leave it blank.

1. There are many reasons why people attend appointments. Could you please tick any that applied to you when you attended your first appointment?

My GP advised me to	☐1
I wanted to feel better	☐2
I felt better but still attended because my GP had advised me to	☐3
I knew what a psychologist did	☐4
I was not aware what a psychologist did	☐5
I felt a psychologist could help me	☐6
I was not sure whether a psychologist could help me	☐7
Even though I felt I had to wait too long for the appointment I attended it anyway	☐8
Even though it was financially difficult I still wanted to attend the appointment	☐9
I attended even though I do not like giving information about myself to others	☐10
If I had wanted to cancel or change the appointment I was unsure of who to contact	☐11
Other (please explain)	

2. Did you seek help for your problem in addition to visiting the Clinical Psychologist?

No	☐1
Yes	☐2

If yes, when did you seek help? .....
What profession did you seek help from? .....
Where does that person work? .....
How long did you see this person for? .....
Did they help you with your problem?

No	☐1
Yes	☐2

3. Who suggested to you that you meet with a Clinical Psychologist?

I thought of it	☐1
My GP	☐2
My partner	☐3
A relative	☐4
A friend	☐5
A work colleague	☐6
Other (please specify)	

4. What problem were you referred to this Department for?

.....

APPENDIX 1.3 continued

5. How often did you discuss meeting a Clinical Psychologist with your GP?

Once ☐1
Twice ☐2
Three times ☐3
Other (please specify) .....

6. Have you attended a Clinical Psychologist or a Psychiatrist before this referral ?

No ☐1
Yes ☐2

If yes, who did you seek help from?

A Clinical Psychologist ☐1
A Psychiatrist ☐2

When did you seek help? .....
Why did you seek help? .....
Where does that person work? .....
How long did you see this person for? .....
Did they help you with your problem?

No ☐1
Yes ☐2

7. If you answered yes to Question 6 how would you rate the quality of the service you got from the Clinical Psychologist or the Psychiatrist before this referral?

excellent ☐1
good ☐2
adequate ☐3
poor ☐4
very poor ☐5

8. What was the quality of the service you got from the Clinical Psychologist that you attended for this referral?

excellent ☐1
good ☐2
adequate ☐3
poor ☐4
very poor ☐5

APPENDIX 1.3 continued

9. When you attended the appointment how did you travel to it?

Walk	□1
Car	□2
Bus	□3
Train	□4
Taxi	□5
Underground	□6
Other (please specify)	.....

10. How many miles did you travel? .....

11. Do you have any thoughts on how we can improve the service we offer to patients?

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

Thank you for completing this section of the questionnaire. The information you have provided will be **strictly confidential and will only be used for the reason I have stated in the included letter. Neither your name nor your address will be entered onto a computer at any time nor will it be given to any other person.**

The next section of the questionnaire is asking for details about yourself. It would be very helpful if you could complete this also. It is necessary to have detailed information for further analysis of the results. However, if you do not wish to complete this second section I would be very grateful if you could return the questionnaire to me with the first part completed.

GENERAL DETAILS

Where required please tick the appropriate box. If there is a particular question you do not wish to answer please leave it blank.

1. What is your date of birth? .....

2. What sex are you?

Male	□1
Female	□2

APPENDIX 1.3 continued

3. What was your marital status when the appointment was offered?

Single	☐1
Single and living with a partner	☐2
Married and living with a partner	☐3
Separated	☐4
Divorced	☐5
Widow/Widower	☐6
Other (please specify)	

4. Who was living with you in your home at the time the appointment was offered?

Living alone	☐1
Partner	☐2
Partner and Children	☐3
Children only	☐4
Other relatives	☐5
Friends	☐6
Other (please specify)	

5. At what age did you leave full time education? .....

6. Were you in employment at the time of the appointment?

No	☐1
Yes	☐2

If yes, what job did you do? .....

7. At the time of the appointment were you taking any medication prescribed by your Doctor?

No	☐1
Yes	☐2

If yes, can you tell me what the medication was? .....
How often did you take the medication? .....

As in the first section the information provided will be **strictly confidential and only used for the reason I have stated within the included letter. Neither your name nor your address will be entered onto a computer at any time nor will it be given to any other person.**

Thank you very much for your time and co-operation. If you wish to see a Clinical Psychologist in the future please ask your GP to refer you to a Clinical Psychology Department.

APPENDIX 2

Adults with a Learning Disability and Epilepsy: a review

Appendix

2.1 Instructions to Authors "Seizure" 168

APPENDIX 2.1

Instructions to Authors

SEIZURE is an international journal providing a forum for the publication of papers on all topics related to epilepsy and seizure disorders. These topics include the basic sciences related to the condition itself, the differential diagnosis, natural history and epidemiology of seizures, and the investigation and practical management of epilepsy (including drug treatment, neurosurgery and non-medical and behavioural treatments). The journal also reflects the social and psychological burden and impact of epilepsy on the person who has it, his family and society, and the methods and ideas that may help to alleviate such handicaps and stigma as the condition may cause. The aim of the journal is to share and disseminate knowledge between all disciplines that work in the field of epilepsy.

Original research papers should report complete findings and include only as much introductory, review and bibliographic material as is necessary to explain the research and its relevance. Short communications (maximum 1000 words) are also welcomed and would typically comprise one set of data, contradicting or confirming a recent publication or hypothesis or a case report. Some review articles will be directly commissioned, but submission of review articles will always be welcomed.

Papers should be submitted to Dr T.A. Betts, Department of Psychiatry, Queen Elizabeth Psychiatric Hospital, Mindelsohn Way, Edgbston, Birmingham B15 2QZ, UK, and will undergo independent assessment and review.

The submission of the manuscript will be taken to imply that the material is original and has not been submitted in equivalent form for publication elsewhere. If a submitted manuscript is closely related to papers that are in press or have been submitted elsewhere it will be considered for publication only after copies of these papers have also been provided.

The nomenclature for seizures should be that employed by the Commission on Classification of the International League Against Epilepsy of 1981 (*Epilepsia* 1981; **22**: 489–501).

Preparation of manuscripts

Manuscripts should be written in English and must be typed, **double spaced** on one side of good quality paper with at least 25 mm margins on all sides. All pages should be numbered in sequence beginning with the title page. Three copies should be sent in, including the original.

1. Title Page: The title page should bear the names and affiliations of authors, the institute at which the work was carried out, where appropriate, and a short title. Multi-authored papers should be accompanied by a letter of agreement to publish signed by all the authors.

2. Abstract: There should be an abstract which is a summary of the entire work and which, for scientific reports should include a statement of the problem, method, results and conclusions and should not exceed 200 words. Abstracts should be in English, like the rest of the paper, but may be accompanied by an abstract in the language of the author.

3. Key words: A list of up to six key words should be supplied that will adequately index the subject matter of the article: it will be published on the first page of the article. The text of the article should follow the convention (if scientific results are being presented) of Introduction, Method, Results, Discussion and Conclusions, Acknowledgements and References. Figures and tables should be numbered consecutively with arabic numbers and each should have a descriptive legend. All illustrations should be in finished form, suitable for reproduction and should be planned to fit the proportion of the page: a scale should be included where needed. Illustrations in colour can only be accepted if colour is essential to the understanding of the illustration: the cost of colour illustrations will normally be borne by the author.

4. Tables: Tables should be typed on separate pages, numbered consecutively with arabic numbers and collected at the end of the manuscript. All tables must have descriptive headings and should be understandable without reference to the text.

5. References: References should be numbered consecutively in the order in which they are first mentioned in the text. Identify references in text tables and legends by arabic numerals (in parenthesis). References cited only in tables or legends should be numbered in accordance with the sequence established by the first identification in the text of the particular table illustration. Unpublished results, including articles submitted for publication or personal communications should be cited as such in the text. Personal communications should be substantiated by a letter of permission. Abstracts of papers presented at meetings may only be cited if the author of the abstract has a copy of the presented paper or poster for distribution to enquirers. At the end of the article the full list of references should give the name and initials of all authors, unless there are more than six, when only the first three should be given followed by *et al.* The authors' names are followed by the title of the article; the title of the journal, given in full; the year of publication; the volume number and the first and last page numbers. Titles of books should be followed by the place of publication, the publisher, the year and the relevant pages. Examples of correct forms of reference are given.

(a) *Journals*
Slater, E. and Beard, A.W. The schizophrenia-like psychoses of epilepsy. *British Journal of Psychiatry* 1963; **109**: 95–150.

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

The use of SI units is recommended. Abbreviations are discouraged, but if a term, such as electroencephalogram, is to be used frequently in the text it should be written in full, at its first use, followed by the abbreviation (EEG) in parenthesis. Generic names of drugs should be used unless there is a specific valid reason for using their trade name, in which case the generic name should be given.

All authors wishing to use illustrations already published should first obtain the permission of author and publisher and the copyright holders and give precise references to the original work. The statistical methods used in the paper must be fully referenced and fully described. If photographs of patients are presented they must be disguised: if to do so would ruin the point of the photograph patients must have given written consent to publication. An article must also, where appropriate, indicate that full ethical permission was obtained for a particular experiment and in the case of animal research that the research was carried out in an ethical and humane way. Papers which do not satisfy these criteria will not be accepted for publication.

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Protection of patient's rights to privacy

International Committee of Medical Journal Editors

The following statement was agreed by the International Committee of Medical Journal editors (the Vancouver Group) at its meeding last week in San Francisco. It is a complete revision of the initial guidelines on this subject issued in 1991.

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

Identifying details should be omitted if they are not essential, but patient data should never be altered or falsified in an attempt to attain anonymity. Complete anonymity is difficult to achieve, and informed consent should be obtained if there is any doubt. For example, masking of the eye region in photographs of patients is inadequate protection of anonymity.

When informed consent has been obtained it should be indicated in the published article.

Members of the committee are: Frank Davidoff (*Annals of Internal Medicine*), Richard Smith (*BMJ*), Bruce P Squires (*Canadian Medical Association Journal*), George Lundberg, Richard Glass (*JAMA*), Richard Horton (*Lancet*), Martin Van Der Weyden (*Medical Journal of Australia*), Robert Utiger (*New England Journal of Medicine*), Richard G Robinson (*New Zealand Medical Journal*), Magne Nylenna (*Tidsskrift for den Norske Laegeforening*), Linda Clever (*Western Medical Journal*), Louis Ann Colaianni (National Library of Medicine).

APPENDIX 3

Adults with Learning Disabilities and Epilepsy: knowledge about epilepsy before and after a psychoeducational package

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APPENDIX 3.1

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.

APPENDIX 3.2

Adults with learning disabilities and epilepsy: knowledge about epilepsy before and after 'Epilepsy and You'

My name is Alison. I am asking people what they know about epilepsy. I am also asking them what worries them about epilepsy.

I want to know if you will help me. If you do want to help me you will be part of a group of people who have epilepsy talking about it. You will see a video as well. You will be part of the group three times. I hope you will find it useful to learn more about epilepsy.

Other times I will see you alone. I will ask you questions about epilepsy and will ask you to do some tasks for me. You will not find the tasks hard to do. When I ask you questions about epilepsy I will record what we say onto a tape. Another person will listen to the tape later. Everything you say will be private. I will destroy the tapes once I have finished with them.

It is okay if you do not want to help me. You will not lose your place here. If you do take part you can stop helping me any time you want.

I have made a form for you to fill in to let me know if you want to help me.

APPENDIX 3.2 continued

CONSENT FORM - PARTICIPANT

Adults with learning disabilities and epilepsy: knowledge about epilepsy before and after 'Epilepsy and You'

✓ I **do** want to help Alison with her project. ☐ Please mark box.

✗ I **do not** want to help Alison with her project. ☐ Please mark box.

Name _____

Signature _____

Date _____

APPENDIX 3.3

Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

(0141 211 3920)

Dear

Re: Research project: Adults with learning disabilities and epilepsy: knowledge about epilepsy before and after a psychoeducational package.

I am a post-graduate student of Glasgow University training to become a Doctor of Clinical Psychology. I would be very grateful if you could read through this letter that explains the research I am doing at the moment and decide whether you give permission for me to conduct this research within .....

My research is investigating firstly, how much adults with learning disabilities and epilepsy know about epilepsy and what concerns they have and secondly, whether discussion groups can help then gain more understanding about epilepsy and related issues. My research will finish in July 1997.

The research has four phases to it which are described below;

1. An initial assessment of each participant's cognitive abilities and their current knowledge and concerns about having epilepsy. I also may need to contact participant's keyworkers for information about a participant's epilepsy.
2. The participant will attend three discussion groups, during which a video will be shown. Each group will last one hour and will be held at weekly intervals. A co-presenter from ..... will be invited to join me during group sessions. Between sessions participants will be encouraged to approach the co-presenter or keyworkers to reinforce material learnt or to answer queries.
3. An evaluation after the groups have finished of the participant's knowledge and concerns to see if there has been any change. It is anticipated that participants will benefit from learning more about their epilepsy and about epilepsy in general.
4. A visit a month later to re-evaluate the participants knowledge and concerns about epilepsy.

During phases 1, 3 and 4 audiotapes will be recorded of interviews with participants for later analysis. This analysis will require another professional to listen to the tapes. The tapes will be destroyed at the end of the research.

All participants will be informed that their attendance (or lack of it) will not affect their placement at ....., that they can leave the research at any time and that all information gained will be in the strictest confidence.

I would be very grateful if you complete the consent form attached detailing whether this research can be conducted at ..... Thank you very much for your attention.

Alison J. Clark
Trainee Clinical Psychologist

APPENDIX 3.3 continued

CONSENT FORM - MANAGER

Research Project. Adults with learning disabilities and epilepsy: knowledge about epilepsy before and after a psychoeducational package.

I do/do not (delete as required) give permission for the above research to take place at .....

Name _____

Signature _____ Date _____

Designation _____

APPENDIX 3.4

INFORMATION LETTER - KEYWORKER

Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

(0141 211 3920)

Dear

Re: (Name, DOB and Address)

Re: Research project: Adults with learning disabilities and epilepsy: knowledge about epilepsy before and after a psychoeducational package.

I am a post-graduate student of Glasgow University training to become a Doctor of Clinical Psychology who is conducting a short term research project at ..... The Manager and ..... Ethics Committee have given approval for this research to take place. ..... has agreed to take part therefore I am writing to let you know what the research entails.

My research is investigating how much adults with learning disabilities and epilepsy know about epilepsy and what concerns they have. It is also investigating whether discussion groups can help adults with learning disabilities and epilepsy gain more understanding about epilepsy and related issues.

All the research, involving ....., will take place at ..... The research will initially assess each participant's cognitive functioning and current knowledge and concerns about his/her epilepsy. Each participant will attend three discussion groups, during which a video will be shown and then his/her knowledge and concerns will be re-assessed to see if there has been any change following the discussion groups. One month later I will visit each participant to re-evaluate his/her knowledge and concerns about epilepsy. It is anticipated that participants will benefit from learning more about their epilepsy and about epilepsy in general.

I would be very grateful if you could help ..... with any queries he/she has about epilepsy issues between group discussions. If you wish information in order to help answer any queries ..... has been co-presenting the sessions and will be able to help you.

If you wish any further information about the research please do not hesitate to contact me at the above address.

Yours sincerely

Alison J. Clark
Trainee Clinical Psychologist

APPENDIX 3.5

Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

(0141 211 3920)

Dear

Re: Research project: Adults with learning disabilities and epilepsy: knowledge about epilepsy before and after a psychoeducational package.

I am a post-graduate student of Glasgow University training to become a Doctor of Clinical Psychology who is conducting a short term research project at .....

The manager of ..... has given approval for this research study to take place. In addition, the ..... Ethics Committee has given permission for this research study to proceed.

..... has stated he/she would like to take part in the research project. I am writing to inform you what the research will involve, and to request, in your context as his/her next of kin, your consent for .....'s participation in the research. After reading the description below of the research project please could you complete the consent form attached, detailing whether you give consent or not, and forward it to me in the stamped and addressed envelope enclosed.

The research is investigating how much adults with learning disabilities and epilepsy know about epilepsy and what concerns they have. It is also investigating whether discussion groups can help adults with learning disabilities and epilepsy gain more understanding about epilepsy and related issues.

All the research, involving ....., will take place at ..... The research will initially assess .....'s current knowledge and concerns about his/her epilepsy. He/she will attend three discussion groups, during which a video will be shown and then .....'s knowledge and concerns will be re-assessed to see if there has been any change following the discussion groups. One month later I will visit ..... at ..... to re-evaluate his/her knowledge and concerns about epilepsy. During the research audiotapes will be recorded of interviews with participants for later analysis. This analysis will require another professional to listen to the tapes. The tapes will be destroyed at the end of the research. All information collected will be treated with the strictest confidence. It is anticipated ..... will benefit from learning more about his/her epilepsy and about epilepsy in general.

If you have any queries about the research please do not hesitate to contact me at the above address.

Yours sincerely

Alison J. Clark
Trainee Clinical Psychologist

APPENDIX 3.5 continued

CONSENT FORM - NEXT OF KIN

Research Project: adults with learning disabilities and epilepsy.

Please tick the box that applies,

I **do** give consent for .....
to take part in the above research project. ☐

I **do NOT** give consent for .....
to take part in the above research project. ☐

Name _____

Signed _____ Date _____

Relationship to ..... _____

APPENDIX 4

Adults with Learning Disabilities and Epilepsy: knowledge about epilepsy before and after a psychoeducational package (Epilepsy and You)

Appendix

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APPENDIX 4.1

Journal of Intellectual Disability Research

Information for contributors

Papers (in English) should be sent to the Editor, *Journal of Intellectual Disability Research*, University of Wales College of Medicine, Meridian Court, North Road, Cardiff CF4 3BL, Wales, UK. Papers are accepted on the understanding that they have not been and will not be published elsewhere. The original and two copies should be submitted to aid refereeing and these should be typed (with a wide margin), double spaced, on one side of standard paper (A4—30 × 21 cm). A title page should contain the author's name(s), place of work, address for correspondence, full title and short running title. Authors should retain one copy of the text, tables and illustrations as the editor cannot accept responsibility for damage or loss of manuscripts.

Page proofs must be returned to the Publisher within **three days** of receipt. Typographical errors and essential changes can be made at this stage. Major text alterations cannot be accepted. One free copy of the relevant issue will be distributed by the corresponding author to each co-author. Offprints may be purchased at prices determined by the Publisher by returning the form enclosed with page proofs.

The author should provide up to six keywords to aid indexing. Please note that 'intellectual disability', as used in JIDR, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some locales or disciplines.

Full reports of 1500–3000 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions. *Brief reports* of 500–1500 words are encouraged, especially for replication studies, methodological research and technical contributions.

The text should proceed through sections of Abstract, Introduction, Materials and Methods, Results and Discussion. Tables and figures should be submitted on separate sheets and referred to in the text together with an indication of their approximate position recorded in the text margin. The reference list should be in alphabetical order thus:

Giblett E.R. (1969) *Genetic markers in Human Blood.* Blackwell Scientific Publications, Oxford.

Moss T.J. & Austin G.E. (1980) Pre-atherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* 24, 137–41.

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units. Illustrations should be labelled with the figure number and author's name in soft pencil on the back identifying the top edge. Photographs should be glossy bromide prints of good contrast and well matched, preferably with a transparent overlay for protection. Colour photographs will be allowed only in special circumstances and the author will be asked to contribute towards the cost of reproduction. Line diagrams should be drawn with black ink on tracing paper or white card, or supplied as glossy prints. Papers may be judged to require extra-rapid publication by the Editor and referees.

The Journal welcomes the submission of accepted articles on 3.5″ disk. Do not justify the lines of text. All disks must be accompanied by a hard copy of the paper together with details of the type of computer used, the software employed and the disk system, if known. Particular attention should be taken to ensure that any articles submitted in this form adhere exactly to journal style. Further details may be obtained from the Publisher.

Royal Society for Mentally Handicapped Children and Adults (MENCAP)

The Royal Society for Mentally Handicapped Children and Adults is the largest national organization exclusively concerned with people with intellectual disability and their families. The primary objective of the Society is to secure for intellectually disabled people provision commensurate with their needs. To this end, the Society aims to increase public knowledge and awareness of the problems faced by intellectually disabled people and their families, and thus create a sympathetic climate of public opinion as a necessary prerequisite of their acceptance into the community.

The Royal Society for Mentally Handicapped Children and Adults provides:

- through a network of Local Societies and Regional Offices support in all parts of the country;
- funds and support for research;
- specialist advisory and information services for the lay public and for professional workers;
- books and literature and, bi-monthly, the *Journal of Intellectual Disability Research, Parents Voice* and *Viewpoint*, MENCAP's new newspaper;
- an ongoing programme to facilitate the sharing of knowledge by means of symposia, conferences and information exchange;
- residential facilities for further education and for care and holidays;
- support for developing countries to scholarships and journal subscriptions.

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RSMHC & A is a registered charity, supported entirely by voluntary contributions. Applications for membership, or information, are invited by the Secretary General.

APPENDIX 4.2

'EPILEPSY AND YOU' CHECKLIST. QUESTIONS.

Time-Start **Time-Finish**

Number Date

Instructions to subject - I am going to ask you some questions about epilepsy. Do not worry if you do not know the answers. Some questions are hard. It will take about half an hour to do this. I will write down what you say to me. I will also tape what we say. Is that okay? Do you want to ask me any questions about what we are going to do?

Instructions for use *- If the individual does not respond to a question within a maximum of thirty seconds the prompt (if quoted below) is given. Give the individual another thirty seconds to respond to the prompt. Record whether the prompt is used by circling the Y or N for yes and no respectively. Record the individual's answers verbatim under the relevant question and then use the scoring system attached.*

When the participant gives wording they prefer to use instead of fit or seizure use their wording in relevant questions.

1. **How do you know that someone has epilepsy?**
(prompt - when someone has epilepsy they sometimes act in a strange way. What is that called?) *Prompt used? Y/N*

2. **Why does a fit/seizure happen?**
(prompt - a fit/seizure has something to do with the brain. Can you tell me what happens?) *Prompt used? Y/N*

3. **What is an EEG?**
(prompt - an EEG is something to do with epilepsy. Can you tell me what it is?) *Prompt used? Y/N*

4. **What age do people start having fits/seizures?**

APPENDIX 4.2 continued

5. **Does epilepsy ever go away and people not get it again?**

6. **Are there different kinds of fits/seizures?**

7. **Can you tell me about any kinds of fits/seizures?**
(prompt - sometimes people can have little or big fit/seizures. Do you know what they look like?) *Prompt used? Y/N*

8. **Do some people remember what happens when they are having a fit/seizure?**

9. **Do some people know when they are going to have a fit/seizure?**

10. **How do some people know they are going to have a fit/seizure?**
(prompt - sometimes people know they are going to have a fit/seizure because things happen to them. Do you know what these things are?) *Prompt used? Y/N*

11. **If someone knows they are going to have a fit/seizure what can they do to help themselves?**
(prompt - what can they do to make sure they do not hurt themselves?) *Prompt used? Y/N*

12. **Once a fit/seizure starts can it be stopped?**

13. **How can fits/seizures be stopped?**
(prompt - what do people do to stop someone else having a fit/seizure?) *Prompt used? Y/N*

APPENDIX 4.2 continued

14. **Why do you take tablets (or medicine syrup) for your epilepsy?**
(prompt - it is something to do with the amount of fits/seizures you have) *Prompt used? Y/N*

15. **How do tablets (or medicine syrup) help people have less fit/seizures?**
(prompt - the medicine has to reach the brain. Do you know how this happens?) *Prompt used? Y/N*

16. **When is it important to take your tablets (or medicine)?**
(prompt - What time every day is it good to take tablets or medicine?) *Prompt used? Y/N*

17. **Does everybody who has epilepsy take the same type of tablets (or medicine)?**

18. **Why do people with epilepsy take different types of tablets (or medicine)?**

19. **What should someone do if they see a person having a fit/seizure?**
(prompt - how would they make the person safe and well?) *Prompt used? Y/N*

20. **If a person is having a fit/seizure when is it best to phone for an ambulance?**

21. **Why should people keep a fit/seizure diary?**
(prompt - who likes to look at the fit/seizure diary to see how your epilepsy has been?) *Prompt used? Y/N*

APPENDIX 4.2 continued

22. **What should people write in a fit/seizure diary?**
(prompt - what things do the doctor want to know about your fit/scizures?) *Prompt used? Y/N*

23. **When is it best to write in a fit/seizure diary?**

24. **Why do you and other people with epilepsy need to visit the doctor?**
(prompt - what does the doctor do when you visit him/her?) *Prompt used? Y/N*

25. **Is there anyone else you could get help about epilepsy from?**
(prompt - is there an association where you get help from?) *Prompt used? Y/N*

26. **Is there anything else you want to tell me about epilepsy?**

Thank you very much.

APPENDIX 4.3

'EPILEPSY AND YOU' CHECKLIST. SCORING SYSTEM

Number Date

Instructions for use *- The individual is awarded ONE mark for each pertinent point they give that is listed beside the number for each question. If the individual mentions a point similar to one listed they are awarded the relevant point. If the individual gives a correct response that is not listed below they are awarded the relevant point/s.*

Question Number	**Pertinent Points (each worth one point)**
1	• a fit/seizure • act in a strange way • change in awareness level • take medication for epilepsy
2	• electrical messages or activity • in the brain • do not work • as normally do • if medication is not taken • mention of any triggers to epilepsy
3	• a machine • wear on your head • measures brain/electrical activity • can tell if you have epilepsy
4	• any age
5	• normally have it for the rest of your life • for a small number of people epilepsy may go away
6	• yes
7	• person becomes stiff, falls, jerks arm and legs • person falls, jerks arms and legs but does not become stiff • person may not jerk arms or legs but become stiff. May fall • person becomes floppy and falls to ground • person may jerk an arm and/or a leg • person may stare blankly and/or nod head • person may jerk limb, get tingling, get funny feeling in stomach • face move in funny way or fiddling or talking or seems to be doing something
8	• yes
9	• yes
10	• may have funny feeling in head • may have funny feeling in stomach • may get funny feeling in hand • may get funny taste in mouth • may have change in arousal level i.e. becomes sleepy/anxious/restless

APPENDIX 4.3 continued

Question Number	Pertinent Points (each worth one point)
11	• lie/sit down • avoid hurting yourself • stop doing anything that is dangerous • tell someone you are not feeling well • try to change your arousal level to combat the seizure happening
12	• usually not
13	• other people moving the person's arms/legs • other people saying the person's name over and over again
14	• to stop their seizures • so will have less seizures
15	• medication goes into stomach • spreads into blood • when enough medication in blood will go into brain • stop seizures in brain
16	• at the proper time said by the doctor
17	• no
18	• people with different types of seizures take different medications
19	• make the person safe • keep calm • clear a space • loosen tight clothing • put something soft under head • when can pull person onto side • talk to person quietly • tell staff (if required)
20	• if the seizure goes on a while • if the person has hurt themselves
21	• otherwise doctor not know how many seizures you have had
22	• exact description of the seizure • the time it happened • how long it lasted • any changes in your seizures
23	• as soon as possible after the seizure
24	• for the doctor to see the seizure diary • for the doctor to check blood levels • for the doctor to check the medication and change if required
25	• Epilepsy Association of Scotland • any other professional
26	• *Award one mark for EACH other pertinent point given by the individual about epilepsy and associated issues.*

APPENDIX 4.4

WHAT YOU THINK ABOUT 'EPILEPSY AND YOU'

Number Date

I want to know what you think about the 'Epilepsy and You' talks and video. I have some questions for you to answer. There are no right or wrong answers. It will take about five minutes to do this. Other people will not know what you have said.

1. Did you like the 'Epilepsy and You' talks and video? **Yes/No (please circle)**

if yes, what did you like?

if no, what did you not like?

2. Was there anything you liked/did not like? (opposite to No. 1) **Yes/No (please circle)**

what was it?

3. Do you know more about your epilepsy now? **Yes/No (please circle)**

if yes, what do you know more about now?

if no, what did you want to know about?

APPENDIX 4.4 continued

4. Do you know more about other people's epilepsy now? **Yes/No (please circle)**

if yes, what do you know more about now?

if no, what did you want to know about?

5. Is there anything else you want to say about the 'Epilepsy and You' talks and video? **Yes/No (please circle)**

if yes, what do you want to say?

Thank you very much for your help.

APPENDIX 4.5

	Three weeks Pre 'Epilepsy and You'	One Week Pre 'Epilepsy and You'	Immediately Post 'Epilepsy and You'	Four Weeks Post 'Epilepsy and You'
Treatment Group (n=8)				
Mean ±SD	Not Applicable	13.75 ±3.60	17.88 ±3.76	20.12 ±3.14
Deferred Treatment Group (n=10)				
Mean ±SD	14.60 ±2.26	13.70 ±1.96	20.30 ±2.73	18.90 ±2.63

Table 4: Average score for the EY-C for each group in each condition.

	Three weeks Pre 'Epilepsy and You'	One Week Pre 'Epilepsy and You'	Immediately Post 'Epilepsy and You'	Four Weeks Post 'Epilepsy and You'
Treatment Group (n=8)				
Mean ±SD	Not Applicable	1.88 ±0.55	3.25 ±0.68	2.62 ±0.80
Deferred Treatment Group (n=10)				
Mean ±SD	3.00 ±0.62	3.60 ±0.64	4.00 ±0.89	3.80 ±0.85

Table 5: Average score for the EKQ-LD for each group in each condition.

APPENDIX 4.6

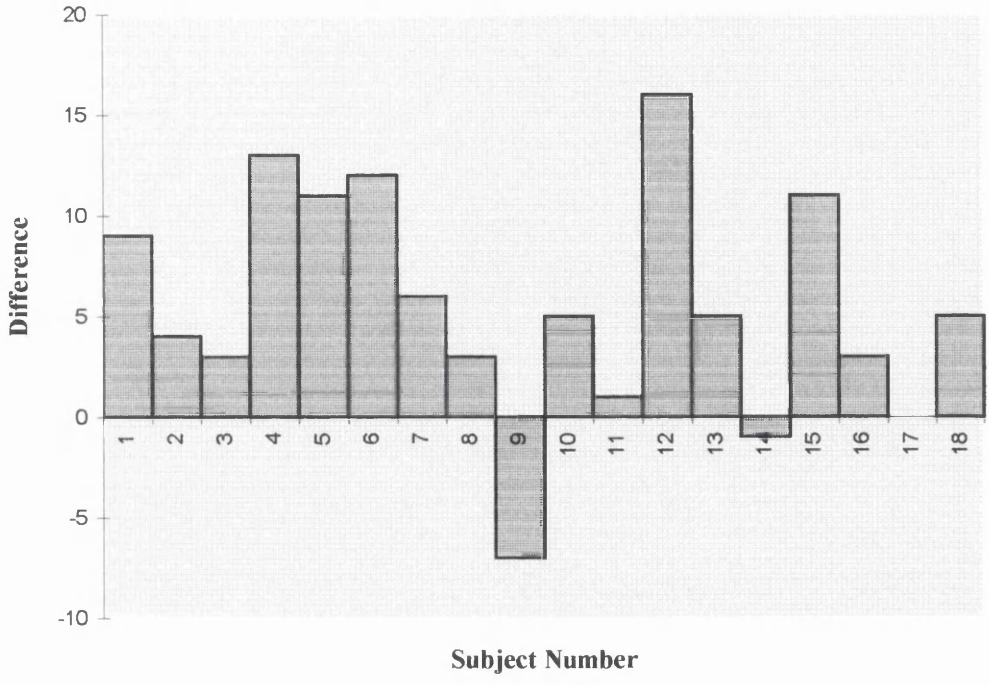

Figure 3. The difference in scores gained, using the EY-C, before and immediately after 'Epilepsy and You' (n=18)

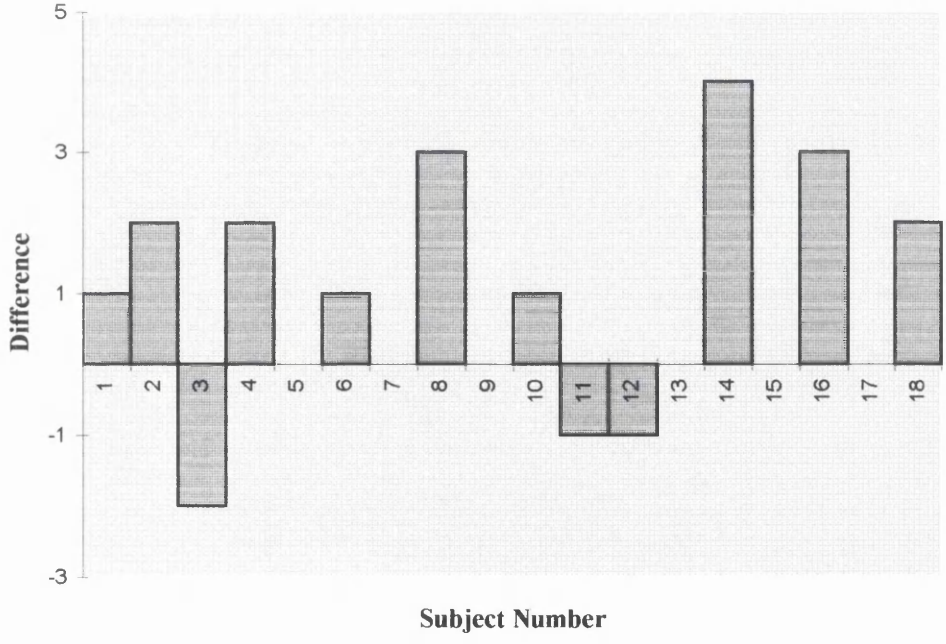

Figure 4. The difference in scores gained, using the EKQ-LD, before and immediately after 'Epilepsy and You' (n=18)

'Epilepsy and You' Checklist (n=18)

Change score (percentile)	Age (percentile)	Sex	RCPM raw score (percentile)	BPVS age equivalent score (percentile)	Seizure type	Approximate number of seizures per year (percentile)	Medication	Approximate age of epilepsy onset (percentile)	Approximate duration of epilepsy (percentile)
>90	***85-90***	Male	*	*	Single	***90***	Polytherapy	*	***85-90***
85-90	***15-20***	Male	*	***15-20***	Multiple	*	Monotherapy	*	***15-20***
80-85	*	Female	*	*	Single	*	Monotherapy	*	*
20-25	***20-25***	Female	*	*	Single	*	Monotherapy	*	***20-25***
15-20	*	Male	***20***	***10-15***	Single	***5***	Polytherapy	***20-25***	*
10-15	*	Female	*	*	Single	*	Polytherapy	***75-80***	*
5	*	Male	*	***80-85***	Multiple	***90***	Polytherapy	*	*

Epilepsy Knowledge Questionnaire-Learning Disabilities (n=18)

>90	*	Female	*	*	Single	*	Polytherapy	***75-80***	*
85	*	Male	*	*	Multiple	*	Polytherapy	***85-90***	*
85	***10-15***	Male	*	*	Multiple	*	Polytherapy	***80-85***	***15-20***
15	***85-90***	Male	*	*	Single	***90***	Polytherapy	*	***85-90***
15	***20-25***	Female	*	*	Single	*	Monotherapy	*	***20-25***
5	*	Male	***15-20***	*	Single	*	Polytherapy	*	***5-10***

*** = 25-75 percentile**

Table 6. Percentile groupings for identifying characteristics of subjects who scored in the higher or lower quartile for each questionnaire

APPENDIX 5

Intrusive Thoughts: a single case treatment failure

Appendix

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APPENDIX 5.1

Instructions to Authors

1. **Submission.** Articles written in English and not submitted for publication elsewhere, should be sent to Paul Salkovskis, Editor, *Behavioural and Cognitive Psychotherapy*, Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford OX3 7JX, UK.

2. **Manuscript preparation.** Four complete copies of the manuscript must be submitted. Original figures should be supplied at the time of submission. Articles must be typed double-spaced throughout on standard sized paper (preferably A4) allowing wide margins all round. Where unpublished material, e.g. behaviour rating scales, therapy manuals, etc. is referred to in an article, copies should be submitted to facilitate review.

Manuscripts will be sent out for review exactly as submitted. Authors who want a blind review should mark two copies of their article "review copy" omitting from these copies details of authorship.

Abbreviations where used must be standard. The Système International (SI) should be used for all units; where metric units are used the SI equivalent must also be given. Probability values and power statistics should be given with statistic values and degrees of freedom [e.g. $F(1,34) = 123.07$, $p<.001$], but such information may be included in tables rather than the main text.

Spelling must be consistent within an article, either using British usage (*The shorter Oxford English dictionary*), or American usage (*Webster's new collegiate dictionary*). However, spelling in the list of references must be literal to each original publication.

Details of style not specified here may be determined by reference to the *Publication manual of the American Psychological Association* or the style manual of the British Psychological Society.

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(b) *Summary.* This should summarize the article in no more than 200 words.

(c) *Text.* This should begin with an introduction, succinctly introducing the point of the paper to those interested in the general area of the journal. *Attention should be paid to the Editorial Statement which appears in the January and July issues at the back of the Journal.* References within the text should be given in the form Jones and Smith (1973). When there are three or up to and including five authors the first citation should include all authors; subsequent citations should be given as Williams et al. (1973). Authors with the same surname should be distinguished by their initials. The approximate positions of tables and figures should be indicated in the text. Footnotes should be avoided where possible.

(d) *Reference note(s).* A list of all cited unpublished or limited circulation material, numbered in order of appearance in the text, giving as much information as possible about extant manuscripts.

(e) *References.* All citations in the text should be listed in strict alphabetical order according to surnames. Multiple references to the same author(s) should be listed chronologically, using a, b, etc., for entries within the same year. Formats for journal articles, books and chapters should follow these examples:

BECKER, M. R. and GREEN, L. W. (1975). A family approach to compliance with medical treatment: a selective review of the literature. *International Journal of Health Education* 18, 173–182.

THORP, R. G. and WETZEL, R. J. (1969). *Behaviour modification in the natural environment.* New York: Academic Press.

ROSKIES, E. and LAZARUS, R. S. (1980). Coping theory and the teaching of coping skills. In P. O. Davidson and S. M. Davidson (Eds). *Behavioural medicine: changing health lifestyles.* New York: Brunner/Mazel.

(f) *Footnotes.* The first, and preferably only, footnote will appear at the foot of the first page of each article, and subsequently may acknowledge previous unpublished presentation (e.g. dissertation, meeting paper) financial support, scholarly or technical assistance, or a change in affiliation. In concluding (or only) paragraph must be the name and full mailing address of the author to whom reprint requests or other inquiries should be sent.

(g) *Tables.* Tables should be numbered and given explanatory titles.

(h) *Figure captions.* Numbered captions should be typed on a separate page.

(i) *Figures.* Original drawings or prints must be submitted for each line or half-tone illustration. Figures should be clearly labelled and be camera-ready wherever possible.

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APPENDIX 5.2

BASELINE DIARY

Date Target Thought

Time	Frequency b	Total Duration c	Highest Discomfort d	Details and Comments e
Midnight - 8am				
8am - Noon				
Noon - 4pm				
4pm - 8pm				
8pm - Midnight				
Example	*35*	*20 minutes*	*78*	*Was in the garden at 11am when I saw an plant. Thought intrusive thought 25 times in two minutes*

b How many times the intrusive thought happened in that time period.

c Total duration of the intrusive thoughts in that time

d Rate on a 0-100 scale. Give the highest felt in that period. 0= not felt at all. 100= the most that could be felt

e Details of what happened: when, where, what was the trigger, how long taken, number of repetitions etc. of the WORST episode.

APPENDIX 5.3

DIARY FOR AUDIOTAPE TASKS

Date Target Thought

Time	Duration of audiotape **a**	Frequency **b**	Total Duration **c**	Highest Discomfort **d**	Details and Comments **e and f**
Midnight - 8am					
8am - Noon					
Noon - 4pm					
4pm - 8pm					
8pm - Midnight					
Example	*15 minutes*	*35*	*20 minutes*	*78*	*Was in the garden at 11am when I saw an plant. Thought intrusive thought 25 times in two minutes* *70 discomfort*

a Duration of audiotape listened to

b How many times the intrusive thought happened in that time period.

c Total duration of the intrusive thought in that time

d Rate on a 0-100 scale. Give the highest felt in that period. 0= not felt at all. 100= the most that could be felt

e Details of what happened: when, where, what was the trigger, how long taken, number of repetitions etc. of the WORST episode.

f Rate discomfort listening to tape 0-100 each time task done (0-100, none-most)

APPENDIX 5.4

DIARY FOR THOUGHT STOPPING HOMEWORK TASK

Date Target Thought

Time	Frequency **b**	Total Duration **c**	Highest Discomfort **d**	Details and Comments Please enter number of times thought-stopping used **e**
Midnight-8am				
8-12 noon				
noon-4pm				
4-8pm				
8pm-Midnight				
Example	*28*	*15 minutes*	*86*	*Was in the garden at 11am when I saw an plant. Thought intrusive thought 25 times in two minutes. Used TS 50 times*

b How many times the intrusive thought happened in that time period.

c Total duration of the intrusive thought in that time

d Rate on a 0-100 scale. Give the highest felt in that period. 0= not felt at all.
100= the most that could be felt

e Details of what happened: when, where, what was the trigger, how long taken, number of repetitions etc. of the WORST episode.

Rate of discomfort while using thought-stopping 0-100 (no discomfort-most discomfort)?

Rate the ease of using thought-stopping 0-100 (not difficult-most difficult)?

Thoughts stopped?

APPENDIX 5.5

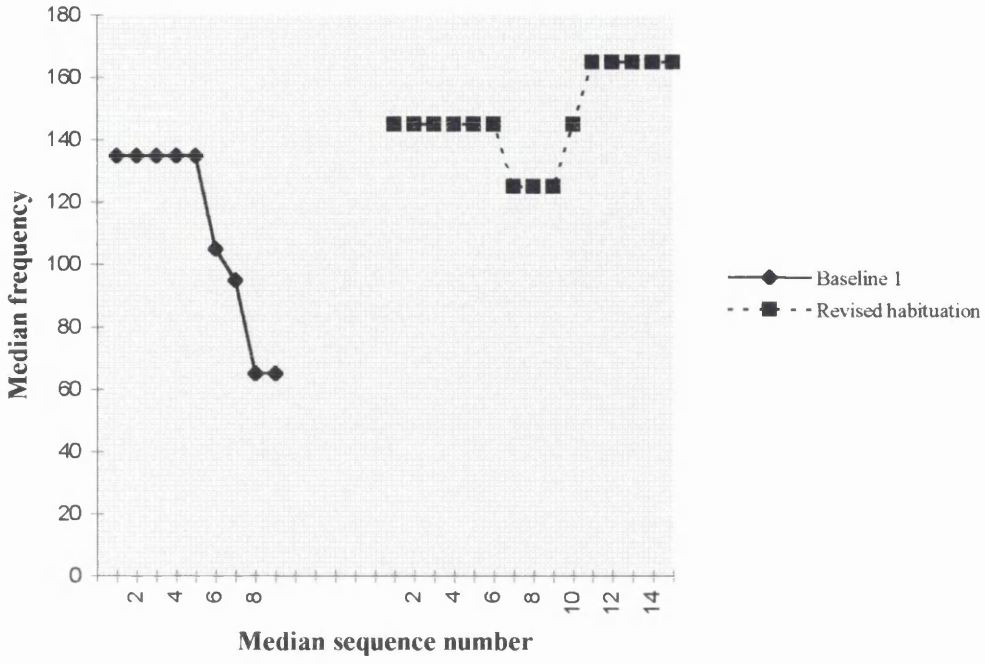

Figure 3. Running medians of five, for baseline 1 and revised habituation (daily intrusive thoughts frequency)

APPENDIX 5.6

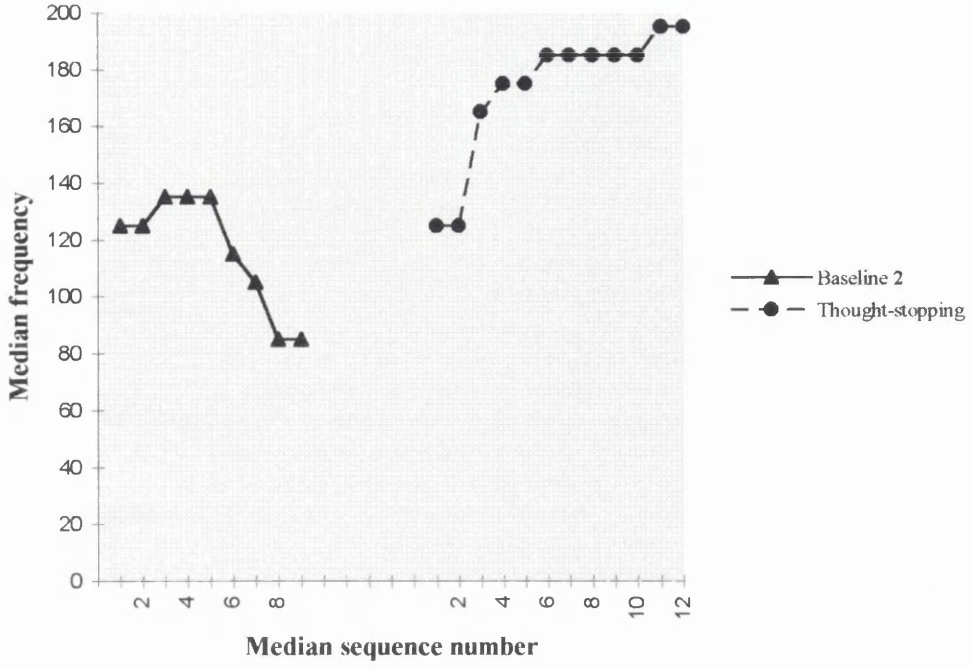

Figure 4. Running medians of five, for baseline 2 and thought-stopping (daily intrusive thoughts frequency)

APPENDIX 6

Addressing Social Withdrawal in a Man With a Learning Disability

Appendix

6.1	Instructions to Authors "British Journal of Learning Disabilities"	199
6.2	Results of the Vineland Adaptive Behaviour Scales	203

BILD Publications, Frankfurt Lodge, Clevedon Hall, Victoria Road,
Clevedon, Avon BS21 7SJ
Tel: 01275 876519 Fax: 01275 343096

British Journal of Learning Disabilities

NOTES ON THE SUBMISSION OF MANUSCRIPTS

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AIMS OF THE JOURNAL

BJLD is a multi-disciplinary professional journal publishing articles which will draw the attention of those who are working in the field of learning disabilities to innovations in professional practice, to new ideas emerging from research, and to evaluations and reviews of on-going work which has general, professional relevance. Material submitted to BJLD should be original and any opinions expressed should be either supported by data or by well-reasoned arguments.

Reports on practice and research papers should be supported by descriptions of methodology and evidence which permits readers to evaluate the conclusions drawn. Reviews (commissioned or otherwise) should be supported by argument, data from relevant references and should place the review topic within the context of other developments in the field.

Submissions which are divided into two or more linked papers will only be accepted in exceptional circumstances and when the subject matter clearly justifies this approach.

LAYOUT

Articles should be typed, double-spaced, on one side only of A4 paper, with a 1.5" margin on each side. Pages should be numbered consecutively in the top right-hand corner, commencing with the title page.

TEXT

The text should be written in the third person, in 'plain English', with an international, multi-disciplinary readership in mind. Descriptions should be clear and concise and terminology specific to a particular profession should be explained for the benefit of people in other professions.

Care should be taken to use non-sexist language and, when referring to disabilities etc., to emphasise the person rather than the disability, so descriptions such as *people with learning disabilities* should be used rather than *the learning disabled.* Clumsy expressions such as *he/she, he or she* or *s/he* should be avoided, for example, by using the plural verb. Use the term 'participants' to describe those involved in research rather than 'subjects'.

Full references to the sources of all statistical measures used must be supplied.

If any technical terms specific to a particular profession are unavoidable, they must be explained briefly in the text immediately following. Statistical information should be translated into simple statements of significance, but the source of the measures used **must** be fully referenced and the full statistical data should be available from the main corresponding author.

COPIES

Four copies should be submitted, one of which should be the original typescript. One copy should be retained by the author.

LENGTH

Articles should not exceed 2,000 words (approximately eight pages of a double-spaced A4 typescript).

ORDER OF CONTENTS

Title Page

The title page should contain a short main title to indicate content and a sub-title if it is necessary to clarify this further

Authors

On a separate page include the first name and surname of each author, with details of their respective professional occupations and addresses. Where there is more than one author, indicate who should receive correspondence.

Summary

A concise 150 word summary should precede the main text. It should indicate the content and findings of the article.

Main Text

The main text should be presented in a logical sequence and be divided by appropriate sub-headings.

Acknowledgements

The author(s) should acknowledge individuals and agencies who have assisted in the work and **must** acknowledge those from whom reprint or photographic reproduction permissions have been obtained. **It is the responsibility of the author(s)** to obtain all necessary permissions and to confirm in writing that such permissions have been granted.

Tables and Figures

Each Table and Figure should be presented on a separate sheet at the end of the work. Each one should be numbered in Arabic numerals and given an appropriate heading. The preferred position in the text should be indicated in the left-hand margin and the text should refer to each Table or Figure in turn.

Photographs

Glossy, sharply defined, black and white photographs are preferred. Each one should be lightly numbered in pencil on the reverse. A list of the photograph numbers and their respective relevant captions should be typed on a separate sheet. **The author(s) must seek** all relevant rights and permissions for using the photographs and must enclose a letter stating that these have been obtained.

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The author(s) are responsible for the accuracy of references and for their correct presentation. References should be listed on a separate sheet, in alphabetical order, following the Harvard system, as follows:

Journal articles Gardner, D. and Rose, J. (1994)
Stress in a social services day centre
British Journal of Learning Disability 22 (4), 130-33.

Books Jones, R.S.P. and Eayrs, C. B. (eds) (1993)
Challenging Behaviour and Intellectual Disability. Clevedon: BILD Publications

Book chapters Oliver, C. (1993) Self-injurious behaviour: from response to strategy. In C. Kiernan. (ed)
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"Kerins, Hickey & Haydock (1985) stated that ..."
or
"In an article about providing modern apartments for adults (Kerins, Hickey & Haydock, 1985) it was stated that ..."

Journal titles should **not** be abbreviated. The letters a, b, c, should be added after the date if more than one paper by the same author(s), published in the same year, is quoted.

Reference lists which are not of an acceptable standard will be returned to the author(s) for correction.

Letters

Letters which either provide or seek information on any aspect of research into learning disability and its associated conditions are welcome, as well as those which discuss the content of previous ***British Journal of Learning Disabilities*** articles. The first name, surname, professional occupation, and address of the correspondent(s) should be given at the end of the letter. Any references quoted should be listed on a separate sheet and prepared in accordance with the guidance given above for *Article References*

LENGTH

Letters should be restricted to no more than 500 words (approximately three pages of A4 double-spaced typescript). Two copies should be submitted.

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Reviews of books detailing research findings and advances in the field will usually be specifically requested by the Editor, but uncommissioned reviews will also be considered. Two copies should be submitted. Reviews should not exceed 500 words.

ASSESSMENT PROCEDURE

All articles submitted to *The British Journal of Learning Disabilities* are assessed by at least two anonymous assessors who are chosen because of their expertise in the specific topic covered. As well as the originality and importance of the content, assessors will be looking for work that is presented in a logical, clear and concise form.

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The Editor reserves the right to edit any contribution to ensure that it conforms with the requirements of *The British Journal of Learning Disabilities*. A copy of the edited contribution will not normally be sent to the author(s) for approval prior to publication. However, where extensive editorial changes are made, papers will be returned to the authors with a request that the paper is retyped with the amendments incorporated. All authors of articles (but not those of letters or book reviews) will be sent a set of proofs for checking.

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	Standard Score	Band of Error 95% confidence	National Percentile Rank	Stanine	Supplementary Norm Group* percentile rank	Adaptive Level	Supplementary Norm Group* Adaptive Level	Age Equivalent
Receptive						Lo	SP Below Average	1 year 2 months
Expressive						Lo	SP Below Average	0 years 9 months
Written						Lo	SP Above Average	3 years 8 months
COMMUNICATION DOMAIN	**<20**	**± 10**	**<0.1**	**1**	**SP 25**	**Lo**	**SP Below Average**	**1 year 0 months**
						Lo		
Personal						Lo	SP Average	2 years 11 months
Domestic						Lo	SP Average	3 years 0 months
Community						Lo	SP Average	1 year 9 months
DAILY LIVING SKILLS DOMAIN	**<20**	**± 8**	**<0.1**	**1**	**SP 45**	**Lo**	**SP Average**	**2 years 9 months**
Interpersonal Relationships						Lo	SP Below Average	0 years 8 months
Play and Leisure Time						Lo	SP Below Average	0 years 1 month
Coping Skills						Lo	SP Average	2 years 4 months
SOCIALISATION DOMAIN	**<20**	**± 8**	**<0.1**	**1**	**SP 30**	**Lo**	**SP Average**	**0 years 10 months**
Gross Motor Skills							SP Average	2 years 4 months
Fine Motor Skills							SP Average	2 years 10 months
MOTOR SKILLS DOMAIN	**Est. 47**	**± 12**	**<0.1**	**1**	**(SP 60)**	**Mod Lo**	**SP Average**	**2 years 8 months**
ADAPTIVE BEHAVIOUR COMPOSITE	**<20**	**± 6**	**<0.1**	**1**	**SP 35**	**Lo**	**SP Average**	**1 year 6 months**

*** supplementary norm group = Ambulatory mentally retarded adults in residential facilities. 18 years 0 months 0 days or over.**

Results of the Vineland Adaptive Behaviour Scales. Interview Edition. Expanded Form.

APPENDIX 7

The Efficacy of CBT for Social Phobia: a single case study

Appendix

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APPENDIX 7.1

Instructions to Authors

1. **Submission.** Articles written in English and not submitted for publication elsewhere, should be sent to Paul Salkovskis, Editor, *Behavioural and Cognitive Psychotherapy*, Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford OX3 7JX, UK.

2. **Manuscript preparation.** Four complete copies of the manuscript must be submitted. Original figures should be supplied at the time of submission. Articles must be typed double-spaced throughout on standard sized paper (preferably A4) allowing wide margins all round. Where unpublished material, e.g. behaviour rating scales, therapy manuals, etc. is referred to in an article, copies should be submitted to facilitate review.

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ROSKIES, E. and LAZARUS, R. S. (1980). Coping theory and the teaching of coping skills. In P. O. Davidson and S. M. Davidson (Eds). *Behavioural medicine: changing health lifestyles*. New York: Brunner/Mazel.

(f) *Footnotes.* The first, and preferably only, footnote will appear at the foot of the first page of each article, and subsequently may acknowledge previous unpublished presentation (e.g. dissertation, meeting paper) financial support, scholarly or technical assistance, or a change in affiliation. In concluding (or only) paragraph must be the name and full mailing address of the author to whom reprint requests or other inquiries should be sent.

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(h) *Figure captions.* Numbered captions should be typed on a separate page.

(i) *Figures.* Original drawings or prints must be submitted for each line or half-tone illustration. Figures should be clearly labelled and be camera-ready wherever possible.

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APPENDIX 7.2

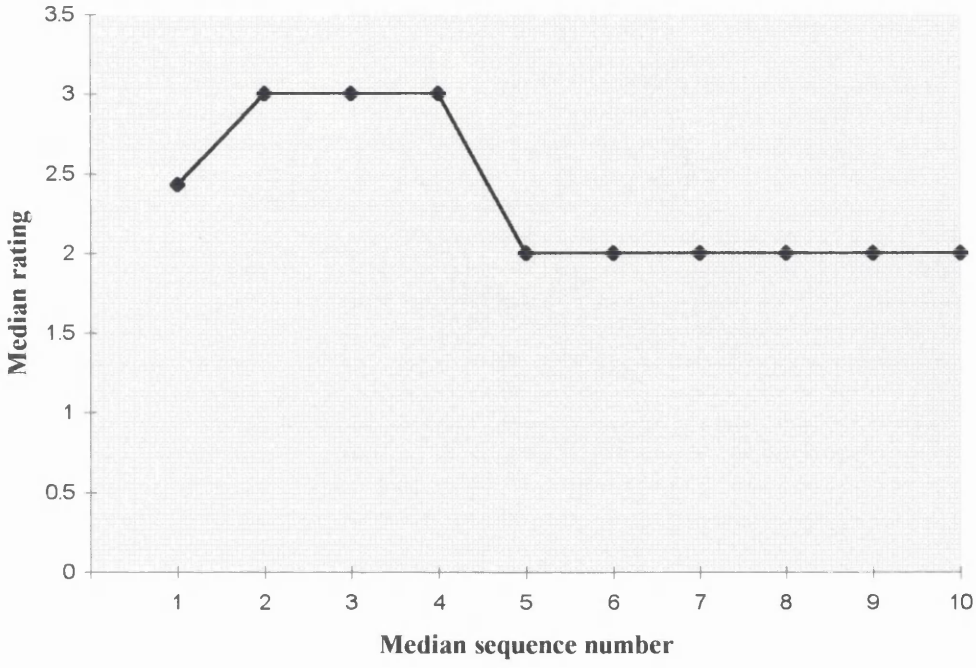

Figure 7. Running medians of five of the average daily anxiety rating for the treatment phase

APPENDIX 7.3

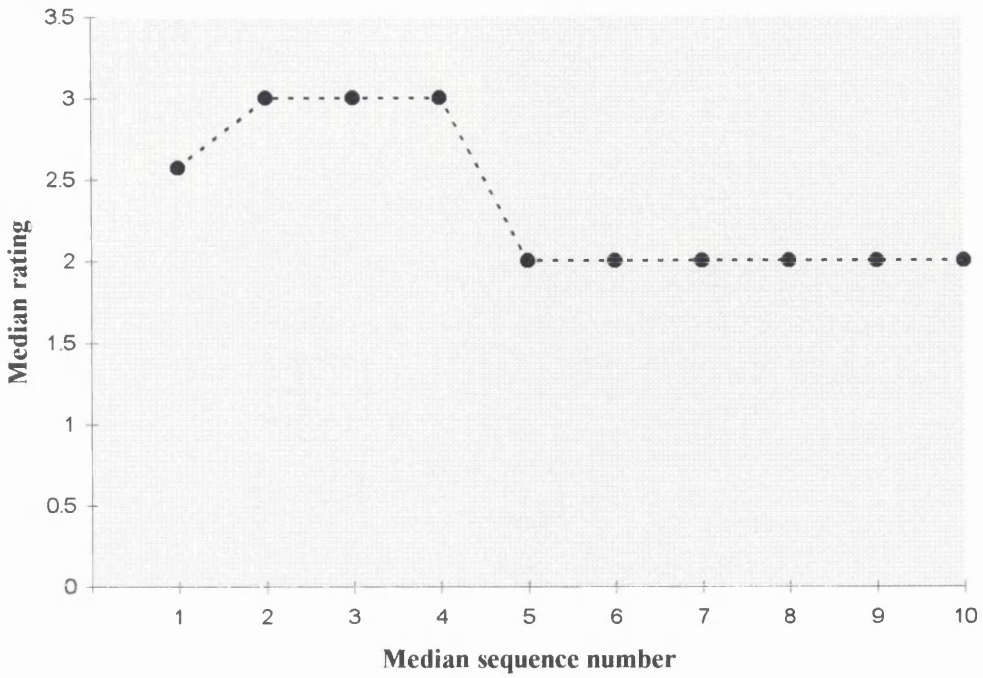

Figure 8. Running medians of five of the average daily low mood ratings for the treatment phase