# PERCEIVED IMPACT OF EPILEPSY AND ASSOCIATED PSYCHOPATHOLOGY IN THE ELDERLY AND RESEARCH PORTFOLIO

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# Section 1. 1- Literature Review

## Physical, Social & Psychological Wellbeing in the Elderly With Epilepsy: A Review of the Literature

Prepared in accordance with the instructions to contributors for Seizure
(See Appendix 1)

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# ABSTRACT

Epilepsy is a comparatively common condition in old age. Not only are the many patients who develop epilepsy early in life living longer, but there is an increased recognition of elderly onset cases. However, this group appears to be under-researched and poorly understood. This is most notable with regards to psychosocial functioning in the elderly with epilepsy.

A review is provided of the available literature concerning the medical and psychosocial features of this group. From this review, it is apparent that this population have a number of unique features and it is apparent that standard treatment procedures for adults should not automatically be extrapolated to the elderly. It is concluded that further research is essential.

## INTRODUCTION

The elderly with epilepsy constitute a comparatively large and growing population. Yet there has been only limited research conducted on this group. While some steps have been taken in recent years to rectify this situation with regards to medical treatment, the literature remains extremely sparse concerning the psychosocial functioning of elderly people with epilepsy (EPWE)(1). This is a particularly important omission as EPWE may be an extremely vulnerable group. The consistent finding of research is that rates of psychological and social problems are elevated in adults with epilepsy (2), while adjustment problems and psychopathology are also prevalent in the elderly, and in particular the elderly with health problems (3).

Clearly, this vulnerability has implications for all who are involved in the health care of the elderly. The World Health Organisation (WHO) stated that effective treatment must take account of the physical, social and psychological wellbeing of the individual (4). Health care should not be simply concerned with the detection of disease but should also concentrate on those aspects which may have an adverse effect on the ability of the patient to lead a normal life. This may be of particular relevance to those with epilepsy for whom the physical manifestations are transient and the psychosocial concerns frequently are of more concern (3).

The aim of this review is to provide an assessment of those aspects which appear integral to the holistic care of EPWE.

## THE PHYSICAL PRESENTATION OF EPILEPSY IN THE ELDERLY

Until comparatively recently it was accepted that epilepsy was a condition which occurred mainly in children and young adults. Indeed "epilepsy of late onset" was conventionally taken to mean epilepsy starting between the ages of twenty and thirty five (5). However, it is now recognised that the condition is much more prevalent among the elderly than was first thought (6).

Difficulties in diagnosis may partly explain why this group has gone largely unreported. Gathering information on "a turn" may be difficult from an anxious and confused elderly person. The problem may be particularly acute for the substantial proportion of this group who live alone where ictal activity frequently may go unreported.

Misdiagnosis is also thought common as there are a variety of competing explanations for "funny turns" in the elderly such as transient ischaemic attacks, syncope, dementia, effects from other chronic medical conditions such as diabetes or hypertension, or from the toxic effects of polypharmacy (7,8,9). Also, the seizure pattern in this group may be unconventional. Tallis (1993) suggested that post ictal states tend to last longer and may be associated with complications such as temporary hemiparesis which may be misdiagnosed as stroke (1). It has also been proposed that seizures may not only be misdiagnosed but overlooked in "the pathologically busy years of late life. Perhaps because they are taken less seriously" (Ref. 10, p.447).

It has also been suggested that prevalence rates have been underestimated as many early studies used specialist hospital clinic samples where the elderly tend not to be referred (8). Indeed, a recent U.K. study found that only 28% of elderly patients who had seizures were referred for specialist investigation (11).

Recent community based studies have indicated that the prevalence and incidence of epilepsy increases with age (10,12,13). Not only are the many patients who develop epilepsy early in life living longer but there is an increased recognition of elderly onset cases (9).

Tallis (1991) reported an epidemiological primary care based study which found a prevalence (number of cases per head of population) of 11.8 per 1000 for those over sixty, as compared to 9.0 per 1000 in the overall population (10). Incidence (number of new cases) was 117 per 100,000 as compared to 69 per 100,000 in the overall population (10). These findings are broadly comparable with other epidemiological studies and indicate that epilepsy is the third commonest neurological condition in old age after cerebrovascular accident and dementia (1,12,13). It has been suggested that for a G.P. with an average waiting list, she/he will have five to six EPWE registered and over one third of new cases on treatment will be over sixty (1). It has also been recognised that these figures can be expected to increase. Demographic predictions indicate that the population is ageing and in particular there will be a steep rise in the "old old" (those over 75) (11). Given that cerebrovascular disease is the commonest cause of elderly onset seizures and that it is strongly correlated with age, it can be anticipated that there will be an increasing number of elderly and very elderly people with epilepsy (1,9,11).

With regards to the aetiology and presentation of seizures in the elderly, as compared to their younger counterparts there are some notable distinctions. Firstly, seizures tend to be much more symptomatic of other organic problems in the elderly. Onset of a primary seizure disorder in this group is rare and indeed it has been argued that primary generalised seizures do not develop after the age of sixty (8,14). Luhdorf et al (1986) described stroke as being the cause of seizures in 32% of their sample and tumours in 14%. The cause of seizures remained unknown in only 25% of the sample and indeed it has been postulated that many ideopathic seizure disorders in the elderly are also vascular in origin and that seizures may be the only marker of undetected ischaemia (5,10,14). Dementia has also been highlighted as a risk factor for developing epilepsy, most notably for those with dementia of the Alzheimer's type (DAT)(8). McAreavey et al found that 9.1% of a sample with dementia had epilepsy (15). It has been suggested that this may be due to a degeneration of cortical neurons. However, it has also been recognised that neuroleptics used in treatment may increase seizure propensity (12,15).

Seizures tend to be partial, with the majority also having secondary generalised seizures (5). Post-ictal states may be more prolonged and may last from a matter of hours to as long as a week (1).

While there has been only limited data on the course and impact of theraputic treatment, there would appear to be a broad consensus that seizures are relatively easy to treat at anti-epileptic drug levels at the low end of conventional "target" ranges, and that intractable epilepsy is comparatively rare in old age (8,9,12). However, it has been highlighted that the elderly are more susceptible to adverse side effects, most notably cognitive impairment, but also other problems such as diplopia, ataxia and drowsiness which in turn may lead to potentially serious sequelae such as falls, fractures and burns (8,16).

In summary, EPWE present a number of distinctive features in terms of prevalence, diagnosis and treatment. Therefore, standard theraputic approaches may not only be unhelpful, but may be potentially damaging. While for most, seizures appear to be comparatively well controlled, there is a growing recognition that it is not seizure frequency per se that is regarded by patients as the most serious aspect of the condition. Rather, it is the perceived impact of the severity of seizures and their treatment and the consequent psychological and social distress that is of more pressing concern (2). This will be examined next.

## PSYCHOLOGICAL MORBIDITY IN THE ELDERLY WITH EPILEPSY

Betts (1993) stated "it is probable that psychiatric disturbance of all kinds is commoner in people with epilepsy than in the general population" (Ref.2, p.397). In fact such accompanying problems may be more disabling than the seizure disorder itself (2,17).

Perhaps the most commonly experienced problems concern anxiety and depression. Trimble & Perez (1980) found that anxiety and depression in people with epilepsy was not only significantly higher than controls, but was equivalent to levels found in psychiatric populations (18).

It has been postulated that levels of psychological disturbance in EPWE will be comparable or indeed elevated due to the increased prevalence of vascular and degenerative disease in this group, and also due to the burden of having to cope with a chronic medical condition in old age (3,19). Nonetheless, there is very little evidence concerning the nature of psychopathology in the elderly with epilepsy.

Clearly this is a area that merits attention in future research. However, some understanding of this population is provided by an examination of the available literature on psychopathology in the general elderly population, and more specifically concerning the elderly with chronic medical conditions. This highlights that not only is psychopathology prevalent among the elderly, but as with the medical presentation of epilepsy, there are a number of important features which differentiate this group from their younger counterparts.

By far the most common presenting psychological or psychiatric condition in the elderly is depression. It has been suggested that 20% to 40% of patients seen in the primary care setting for depression are over sixty five, while 5% to 10% of the elderly who attend primary care clinics at any one time qualify for a diagnosis of major or minor depression (20,21). Anxiety is thought to be comparatively rare as a primary difficulty and is usually picked up as a feature of a depressive illness (21).

Rates of depression are further elevated for those with a physical illness. Ferentz (1995) found that the prevalence of depression rose to 15% in this group (20). While there have been no specific studies on those with epilepsy, there have been studies carried out on some of the major causes of depression in the elderly with health related problems. Indeed, perhaps the most extensively studied area concerns stroke. Post-stroke depression has been found to affect between 25% to 50% of stroke patients (20). A study by

Folstein et al (1977) which compared stroke and orthopedic patients found depression had developed in 45% of patients in the year after stroke as compared to only 10% of orthopedic patients (22). While depression may well be directly related to neurological damage and the extent of depression has been related to the site and extent of the lesion, the level of functional disability caused by the stroke is also an important determinant (22). This has obvious implications for the elderly with seizures subsequent to cerebrovascular damage.

It has been suggested that many studies have underestimated the degree of psychological distress in the elderly ill as this group react to ill health in a different manner from the young and indeed rarely present with the classic psychiatric syndromes (3,23). Rather, frequently they exhibit so called partial or atypical states characterised by perhaps one element of the typical syndrome, or several elements but combined in unusual ways (3).

With regards to the presentation of depression, features such as increased emotional lability (particularly tearfulness), without depressive cognitions or pervasive mood disorder are common (3). It has also been observed that the elderly demonstrate a reluctance to verbalise feelings of depression. Instead they appear more inclined to present with somatic complaints, insomnia, irritability and concerns regarding cognitive deterioration (3,21,24). Also, of particular relevance for those with epilepsy, it has been suggested that for those where the mood disorder is masked by concurrent physical problems, there is a tendency to treat somatic complaints as genuine (21).

The potentially serious consequences of such underdiagnosis of depression was emphasised by Reynolds (1995) who described a study which found that many elderly people who committed suicide visited a primary care physician in the month prior to death (21). However, there are grounds for optimism for those who receive treatment for depression. Reported rates of between 45% and 60% have remained well or have had relapses successfully treated following a course of pharmacological and/or psychological therapy. However, care is necessary for those with epilepsy as tricyclic antidepressants may lower the seizure threshold (19,21).

While it is probable that organic damage is a significant component in the aetiology of psychological distress, this provides only a limited understanding of the complex relationship between psychopathology and epilepsy. A more comprehensive framework is provided by the World Health Organisation's classification of impairments, disabilities and handicaps (4). Impairment relates to the direct psychological consequences of the disease process, such as organic symptoms of depression resulting from stroke. Disabilities are tasks of daily living which can no longer be done individually as a consequence of ill health, such as the ability to drive in epilepsy. Handicaps are perhaps the most important consequence of disease and relate to impact on lifestyle or role (4).

Clearly an understanding of the perceived impact of epilepsy (which may not relate directly to the objective characteristics of the condition) on the individual is essential. Clinically, this can provide a shared language between the health professional and the patient and should ultimately help provide a service which effectively meets the needs of the patient. The features which appear relevant to the perceptions of epilepsy in the elderly will be considered next.

## PERCEIVED IMPACT OF EPILEPSY IN THE ELDERLY

Previous research has highlighted a number of core inter-related areas concerning how adults with epilepsy view the impact of their condition; namely perceived social and interpersonal impact, perceived physical and medical risk, and perceived control (25). The relevance of each of these areas with regards to the elderly will be examined.

### Perceived Social and Interpersonal Impact of Epilepsy

Much of current understanding of the perceived effects of being diagnosed as having epilepsy comes from the literature on the concept of stigma. Central to this model is the work of Goffman (1968) who proposed that stigma referred to any deeply discrediting attribute (29).

Previously, stigma was taken to refer to objective acts of discrimination. However, more recently an important distinction has been made between "enacted" and "felt" stigma. The former refers to the attitudes and beliefs held by others which results in acts of discrimination. This excludes instances of "legitimate" stigma such as driving bans. Felt stigma refers to the perceived social and intepersonal impact. The available evidence has suggested that the two do not necessarily correlate. Perceived, or felt stigma has been found to be disproportionately high and frequently has been found to be a source of psychosocial distress (27).

It is suggested that EPWE may be particularly vulnerable as both epilepsy and old age have been associated with stigma (1,7,27). It is suggested that the negative self image associated with epilepsy and old age develops from three main arenas; lay culture, medical professionals and the family.

**Lay Culture:** While there is some evidence of encouraging changes in public attitudes, public ignorance and discriminatory attitudes towards people with epilepsy remain high. Similarly, popular culture generally devalues old age; the elderly are frequently regarded as dependant, mentally confused, lonely, rigid in attitude, poor, depressed and passive (30,31). A common reaction to perceived or felt stigma is withdrawal and avoidance of potentially rewarding activities with consequent psychological distress (27). This, in turn, may reinforce stereotypes of an infirm and debilitated group (1).

**Medical Professionals:** Perhaps surprisingly, elements of the attitudes outlined above are not uncommon among health care workers. In the U.K., G.P.s, health visitors and community nurses have expressed reluctance to become involved in working with the elderly whom they have described as having little patience with and were seen as "boring" (7). Also, a recent examination of G.P. care for people with epilepsy found that consultations were brief and infrequent with little time or importance being given to a discussion of the patient's concerns (32).

**The Family:** The family have been considered key "stigma coaches". For instance, the more family members think of epilepsy as something "bad" and not to be discussed, the more likely the person with epilepsy is to see it as something to be ashamed of (27). Also, the overprotection of the elderly person with epilepsy may further reinforce beliefs about infirmity (27). It has been suggested that the family provide a particularly strong learning model as old age is commonly associated with social networks which are dominated by the family (7).

## The Perceived Physical Effects

It has been acknowledged that the perceived impact of seizures, diagnosis and treatment is likely to be both profound and complex (1). However, once again, there is comparatively little research on this area. Much of current understanding is based on the work of Mittan and his colleagues (1986)(29).

Mittan (1986) reported that the major expressed concern from an adult sample with epilepsy was fear of death due to a seizure. While it has been observed that the elderly tend to hide their fears more during consultations, this would appear to be a commonly expressed concern among the elderly (21). However, while mortality is comparatively higher in EPWE than their younger counterparts, this would appear to be attributable to comorbid medical problems and indeed there is some evidence that epilepsy related mortality in the elderly is comparatively low (14,24). Tallis (1993) suggested that part of this fear in the elderly is concerned with the inability to differentiate potentially fatal "funny turns" which have a cardiac basis from epileptic seizures (1).

Fear of brain damage and cognitive impairment have also been expressed frequently (29). Given the aetiology of seizures in the elderly, for many there would appear to be a basis in reality for these concerns (19). However, while minor cognitive and physical decline is regarded as a normal feature of the ageing process, major impairment is rare (30). Concerns regarding the potential cognitive and physical effects of medication were also expressed in

Mittan's study (29). Again, this may have some basis in reality as the elderly appear particularly vulnerable to adverse medical effects which can result in impairment of higher mental functioning and also put at greater risk of falls and injury (1,4,9,12).

Fears of injury have not only been related to medication effects, but also to seizures. It has been highlighted that seizures are comparatively more likely to lead to serious injury, partly as osteoporotic bones are more likely to fracture in a fall (1). Tallis (1993) compared seizures to falls in the elderly which have been associated with a sharp decline in independence, loss of confidence and fear of subsequent falls (1).

## Perceived Control

Chronic illness and old age both have been described as naturally occurring stressful life changes which may result in loss of perceived control and an increased dependence on others (36). Such feelings of powerlessness have been related to fear, anger and helplessness (3).

Epilepsy is perhaps unique among chronic illnesses in its ability to engender feelings of lack of control. Perceived control is diminished through dependency on health professionals, medication and through considerable social, legal and economic restrictions. Also, seizures, by their very nature present a temporary and unpredictable loss of control.

The psychosocial implications of such perceived loss of control are considerable as it has been suggested that this may generate to feelings of powerlessness and futility in other aspects of voluntary behaviour and consequent psychological distress (36).

## INDIVIDUAL DIFFERENCES IN THE PERCEIVED IMPACT OF EPILEPSY

It has frequently been emphasised that the elderly are not a homogeneous group and that there is considerable variability in the ability to cope with chronic physical illness.

The first important point to emphasise is that old age covers a wide age range. Conventionally, it has been split into the young-old (60's to mid 70's), old-old (mid 70's to mid 80's) and the oldest-old (mid 80's plus) (3). Given that the prevalence of epilepsy, along with many other medical conditions, rises with age, as does the frequency of major life events such as the death of peers or a partner, the oldest-old appear to be at greatest risk while the youngest old have been regarded as predominantly healthy, active and capable (3,7).

It has also been highlighted that the knowledge a person with epilepsy has about his/her condition is vital in coping with the medical implications of the condition. Also, the knowledgeable patient is better able to make an accurate assessment of the social, functional and vocational limitations imposed by the condition and consequently minimise potential functional and emotional disturbance (31).

Knowledge, however, is not enough for an adaptive adjustment. The resourcefulness or self efficacy beliefs that the person with epilepsy has are also of vital importance. This refers to "the beliefs in one's capabilities to mobilise the motivation, cognitive resources and courses of action needed to meet given situational demands" (Ref.32, p1). This has been closely related to how people with epilepsy perceive their ability to cope with their condition, and to consequent levels of anxiety and depression (33).

While it may be strongly suspected that other factors such as the frequency and type of seizures, the nature of associated pathology and the extent and type of social contacts will also be key components in the psychosocial adjustment of the EPWE, such suggestions must remain open to conjecture in the absence of convincing research findings (3).

## CONCLUSION

While research concerning the elderly with epilepsy is sparse, the available literature has suggested that this is a population with specific physical, social and psychological needs. However, there is little evidence that these needs are being met effectively. This would appear to be due in part to a lack of awareness of the subtle differences in presentation in this group. However, this also appears to be due to widespread and unjust prejudices towards working with the elderly.

Finally, much of the research reviewed concerning psychopathology and the perceived impact of epilepsy in the elderly was based on general adult epilepsy patients, and on physically ill elderly patients. Therefore the applicability to elderly people with epilepsy must remain somewhat speculative. Clearly there is a pressing need for further research in this area.

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# Section 1. 2- Research Proposal

## Psychosocial Functioning in the Elderly With Epilepsy

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## SUMMARY

While there has been considerable work on psychological functioning and quality of life models on paediatric and adult populations of people with epilepsy, there has been little attention paid to the specific needs and problems of the elderly with epilepsy. It is argued that this is a significant omission.

This research project aims to redress this balance by providing a detailed study of the extent to which this group perceive their condition as having a detrimental psychosocial impact. Specific examination will be made of the perceived physical risk and control, perceived stigma and social limitations and beliefs and about the effectiveness of medical intervention. Comparison will be made between this group and their younger counterparts. Also, within group differences will be examined with regards to a series of relevant socio-demographic and medical variables. It is suggested that this information can be used usefully to help develop medical and psychological services which more ably meet the needs and expectations of the elderly with epilepsy.

It is proposed that the study be carried out at the Epilepsy Research Unit at the Western Infirmary, Glasgow. Subjects would comprise a sample of the elderly population attending the Epilepsy Clinic at the Hospital. Information would be gathered initially from a postal questionnaire which would consist of a short series of scales which have been used previously in epilepsy research projects. Subjects would also be encouraged to highlight any areas of concern which have not been covered by these scales. As a second stage of the project, it is intended to run a short series of workshops comprising volunteers from the first stage. It is hoped that this will provide further qualitative information on the concerns of this group.

## INTRODUCTION

In recent years there has been a growth of interest in the psychological functioning and quality of life of people with epilepsy. The consistent finding of research has been that people with epilepsy tend to have greater psychological and social problems than healthy controls (1).

Such research has provided detailed analysis of both child and adult populations. However, there has been comparatively little attention given to the population of elderly people with epilepsy (EPWE).

Given the considerable size of this group, this would appear to be a notable area of omission. The available evidence has highlighted that the possibility of developing epilepsy significantly increases with age and that seizures are twice as common over the age of 65 than between the ages of 25 and 642. Also, the population of the U.K. is ageing (estimates have projected that between 1988-'96, the over 65 group will grow by 2.5%, while the over 75's will rise by 37.5%2). Therefore, it can be anticipated that there will be an increasing number of elderly people with epilepsy. Clearly, the need for a comprehensive assessment of the specific adjustment difficulties of this group is strikingly apparent (2).

Reviews of the psychosocial functioning of general elderly populations have suggested that they differ from their younger counterparts in terms of rates of psychological morbidity and also in terms of the content of their worries, aspirations and concerns (2,3). It is suggested that this profile may also be applicable to the population of people who have epilepsy. Previous research has highlighted a variety of social, physical and psychological concerns among people with epilepsy such as problems or worries with employment, participation in strenuous physical recreational activities or pregnancy (1). Such areas may not have the same relevance to the elderly as for instance domestic safety, inability to drive, dependency on, or concern over the loss of significant others such as friends or spouses, or worries over the potentially more serious neurological implications of late onset epilepsy (4).

Also, previous research has indicated that the ways in which people with epilepsy view their condition is intimately related to psychological distress, most notably anxiety and depression (5). However, to date their is little available research regarding the specific concerns of EPWE, or of the relationship between these concerns and psychological morbidity.

## AIMS

The aim of this project would be to provide a detailed examination of the perception of psychosocial impact that a sample of EPWE have concerning their condition. It is hoped that the results of this research will assist in the process of developing medical and psychological services which meet the needs and expectations of this group.

Previous research has highlighted epilepsy knowledge, perceived self efficacy, perceived physical risk, perceived control of epilepsy, perceived stigma and social limitations and beliefs about the effectiveness of medical intervention as core inter-related features of how people with epilepsy view their condition(5). These areas would provide the theoretical framework for investigation in this study. However, subjects will also be given the opportunity to highlight areas of concern which had not been covered by the above.

The specific areas which this study would wish to address are-

(1) While elevated rates of psychological distress have been a common finding of previous research on adult samples of people with epilepsy, there is little specific information concerning the elderly. Therefore, the first area of investigation will be to examine whether EPWE also experience significant levels of anxiety and depression.

(2) As has been indicated, adjustment problems are common among people with epilepsy. The second area of investigation will be to examine whether this is the case with EPWE. Also, the extent to which adjustment problems are related to psychopathology will be examined.

(3) The next level of investigation will be to provide a more detailed examination of the specific concerns EPWE have regarding their condition.

(4) Fourthly, an examination wil be made of the main discernible aetiological and maintaining factors concerning perception of epilepsy among EPWE.

## PLAN OF INVESTIGATION

### Subjects

Subjects would be recruited from the Epilepsy Research Unit at the Western Infirmary. It is intended to contact all EPWE who attend this clinic who meet the inclusion and exclusion criteria (see below). Preliminary examination of the clinic's patient database has suggested that there would be approximately 100 potential subjects.

Inclusion criteria:

(a) The conventionally used definition of elderly as being males over 65 and females over 60 would apply.

(b) Seizure frequency- Previous studies have varied considerably on this variable. In order to obtain as broad a sample as possible, it is intended to contact subjects who are comparatively well controlled but can still be regarded as having active epilepsy, through to those with frequent seizures. It is therefore proposed that subjects will have had at least one seizures in the previous six months.

(c) Duration of epilepsy- It is intended contacting a broad range of individuals on this variable from those recently diagnosed and receiving treatment for epilepsy through to those of long standing duration.

Exclusion criteria:

(a) Subjects with significant cognitive impairment (e.g. advanced dementia, major head injury) such as to prevent the reliable completion of the questionnaire.

### Measures

It is intended to use a series of questionnaires which have been used previously in epilepsy research. These measures would provide assessment of overall psychopathology and of the subjects' perceptions of the psychosocial impact of their condition.

### 1- Anxiety and depression

(1) The Hospital Anxiety and Depression Scale (6)- This scale was selected as a short, reliable measure of anxiety and depression which has proven to be a valid and sensitive measure with epilepsy populations.

### 2- Adjustment/perception of epilepsy

The model of perception of epilepsy which it is intended to use for this study involves an examination of epilepsy knowledge, efficacy beliefs, perceived physical and social risk and perceived control. The following measures would be used to asses these areas:

1-The Epilepsy Knowledge Profile (7). The first section of this scale provides an assessment of knowledge of epilepsy. The second section consists of a series of questions which enquire about specific aspects of the persons own condition including satisfaction with medical treatment, perceived control and predictability of seizures, perceived limitations of having epilepsy and satisfaction with knowledge of condition.

2- The Adjustment to Disability Scale (Amended for Epilepsy) (8). This scale provides overall assessment of the extent to which individuals are able to see values other than those in direct conflict with their epilepsy, whether individuals spread the effects of epilepsy to other aspects of their functioning self and the extent to which they compare themself to others in terms of limitations and liabilities. This scale also includes a 6 item fear of seizures scale.

3- The Self Efficacy Scale (9). This scale provides an assessment of individuals perceived ability to self regulate cognitions, emotions and behaviour.

In addition to these measures, space will be provided for subjects to highlight any concerns they have about their condition which they feel has not been dealt with adequately by the above questionnaires. Also, in order to obtain further detailed qualitative information on subjects' perception of their condition, it is intended to offer subjects the opportunity to attend a workshop to discuss issues which have been raised by the study and also to allow participants to share experiences which have not been covered by the questionnaires.

### 3- Maintaining/aetiological factors

For each subject, the following demographic and medical information will be obtained: Age, sex, marital status, seizure type and frequency, age at diagnosis and cause of onset (if known), duration of epilepsy, current pharmacological treatment and information concerning any other medical condition or physical disabilities.

## Design and Procedures

Questionnaires will be posted to potential subjects and will be returned by post. The scales will be accompanied with a covering letter which will explain the purpose of the study, will emphasise that participation is voluntary and non participation would not effect future medical care, and would provide brief instructions. Subjects would also be asked at this stage whether they would be willing to participate in one of the workshops. Background subject information would be obtained from medical notes. Subjects' confidentiality would be respected and maintained at all stages of the research.

With regards to the workshops, it is proposed that these could be conducted at the Epilepsy Research Unit at the Western Infirmary. This was selected as it provides a central, easily accessible location with which participants would be already familiar. Workshops will be semi structured and open ended. A proforma will outline the key questions for discussion. Responses will be recorded on flipcharts for collation purposes. It is proposed that each group consists of no more than 12 subjects with a minimum of 3 facilitators to run the groups. Each group would last for no more than half a day. The number of groups will be determined by the level of interest shown by subjects from the first stage of the study. The format of these groups would be semi-structured. Information gathered from these workshops would be collated, examined for recurrent themes and categories and added to the information gained from the first section of the study.

The first stage of this project would involve a review of all potential subjects who attend the clinic. This information can be obtained from a computer patient data base.

The second stage would involve a pilot study on a small sample of this group in order to determine whether there are any major problems in the administration, completion and scoring of the assessment measures.

Following the completion of this stage and following any changes which are required as a result of this, the third stage will involve the administration of the main assessment measures and completion of the subject information sheets as described above.

The fourth stage will involve scoring and computer coding of results and the administration of the workshops.

## Data Analysis

Data from the questionnaires will be scored manually and analysed on the Statistics Package for the Social Sciences (SPSS-X). With regards to the first area of research highlighted above (levels of anxiety and depression) examination will be made of means and spread of scores. Consideration will also be given to recognised clinical caseness cut-off points. With regards to the second and third areas, initial descriptive and qualitative information will be examined from the Epilepsy Knowledge Profile and from information obtained from the workshops. It is suggested that the procedure highlighted by Orford (1995)10 of collecting unstructured data, coding into broad categories, making preliminary interpretations and consequently identifying core themes will be employed. Thereafter, it is suggested that analysis will involve an examination of association between variables. Therefore, examination of scattergrams, and the utilisation of measures of correlation and regression will be most frequently relied upon to clarify the relationship between measures of perception of epilepsy and psychopathology and measures of perception of epilepsy and aetiological and maintaining factors.

## Timescales

It is suggested that identification of potential subjects and the completion of the pilot study could be completed in 3 weeks. If there were any problems (as long as they were not fundamental to the procedure) it is estimated that these could be rectified within 2 weeks. With regards to the main study, once potential subjects were identified, all questionnaires could be photocopied and posted from the Epilepsy Research Unit in 1 day. Subjects would be requested to return forms within 2 weeks. However, previous experience has indicated that these were still being returned 6 weeks later. During this time, information could be gathered from subjects' medical notes. It is suggested that this stage may take up to 2 months.

The next stage would involve scoring, coding and preliminary interpretation of data. This stage will also involve the organisation and administration of the Workshops. An estimated allowance of 3 months is made for this stage.

The final stage of his project will consist of final data analysis and writing up of results. A further 3 months will be allowed for this stage of the project.

In total, it is estimated that the full research project could be completed in under 10 months. If the project comenced in July,1995, this leaves some leeway for unanticipated problems and time delays.

## PURPOSE

As was highlighted in the introduction, the psychosocial needs of people with epilepsy are not well catered for. While in the past this was because they tended to be simply ignored, at present this is also because our limited understanding of these needs means that general rules of care and treatment are applied, regardless of the particular needs of specific groups or individuals. It is suggested that this research project will focus on the specific needs of the elderly with epilepsy and may also highlight the particular concerns of subgroups within this population. It is hoped that results from this project can be used to develop a more effective and rewarding relationship for both the patient and the clinician.

## Ethical Approval

Ethical Approval has been obtained from the Western Infirmary LREC.

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# Section 1. 3- Major Research Paper

## Perceived Impact of Epilepsy and Associated Psychopathology in the Elderly

Prepared in accordance with the instructions to contributors for Seizure
(See Appendix 1)

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## INTRODUCTION

Until comparatively recently, it was accepted that epilepsy is a condition that occurred mainly in children and young adults. However, it is now recognised that epilepsy is much more prevalent in the elderly than was first thought (1). Not only are the many people who develop epilepsy early in life living longer, but there is also an increased recognition of elderly onset cases (2). Indeed, epidemiological research has indicated that epilepsy is the third commonest neurological condition in old age after cerebrovascular accident and dementia (3,4,5). Tallis (1993) suggested that a G.P. with an average waiting list will have five to six elderly people with epilepsy registered and over one third of new cases of epilepsy will be over sixty (3).

Despite this recognition that the elderly with epilepsy constitute a comparatively large and growing population, there has been only limited research conducted on this group (6). The available literature has highlighted a number of distinctive features with regards to the aetiology, presentation and treatment of seizures and it is apparent that standard treatment procedures for adults should not be extrapolated automatically to the elderly (2,6,7,8,9).

In recent years there has been a growth of interest in psychosocial and quality of life issues in people with epilepsy. However, once again there has been little specific research conducted on the elderly (3). It is suggested that this is a particularly important omission as elderly people with epilepsy may be an extremely vulnerable group. Rates of psychological and social problems have been found consistently to be elevated in adults with epilepsy (10), while adjustment problems and psychopathology are also prevalent in the elderly, and in particular the elderly with health problems (11).

The aim of the present study was to provide an evaluation of the perceived impact of epilepsy and associated psychological distress in the elderly. Previous research on adult populations has highlighted that impact can be divided usefully into the perceived social and physical consequences of the condition, while the most commonly reported psychological problems are anxiety and depression (12,13). These areas formed the basis for the present investigation. Standard questionnaire assessment measures were used. However, given the limited understanding of the specific concerns of this group, emphasis was placed also on exploratory questions which allowed the provision of free text (3). Detailed examination was made of both quantitative and qualitative data obtained.

## METHODS

### Subjects

Subjects were obtained from the outpatient clinic at the Epilepsy Research Unit at the Western Infirmary, Glasgow. The conventionally used UK definition of elderly as being males over 65 and females over 60 was used. From a total of 2,300 patients registered at the clinic, there was a total of 141 females over 60 and 103 males over 65. Of this sample, only those with a diagnosis of epilepsy registered in the patient's medical notes and who had been started on anti-epileptic medication were selected. Also as the mortality rate within this group is comparatively high, only those who had been in contact with the clinic over the previous 12 months were approached. A further exclusion criterion involved reviewing patients' medical notes for evidence of significant cognitive impairment (e.g. advanced dementia, major head injury) such as to prevent the reliable completion of the questionnaires. This resulted in a total subject pool of 97.

### Procedure

Three forms of data were gathered. Firstly, quantitative data were obtained from standard questionnaire assessment measures. Secondly, qualitative data were obtained from free responses to a series of open ended questions. Finally, data was gathered from a workshop. The aim of the workshop was to elicit further qualitative information to complement and add to information gathered from the first stages of data collection.

Data were collected by mailed questionnaires. Questionnaires were either sent directly to individuals' home addresses or were given to potential subjects on attendance at the hospital outpatient clinic. Questionnaires were accompanied by a stamped addressed envelope and a covering letter which explained the purpose of the study, provided instructions and asked if individuals would be interested in participating in the workshop.

Prior to commencing the main study, a brief pilot study was conducted. The aim of his study was to determine whether there was any major problem with the administration, completion and scoring of the main assessment measures. From the results of this it was concluded that there were no significant problems to the planned procedure (see Appendix 2).

## Measures

For each subject, the following demographic and medical information was obtained: Age, sex, marital status, seizure type and frequency, age at diagnosis and cause of onset (if known), duration of epilepsy, current AED treatment and information concerning any other medical condition or physical disabilities.

A series of standardised questionnaires which provided both qualitative and quantitative data were selected to provide assessment of overall psychopathology and of the subjects' perceptions of the psychosocial impact of their condition.

The Hospital Anxiety and Depression Scale (14) was selected as a short, reliable measure of anxiety and depression. Assessment of the perceived social limitations of epilepsy was measured by the Adjustment to Disability Scale (Amended for Epilepsy) (15) and from open ended questions from the Epilepsy Knowledge Profile (Personal) (16). Assessment of the perceived physical consequences of having epilepsy was measured from a 6 item Fear of Epilepsy scale which examines concerns about seizures and treatment, and from open ended items from the Epilepsy Knowledge Profile (Personal) (16,17).

Knowledge about epilepsy and self efficacy beliefs have also been implicated as key features of how people with epilepsy perceive their ability to cope with their condition (19,20). These areas were measured using the Epilepsy Knowledge Profile (General) and the Self Efficacy Scale (18,19).

In addition to these measures, opportunity was provided for subjects to highlight any concerns they had about their condition which they felt were not dealt with adequately by the above questionnaires.

Quantitative data from the questionnaires were scored manually and analysed on the Statistics Package for the Social Sciences (SPSS-X).

Qualitative data from the Epilepsy Knowledge Profile was analysed by collecting the unstructured individual responses, coding into broad categories, making preliminary interpretations and identifying core themes.

Response Rate

Of the 97 subjects contacted, a total of 43 completed replies were received (a 44% return rate). Nine subjects were contacted at the outpatient clinic with 6 replies and 88 were contacted by post with 37 repies. Subjects comprised 24 females (55.8%) and 18 males (44.2%). Age ranged from 60 to 91 (Mean=70, SD=6.38). Age at onset of epilepsy ranged from 5 to 87 (Median=59). Sixty five percent indicated that they had less than 1 seizure per month, while 22.5% had greater than or about 1 seizure per week. The most frequently experienced seizure types were complex partial seizures (59%) and secondary generalised seizures (53.8%). Sixty three point four percent were on monotherapy. The remainder of the sample were on polytherapy. (For full demographic information, see Appendix 3).

Twelve subjects indicated an interest in participating in the workshop. Of these, 6 attended the workshop and 2 subjects were interviewed by phone. Comparison of the demographics and questionnaire replies of this group with the total sample revealed a broadly similar profile. The most notable difference was with regards to sex with there being a much higher proportion of females (6 females, 1 male) in the workshop than in the total sample (see Appendix 3).

The workshop format was semi structured and open ended. A proforma outlined the key questions for discussion (see Appendix 4). Responses were recorded on flipcharts for collation purposes. Three facilitators were involved in running the group. The workshop lasted for half a day. Information gathered from the workshop was collated and examined for recurrent themes and categories. A summary of results was sent to facilitators for comments. Final results were added to the information gained from the first section of the study (see Appendix 5).

## RESULTS

Examination of results is presented in 4 distinct stages. Firstly, an examination is made of the overall perceived impact of epilepsy. Secondly, the specific concerns of the sample is examined. Both qualitative and quantitative data is considered. Thirdly, an examination of the relationship between impact of epilepsy and anxiety and depression is made. Finally, the association between both impact and psychopathology, and a series of medical and demographic variables is made.

### 1- Perceived Impact of Epilepsy: Overall Effect

Assessment of the overall impact of epilepsy was obtained from responses to the questions "Do you feel that epilepsy makes a big impact on your day to day life?" and "What would you say are the greatest limitations about having epilepsy?".

As can be seen from Table 1, almost half of subjects indicated that their condition did make a major impact on their lives, while approximately three quarters of the subjects indicated that epilepsy limited their lives in some notable way. Even amongst those who did not feel that epilepsy imposed any distinct restrictions, some concerns were voiced about their condition, most notably concerning a lack of information about epilepsy and in particular about the potential side effects of medication (see Table 2).

Among those who indicated that epilepsy did not significantly affect their lives, the most commonly reported response was that this was due to seizures being well controlled. This was also the most commonly reported reply in the "additional comments" section (see Table 2). A dichotomy was found between those who were not concerned about epilepsy and were otherwise healthy and those who had other health problems of more pressing concern.

(INSERT TABLES 1-2 HERE)

## 2- Perceived Impact of Epilepsy: Specific Concerns

### 2.1- Quantitative Questionnaire Data

Firstly, there was a significant association between quantitative measures of social and physical impact; high social impact was related to high physical impact (Corr.=.402, P=.011).

Efficacy beliefs and epilepsy knowledge have been implicated as integral features in the perception of epilepsy. Indeed, in the present sample, lack of epilepsy related information was cited as a cause of concern and 56.1% of the sample indicated that they felt that they did not know enough about their condition. However, there was no significant relationship between knowledge and physical or social impact of epilepsy. With regards to efficacy beliefs, there was a modest correlation with social impact (Corr.=.392, P=.014), and no notable association with physical impact.

### 2.2 Qualitative Data: Perceived Social Limitations

(Full subject responses are provided in appendices 6-11)
As can be seen from Tables 1 and 3, a wide variety of social limitations were reported. However, a number of recurrent themes were identified. Firstly, many responses were related to practical difficulties, most notably the inability to drive. This was the most frequently cited limitation from both the questionnaire data (23.2%) and from the workshop. It was indicated that this not only made practical routines more difficult, but it also limited social contacts and participation in hobbies and recreational activities. A reported consequence of being unable to drive was an increased dependency on others, most often other family members, which was a source of frustration. Indeed, concern

about being alone and the perceived loss of independence was mentioned frequently by subjects (23.2%) (Tables 1 and 3).

As can be seen from Table 3 and Appendix 9, epilepsy appeared to have affected participation in a wide variety of recreational activities such as swimming, bowling and walking (20.7%).

As can be seen from Table 1, Work related limitations were also mentioned by 6.9% of the sample and it is perhaps worth emphasising that there is an increasing number of people who are continuing to remain in employment after the statutory retirement age while many others are involved in voluntary work (7).

While felt stigma was certainly not the most frequently reported social problem in either the questionnaires (6.9%) or in the workshop group, there was some evidence that this presented as a problem and potential souce of shame and embarrassment and had limited participation in activities such as involvement with the church.

Finally, much of the above would appear to be most directly relevant to those whose epilepsy is of short duration. The response from one subject highlighted the possibility that longer duration may result in a greater focus on long term limitations and missed opportunities, rather than frustration and fear at recent restrictions (see Table 2).

(INSERT TABLE 3 HERE)

## 2.3 Qualitative Data: Perceived Physical Limitations

Many issues were raised with regards to the treatment and consequences of seizures. Comments can be subdevided usefully into medication issues, seizure issues and control issues.

### 2.3.1. Medication Issues

As can be seen from Table 3, almost three quarters (72%) of subjects were happy with the treatment that they were currently receiving for their epilepsy and 86% believed that their AED's were effective in controlling their epilepsy. However, some dissatisfaction was expressed with primary care services, particularly with regards to the lack of information which was passed on about diagnosis and treatment (see Appendix 8).

Concern was also expressed regarding a number of areas of medical treatment, most notably regarding fatigue (11.5%) and the perceived cognitive effects of medication such as memory impairment and poor concentration (4.6%). These areas of concern were also expressed by participants in the workshop, as were a variety of other medication related symptoms such as ataxia, diplopia and rashes.

### 2.3.2. Seizure Related Issues

Examination of mean responses to individual items on the Perceived Physical Impact of Epilepsy questionnaire highlighted that the greatest expressed concern was with regards to reduced ability to think clearly. This was consistent with responses to other questions and to feedback from the workshop where concern was expressed regarding prolonged post-ictal confusion and many subjects indicated that they needed at least a day to fully recover from a seizure (see Appendix 5).

Concerns regarding injury were also evident. Six point nine per cent of subjects reported experiencing injuries directly from falls and indirectly from, for instance, scalding or burns from cigarettes during complex partial seizures.

### 2.3.3. Control Issues

A major expressed concern was regarding the perceived unpredictability of seizures. Only 23.3% of subjects indicated that they were able to predict times or places where seizures were likely to occur. Fewer (16.3%) stated that they were able to control seizures with the most frequently cited strategy being relaxation and distraction. However, it should be recognised that these figures may be low as for many, seizures appear to be well controlled through medication. A greater proportion of the sample were actively taking measures to control the adverse consequences of a seizure by taking precautions within and outwith the home. Within the home a variety of apparently appropriate precautions were taken such as care when cooking or not locking the bathroom door. Outwith the home the most common strategy was to go out with a companion. Six point nine per cent of subjects also indicated that they carry epilepsy identification cards.

## 3- Perceived Impact of Epilepsy: Association with Anxiety and Depression

With regards to anxiety and depression, the authors of the H.A.D. scale suggest that scores of between 8 and 10 are recognised clinical caseness cut-off points. With regards to depression, 27.9% of the sample had scores of 10 and above and 34.9% had scores of 8 and above. With regards to anxiety, 30.2% had scores of 10 and above and 40.5% had scores of 8 and above. These results suggest that, even when using the more conservative estimate, a sizeable proportion of the sample were suffering from clinically significant symptoms of anxiety and depression.

An examination of the association between impact and psychopathology was conducted at 3 levels. Firstly, a parametric correlational analysis was conducted on continous variables. Secondly a series of Student's t tests were conducted on dichotomous impact variables. Finally regression analysis was used to examine the overall predictive power of the perception model.

With regard to the relationship between impact and depression, correlational analysis revealed a significant association between measures of social and physical impact and depression (see Table 4). Also, a comparison of mean depression scores demonstrated that levels of depression were higher among those who indicated that epilepsy made a big impact on their lives (t=3.7, Sig.=.001), and that it resulted in limitations (t=2.5, Sig.=.019). Regression analysis produced results broadly comparable to correlation results and suggested that measures of impact accounted for a meaningful proportion of the variance of depression scores (Adj. R Squared=.491) (see Table 4).

With regards to anxiety, correlational analysis produced a modest relationship with social impact and a strong relationship with physical impact. As with depression, levels of anxiety were higher among those who indicated that epilepsy made a big impact on their lives (t=2.6, Sig.=.013), and that it resulted in limitations (t=2.6, Sig.=.015). Regression analysis suggested that measures of perceived impact also accounted for a meaningful proportion of variance of anxiety scores. However, this was substantially due to the strong relationship with the perceived physical consequences of epilepsy (Adj. R Squared= .331).

(INSERT TABLE 4 HERE)

### 4- Perceived Impact of Epilepsy and Psychopathology: Association with Medical and Demographic Variables

A series of medical and demographic variables were examined (see "measures" section).

Firstly, with regards to measures of impact, physical impact, and in particular a continual dread of seizure occurrence, was positively associated with seizure frequency (Physical impact; Corr.=.385, Sig.=.019, Dread of seizures; Corr.=.385, Sig.=.019). No notable association was found with other measured variables. Regression analysis indicated that medical and demographic variables failed to account for a significant proportion of variance in scores. With regards to the perceived social consequences of epilepsy, seizure frequency produced the only significant association for both correlational and regression analysis (Corr.=-.444, Sig.=.006, Beta=.386, Sig. t=.032).

With regards to anxiety and depression, the only statistically significant finding was a positive association between depression and seizure frequency on both correlational and regression analysis (Corr.=.385, Sig.=.015, Beta=.408, Sig. T=.018).

## DISCUSSION

The aim of this study was to provide an evaluation of the perceived impact of epilepsy and associated psychological distress in the elderly. Results indicated that, as with adult populations with epilepsy, the condition has a significant social and physical impact and that this impact is related to levels of psychopathology, most notably depression. However, there was also a significant relationship between physical impact and anxiety.

While the concerns expressed by subjects covered broadly the same areas as adult populations, there were a number of features which are indicative of the different aetiology and presentation of seizures in this population and of the distinctive reaction of the elderly to chronic health problems.

Firstly, studies of child and adult populations have emphasised frequently the social stigma associated with a diagnosis of epilepsy (23). While stigma was certainly present within this sample, this was not the most significant concern and indeed many indicated that they actively make a point of telling others that they have epilepsy in case they have a seizure. Perhaps, as most subjects were no longer in gainful employment, the risks associated with disclosure are not perceived to be as great.

For many, there was a far greater emphasis on practical limitations related to seizures, most notably the inability to drive. A wide variety of recreational activities had also been affected. However, with appropriate precautions there appeared to be little reason for non participation. While this may in part be due to a lack of epilepsy knowledge, other factors such as lack of social supports or associated health problems may be relevant.

Concern was also high regarding potential injury from seizures, prolonged post-ictal effects of seizures and regarding the potential side effects of medication. It has been highlighted that seizures in the elderly have a greater potential to result in serious injury, partly as osteoporotic bones are more likely to fracture in a fall (3). Tallis (1993) compared seizures to falls in the elderly which have been associated with a sharp decline in independence, loss of confidence and fear of subsequent falls (3). Also, the elderly appear to be particularly vulnerable to adverse medical effects which, along with a variety of other potential effects, may result in impairment of higher mental functioning and may place at greater risk of falls and injury (1,2). Therefore, perhaps it is not surprising that the relationship between seizure frequency and the perceived impact of epilepsy appeared to be closer in the elderly than in adult samples (21,22).

With regards to associated psychopathology, features which were highlighted by subjects such as perceived loss of control, dependency on others and having limited social outlets have been associated with psychopathology in the elderly with chronic health problems (24). With regards to anxiety, while the presence of clinical symptoms appeared to be more prevalent than in the general elderly population or in the chronically ill elderly, this was comparable to adult epilepsy populations and appeared to be intimately related to concerns regarding seizures and their treatment (25).

An interesting dichotomy was also found between those who were not concerned about epilepsy and were otherwise healthy and those who had other health problems of more pressing concern. This is of interest as not only are health problems more common in the general elderly population than in their younger counterparts, but also epilepsy in the elderly is frequently symptomatic of other health related difficulties (1,7). It has been suggested that such associated health difficulties may be a contributory factor towards elevated rates of psychopathology (27). However, no such relationship was found in the present study. It should, however, be recognised that this may be due to a methodological weakness in the present study. Information was not obtained from the subjects' main medical notes, but from notes specifically kept for the Epilepsy clinic. Therefore, important information may have been unavailable. Also, the scope of social and demographic information obtained was limited by the information available in the notes. It is suggested that future research should address these issues in greater depth.

It should also be recognised that he current sample consisted of those attending a specialist epilepsy clinic. It has been highlighted that most elderly people with epilepsy are not referred to such clinics and therefore subjects may not be representative of the total population. It has been postulated that those attending such clinics will be the more complex and refractory cases (28). However, examination of seizure related information demonstrates that a broad range of subjects were obtained and that the profile of this group was comparable to available epilepsy related demographics for this population (1).

Epilepsy has been described as "less of a social and economic handicap" in the elderly than in younger adults (Ref.26,p 58). This may be the reason why issues concerning the perceived impact of the condition do not appear to be routine practice in medical consultations (3). This research has demonstrated that epilepsy related issues are a major concern for the elderly and deserve greater attention. Time should be taken to provide basic information about epilepsy, highlight the purpose of treatment and potential AED side effects and listen to concerns relating to the condition. Where possible consultations should also include a spouse, family member or close friend. Many of these duties could be carried out effectively by a nurse specialist attached to a primary care clinic. Such attention may not only reduce patient fears and anxieties but may also improve compliance (18).

There is growing awareness of the efficacy of psychological treatments for people with epilepsy (29). However, there have been no reported treatment programmes for the elderly. As with medical treatment, it is apparent that standard adult treatment should not be extrapolated to the elderly. Not only must the specific concerns of this group be taken into account, but standard techniques such as cognitive behaviour therapy may require modifications for the elderly, particularly those with cognitive impairment (11). It is hoped that future research will address the efficacy of such treatment procedures in the elderly.

In conclusion, while this research has highlighted many of the significant concerns of this group, clearly there are many issues which need to be addressed in more detail. It is hoped that future research will be conducted with larger samples which also include primary care attenders. It is also recognised that assessment measures used in this study were not specifically designed for the elderly and indeed the lack of specific psychological assessment tools for the elderly is an accepted problem. It is suggested that future research trials would benefit from the development of measures specifically for the elderly with epilepsy.

# Table 1- Perceived Impact and Limitations

**Q.1-Do you feel that epilepsy makes a big impact on your day to day life?** Yes- 46.5% (20) No- 53.5% (23)

**Q.2-What would you say are the greatest limitations about having epilepsy?** No limitations-23.5% (10)
Limitations Provided- 76.5% (33)

| Main Themes | Q1 | Q2 | Example |
|---|---|---|---|
| **Perceived Social Impact** | | | |
| Inability to drive/independent travel | 4.6%(2) | 23.2%(10) | "No driving at present (for 12 months)" |
| Restricted to Home | 4.6%(2) | | "Afraid to go out on my own and feel restricted to home area, in case of a seizure" |
| Loss of Control/Independence | 2.3%(1) | 23.2%(10) | "Unable to do my own shopping etc." |
| Work Limitations | 2.3%(1) | 6.9%(3) | |
| Felt Stigma | | 6.9%(3) | "I do not allow it to interfere with my life in any way, but of course it occasionally takes its revenge. Alas, some friends were rather wary about being with me, but this has lessened considerably" |
| **Perceived Physical Impact** | | | |
| Fatigue | 11.5%(5) | 2.3%(1) | "Doesn't do all the things he used to do. He is easily done in" |
| Fear of Seizures | 6.9%(3) | | "I used to smoke and when I "went away" for a while I would drop the cigarette" |
| Loss of Control/Unpredictability of Seizures | 6.9(3) | | "Knowing that a seizure may occur at any time and that a serious injury may result" |
| Cognitive Impairment | 4.6%(2) | 6.9%(3) | "Loss of time, memory" |

# Table 2- Additional Comments

## Are there any other comments you wish to make?

| Main Themes | %/Count | Example |
|---|---|---|
| **Perceived Social Impact** | | |
| Felt Stigma | 2.3%(1) | "I feel we live in the dark ages. I am 69 and it is still something which is not talked about" |
| Lack of Knowledge | 2.3%(1) | "I would like to know more, not to be asked my opinions which may easily be wrong. I know nobody else who is epileptic" |
| **Perceived Physical Impact** | | |
| Lack of Information-Treatment | 4.6%(2) | "I would like to know more about side effects of medication" |
| lack of Information-Assessment | 2.6%(1) | "No one has explained to me why I should have begun epileptic seizures in middle life" |
| **No Significant Epilepsy Related Limitations** | | |
| Seizures Well Controlled | 13.8%(6) | "I have mild epilepsy and have only had 2 or 3 seizures" |
| Seizures well controlled- Otherwise healthy | 4.6%(2) | "I am 74 years of age and apart from slight creaking of the knees, feel as fit mentally and physically as ever" |
| Other health problems of more significance | 4.6%(2) | "I have lived long enough with epilepsy but I find that if I am content and have no distress I can manage. I now have age related macular degeneration. I am now getting laser treatment so I have less time to worry about epilepsy" |
| Adjustment made to condition | 4.6%(2) | "I found it hard at first to come to terms with my condition" |
| **Miscellaneous** | 18.4%(8) | "I am over 60 now and a lot of the problems I had don't seem so important now, although I do use my epilepsy to excuse the fact that I didn't do more with my life" |

## Table 3- Perceived Social and Medical Impact of Epilepsy

### (1) Social Consequences- Are there any activities or hobbies that you are not able to do because of your epilepsy?

| Main Themes | %/Count | Example |
|---|---|---|
| **Statutory Limitations** | | |
| Driving | 18.6%(8) | "Not allowed to drive" |
| **Recreational Activities (Miscellaneous)** | 20.7%(9) | "Swimming""My hobby is outdoor bowling and I do not enter club competitions- I only play friendlies" |
| **Social Activities** | 9.2%(4) | "I was an active member of the church but when they came on you, after, the members would ask if you are alright" |
| **Long Term Consequences** | 2.3%(1) | "When younger could not go dancing, could not learn driving. No swimming" |

### (2) Perceived Medical consequences

| | |
|---|---|
| **(2.1) Do you know what your anti-epileptic drugs are supposed to do?** | |
| No | 27.9%(12) |
| Partial Understanding | 67.4%(29) |
| Good Understanding | 2.3%(1) |
| **(2.2) Do you feel that they help control you epilepsy?** | |
| No | 4.7%(2) |
| Yes | 86%(37) |
| Don't Know | 2.3%(1) |
| **(2.3) Are you happy with the treatment you are getting at present from your doctor(s) for your epilepsy?** | |
| No | 9.3%(4) |
| Yes | 72.1%(31) |
| No reply | 18.6%(8) |

| **(2.4) Are there any precautions that you take in the home because of your epilepsy?** | Yes-37.2%(16) None Supplied-62.8%(27) | |
|---|---|---|
| **Main Themes** | **%/Count** | **Example** |
| To prevent injury from a seizure | 25.3%(11) | "I don't cook or use the cooker", Keep the bathroom door unlocked" |
| To prevent cognitive problems | 4.6(2) | "Repeat care: Electricity, plugs, switches, locks. Keep memo-pad handy |
| **(2.5) Are there any precautions that you take outwith the home because of your epilepsy?** | Yes-41.8%(18) None Supplied-58.2%(25) | |
| **Main Themes** | **%/Count** | **Example** |
| Go out with companion | 16.1%(7) | "Someone with me at all times" |
| Carry Epilepsy I.D. card | 6.9%(3) | "I always carry an epileptic card" |
| To prevent injury | 11.5%(5) | "I try to avoid physical fatigue and irritation and stress etc." |

# Table 4- Results of Measurements of Association With Perception of Epilepsy and Psychopathology

## (1) Pearson's Product Moment Correlation Results

| | | | | | | |
|---|---|---|---|---|---|---|
| **Soc. Imp. (Mn=210, SD=55.8)** | | | | | | *P<.05<br>**P<.005<br>***P<.001 |
| **Phys.Imp. (Mn=23.2, SD=7.6)** | -0.402*<br>P=.011 | | | | | |
| **Self Eff. (Mn=99.9, SD=33.5)** | 0.392*<br>P=.014 | -0.133<br>P=.427 | | | | |
| **Med.Knowl. (Mn=23.8, SD=3.7)** | 0.158<br>P=.158 | -0.171<br>P=.305 | 0.110<br>P=.506 | | | |
| **Soc.Knowl. (Mn=16.5, SD=15.3)** | -0.224<br>P=.171 | 0.248<br>P=.191 | -0.232<br>P=.156 | -0.125<br>P=.442 | | |
| **Anxiety (Md=6, Q1=4,Q3=10** | -0.302*<br>P=.050 | 0.599***<br>P=.000 | -0.246<br>P=.122 | -0.120<br>P=.461 | 0.183<br>P=0.259 | |
| **Depression (Mn=5.3, SD=3.2)** | -0.580***<br>P=.000 | 0.456**<br>P=.004 | -0.539***<br>P=.000 | -0.352<br>P=.026* | 0.241<br>P=.135 | 0.695***<br>P=.000 |
| | **Soc.Imp.** | **Phys.Imp.** | **Self Eff.** | **Med.Knowl.** | **Soc.Knowl.** | **Anxiety** |

## (2) Multiple Regression Analysis

### (2.1) Anxiety

Method- Enter

Multiple R= .651

Adj. R Squared= .331

F=4.571 Signif. F=.0031

**Independent Variables**

| | Beta | Signif. T |
|---|---|---|
| **Soc.Imp.** | -0.005 | 0.972 |
| **Phys.Imp.** | 0.583 | 0.005 |
| **Self Eff.** | -0.038 | 0.805 |
| **Med.Knowl.** | 0.138 | 0.412 |
| **Soc.Knowl.** | 0.273 | 0.775 |

### (2.2) Depression

Method-Enter

Multiple R= .749

Adj. R Squared= .491

F=7.946 Signif. F=.0001

**Independent Variables**

| | Beta | Signif. T |
|---|---|---|
| **Soc.Imp.** | -0.272 | 0.063 |
| **Phys.Imp.** | 0.253 | 0.062 |
| **Self Eff.** | -0.256 | 0.035 |
| **Med.Knowl.** | -0.133 | 0.366 |
| **Soc.Knowl.** | 0.194 | 0.216 |

**(Soc.Imp.= Perceived Social Impact of Epilepsy; Phys. Imp.= Perceived Physical Impact of Epilepsy; Self Eff.= Self Efficacy; Med. Knowl.= Medical Knowledge of Epilepsy; Soc. Knowl.= Social Knowledge of Epilepsy. Anxiety scores transformed for parametric analysis)**

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# Section 2- Small Scale Service Evaluation Project

# An Evaluation of Staff Satisfaction with a Day Care Facility For People With Learning Disabilities And Challenging Behaviour.

Prepared in accordance with the instructions to contributors for the British Journal of Learning Disabilities
(See Appendix 12)

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## SUMMARY

*The treatment and care of people with challenging behaviour and learning disabilities has proven to be problematic. Not only have the treatment regimes been frequently criticised but also staff dissatisfaction and "burnout" have been reported as prevalent..This article provides an examination of a day care unit for this client group. Staff's perceptions of satisfaction with the unit in term of service provision and personal job satisfaction were obtained. From this study, staff indicated that they found the unit to be rewarding for clients and was effective in dealing with the challenging behaviour. Overall, staff were content with their role in the unit. However, greater support was requested from management. The implications of these results for this unit, and for the general applicability of this model are discussed.*

## INTRODUCTION

Over the last decade there have been considerable changes in both philosophy and policy concerning people with challenging behaviour and learning disabilities (Mansell 1992). Previously, such individuals were most frequently cared for within large, generally impoverished, hospital environments. The majority of services appeared to place little emphasis on skill building. Rather, the main focus was containment and restraint (Murphy 1993). Emerson (1990), for example, reported that learning disabled clients who also exhibited challenging behaviour were less likely to have a written daily programme, were more likely to be ignored or physically abused by staff and were more likely to constrained, either physically or medically.

Recent changes have emphasised that even those with the most seriously challenging behaviour are viewed as individuals whose needs can and should be met by community services. Therefore, there has been a shift in values whereby challenging behaviour has come to be seen as a complex social problem, rather than one whose cause and treatment lie principally within the individual (Clements 1992). Also, the nature of the problem has come to be redefined to emphasise the detrimental effect of the challenging behaviour on the individual's quality of life (Emerson 1993).

With the ongoing rundown and closure of large institutions, the treatment of clients with challenging behaviour now tends to be conducted within specialist residential units.These units are able to provide a controlled, intensive, individualised programme which is developed by staff with expertise in this area. However, such units have been criticised as they remove clients from the "normal" environment and, as at present there are a comparatively small number of units, they frequently remove the client from his locality, family and friends. Also, attendance at such units has been associated with subsequent labelling and stigma (McGill 1993).

A further problem with units dealing with learning disabled clients with challenging behaviours concerns the level of stress and job dissatisfaction experienced by staff. Traditionally, it has long been recognised that working with this client group is highly stressful and has been implicated in low staff morale, high sickness rates, high staff turnover and in the development of negative, cynical attitudes and feelings towards clients (Harris & Thomson 1993). However, given the changes outlined above, it is suggested that it is not unreasonable to assume that such problems may not be as significant as they once were. Not only is the nature of the job much more positive but factors such as regular staff training, appraisal and support, which have been implicated as key factors in job satisfaction, are now much more prevalent. Yet, there have been surprisingly few accounts of staff perceptions of both the effectiveness of the service which they provide or of their job satisfaction.

This paper is concerned with a health service day care facility for people with learning disabilities and challenging behaviour, the Dean Therapy Unit, which is based in the Ayrshire region of central Scotland. Potentially such a unit could overcome many of the difficulties outlined above. For instance, all clients attending the unit are from the locality and indeed all reside within their parental home. Therefore, this provides the opportunity to attend to the challenging behaviour within the context of a familiar community setting. Also, features such as the regular hours may prove attractive to staff.

The aim of this study is to provide an examination of staff satisfaction with this unit. This can be usefully subdivided into two areas; satisfaction with the service provided to clients and satisfaction with the job which they do.

Prior to this, some background information on the unit is essential. Therefore, a brief description of the development of the unit will be provided. Following this a description of the structure of the unit as it was at the time of assessment will be given. Thereafter, the main section of the current research will be described; namely an examination of staff views of the nature and effectiveness of the work conducted in the unit and of their level of satisfaction or dissatisfaction with their job.

## Development of the Dean Therapy Unit

The Dean Therapy Unit came into existence approximately one and a half years prior to the current study. Its emergence would appear to be more attributable to astute crisis management rather than through strategic planning: At this time a number of adult clients with challenging behaviour became known to the services. These individuals all lived at home but had no day placement. This was due to a variety of reasons such as the individual having left the child services and having no appropriate adult placement or through the breakdown of existing placements due to the client's behaviour.

In all cases, the parents were willing to have the client live at home but were in need of some form of day care facility for their son or daughter. In reaction to this problem, space was made available within a health service resource centre for people with learning disabilities. This was staffed by one trained nurse and three nursing assistants who were previously employed within the resource centre and volunteered to work in the unit. A total of five clients attended the unit at the time of its opening.

The unit was designed to run along therapeutic lines. Therefore, therapists from a variety of background who were associated with the resource centre were actively involved in the development of the unit. General operational procedures were drawn up for the unit covering areas such as the general philosophy of the unit through to specific guidelines on how to manage incidents of aggression. Staff were also given training on working with this client group. Each of the clients had a specific care plan and a structured timetable of activities while in attendance at the Unit.

## The Dean Therapy Unit at the Time of Assessment

The unit is based within the main block of the resource centre. It consists of a large lounge, a soft play room, a wet play or sensory bathroom, a sensory environment or snoezelen room, a music room, a kitchen and a small office. While the majority of activities are conducted within the unit, whenever possible community resources are also accessed. At the time of assessment, all of the four original staff members were still employed at the centre and indeed all of the five original clients were also still in attendance with one additional client added (see table 1). The staff indicated that the general atmosphere at the time of assessment was fairly typical for the unit.

**Table 1- Client Profile at Time of Assessment**

| Client | Age/Sex | Severity of Challng. Behav. | Nature of Challenging Behav. |
|---|---|---|---|
| A | 21/Male | Severe/Frequent | Physical Aggression |
| B | 45/Female | Mild/Infrequent | Scratching,nipping |
| C | 22/Female | Moderate/Infrequent | Self Inj., Aggression |
| D | 24/Male | Mild/Infrequent | Aggression, Verbal Threats |
| E | 23/Female | Severe/Frequent | Physical Aggression |
| F | 24/Male | Mild/Infrequent | Self Inj., Slapping, pinching |

## METHODS

Two scales were use as a measure of staff's perception of the unit: The Ward Atmosphere Scale (WAS) (Moos 1989) and the Staff Support Questionnaire (Harris & Thomson 1993). The WAS i s a 100 item true/false scale which consists of 10 subscales which provide a valid measurement of the treatment environment of a ward or unit. Of these subscales, one (personal problem orientation) was omitted as this was felt to be inappropriate for a predominantly non-verbal client group. The authors of the scale describe 3 underlying domains or dimensions within the scale; Relationship, Personal Growth or Goal Orientation and System Maintenance dimensions. Staff were requested to complete 2 forms of the scale; a real and an ideal version to reflect how the staff perceived the unit at present and to highlight any dissatisfaction or potential areas of change.

The Staff Support Questionnaire was designed specifically for staff working with learning disabled clients with challenging behaviour. It consists of a 24 item scale which can be subdivided into 4 main sections; Role Ambiguity/clarity, Practical Support in Crisis Situations, Identification of Risk Situations and Overall Job Satisfaction. A final open ended question was included requesting staff to comment on any areas they felt had not been covered by the scales.

All 4 staff members at the unit completed the scales. Staff were requested to complete the measures at home and not to discuss the content or possible responses prior to completion. The Day Services Manager for the unit was also approached and agreed to complete the real and ideal WAS forms.

## RESULTS

### 1- The Ward Atmosphere Scale (WAS)

The results can be split usefully into 4 distinct areas of enquiry:

1- How did the staff group perceive the unit atmosphere at present?

2- To what extent did this profile differ from their ideal view of the unit?

3- How did the line manager of the unit see the unit at present, and ideally?

4- How did the manager's profiles differ from the staff group?

#### 1-Staff WAS Scores: Real

The first important point to note is that there was a broad similarity between the responses of individual staff members for the WAS real form. This demonstrated that there appeared to be a general consensus on the atmosphere of the unit at the time of the assessment (See Appendix 13 for individual WAS scores).

As can be seen from Figure 1, there is considerable emphasis on the Relationship dimensions (I, S & Sp.) while there is comparatively little emphasis placed on staff control. Indeed, the scores on the Relationship dimensions are comparable to published norms collected from a variety of programmes and are higher than published norms of comparable disturbed or challenging behaviour programmes (See Moos 1989).

It can be seen that support is comparatively low within the Relationship dimension. From an examination of item responses, this would appear to be attributable to staff's belief that, while staff were supportive of clients, clients were not supportive of each other (See Fig. 1).

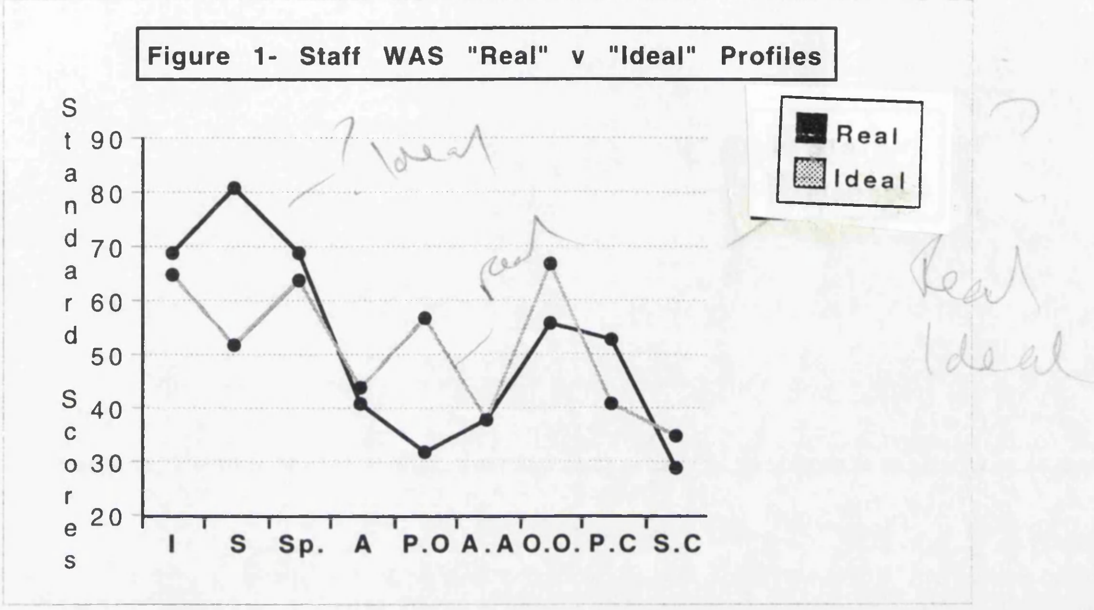
The profile suggests that staff perceived the unit as being a spontaneous and flexible environment within which autonomy is encouraged. The high anger and aggression score is perhaps not surprising in such a unit. Perhaps the most striking feature of the profile is the low emphasis that appeared to be placed on practical orientation (See Fig.1).

### 2- Staff WAS Scores: Real v Ideal

As can be seen from figure 1, the staff real and ideal profiles were broadly similar. Therefore, there would appear to be an overall contentment with the way in which the programme was being run. However there were a number of significant differences which require consideration.

With regards to the Relationship dimension (I, S & Sp.) , this is clearly an area that staff would like to develop further. This was most clearly demonstrated with regards to the support subscale. With regards to the Personal Growth dimension (A, P.O, A&A) , developing autonomy and practical skills and planning for the future were not seen as priorities for the unit. Perhaps not surprisingly, reducing the level of anger and aggression was a major goal (See Fig. 1).

On the System Maintenance dimension (O.O, P.C, S.C) there were little significant differences between current and ideal: Therefore, there appeared to be agreement that the daily programme was as organised and as clearly structured as was necessary. Also, the profile indicates that staff wished to reduce further the low level of staff control (See Fig. 1).



(I-Involvement, S-Support, Sp-Spontaneity, A-Autonomy, P.O-Practical Orientation, A.A-Anger & Aggression, O.O- Order & organisation, P.C-Programme Clarity, S.C- Staff Control)

## 3- Unit Manager WAS Scores: Real v Ideal

As can be seen from figures 2 & 3, the unit manager's profile for both the real and ideal forms was identical. This, along with a series of attached comments indicated that the unit was perceived to be running in a way which was appropriate for the client group. This profile is compared to staff real and ideal profiles below.

Figure 2- Staff & Management WAS "Real" Profiles

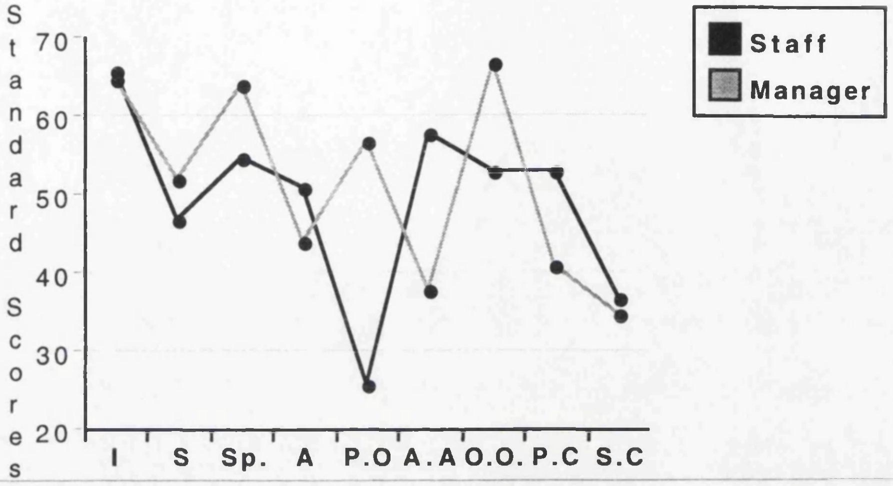
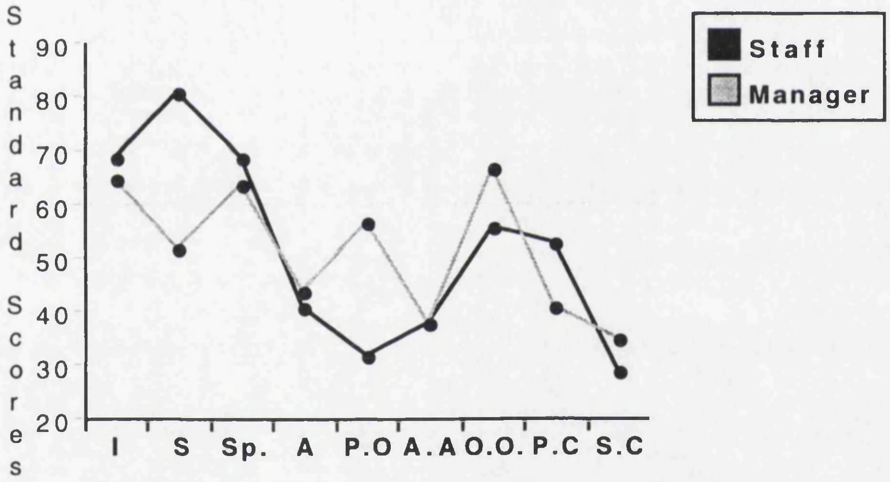


Figure 3- Staff & management WAS "Ideal" Scores



**(I-Involvement, S-Support, Sp-Spontaneity, A-Autonomy, P.O-Practical Orientation, A.A-Anger & Aggression, O.O- Order & organisation, P.C-Programme Clarity, S.C- Staff Control)**

4- WAS Staff and Management Real and Ideal Scores

As can be seen from figures 2 & 3, on the relationship dimension (I, S, Sp.) there was broad agreement on the need to actively involve clients in the unit programme and there was also agreement that this was at about the right level at the time of assessment. While there was broad agreement on the level of current support, as has already been indicated, staff would have liked this to have been increased. However, the manager did not see this as a priority. Also, while staff indicated a desire for more spontaneity and openness within the programme, the manager indicated a belief that this was already acceptably high.

With regards to the Personal Growth dimension, the major difference of opinion concerned the practical orientation subscale which was perceived as being of low priority for staff, yet the manager perceived this to be significantly higher. Also, there was a notable difference of opinion concerning the current level of client anger and aggression which was felt to be much higher by staff (See Figs. 2 & 3). This clearly has implications for both the role of the unit and, potentially, for job satisfaction. This will be examined in the discussion.

With regards to the System Maintenance dimension, the major area of discrepancy concerned order and organisation which was perceived to be much higher by management. Also, the unit programme was thought to be less clear by the manager.

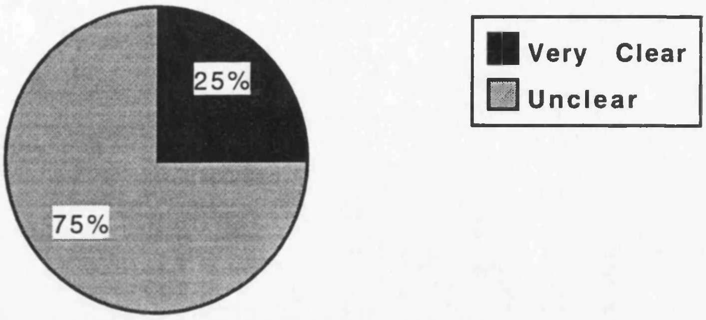
## 2- The Staff Support Questionnaire

As can be seen from Appendix 2, there was a significant consensus between staff members concerning satisfaction with various areas of their job. The results from this scale will be examined with regards to the 4 sections of the questionnaire. Namely role ambiguity/clarity, practical support in crisis situations, identification of risk situations and overall job satisfaction.

### 1- Role Ambiguity/Clarity

The results highlight that staff are either clear or very clear concerning the objectives of the unit and of their role within it. However, staff appeared unclear as to how satisfied their superior was with what they do (See Figure 4). These findings are consistent with the WAS findings, most notably on the Systems Maintenance and Practical Orientation areas which demonstrated a significant gap between the perceptions of the management and staff

Figure 4- Staff Clarity of Managers Satisfaction With Work in Unit



concerning the unit (See Figs. 2 & 3).

### 2- Practical Support in Crisis Situations

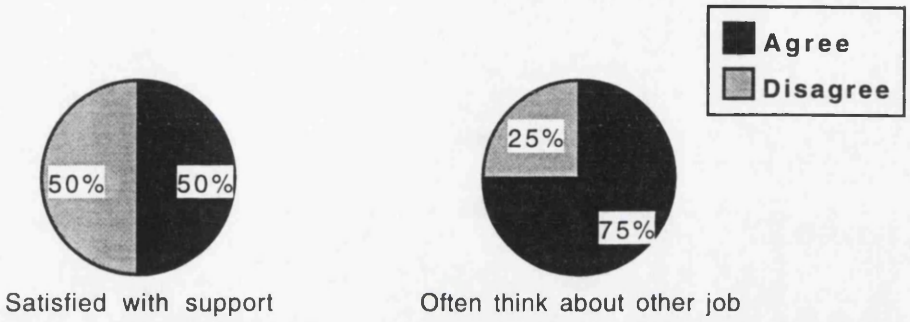
All staff members recognised that there was a practical support network, both in terms of someone to talk to if there was a work related difficulty and in terms of practical assistance in a crisis situation. However, not all were entirely satisfied with this service. It was also observed that the only member of staff who received regular supervision or performance reviews was the trained staff member. The remaining staff indicated that they were not satisfied with this situation. This clearly relates to the issues surrounding clarity outlined above (see Appendix 14).

### 3- Identification of Risk

Staff were unanimous in agreement that clear policies had been developed regarding the recognition and management of risk situations, and were satisfied that they had been involved in the development of policies (see Appendix 2). This is congruent with findings from the WAS which demonstrated that the order and organisation and programme clarity dimensions were comparatively high and that there was little difference between the real and ideal forms on these subscales (see Fig. 1).

4 -

Figure 5- Staff Support Questionnaire: Job Satisfaction



Overall Job Satisfaction

There was a broad consensus (although not unanimous) concerning satisfaction with the current situation at work and with regards to involvement in indecision making. However, as can be seen from Fig. 5, half of the staff group were unhappy with the degree of support received at work, and perhaps more ominously, three out of the four indicated that they often thought about finding another job. This was reinforced by the additional comments which focused on the need for more support and assistance from management (see Appendix 14).

## DISCUSSION

The aim of this study was to examine a recently opened day care unit for people with learning disabilities and challenging behaviour. Two aspects of staff satisfaction with the unit were examined: Staff satisfaction with the service provision for clients and personal job satisfaction. Undoubtedly, these issues are not completely independent. However, for the sake of clarity, discussion will be made concerning each of these areas.

### Staff Satisfaction With the Service Provision for Clients

From the results provided by the WAS, it is apparent that the overall atmosphere of the unit was very much different from the "old style" challenging behaviour units and reflected many of the recent policy and treatment innovations in this area. Also, perhaps more significantly for those involved in the Dean Therapy Unit, the unit was felt to be operating within the aims and objectives which were devised at its inception: There was little emphasis on methods of staff control (particularly the more punitive aspects of control) and indeed the non aggressive open expression of feelings was not discouraged. The unit and the individual programmes were felt to be clear, useful, well structured and flexible. The major emphasis was on actively involving the clients in stimulating and socially rewarding activities. Particular weight was placed on the need to develop supportive relationships between staff and clients and within the client group.

Perhaps the area which was most surprising concerned the low priority which was given to developing practical skills and making plans towards eventual discharge from the unit. Two potential reasons are suggested for this. Firstly, it may be the case that the primary focus of the unit is on reducing the challenging behaviour, which is the main reason that clients have been excluded from other community facilities. Once this has been achieved then the development of such skills would take priority. A second possible explanation may be related to the development of the unit whereby the primary aim was to ensure that the clients had some form of day care facility. The second aim was to develop this to meet the needs of the clients. As the unit is still comparatively new, the issue of moving on clients may not have been pertinent. Indeed, at the time of assessment all of the original clients were still in attendance. Therefore, despite the issue of developing future placements being highlighted as a priority in an objectives document for the unit, there is evidently some ambiguity in policy. It is suggested that the unit may benefit from clarifying its policy as to whether it is prepared to provide long term support for clients or whether it intends to reintegrate clients into existing resources. Given that the unit is a rare and valuable resource, the latter would appear to be preferable. It would appear that part of the difficulty in this area is that the unit is currently based within a health service resource centre. It has been recognised by the manager that the unit would perhaps be more suitably placed in the community. Greater liaison between health and social services would be beneficial in this respect. For instance, some form of "half way house" within an Adult Training Centre may prove a valuable stepping stone.

While there was overall satisfaction with the way in which the unit was being run, staff highlighted areas of potential change and development for the programme. The major thrust of these, perhaps not surprisingly, concerned reducing the level of anger and aggression through the further development of supportive, structured and individually relevant programmes. Ideally, less emphasis would be placed on aspects of staff control. Such findings indicated that staff had a positive and optimistic attitude to the work that was being done for clients and were keen to develop this.

When the staff's perception of the unit was compared to that of the unit manager, while there was broad agreement it was apparent that there were some notable differences of opinion. This would appear to be attributable to a lack of effective communication. This will be discussed in the job satisfaction section below. However, this also has implications for the effective running and direction of the unit. Results indicated that the unit manager felt that the way in which the unit was running was ideal for the clients. However, as has been indicated above, staff highlighted a number of areas for development. Also, there were significant discrepancies between the way in which staff and the manager saw the unit at the time of assessment. It is apparent that there is a need for more frequent and more effective communication in order to develop clarity about the future development of the unit.

## **Staff Job Satisfaction**

As was indicated above, there was satisfaction that the unit was running in an effective and acceptable way. Consequently, staff indicated that they were clear and content with the practical aspects of their job, such as regarding the identification and management of aggression, and about their involvement in the development of policies. Staff also indicated that they were supportive of each other in crisis situations. Clearly this was a major strength of the unit and is a major factor in the reduction of job related stress.

A major identified problem concerned the dissatisfaction with the level of supervision and support from management. It is suggested that there are at least two significant causal factors involved. Firstly, at the time of assessment there were a series of management personnel changes which appeared to have resulted in a general uncertainty and lack of direction. However, as was indicated above, there was dissatisfaction concerning the level of communication from the unit manager. Not only did this result in a lack of clarity concerning the future direction of the unit , but also the staff felt that they were not getting appropriate recognition and support for the work they were doing.

Clearly there is a need for the development of a system of regular staff appraisal and development. Indeed, at the time of assessment, this was under review.

## Conclusions

This assessment of a day unit for people with challenging behaviour, the Dean Therapy Unit, indicated that staff find this unit a positive and effective environment for this client group and a stimulating one for staff. Clearly there are areas to be developed, such as those concerning the development of practical skills for community reintegration and the development of more effective channels of communication. These findings will be presented to staff and management at this unit and it is hoped that they will be of assistance in the further development of the unit. However, it is suggested that these findings have more general applicability. The provision of such a day care facility allows the client to live in the community and attend a unit which confronts the challenging behaviour in a positive manner. Such a service would appear to be preferable to residential units for both staff and clients. Also, it would appear that one of the major reasons for the sparsity of resources for this client group is the high cost. It is proposed that such a service a has the advantage of being financially efficient in the short term and, as it would appear to be effective in reducing challenging behaviour, potentially in the long term.

Finally, it should be remembered that only the staff perception of the unit has been obtained. It is apparent that some form of assessment of client satisfaction should be developed. Also, in order to fully assess the effect of the day unit, consideration should be given to the parents and carers of clients and of the clients' behaviour outwith the unit. there is no room for complacency in this valuable resource!

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# Section 3- Single Case Research Studies

# Section 3. 1- Case Study 1

# Cognitive Behavioural Intervention for Medically Undiagnosed Physical Disability: A Case Study

Prepared in accordance with the instructions to contributors for Behavioural and Cognitive Psychotherapy
(See Appendix 15)

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## SUMMARY

Cognitive and behavioural techniques have been applied successfully to assist in the treatment of chronic health problems and for functional somatic problems. Treatment guidelines are based frequently on an assumption of a clear distinction between physical problems and somatic concerns.

This paper presents a case study of a patient who presented for psychological treatment with apparently genuine but undiagnosed physical symptoms. An approach which combined elements of cognitive behavioural treatment models for somatic and physical problems was adopted to good effect. The patient reported a significant reduction in functional disability and associated psychological distress.

# INTRODUCTION

The importance of psychological processes for the treatment of physical disorders has become increasingly acknowledged (Edelmann, 1994). A broad distinction has been drawn between psychological treatments designed to help cope with the sequelae of chronic health problems such as asthma, arthritis and chronic pain, and treatment of functional somatic symptoms (Mayou, 1995). The latter refers to body sensations which do not result from physical disease or injury but which patients respond to as if they did (Sharpe, Peveler & Mayou, 1992).

Such a dichotomy is based on an assumption that a clear distinction can be made between what is and is not a genuine health problem. However, in many cases this diagnostic clarity is absent. Often, patients present with atypical forms of standard conditions while many others present with symptoms which do not fit in readily to any diagnostic category. This not only presents a dilemma for medical treatment, but also potentially for psychological treatment. For instance, treatment goals for those with diagnosed medical conditions may involve developing an acceptance of the symptoms and possible course of a disease or disability and reducing the functional disability associated with symptoms. Alternatively, for those with functional somatic symptoms, there will be a greater focus on challenging beliefs concerning the physical aetiology of symptoms and to limit inappropriate use of medical care (Sharp etal, 1992;

Salkovskis, 1989). It is suggested that for such cases where the origin of the medical problem is uncertain, but psychological treatment may be appropriate, a treatment approach which combines elements from each area outlined above would be most efficacious.

This paper presents a case study of a woman with physical problems of unknown origin who was referred for psychological assessment and treatment.

## METHOD

### Presenting Problems

Mrs. A was referred to the psychology department by a consultant orthopaedic surgeon. The referral letter stated that initially she had presented to the medical services approximately five years previously as she had been experiencing problems with her gait. As a consequence of this difficulty, her legs continually buckled under her, and during the time that she had been known to the hospital services, her condition had deteriorated to such an extent that she was unable to walk without the aid of long leg calipers and used a wheelchair at home.

The referral letter indicated that her condition had been extensively investigated and no specific diagnostic features had been found and indeed the referring agent stated that he was "at a loss to explain why she had these problems". Referral was made to psychology in order to asses whether there was any evidence of a functional element to her symptoms.

### Assessment Interview

A structured cognitive behavioural interview was conducted over two sessions. This covered the principal areas of assessment for physical and somatic problems recommended by Salkovskis (1989). This consisted of an examination of attitude to referral, a detailed account of the problem, modulators, degree of handicap, beliefs about the origin, cause and course of the problems and general beliefs about the nature and meaning of physical problems.

### Attitude to Referral

At interview, Mrs. A was accompanied by a friend who was also a trained nurse. Mrs. A was clearly angry at the referral to the psychology department as she interpreted this as suggesting that her problems were purely functional in nature and indeed she emphasised frequently throughout the sessions her belief that her difficulties had a physical aetiology. Consequently, she indicated that she could see little point in attending for psychological treatment and had only been talked into attending for her appointment by her friend and husband.

### Details of the Problem

Mrs. A was a forty year old married woman with three teenage children. She stated that her difficulties began after a fall some six years previously. While initially this resulted in only a painful knee, there had been a steady decline in her condition over the years.

While she indicated that she was coping well, her friend suggested that this was not the case and that frequently she was tense and angry and had some difficulty accepting the limitations that her reduced mobility had imposed. Mrs. A conceded that this was the case. However, she stated a determination to "fight and not give in" to her condition, at least until she knew what was wrong with her. Indeed, she indicated that the uncertainty surrounding diagnosis was perhaps the major difficulty in coping with her condition.

### Modulators

The patient was unable to identify any features which made the physical discomfort better or worse. However, she was able to identify variations in her mood in relation to her physical difficulties. This was most notable with regards to medical consultations. Prior to consultations she stated that she would have high expectations of receiving a diagnosis and treatment. When this was not forthcoming, she stated that she could become very low and depressed for the following weeks or months.

### Degree of Handicap

Mrs. A conceded that her condition had made a huge impact on her quality of life. She been forced to give up a job as a nurse which she enjoyed and was unable to participate in many previously enjoyed leisure activities such as swimming and ice skating. She also stated that not only did she experience constant discomfort from the pain in her legs, but also she found the calipers which she was forced to wear extremely heavy, warm and uncomfortable. They also caused a number of practical difficulties, such as the time it took to put them on and off each morning and evening. She was also extremely concerned about their appearance and stated that when she went out she could wear only full length skirts. In addition, she indicated that the combination of the problem with her legs and the use of the calipers had made sexual intercourse difficult.

### Beliefs About the Origin, Cause & Course of the Problem

Mrs. A had used her medical training to pursue various lines of enquiry. However she had no firm beliefs about the cause and nature of her difficulties, other than that they had a physical basis. She was also highly concerned regarding the potential course of her problem.

She indicated that the emotional investment that she had made with regards to diagnosis and treatment was taking its toll on both her and her family and that she now realised that a "cure" appeared only a remote possibility.

### General Beliefs About the Nature and Meaning of illness & Physical Problems

Mrs. A had very strong, clear and somewhat inflexible attitudes in this regard. She stated that since childhood she has always been of the belief that "you should never lie down to illness" and that you should carry on with your life in as normal a manner as possible. She indicated that she could not remember having a day off school or work due to ill health.

This interview also revealed that Mrs. A tended to equate physical disability with learning disabilities and mental health problems. Consequently, she was keen not to associate herself with being physically disabled.

Further assessment through the completion of psychological questionnaires was requested. However, she stated that she was unwilling to do this as she was concerned that she would be "diagnosed" and labelled as having mental health problems.

## Formulation

It has been recognised that physical and somatic problems are potentially threatening in two major ways; firstly, directly from the physical handicap or disability arising from the problem, and secondly, from the emotional reaction to the problem (Salkovskis, 1989). From the two assessment sessions, it was apparent that Mrs. A was experiencing considerable problems with regards to both of the above areas.

The unique feature of this case appeared to be with regards to the aetiology and presentation of her physical symptoms. From her physical presentation at assessment and from a review of her medical notes, it was apparent that there was an observable disturbance of body functioning and that her difficulties could not be attributed primarily to functional somatic symptoms. However, despite extensive investigation, no medical diagnosis had been made.

The failure to provide an adequate diagnosis appeared to be the major factor maintaining the patient's distress. Uncertainty surrounding the cause and prognosis of the condition was both a source of anxiety and prevented a satisfactory adjustment to the limitations imposed. Mrs. A was particularly concerned that if she learned to live with her condition, she would stop looking for a cause and potential treatment.

Mrs. A's difficulties also appeared to be maintained by her cognitions on health and illness which presented as being both inflexible and maladaptive. In particular, a consistent theme which was apparent from assessment was the perceived need to be healthy and to carry on with life in as normal a manner as possible when suffering any health problems. This problem was particularly acute and a source of current distress as, not only did her physical limitations prevent her ability to carry on as "normal", but also, she was concerned that in the absence of a diagnosis, many medical professionals whom she had come into contact with would be of the opinion that she was malingering.

Underlying these beliefs about health, it was apparent that there was a strong perceived stigma regarding physical disability. She stated that perhaps she had developed this attitude when working as a nurse with the physically disabled who also had learning disabilities.

## Treatment Procedures

### Aims of Treatment

Based on the above formulation, the broad cognitive behavioural treatment aims for physical and somatic problems of reducing stress, and reducing reducing functional disability were adopted (Salkovskis 1989, Sharpe et al 1992). A first goal of therapy was to establish engagement in therapy and to develop a collaborative approach. The second aim was to encourage the patient to question a simple physiological explanation for her condition and to consider the role of psychological and social factors. The third goal of therapy was to examine cognitive and behavioural methods of reducing functional disability.

Engagement in Treatment

Given Mrs. A's previous hostility to psychological treatment, time was taken at initial sessions to develop trust and a working theraputic alliance. Therefore, at the third and fourth sessions, initial discussion was centred on allowing Mrs. A to ventilate her concerns about her condition and express her frustration at the perceived failure of the medical profession. Thereafter emphasis was place on obtaining the patient's agreement about the aims and methods of treatment outlined above. With regards to the duration of treatment, a further six sessions were agreed with a review of progress at this stage.

With regards to her physical symptoms, it has been recommended that for the treatment of functional somatic symptoms, it is desirable to request the termination, or at least suspension of other lines of investigation and treatment (Sharpe et al, 1992). However, for those with chronic medical conditions, emphasis should be placed on the development of a good working knowledge of the condition and on the compliance with medical treatment (Mayou, 1995). Clearly, Mrs. A did not fit readily into either category. Therefore, it was agreed that as already she had undergone extensive medical assessment, and as she already had considerable knowledge concerning the multiple potential causes of her condition, there was little to be gained from further investigations, at least for the duration of therapy. Rather emphasis would be placed on coping with current limitations and associated distress. With regards to her concern that if she learned to cope with her condition, she would no longer attempt to pursue a diagnosis and treatment, it was agreed that this was unlikely outcome. Therefore, it was agreed that future medical investigations would not necessarily be inappropriate. However, an agreed goal was that these would be limited, and that she would no longer "put her life on hold" in the hope of returning to her premorbid state.

## Examination of Psychological and Social Maintaining Factors

Attention at sessions 5 and 6 focused on the patient's disfunctional cognitions regarding health. Prior to session 5, Mrs. A was requested to keep a three column diary of her automatic thoughts whenever she felt ditressed concerning her condition. Discussion based on these revealed that she a dichotomous approach to health issues; conditions were either psychological (which indicated malingering and laziness) or genuine. In the absence of a diagnosis, she felt that others would regard her as the former. Consequently, she felt that she had to make every effort to "appear normal" which resulted in considerable distress. Thereafter, the content of the sessions focused on a reevaluation of these cognitions.

At sessions 6 and 7 she was requested to continue keeping the diary. The focus of therapy at this stage involved a more detailed examination of her assumptions regarding health and disability.

Firstly, Mrs.A was encouraged to evaluate the relative merits of keeping her current beliefs and coping style. While she concluded that her beliefs had been inflexible and unhelpful, she remained concerned that if she gave up this perceived "strong" way of coping, she would not be able to manage her life and that her husband would not love her. She believed that this may be the case as she was doubtful if she could love someone who appeared weak and was disabled. However, she had not discussed this with him. It was agreed that an appropriate "behavioural experiment" would involve a discussion of this matter with her husband and that if possible he would attend the next session. At session 7 she attended with her husband. He stated that he was very supportive of her, as were her children and indicated that he did not share her beliefs regarding health and disability. At this stage Mrs. A agreed that not only was her current approach causing significant distress, but was also increasingly untenable given her physical limitations.

Session 8 was the final agreed session. It was agreed that progress had been made in therapy. She stated that she had developed a greater holistic insight into her difficulties, was generally less anxious and angry and that her relationship with her husband and children had improved. However, it was agreed that further progress could be achieved and a further 4 sessions were agreed.

At the following 2 sessions, she continued to keep her diary and the focus of sessions was concerned with her cognitions regarding health and disability.

Mrs. A revealed that she had developed her negative beliefs concerning physical disability during her work with a learning disabled group with chronic physical disabilities. She was encouraged to challenge these assumptions by examining relative degrees of health and disability. from this it was agreed that she would attempt to perceive herself as having only relatively mild physical problems. It was also acknowledged that many people who do not have physical problems have learning disabilities and psychological problems, while many who do have even profound physical disabilities are intellectually able and do not suffer significant mental health problems.

With regards to the perceived discriminatory attitudes of others, it was apparent that she had only limited evidence regarding the attitudes of others and that much of this was based on her own attitudes. It would agreed that it would be useful to confront these assumptions by trying a series of behavioural experiments. A number of social situations were identified which she found difficult and it was agreed that she would attempt to enter these situations and monitor and re-evaluate her automatic thoughts in these situations.

### Reducing of functional disability.

At session 11, Mrs. A indicated that she had felt a significant change had taken place in the preceding two weeks. She indicated that she had considered the issues covered over the preceding weeks, and had decided to "tackle the problem head on". However, She also indicated that she had become frustrated with things that she was unable to do due to her lack of mobility, pain and in particular lack of stamina.

At this stage it was agreed that the focus of therapy should shift to provide an examination of cognitive and behavioural methods of reducing functional disability.

A behavioural approach involving timetabling activities and developing stamina through exercises was developed, based on strategies for the treatment of chronic pain (Weisenberg, 1987).

This was continued and modified over the next two sessions. At the final session, a review of progress was made. Mrs. A indicated that while there had been little or no change to her physical condition, she did not feel as "disabled" by it and was able to cope with the limitations it imposed and indeed indicated that these were much less significant than they had been previously. She indicated that she had not and would not give up the attempting to find an explanation for her difficulties. However, it was apparent that she had begun to formulate long term goals for her life which were based round her current difficulties. For instance, she had begun to look for suitable employment; she felt that given her nursing experience, she could be employed usefully as a medical secretary. Also, she showed interest in undertaking an Open University course.

With regards to long term prognosis, much would depend on any medical developments. However, it is suggested that the outlook appeared positive as it was apparent that this patent was an extremely energetic and resourceful woman with a very supportive family who appear determined to cope to the best of her abilities.

## DISCUSSION

The approach to treatment taken in this case was to modify standard cognitive behavioural treatment for somatic problems to accommodate the ambiguity concerning physical symptomatology. The major modification involved limiting, but not preventing further medical consultations and enhancing perceived control over symptoms. It is suggested that the end result was successful with regards to the two main treatment aims: reduction of functional disability and reduction of associated distress. However, it is recognised that caution must be exercised in in such an interpretation of change of function, as this was based only on self reports of well being as the subject was unwilling to complete any psychological assessment scales.

This case demonstrated the potential distress for those with apparent physical symptoms, but with no known cause or clear treatment. Much of the emphasis is placed frequently on the individual who is often assigned pejorative terms such as "untreatable" or "malingerer" (Sharpe etal, 1992). Clearly, such a perception of the individual can only add to the distress caused by unpleasant and unexplained physical symptoms. Perhaps, rather than "blaming" the patient, the medical profession should apportion more blame on itself for the failure to satisfactorily meet the needs of such patients. In this regard it is suggested that psychological help may be utilised earlier on in treatment as referral to a clinical psychology department is usually only after a long process of intrusive and demoralising medical procedures. Indeed, the ultimate referral to psychology is often taken to mean that the problem is the patient's fault, and that it is all in the mind.

With regards to the psychological treatment of such patients, from this case it was apparent that one of the main features towards a successful intervention was placing great emphasis on the development of trust and being prepared to accept the patient's account of her difficulties and emphasising that a collaborative approach will be taken. This will often prove to be a novel experience for patients. Also, unlike in the treatment of functional somatic symptoms, the subject's desire to pursue a medical explanation was not completely discouraged. However, care must be taken that such investigations do not involve an inappropriate use of medical care or does not impede attempts to cope with the condition.

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# Section 3. 2- Case Study 2

# Child Temperament or Clinical Syndrome. an Assessment Case Study.

Prepared in accordance with the instructions to contributors for the Journal of Child Psychology and Psychiatry (See Appendix 16)

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# INTRODUCTION

In recent years there has been an increased interest in the efficacy of diagnosing "syndromes" in children with social or educational difficulties. On one side it has been argued that such diagnoses are quasi-medical and provide an over simplistic "within child" explanation of complex psychosocial problems, whilst on the other side, it has been argued that recognition of the often subtle features which comprise, for instance, Asperger's or Autistic Continuum disorders is essential in order to plan for the needs of a small but often misunderstood group of children (Gross 1994). This debate becomes particularly acute for children with a mild variant of the condition: Is diagnosis helpful or does it simply provide a stigmatising label?

This paper provides a clinical case discussion of C, a seven and a half year old boy who was referred to the Department of Child Clinical Psychology for assessment by his G.P.. The referral letter indicated that he had "some unusual behaviour patterns and difficulty with language and communication skills with a particular problem with comprehension". C.'s G.P. had been notified of his difficulties by his school teacher who had suggested to him that he had displayed "some mildly autistic tendencies".

## PRESENTING PROBLEM

C. attended the department with his mother on three occasions. The first two sessions involved assessment whilst the third involved feedback of results and the provision of recommendations.

C. was the only child of professional parents. C's mother did not work during his pre-school years but had returned to employment once he commenced school.

His mother indicated that his was a planned pregnancy and there were no significant problems during the neonatal period. She also indicated that he reached all developmental milestones (such as walking, using first words and toilet training) on time.

She stated that she and her husband felt that he was a very mild mannered child. However she also indicated a concern that he often presented as somewhat withdrawn, socially anxious and aloof to the concerns of others. He was also described as being occasionally inflexible with regards to interests and routines. For instance he took great interest in his model train set and the "Thunderbirds" television programme, from which he had collected most of the associated toys and merchandising. C. was happy to talk about these interests and indeed made a point of bringing in some of his toys to show at his second appointment. With regards to his inflexibility concerning routines, an example was provided at the second appointment whereby his mother's car had broken down and she travelled to the hospital in a hired car. This change proved to be upsetting for C. and indeed he was sick in the car.

C.'s mother also expressed concern with his progress at school. Contact was made with the school from which his class teacher indicated that his progress had been slow. Particular difficulties were highlighted with regards to written work and it was also found to be difficult to get him motivated in a subject which he had little interest in.

It was also noted that he did not mix particularly well with others and that his social skills were were not thought to be good. For instance, eye contact was poor and he would make occasional inappropriate comments in class. However, it was noted that in recent months there had been some improvement and indeed he had managed to become friendly with one of his classmates.

At assessment C. presented as a very pleasant and cooperative boy who appeared to enjoy testing. While he rarely initiated conversation and made little direct eye contact during sessions, a rapport was developed fairly quickly and he was happy to allow his mother to leave the room during formal testing.

During our conversations a number of unusual linguistic features presented. Firstly, his tone of voice was somewhat flat and monotone and there was also frequent repitition of words or statements used by either myself or C.. Secondly, it was noted that he made very literal interpretations of statements or questions. It was also noted that he had an unusual memory for apparently trivial incidents such as providing the date and time of, for instance, car journeys some months prior to assessment or the last occassion on which it had snowed. Finally he appeared to have some difficulty understanding emotionally laden material. For instance, he appeared to have problems replying to questions concerning his likes and dislikes or what made him or others happy or sad.

## MEASURES OF ASSESSMENT

The aims of assessment were to provide an overall profile of his strengths, weaknesses and attainments. The following tests were used:

1- The Wechsler Intelligence Scale for Children Revised-Scottish Version (WISC-RS).

2- The Bender-Gestalt Test.

3- The Neale Analysis of Reading Ability.

## Results

(Insert Table 1 here)

### 1- Wechsler Intelligence Scale for Children Revised-Scottish Version (WISC-RS)

Results provided an unusual profile of abilities with there being a highly significant difference of over 3 standard deviations between his verbal and performance I.Q. scores.

While his non-verbal or performance based skills were consistently above average for his age, there was an equally consistent poverty of aptitude on verbal based subtests (See Table 1).

With regards to the verbal based subtests, while his literal understanding of word meaning was comparatively good, and his verbal memory also appeared to be highly efficient, he appeared to have major problems with the pragmatic functional use of language. He frequently had great difficulty with comprehension of requests, particularly on those areas which depended on an abstract use of language. It was also noted that on the similarities subtest which requires the testee to construct an abstract association between two items, C. was almost completely unable to do this. Indeed while he managed to obtain the correct answer to the first question (wheel and ball- Shape), he then perseverated on subsequent questions by attempting to associate by shape, despite being informed that this was no longer appropriate.

On the performance based subtests, in contrast to the verbal subtests, it was observed that he became exited and appeared to enjoy those tasks. He not only attempted to do these as quickly and efficiently as he could, but also appeared disappointed when he managed to finish a set and had no more to do. It was also noted that his visual memory was good and indeed he was able to remember specific items from subtests at subsequent appointments some weeks after assessment.

### 2- The Bender Gestalt Test

This test which involves copying a series of 9 figures was selected as a reliable means of assessing C.'s graphomotor abilities (see Table 1). An error score of 1 demonstrated acceptable overall abilities for his age and is broadly consistent with the scores obtained on the WISC-RS. However, it was noted that he used an unusual pencil grip and required taking considerable time over his drawing and frequently had to make changes. Therefore, it was felt that while his final performance may be adequate, this was an area of vulnerability for C..

### 3- The Neale Analysis of Reading Ability

Results highlight that C. was having marked difficulty reading and comprehending what he had read. This was perhaps not surprising, given the nature of his linguistic problems.

It was also observed that once he had begun to have difficulties, he very quickly lost interest and stopped trying. Such findings on the nature and extent of his reading difficulties were consistent with reports from school.

## FORMULATION

The results of assessment and psychometric testing indicated that C. had excellent verbal and non verbal memory and good perceptual comprehension abilities. However, he did appear to have slow and vulnerable graphomotor skills.

The major deficit which was uncovered by the assessment was his considerable linguistic problems. Underlying these difficulties appeared to be a deficit of pragmatic comprehension. While his vocabulary was comparatively good, he had difficulty applying pragmatic, abstract rules of language which are integral in effective social communication and learning.

In conjunction with the above, a number of other features highlighted earlier were considered in reaching a formulation. C. was described as being withdrawn, timid, aloof and tended to have specific fixed interests and had rigid patterns of activity.

It was felt that such a profile may be consistent with three potential aetiologies. Firstly, consideration was given as to whether C. was a child whose difficulties were primarily related to a specific language impairment. Secondly, the possibility of C. having an extreme temperament in conjunction with a developmental language disorder was looked at. Finally, the evidence for C. having an autistic disorder was considered. The case for each will be given brief consideration.

As has been indicated above, C. had clear linguistic difficulties. These problems appeared to be concerned with verbal comprehension and the ability to use language in social situations. Such features are highly descriptive of the specific language impairment known as Semantic Pragmatic Disorder (Bishop, 1992).

Children with this disorder have been described as having problems with understanding verbal information and of having poor listening and attention skills. Verbal information is often interpreted in its literal meaning and there is frequently a difficulty understanding causal relationships. Therefore, the ability to understand questions, particularly "why" questions may be compromised. Similarly, there have been difficulties described in processing whole utterances and selecting the relevant parts. This difficulty in going beyond a given meaning has been thought to result in general problems understanding abstract concepts such as time (Bishop, 1992).

With regards to the pragmatics of language, such children have been thought to have problems learning the rules governing social interaction and of inferring a deeper meaning from utterances, situations and feelings which are automatic to most children. Such children may have problems maintaining eye contact when speaking, in turn taking or of knowing what is appropriate to say in different situations (Bishop, 1992). Clearly such problems will have a significant social and educational impact.

While the above was thought to be highly descriptive of C., it was felt that Semantic Pragmatic Disorder did not fully account for other features of his profile; most notably his fixed interests and inflexibility concerning routines. Alternatives or additions to this formulation were considered.

There has been a growing literature on the nature of temperament and the development of temperamental "types" (for a review, see Prior 1992). One of the most influential studies has been the New York Longitudinal Studies carried out by Thomas & Chess (1977) who identified three broad temperament types; easy, difficult and slow to warm up. While descriptions of C. did not appear to correspond to the first two, there do appear to be some similarities with the slow to warm up profile. Such children are said to have few intense reactions either positive or negative, although once they have adopted to something new, their reaction tends to be positive. They are also said to display passive resistance and can be withdrawn and anxious (Prior, 1992; Thomas & Chess, 1977; Graham, 1986). Such a profile, in combination with the specific language disorder described above was thought to be broadly descriptive of C.

With regards to the possibility of an autistic disorder, there has been strong evidence demonstrated above to support the contention that C. displayed features of the classic triad of impairments in social interaction, social communication and imagination (Wing, 1994). However, it was felt that a related syndrome; Asperger's syndrome may be more descriptive of his condition. There has been some controversy as to whether Asperger's can be classified as a syndrome distinct from autism, particularly as it is based around the same triad of impairments (Wing, 1981). However it has been argued that the nature of difficulties are more subtle in Asperger's (Gross, 1994). The major distinguishing feature identified by DSM-IV (1994) is the lack of language delay in Asperger's as compared to Autism. From reports provided by his mother, there did not appear to be significant language delay in C.'s case. Also, Gross (1994) highlighted that the impairment in social interaction found in Asperger's can also be differentiated from an autistic disorder in that while the latter is typified by withdrawel, the former tends to involve a willingness to communicate but an awkwardness caused by an impaired recognition of the rules of communication. Again, this latter description appeared more fitting for C.. Also, the fundamental inability to appreciate the perspective and feelings of others (the so called "theory of mind") found in Asperger's was highly descriptive of C.. However, perhaps the features of Asperger's which appeared most descriptive of C. concerned the features of language use. For instance, the slow, deliberate, monotone delivery of language, difficulty talking about emotions, the inability to read the subtleties of language accompanied by a literal understanding of words used which were present with C. have all been included as descriptive features of Asperger's (Wing, 1981; DSM-IV, 1994).

On reflection, it was felt that C.'s profile was more descriptive of Asperger's than of either an Autistic Continuum Disorder or of an extreme Slow to Warm Up Temperament with a Semantic Pragmatic Disorder. However, given that C. had been improving over the previous few months with regards to the above features and given the long term implications of Asperger's, there was a reluctance to make a firm commitment to this as a final formulation. As was discussed in the introduction, there are two schools of thought concerning diagnosis of Asperger's. There are those who suggest that it is important to make a diagnosis as quickly as possible in order to develop an early, effective remediative structure for the child (Gross, 1994), whereas there are those who have proposed that in those who present with a milder form of the disorder, it may not be in the child's interest to make a daunting sounding diagnosis (Graham, 1986). It was felt that in C.'s case a compromise between these two positions was the most appropriate procedure. This will be described in more detail next.

## MANAGEMENT PROPOSALS

It was decided that there were 5 required courses of action in the management of this case:

1- Feedback results of assessment to parents and provide management guidelines.

2- Feedback to his school with management guidelines.

3- Feedback to the referring G.P..

4- Refer to Speech Therapy.

5- Routinely review progress by Psychology.

1- C.'s mother attended for the review session. The results were discussed in some detail and the probable causes were considered. However, it was stated that future reviews may help clarify the cause and prognosis of his problems. His mother appeared pleased that the assessment had shed some light on his difficulties.

With regards to his language, it was recommended that parent's should avoid metaphorical language and irony and idiom and also clear and precise instructions and information were to be provided as often as possible.

With regards to his routines and interests, his parents were advised not to be lead by the child into inappropriate interests or be overwhelmed by these behaviours. If he persisted in inappropriate behaviour it was recommended that he should be told firmly to stop and a more appropriate behaviour should be modelled. Also, appropriate behaviour was to be modelled and encouraged. if there were to be any changes in his routine, it was recommended that it would be useful to give him as much notice as possible in order to allow him to adapt. His mother felt that these suggestions would be useful and wouldn't entail any major problems.

2- With regards to the school, the above information and recommendations to his parents were provided. Further recommendations involved highlighting the need for routine and predictability in the class. For instance, if there were to be any changes to the class routine it was thought to be advisable to explain this to him beforehand. It was also felt that he may respond best to more traditional methods of teaching as opposed to group work and problem solving. However, peer interaction was to be encouraged and he should be given as much "social skills" training as possible regarding areas such as reading the non-verbal cues of other children.

3- With regards to the G.P. all results, interpretations and recommended courses of actions were provided.

4- It was felt that a referral to the Hospital Speech Therapy Department would be useful in providing a more precise analysis of his linguistic difficulties and additional management advice.

5- Given the nature of C.'s difficulties and that he appeared to be making progress at the time of assessment, it was felt to be prudent to provide routine assessment of this case. To this end a follow up appointment was arranged for 6 months time. At the time of writing, C. had not yet been seen for his follow up appointment. However, his school reported that he was continuing to make steady progress and while he could still be somewhat inappropriate, he is managing fairly well.

In conclusion, it is suggested that this case demonstrates that even for those children who appear to have a mild variant of Asperger's syndrome, the consideration of the possibility, or indeed probability, of the presence of Asperger's provided a useful framework for understanding behaviour and planning for the child's needs. However, it hoped that it also demonstrated that such children should not be "pigeonholed": Alternative explanations could not be discounted and while this did not significantly influence short term management proposals, clearly there are major long term implications. Therefore, the need for regular reviews in such cases is strikingly apparent.

## TABLE 1- RESULTS OF MEASURES OF ASSESSMENT

### 1- Weschler Intelligence Scale for Children- Revised Scottish (WISC-RS)

| Verbal Tests | | Performance Tests | |
|---|---|---|---|
| Information | 3 | Picture Completion | 11 |
| Similarities | 3 | Picture Arrangement | 13 |
| Arithmetic | 4 | Block Design | 13 |
| Vocabulary | 7 | Object Assembly | 13 |
| Comprehension | 3 | Coding | 13 |
| Digit Span | 4 | (Mean=10, S.D.=3) | |

| | |
|---|---|
| Verbal I.Q. | 69 |
| Performance I.Q. | 117 |
| Full Scale I.Q. | 90 |

(Mean=100, S.D.=15)

### 2- The Bender Gestalt Test

Error Score 1

### 3- The Neale Analysis of Reading Ability

Reading Age (Accuracy) 5yrs 11mnths
(Eqiv. age range= 4yrs 6mnths- 7yrs 3mnths)

Reading Age (Comprehension) 5yrs 6mnths
(Eqiv. age range= 4yrs 1mnth- 6yrs 11mnths)

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## Section 3. 3- Case Study 3

# Comorbidity of Chronic Pain and Post-Traumatic Stress Disorder: A Clinical Treatment Case Study

Prepared in accordance with the instructions to contributors for the Journal of Psychosomatic Research (See Appendix 17)

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## INTRODUCTION

Perhaps the most frequently used psychological techniques for the treatment of chronic pain are behavioural methods which aim to reduce "pain behaviours" and increase "well or healthy behaviours" through functional analysis of contingent reinforcers and cognitive strategies which aim to examine and modify subjective appraisal of pain, or usually a combination of the above methods (1,2,3).

Reviews have suggested that these techniques are effective in reducing psychological distress and functional disability and have resulted in an improved quality of life (1,4).

A potential weakness of these treatment models is that much of the focus of intervention is on the "hear and now" and there is rarely attention given to the aetiology of the problem (1,4). This is particularly notable where pain is a consequence of traumatic injury where careful assessment of the circumstances concerning the onset of the problem is vital as exposure to a traumatic event can in itself result in severe psychological distress (5). Further, this distress could potentially heighten and maintain chronic malignant pain. Yet, perhaps surprisingly, the literature concerning the assessment and treatment of co-morbidity of these disorders is sparse (5).

This paper provides a case report of a 56 year old man who presented for psychological treatment after he had received a crushing injury to his left foot following a rail crash some 8 years previously and who had been bothered with persistent pain ever since.

## METHODS

### Presenting Problem

Assessment revealed that Mr. M. suffered his injury following a train crash in which he was the train driver. He indicated that his train crashed into the back of a stationary goods train. He stated that there were no fatalities or serious injuries other than his own injury. This, he attributed substantially to his vigilance and fast actions: He stated that, on seeing the stationary train on his line, after applying the brake he moved from the drivers cabin to the first passenger coach to inform passengers of the imminent impact. His own injury occured as his foot became trapped between the two coaches.

Following the crash Mr. M. was taken to hospital where he underwent a series of operations to his foot. He then indicated that after approximately 3 to 4 days, he was visited by British Rail management, whereupon he was informed that he was being held responsible for the crash as he was thought to have gone through a red light. However, no disciplinary action was taken against him. As a consequence of his injuries he was offered early retirement, which he accepted.

At the time of assessment Mr. M. indicated that this incident had a pervasive effect on his life. As a consequence of the injuries sustained, he was forced to leave a job which he stated that he enjoyed and took great pride in, and was left with constant distressing pain to his foot. Also because of this pain, he felt that there was only a limited number of activities he could become involved in. It was also observed that he still had considerable anger and resentment towards his employer. He also indicated that he was frequently bothered by distressing thoughts, images and dreams concerning the crash.

He indicated that, as a result of the above, he was generally more anxious and irritable than he used to be and could on occasion be quite depressed and weepy. Indeed, he indicated that when he became particularly anxious, this usually resulted in an increased throbbing pain to his foot which in turn, frequently lead to thoughts of the accident and its aftermath which further increased his anxiety levels and consequent levels of pain.

## Psychological Formulation

Initial formulation from assessment was that this man was suffering from chronic, malignant pain to his left foot with associated major behavioural and emotional disturbance.

There appeared to be 2 components to his difficulties at assessment. Firstly, it was apparent that he had not fully come to terms with events surrounding the crash and its aftermath. Indeed their was sufficient evidence to suggest the presence of post traumatic stress disorder (D.S.M. IV, 309.89)(6). He was experiencing recurrent and distressing recollections and dreams of the crash, he would attempt to avoid thoughts of the crash or places which may precipitate thoughts of the crash such as rail travel or visiting the crash site. He also indicated that he had become notably more hypervigilant, particularly when driving. His sleep was also disturbed, his concentration was poor and he felt that he had become significantly more irritable. However, he felt that the latter symptoms were largely caused by the pain in his foot, although the pain in turn tended to precipitate thoughts of the crash.

It was also observed that a major difficulty in his adjustment to his acquired disability was related to the perceived injustice that had been done to him by his employer.

Secondly, he appeared to be suffering from anxiety and occassional bouts of depression as a consequence of his direct experience of pain. While he felt that this was fairly constant throughout the day, he was able to identify certain factors which heightened the intensity of pain. For instance, as has been identified above, stress and anxiety tended to result in greater perceived pain, as did any form of prolonged physical exercise. It was also noted that he felt that he tended to avoid activities or places which he felt may result in increased pain.

From this formulation, 2 objectives were identified: Firstly an attempt was made to quantify the nature and severity of the presenting problems through a series of selected questionnaires (see Table 1). Secondly, an agreed treatment strategy was developed.

## Measures of Assessment

Clearly, some assessment had to be made of Mr. M.'s experience of pain. The McGill Pain Questionnaire provides an indication of the nature, pattern and intensity of pain (7). As can be seen from Table 1, he described his pain as a constant, distressing pain. Salkovskis (1989) (8) highlighted that it is also frequently useful to develop an ongoing assessment measure which relates to the individuals specific experience of pain. It was therefore agreed that he should keep a daily diary, rating his pain on an hourly basis, while also providing a brief description of what was occuring during any major fluctuations in pain (for an example, see Fig. 1).

**(Insert Table 1 and Figure 1 here)**

Secondly, initial assessment was made of his overall symptoms of anxiety and depression using the Hospital Anxiety and Depression Scale (HAD) (9). These results indicated borderline anxiety and moderately low levels of depressive symtomatology (see Table 1).

Specific assessment was also made of symptoms of post traumatic stress disorder using the Revised Impact of Events Scale (10). This indicated that in the week prior to assessment, he had experienced moderate levels of intrusion and avoidance related to the rail crash (see Table 1).

### Treatment Procedures

It was agreed that the most logical treatment approach would involve three stages; dealing with the past, thereafter dealing with problems in the present and finally planning for the future.

With regards to dealing with the past, it was decided that this would consist of cognitive behavioural techniques to help cope with the symptoms of post traumatic stress disorder and also to help deal with his feelings of anger and resentment towards his ex-employer.

Following this, standard psychological pain management techniques were to be provided. Thereafter, the final sessions were to concentrate on relapse prevention.

### Development and Outcome of Treatment

From session 2 onwards the first 5-10 minutes involved covering the previous weeks pain charts and daily diaries with the aim of identifying recurrent themes relating to increased or decreased pain.

Sessions 2 and 3 consisted of anxiety management and the provision of information on post-traumatic stress disorder. Emphasis was placed on the rational of the cognitive treatment technique known as "rehearsal" which involves the repeated telling of the trauma story in such a way that it results in a reawakening of the associated emotions in such a way that they can be tolerated and processed without rapid retreat into avoidance (5).

For sessions 4,5 and 6 which involved covering his story of the crash, 11/2 hours was allocated to allow time to cover his story in some depth. Mr. M was able to recall the events leading up to and following the crash in great detail. It was significant that he was able to recall looking at each signal leading up to the crash and there appeared to be no doubt in his mind that he had not passed a stop signal. During both sessions, he became moderately emotional during the recall of events, but appeared to take great consolation from his belief that he had acted in an appropriate manner.

However, it was noted that he became considerably more agitated when recalling the events surrounding his being informed that he was being held responsible for the crash. This area was discussed in more depth in session 6. It was agreed that while he may have had cause to feel aggrieved, frequent ruminations over these events served only to increase both his emotional distress and consequent levels of pain. He felt this to be a valuable insight and agreed to try and prevent such ruminations through distraction and cognitive re-evaluation. At this stage it was agreed that all issues surrounding the crash had been adequately covered and treatment should focus directly on coping with his pain.

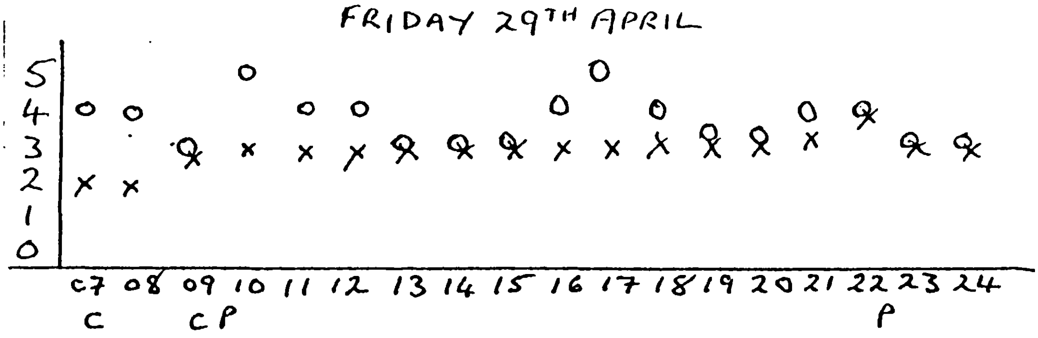
During sessions 7, 8 and 9 Mr. M. was instructed in the use of standard cognitive behavioural pain management techniques. While these were principally developed through specific themes uncovered in his daily diaries and pain charts, the methods employed broadly corresponded to those identified by Weiseberg (1987) as being effective in coping with chronic pain (1). These being increased perceived control over the experience of pain, behavioural strategies which aimed to modify environmental contingencies which reinforced pain behaviour and cognitive techniques such as the use of imagery, self statement and attention diversion. It was also agreed that, in addition to keeping an hourly rating of pain levels, he would attempt to rate emotional distress (see Fig. 1). This proved to be of considerable benefit as he came to realise that the two did not directly correlate. For instance, enjoyable physical exercise such as working on his garden invariably lead to increased pain but low distress, while during times when he was inactive he would tend to focus on his foot, become gradually more distressed, which in turn would lead to increased pain. Consequently, the use of activity scheduling and the cognitive techniques outlined above were felt to be helpful. Session 10 was used as both a review session and also to plan for potential future problems. Overall, Mr. M. felt that the treatment for his symptoms of P.T.S.D., and examination of his feelings of anger and resentment towards his ex-employer had been of most benefit. This is well reflected in the comparatively low scores on the Revised Impact of Events Scale. He indicated that the pain management techniques had also been of use. As can be seen from Table 1, while there was only moderate change of his perceived levels of pain, he felt less anxious and depressed and felt more able to cope with his injured foot. With regards to relapse prevention, he recognised that the key components were keeping both mentally and physically active and controlling stress. Finally, in order to prevent Mr. M. becoming "rusty" on the techniques covered during treatment, he was provided with a booklet on coping with pain (11).

## DISCUSSION

It is suggested that this case highlights the importance of conducting a comprehensive assessment of not only current symptomatology, but also of the cause and development of pain disorders when traumatic injury has been involved. Also, it demonstrated how standard cognitive behavioural strategies for the treatment of both post traumatic stress disorder and pain can be combined usefully.

## FIGURE 1

## Example of Daily Pain Diary



0730 Early start to put the car in for a repair, I had one of those restless nights and I'm glad I'm up.

1400 Think will see if the weather is better at the coast.

1730 Time for home and it has started raining. Girvan was very nice.

2230 That was a good hour of comedy. Now for a movie.

O = Pain
X = Distress

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# Appendices

# Appendix 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, Edgbaston, 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).

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.

## APPENDIX 2- DETAILS OF PILOT STUDY

The aim of this study was to determine whether there were any major problems with the administration, completion and scoring of the main assessment measures. A total of 7 people were randomly selected from the total subject pool and were sent the questionnaires by post. In addition to the main research questions, subjects were asked how long it had taken to complete the measures, whether they had any problems filling them in and whether they had any other comments to make on the study.

Of the 7 questionnaires sent out, a total of 5 were returned. All were completed satisfactorily, with the exception of 1 individual who stated that he did not believe that he had epilepsy. None of the individual scales presented any notable difficulties. Time to complete the measures ranged from half an hour to an hour and a half. Two subjects indicated some difficulty completing the forms; one stated that she had required assistance from her son in completing the forms while the other stated that she had difficulty concentrating for any length of time and had completed the forms over the period of a week. Scoring each of the scales and recording qualitative responses took approximately 15 minutes for each subject.

## APPENDIX 3- SUBJECT DEMOGRAPHIC INFORMATION

### SEX

Female 58.2%(24) Male 41.8%(18)

### AGE

Mean=70 (SD=6.38), Range= 60-91

### DURATION OF EPILEPSY

Median=7.33 (Q1=4.4, Q3=22.5), Range=1-64

### AGE AT ONSET

Median=59.5 (Q1=46.5, Q3=66.0), Range=5-87

### SEIZURE FREQUENCY

Less than 1 per month- 65.0%
About 1 per month- 2.5%
Greater than 1 per month- 10.0%
About 1 per week- 10.0%
Greater than 1 per week-7.5%
About 1 per day-2.5%
Greater than 1 per day-2.5%

### SEIZURE TYPE

Absence- 2.6%
Simple partial-12.8%
Myoclonic- 5.1%
Atonic-2.6%
Tonic Clonic-30.8%
Secondary Generalised-53.8%
Complex Partial-59.0%
Other- 2.6%

### ANTI-EPILEPTIC DRUG (AED) USE

Carbamazepine/Retard-41.5%
Lamotrogine-19.5%
Phenytoin-17.1%
Sodium Vaproate/Chrono-34.2%
Gabapentin-17.1%

Monotherapy-63.4%
2 AED's-31.7%
3 AED's- 4.9%

### AETIOLOGY OF EPILEPSY

Vascular-34.9%
Head Injury-11.6%
Cerebral Atrophy- 2.3%
(cause uncertain)
Post Operative- 2.3%
Alcohol Abuse- 2.3%
No Identified-46.5%
Cause

### ASSOCIATED HEALTH PROBLEMS

Multiple problems-20.0%
Hypertension/Heart Disease- 9.2%
Cataracts- 6.9%
Parkinson's Disease- 2.3%
None in notes-47.5%

### DEMOGRAPHICS OF WORKSHOP PARTICIPANTS

Total Participants-8 (6 at group, 2 by telephone)
Sex- Female 7, Male 1; Age- Mean=65.8; Duration- Mean=7 yrs (based on 7 subjects, 1 subject= 52 yrs); Seizure frequency- Median=0 ((Min.=0, Max.= Greater than 1 per day)

## APPENDIX 4- WORKSHOP AIMS AND FORMAT

**Aims:** To elicit qualitative information to complement and add to data gathered from the questionnaires. Information will be sought firstly with regards to the "perception of epilepsy" model; namely, perceived social limitations, physical limitations, perceived control, knowledge of condition and efficacy beliefs. Secondly it is hoped to highlight any areas which are of concern for this client group, but have not been effectively covered by the above model.

It is intended to hold 1 workshop which will last for a morning. There will be a maximum of 12 participants with 4 facilitators. The group structure and an outline of the key questions for discussion are provided below. The format will be semi structured and open ended. Flip charts will be used to record information for collation purposes.

**Time and Location:** The group will be held on Friday, 22nd, March, from 10 am until 12:30 pm. The location will be the Epilepsy Research Unit at the Western Infirmary, Glasgow.

**Structure and Timetable:**

10am - 10.15 General introduction

10.15 - 11.00 Group session 1-
(1) Perception of social limitations
(2) Perception of physical problems
(3) Perceived control

11.00 - 11.15 Tea/coffee

11.15 - 12.00 Group session 2-
(1) Overall psychosocial impact of epilepsy
(2) Problem areas not covered by group session 1
(3) Coping strategies used

Questions and evaluation forms

## APPENDIX 5- WORKSHOP FOR THE ELDERLY WITH EPILEPSY; SUMMARY OF FINDINGS

### Perceived Social Limitations

The majority indicated that they did not feel significantly stigmatised by their condition and stated that they did not "have a problem" about telling others that they had epilepsy. Indeed, this was often seen as a useful precaution if it was felt likely that they may have a seizure in public. However, there was agreement that epilepsy did result in being treated differently by others and it was indicated that it was frequently associated with "mental deficiency" by peers.

Most participants' epilepsy was of short duration and had affected participation in a number of activities such as church activities. For instance, one participant believed that people from her church who previously had been friendly towards her had begun to avoid contact. Consequently, she was left with the impression that her involvement in many church activities was felt to be inappropriate.

One participant who's epilepsy had begun in childhood provided a slightly different profile: Her view was that while many may still have negative attitudes concerning people with epilepsy, it was felt that this situation had improved in recent years. She attributed this to an increased awareness of the condition and a greater willingness to openly discuss issues concerning people with epilepsy. She felt that this contrasted with her youth where epilepsy, most notably alongside cancer, was a condition which was misunderstood and not talked about. She also stated that while she still had frequent seizures, her long history of epilepsy had helped her develop resources to cope with her condition.

The most frequently voiced social limitation concerned the inability to drive. Also many were concerned about the dependency on others (most often a spouse or other family members) and were worried that they were a burden. For some, most notably those who were unable to attend the group and were contacted later by telephone, this was not only related to epilepsy, but also to other physical difficulties. There were also some concerns that participants had been excluded from some "traditional" family roles, such as babysitting grandchildren.

Finally, alongside the physical consequences of seizure occurrence, most expressed experiencing a sense of shame and embarrassment following a seizure in a public place.

## Perceived Physical Problems

<u>1- Seizure Related Problems</u>- The major concern appeared to concern cognitive impairment, most notably regarding memory impairment and post-ictal confusion and indeed many indicated that at least a day was needed to fully recover from a seizure. No participants expressed major concerns regarding injury, although all stated that they had received injuries which ranged from bitten mouths and burns through to fractures following falls. Of those who were unable to attend the group, associated physical problems were felt to be of more pressing concern than seizures. For instance, one participant was partially sighted, whilst another had hemiparesis following a stroke.

Only one participant expressed a concern that she may die from a seizure. This appeared to arise from a misunderstanding regarding the nature of status epilepticus.

Most participants strongly disliked pre and post ictal symptoms such as increased agitation and fatigue and sudden and uncomfortable body symptoms such as changes in temperature or nausea. One participant who's seizures were nocturnal and frequently were accompanied by incontinence found this to be embarrassing, unpleasant and an expensive hassle.

One participant reported that she had concerns regarding her safety and wellbeing as she had been robbed during a seizure.

Concern was also expressed regarding whether a genetic predisposition made it likely that children and grandchildren would also have epilepsy.

<u>2- Medication Related Problems</u>- Perhaps the greatest overall concern expressed from this group was with regards to side effects of medication. Participants reported experiencing a number of difficulties such as blurred or double vision, rashes, ataxia, weight gain and fatigue. There was also considerable resentment at having to take tablets on a long-term basis. This was seen as restricting and was thought to be a constant reminder of their condition.

There was agreement that participants felt that they did not have adequate information about the type and possible side effects of the medication that they were on. Consequently, they felt that they were unable to ask appropriate questions and were unsure whether to attribute problems to AED's or to other physical problems. For instance, one participant was concerned that her AED's may have been cancerogenic as she had experienced slight hair loss which she associated with the treatment of cancer.

There was also some dissatisfaction with the lack of information which was provided concerning the purpose and results of assessment procedures such as CT scans and EEG's. However, most did not appear greatly concerned on this matter and were happy to put their faith in the clinician's judgement.

The main focus of dissatisfaction was concerned with G.P.s whose knowledge about epilepsy was felt to vary considerably and indeed it was felt that some had misdiagnosed participants. For instance, one participant stated that she had been told that her seizures were due to panic attacks. Also, some had been treated for epilepsy, but had not been informed of this diagnosis. Most stated that the only information that they had obtained about epilepsy was through independent sources such as through magazines.

## Perceived Control

Some participants indicated experiencing an aura and consequently were able to take precautions to help limit the potential consequences of a seizure through methods such as lying down in order to avoid a fall or controlling the environment such as moving tables or chairs out of the way.

One participant indicated that occasionally she was able to "fight off" seizures through cognitive distraction techniques, while another participant stated that she found behavioural relaxation techniques to be useful.

## Conclusion

It was apparent that the major reason for participants' attendance at this group was to obtain practical information about their condition and this is perhaps reflected in the content of their input summarised above.

All participants appeared to have made considerable efforts to limit the effect that epilepsy had on their lives and overall, appeared to be coping well.

## APPENDIX 6- PERCEIVED IMPACT OF EPILEPSY

Do you feel that epilepsy makes a big impact on your day top day life?

(Yes-46.5%, No-53.5%)

**Perceived Social Impact**
(1) Inability to drive
"No driving at present (for 12 months)"
"Being unable to drive"

(2)Restricted to home
"Always at home"
"Afraid to go out on my own and feel restricted to the home area in case of a seizure"

(3)Economic Effects
"I cannot do the business I used to do as I cannot get insurance. In the late '60's I earned 20,000 P.A. I now have a much smaller house, no car and a much smaller income"

(4)Loss of Control/Independence
"Unable to do my own shopping etc"

(5)General Restriction on Activities
"Restricted movements"

**Perceived Physical Impact**
(1)Fatigue
"It tires you"
"Feel more tired"
"Sometime tired or depressed"
"Feel more tired"
"Doesn't do all the things he used to. He is easily done in"

(2)Fear of Seizures
"Knowing that a seizure may occur at any time and that a serious injury may result"
"Fear of a fit"
"I used to smoke and when I went away for a while I would drop the cigarette"

(3)Loss of control/Unpredictability of Seizures
"Always at back of mind"
"Knowing that a seizure may occur at any time and that a serious injury may result"
"I used to smoke and when I went away for a while I would drop the cigarette"

(4)Cognitive Impairment
"Loss of time, memory"
"Difficulty concentrating"

**Perceived Physical Impact**
(1)Fatigue
"Staying on your feet all day without tiring"

(2)Cognitive Impairment
"In my case memory lapses and in concentration"

(3)Medication Related
"Shaky hands"
"Seem to sleep a lot but may be due to tablets"

**General Limitations**
"Changing my lifestyle"
"Have made him bad tempered and difficult altogether. Cannot do what he could do"

## APPENDIX 7- PERCEIVED LIMITATIONS CAUSED BY EPILEPSY

**What would you say are the greatest limitations about having epilepsy?**
(No limitations-23.5%, Limitations-76.7%)

**Perceived Social Impact**
(1)Driving/Independent Travel
"Driving"
"Getting about"
"Not being able to get out on my own and not being able to drive"
"In my case driving"
"Travelling distances alone at my age (90)"
"Car driving"
"Driving a car"
"Unable to travel by myself to friends"
"Not being able to drive"
"Not being able to drive for 2 years"

(2)Loss of Control/Independence
"Anxious about being left alone"
"Not being able to get out on my own and not being able to drive"
"Being afraid to go out alone"
"Unsure of myself"
"Being afraid to be on my own"
"Cannot be left on my own"
"Unable to travel by myself to friends"
"Being left on my own"
"Lack of confidence"
"I do not make plans too far in advance to go out with my friends"

(3)Felt Stigma
"I do not allow it to interfere with my life in any way, but of course it occasionally takes its revenge. Alas, some friends were rather wary about being with me, but this has lessened considerably"
"People knowing you have it"
"Informing friends and relatives what to do during an attack"

(4)Work Limitations
"It is an embarrassment to me- I would be very cautious of admitting it, and certainly not to an employer for fear of losing a job"
"Physical work activities"
"I feel I could have had more promotion at work but held back from responsible position because when young I would be embarrassed having a seizure"

(5)Sport/Recreation
"Driving/Swimming"

**Perceived Physical Impact**

(1)Fatigue
"Staying on your feet all day without tiring"

(2)Cognitive Impairment
"In my case memory lapses and in concentration"

(3)Medication Related
"Shaky hands"
"Seem to sleep a lot but may be due to tablets"

**General Limitations**
"Changing my lifestyle"
"Have made him bad tempered and difficult altogether. Cannot do what he could do"

## APPENDIX 8- ADDITIONAL COMMENTS

**Are there any other comments you wish to make?**

**Perceived Social Impact**
(1)Felt Stigma
"I feel we live in the dark ages. I am 69 and it is still something which is not talked about"

(2)Lack of Knowledge
"I would like to know more, not to be asked my opinions which may easily be wrong. I know nobody else who is epileptic"

**Perceived Physical Impact**
(1)Lack of Information-Treatment
"I would like to know more about side-effects of medication"(2)
"I would like to know investigate about my condition, but where do I apply?"

(2)Lack of Information-Assessment
"No one has explained to me why I should have begun epileptic seizures in middle life"

**No Significant Epilepsy Related Limitations**
(1)Seizures Well Controlled
"Answers have not been given to some questions as, because I don't have seizures, I believe this does not apply to me"
"My last seizure was last year. My son called late doctor. My recovery was quick. I made appointment with my doctor who did necessary tests which she found to her satisfaction and made a 30 day rest period before resuming. I would like to add that she was responsible for me attending the Western Infirmary in 1993. My seizures have greatly improved since then" "I do not take fits now and only really have going away fits now"
"I have mild epilepsy and have only had 2 or 3 seizures"
"I am very impressed with the success these tablets have been for me since Dr. Brodie prescribed them"
"I have not had a fit for about a year and was taken off epilim"

(2)Seizures Well Controlled-Otherwise Healthy
"I am 74 years of age and apart from slight creaking of the knees feel as fit mentally and physically as ever"
"I feel that the questions don't apply to me. I did have tests at the Western. I was never told results. I hold down a responsible job. My personality can be described as easy going"

(3)Other Health Problems of More Significance

"I have lived long enough with epilepsy but I find that if I am content and have no distress I can manage. I now have age related macular degeneration. I am now getting laser treatment so I have less time to worry about epilepsy"

"I found it hard to answer questions truthfully as I am a stroke victim and my life has changed considerably. Not through epilepsy as such"

(4)Adjustment made to condition

"I found it hard at first to come to terms with my epilepsy"

"I did attend Dr. Brodie's clinic. I could not come to terms that I was diagnosed epileptic, and I have never admitted to anyone or myself that I had this condition.

If I remember correctly, it was 7 years ago and I was not well myself at that particular time. I was under a great deal of stress. The period I was not well lasted 6 months. I keep fine now, and have done so for a long, long time now. Out of curiosity, can stress cause seizures?"

Miscellaneous

"I am over 60 now and a lot of the problems I had somehow don't seem so important now, although I do use my epilepsy to excuse the fact that I didn't do more with my life. I don't know if that's true or not"

"Memory not as good as it used to be"

"I hate filling in forms and have a job to concentrate for long"

"Worry about pills (also non epileptic) making one feel a bit senile?"

"Being a person of almost 71 years of age, I wonder if this is relevant" "Being a senior citizen, I felt that some of the questions were aimed at a younger generation"

"I am unable to write and I had to have the assistance of my wife"

"Just that my husband could not fill this in as he went back a lot in the last 2 years"

## APPENDIX 9- PERCEIVED SOCIAL RESTRICTIONS; ACTIVITIES & HOBBIES

**Are there any activities or hobbies that you are not able to do because of your epilepsy?**

**Driving**
"No driving for 12 months"
"Driving, swimming"
"Driving a car"
"Mostly reading and driving"
"Driving"
"Not allowed to drive"
"Driving"
"Doing things outside and driving a car"

**Recreational Activities-Miscellaneous**
"Swim out of my depth"
"Driving, swimming"
"Dancing, swimming"
"Doing things outside and driving a car"
"Physical activities"
"Car driving, golf, babysitting my grandchildren"
"Hobby is outdoor bowling and do not now enter club competitions- I only play friendlies" "My church activities, going camping holidays, walking, cycling"
"Cannot socialise anymore. Can't do anything in the house like repairing anything which he used to like doing"

**Social Activities**
(1)Church Involvement
"I did a lot of church work but your memory is not the same"
"I was an active member of the church but when they came on you, after the members would ask are you alright"
"My church activities, going camping holidays, walking, cycling"
"Cannot socialise anymore. Can't do anything in the house like repairing anything which he used to like doing"

(2)Voluntary Work
"Lack of initiative. Being unable to do all my voluntary work"

**Long Term Consequences**
"When younger did't go dancing. Could not learn driving. No swimming"

## APPENDIX 10- DOMESTIC PRECAUTIONS DUE TO EPILEPSY

**Are there any precautions that you take in the home because of your epilepsy?**

**To Prevent Injury From a Seizure**
"I don't cook or use the cooker"
"Avoid stairs or climbing steps"
"I need someone with me when cooking, having a bath or shower as I do not know when I am going to have a seizure"
"Early in the morning in the kitchen! (A small one, now "decorated" with dusters over drawer handles etc- to soften the fall"
"I try to be careful as to where I place varying items but I am under extreme difficulty- I suffer from temporal lobe epilepsy and cannot control my actions when I am in a "blackout""
"Keep the bathroom door unlocked"
"Try to stay downstairs as much as possible"
"Medication"
"Not to be left on my own"
"Sometimes my head is light and I have to hold on until it comes alright. Of cours I am nearly 70 years of age"

**Cognitive/Confusional State Precautions**
"Repeat care: Electricity, plugs, switches,locks, keep memopad handy"
"Doesn't go upstairs until someone is already upstairs. Can't use the gases because he leaves them burning or use the kettle. Try to keep him out of the kitchen. Can be difficult"

**Precautions to Avoid Discomfort**
"I have a plastic/cotton cover on the mattress as I always wet the bed during a seizure. I keep a stock of strong pain killers"

**Precautions to Avoid Epilepsy Related Fatigue**
"Sit down when feel tired"

**Epilepsy Not a Significant Problem**
"As I am confined to a wheelchair due to a stroke I do not harm myself during a seizure"

**Non-Epilepsy Related Precautions**
"Take an aspirin to keep blood pressure down"

## APPENDIX 11- PRECAUTIONS TAKEN OUTSIDE DUE TO EPILEPSY

**Are there any precautions that you take outwith the home because of your epilepsy?**

**Go Out With Companion**
"Always someone with me"
"Don't go out alone for long"
"Someone with me at all times"
"Usually a companion with me"
"Always go out with someone accompanying me"
"Never go out alone. Can't go anywhere himself"
"Always go out with someone. Do not drive"

**Carry Epilepsy I.D. Card/Inform Others**
"I always carry an epileptic card"
"In my handbag there is a fairly large "notice" explaining my predicament. Also, I have a notice with the names of my doctors plus address- Theirs and of course mine" "I have informed my children (now grown up) of my condition, my 2 sisters (Toronto and Capetown!) and my close friends"

**To Prevent Injury/Problems from a Seizure**
"Try not to worry to much"
"I always check the contents of the house in case I've been in a "blackout"- I do not know if I've had an epileptic attack unless I am told or I notice damages that have occurred" "Travel in wheelchair. Keep warm"
"I try to avoid physical fatigue, irritation and stress etc."

**Driving**
"Not to drive for 12 months"
"No driving of car"
"I always have someone with me. Do not drive"

**To Prevent Problems From Confusional States/Cognitive Problems**
"Extra care with money, keys etc. All due to state of memory and lack of concentration"

# Appendix 12

MENTAL HANDICAP VOL. 18 JUNE 1990

## Extract from Mental Handicap Journal Information for Authors document

### Aims

*Mental Handicap*, a quarterly journal with a multidisciplinary appeal, contains information on current policies and practices in relation to prevention of mental handicap, alleviation of its effects, and provision of services for people with mental handicaps and those who care for them. Its practical orientation is intended to encourage the best possible standards of care, treatment, education, and training.

### Content

Contributions *must be original* and will not be accepted if they have been or are intended to be submitted for publication elsewhere. Subjects include: current trends in residential and day care services; integration, rehabilitation, and quality of life; education and training; employment and occupation; recreation and leisure; advocacy and rights; family and carers; adoption and fostering; prevention, causes, and management of specific syndromes; staff training; new technology in practice.

### Articles (maximum 2,500 words)

Articles should be typed, double-spaced, on one side only of A4 paper with a 1½" margin on each side of the text. 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 simple "everyday English" suitable for an international multidisciplinary readership. The term "mental handicap" should be used in preference to "learning difficulties" except where the content is concerned specifically with "pupils with severe learning difficulties" as covered by current UK legislation. Care should be taken to use non-sexist language and to emphasise the person rather than the disability, so descriptions such as "people with mental handicaps" should be used rather than "the mentally handicapped". Clumsy expressions such as "he/she", "he or she", or "s/he" should be avoided, for example, by using a fictitious name or the plural verb. 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

Three copies should be submitted, one of which should be the original typescript.

ORDER OF CONTENTS

**Title Page.** The title page should contain: a short main title to indicate the content of the article; a sub-title if it is necessary to clarify this further; the first name and surname of each author together with details of their respective professional occupations and addresses; an indication, where there is more than one author, of the main corresponding author.

**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 subheadings.

**Acknowledgements.** The author(s) can acknowledge individuals and agencies who have been of assistance during the work described and *must* acknowledge those from whom reprint permissions for textual extracts and/or photographs have been obtained. *It is the responsibility of the author(s)* to obtain permission from other publishers to reproduce extracts of any previously published material included in the article and *to confirm in writing that such permission has 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.

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

*Journal articles* — Kerins, D., Hickey, C., Haydock, R. E. Moving with the times: providing modern apartments for adults. Mental Handicap, 1985; 13:4, 142-144.

*Books* — Gardner, J., Murphy, J., Crawford, N. The Skills Analysis Model. Kidderminster: BIMH Publications, 1983.

*Book chapters* — de Lissovoy, V. Head banging in early childhood: a study of incidence. In Murphy, G., Wilson, B. (Eds.). Self-injurious Behaviour. Kidderminster: BIMH Publications, 1985.

Reference lists which are not of an acceptable standard will be returned to the author(s) for correction. All references listed must be cited appropriately within the text.

### Letters (maximum 750 words) and Reviews (maximum 400 words)

Full details of content and presentation are given in the full Information for Authors document.

### Assessment Procedure

All articles submitted 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.

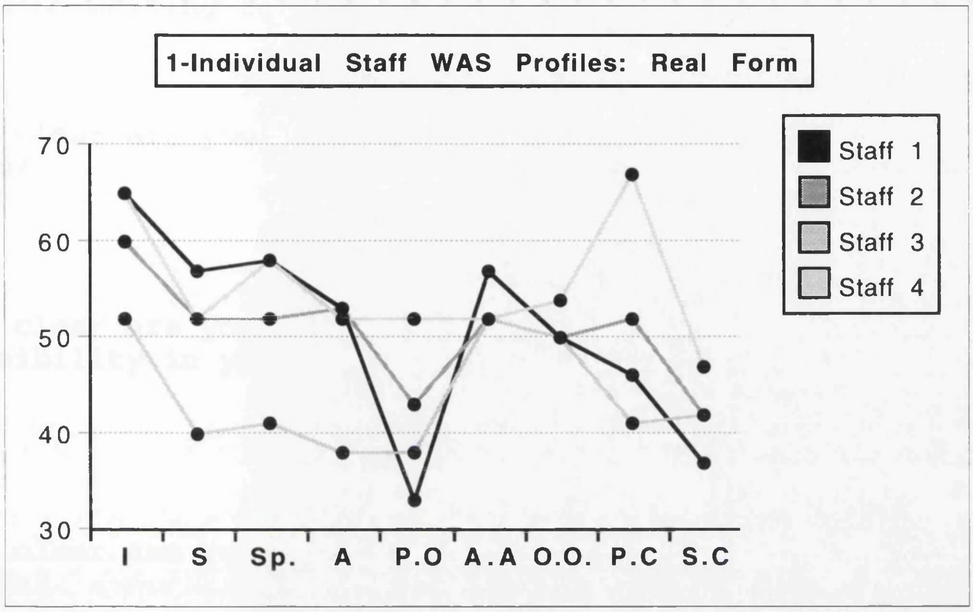
The initial assessment process usually takes between two and three months. Following this the Editor will inform the author(s) whether the article is to be accepted as it stands, accepted subject to satisfactory minor revision, requires more extensive change and reassessment before it can be accepted, or is rejected as unsuitable for publication in *Mental Handicap*. The assessors' reasons for acceptance, change, or rejection will be made known to the author(s).

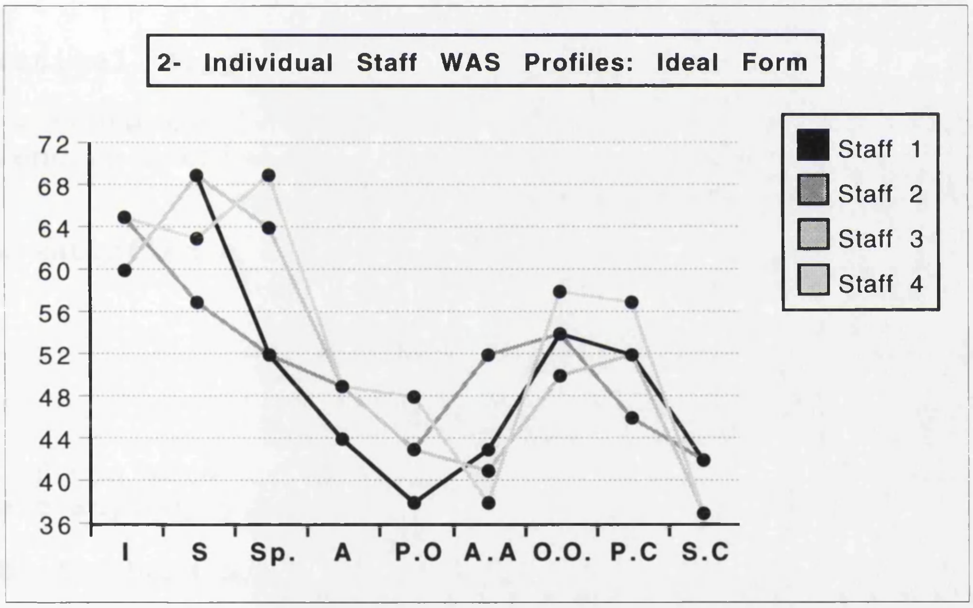
**Authors are advised to retain one complete copy of any article, and its accompanying illustrations and tables, or any other contribution they submit as the Editor cannot accept responsibility for loss or damage of such materials.**

### Address for correspondence

**All contributions should be sent to: The Editor, Mental Handicap, BIMH Publications, Stourport House, Stourport Road, Kidderminster, Worcs., DY11 7QG.**

# APPENDIX 13- INDIVIDUAL WAS PROFILES


1-Individual Staff WAS Profiles: Real Form


2- Individual Staff WAS Profiles: Ideal Form

## APPENDIX 14- The Staff Support Questionnaire: Results

### 1- Role Ambiguity/Clarity

1) How clear are you about the main objectives you should be working towards in your job?

Very clear- 25%
Clear- 75%

2) How clear are you about what your superior expects of you?

Very clear- 50%
Clear- 50%

3) How clear are you about the limits of your authority and responsibility in your present position?

Clear- 75%
Undecided-25%
Undecided- 25%

4) How clear are you about how satisfied your superior is with you?

Very clear- 25%
Unclear- 75%

### 2- Practical Support in Crisis Situations

1)(a) Is there somebody you can talk to at work if you are experiencing a crisis?

Yes-100%

(b) How satisfied are you with this?

Very satisfied- 25%
Satisfied- 25%
Undecided-50%
Undecided- 50%

2)(a) If you were unable to cope with a situation at work is there anybody you can call on for practical help?

Yes- 100%

(b) Is there always someone available?

Yes- 75%

No- 25%

(c) How satisfied are you with this?

Satisfied- 50%
Undecided- 50%

3)(a) Do you receive regular supervision sessions or performance reviews as part of a regular programme of staff development?

No- 75%
Yes- 25%

(b) How satisfied are you with this?

Satisfied- 25%
Undecided- 75%

## 3- Identification of Risk Situations

1)(a) Have risk situations been clearly identified at your place of work?

Yes-100%

(b) If yes, were you involved in identifying the risks?

Yes-100%

2)(a) Have clear guidelines been established about what to do if something goes wrong?

Yes-100%

(b) If yes, do you agree with the guidelines?

Yes-100%

## 4- Overall Job Satisfaction

1) Are you satisfied with present situation at work?

Yes- 75%
Undecided- 25%

2) Are you satisfied with your present level of involvement in decision making at work?

Yes- 75%
No- 25%

3) Are you satisfied with the degree of support you receive in your job?

Yes- 75%
No- 25%

4) Do you often think about finding another job?

Yes- 75%
No- 25%

**Additional Comments**

1) "Need for more backup and support from management".

2) "I do not feel that I am suitably graded for the responsibility my job entails".

3) "We could do with a little more cooperation from the management side".

4) "Dissatisfied with support given by manager".