CORE BELIEFS AND TREATMENT OUTCOME IN PAEDIATRIC EPILEPSY

and

RESEARCH PORTFOLIO

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SMALL SCALE SERVICE EVALUATION PROJECT

URGENT REFERRALS TO AN OUT-PATIENT PSYCHOLOGY CLINIC

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URGENT REFERRALS TO AN OUT-PATIENT PSYCHOLOGY CLINIC

ABSTRACT

Many clinical psychology departments have adopted systems to deal with urgent referrals to overcome the problem of inaccessibility of the service because of long waiting lists. The present study was conducted at an Adult Mental Health Clinical Psychology Department in Glasgow to evaluate the pattern of urgent referrals and establish the factors which referrers and clinical psychologists associate with urgency. Results indicated that 7% of all referrals received by the department were classified as urgent but that 12% of these do not attend for their first appointment. Also it appears that the same problems are being seen urgently and routinely, and that there are no significant differences in the number of additional criteria associated with routine or urgent referral according to the referral letters. However, a wider variety of additional criteria are associated with urgent referrals and these criteria are consistent with those proposed by clinical psychologists.

INTRODUCTION

Many clinical psychology departments have adopted systems to deal with urgent referrals in an attempt to overcome the general inaccessibility of the service. Within clinical psychology it has been noted that there is a demonstrable need for psychological therapies in primary care but these are often inadequate and unevenly distributed (BPS, 1990). The resultant situation is that waiting lists for such services are often unacceptably long. In a survey of NHS clinical psychology services it was estimated that 44.2% of referrals are made to departments in which it might take over six months to be seen and 15% to departments in which it might take over one year to be seen. (DCP, 1993). In a survey of GPs (Chadd & Svanberg, 1994), clinical psychologists were regarded the least accessible of the mental health professionals and it was speculated that what GPs value most is speed of response. It has also been suggested that some patients are being referred inappropriately to different mental health professionals because of the lack of availability of others (Wilkin & Smith, 1987).

The availability of services is further reduced by the problem of patient non-attendance, which as well as carrying a threat to the patient's health and well-being, also leads to inefficient use of professional time and resources, resulting in larger waiting lists and longer waiting times (Barron, 1980; Starkenburg, et al, 1988). Within clinical psychology out-patient clinics, rates of initial appointment non-attendance of up to 30% have been reported (Spector, 1988). Several factors have been studied in association with initial appointment failures and treatment attrition, including socio-economic status, length of waiting time, referral source, history of previous treatment, clinical characteristics, distance from clinic and demographic characteristics. However, research

has not identified a particular kind of habitual non-attender and indeed a study by Mason (1992) revealed that 32% of those traced defaulted for reasons relating to inefficient hospital administration.

It has been suggested that non-attendance might be related to the referral process, including the selection of patients for referral and the quality of communication between GP and patient (Lloyd et al, 1993). Patients were significantly less likely to attend if they had been unable or only partly able to discuss their health problem with their GP. Mason (1992) identified unnecessary referrals which come from GPs who "give in" to demanding patients. Trepka (1986) identified that non-attenders tended to come from referrers who were less familiar with the psychologist and presumably made less appropriate referrals or gave patients a less clear idea of what to expect from the psychologist. Inappropriate referrals are often reflected in referral letters and indeed these seem to predict non-attendance in other mental health settings (e.g. Farid & Alapont, 1993). An analysis of referral communications in two specialties showed that letters accomplished the basic objective of transferring clinical and administrative information but were less likely to contain items of a social-psychological type and non-clinical matters that can be a complicating factor in a proportion of referrals (Newton et al, 1994).

Prolonged waiting times for initial appointments have been repeatedly linked to failure to attend at out-patient clinics (Dickey & Morrow, 1991). Also related to non-attendance is the amount of notice given for the appointment. Frankel et al (1989) found that non-attendance was significantly related to length of notice given for the appointment, with patients receiving less notice being significantly less likely to attend.

For urgent referrals there is unlikely to be a prolonged waiting time for initial appointment although it is possible that appointments are scheduled at short notice.

Even within the realm of "urgent" referrals there is still the problem of patient non-attendance. Gerhand and Blakey (1994) found some evidence of patients with more severe problems being less prone to non-attendance, however, Frankel et al (1989) found no significant difference between attenders and non-attenders according to their scale of urgency. In a thorough evaluation Ambuel et al (1964), studied almost 3000 referrals to a Children's Hospital and it was concluded that urgency is one of the most powerful influences on clinic attendance. Also it was clear that unless a sense of urgency is communicated to the patient, the risk of the patient missing the appointment will be increased.

Within many departments, a lengthy waiting list has necessitated a alternative means of offering priority cases a shorter waiting time. These systems employed to deal with urgent referrals, appear to be idiosyncratic to individual departments and their efficacy has not been systematically evaluated. A study by Turken (1993) showed some consensus about what urgency means. This included factors such as suicide risk, acute relationship difficulties, preventative measures or otherwise at risk (e.g. alcohol dependence, PTSD). It is possible that such a system for urgent referrals can be used inappropriately for routine referrals if the waiting list is perceived as too long or if the referral criteria of the system are misunderstood.

In an attempt to evaluate one particular system for urgent referrals, the following study was carried out in an Adult Mental Health Clinical Psychology Department in Glasgow and aimed to establish:

1. the pattern of urgent referrals
2. the initial appointment non-attendance rate for urgent referrals and comparison of this with rates for routine referrals
3. the criteria implicated as important in the referral letters for urgent referrals and compare these to criteria for routine referrals
4. the criteria which clinical psychologists consider appropriate for a referral to be considered urgent

METHOD

Subjects

The sample comprised all adult out-patients referred on an urgent basis within a fourteen month period. This sample was analysed to provide information on the pattern of referral and compared to corresponding information for routine referrals. A random sample of 25 of the urgent referrals was further analysed to provide information on non-attendance rates, diagnosis and referral criteria, and this information was compared to corresponding information for a sample of 25 routine referrals.

Procedure

Data from departmental records were analysed to provide figures for rates of referral, referral source and waiting times of urgent referrals. This information was then compared to corresponding information routinely collected for all referrals.

A random sample of 25 of the urgent referrals was further analysed from case-notes to provide information on non-attendance rates, and this was compared to the overall non-attendance rate within the department. Referral letters from this sample were subsequently analysed to determine diagnosis and additional criteria implicated by referrers. This information was compared to corresponding information from a sample of 25 routine referrals which were matched for age, sex, and geographical location source.

Clinical psychologists within the department were asked to categorise criteria which they deemed appropriated for an urgent referral. This information was then compared to the sample of urgent referrals and the criteria from the referral letters which the referrers associated with urgency.

RESULTS

1. Departmental Records

During the period May 1995 to June 1996, a total of 84 urgent referrals were received by the department. This is the most accurate figure it is possible to obtain although it is likely this underestimates the true number of urgent referrals due to inconsistencies in

record keeping. During this period, the total number of referrals received by the department was 1384, thus urgent referrals constitute 7% of referrals. The mean monthly rate of urgent referrals was 6, with a range from 1 to 16, which again could reflect inconsistencies in record keeping. The sources of referral are iullustrated in Figure 1 For the urgent referrals 52% came from GPs, 35% from psychiatrists and 4% were self referrals. For total referrals, GPs were responsible for 70%, psychiatrists for 25% and the remaining 5% came from other sources. The mean waiting time for urgent referrals was 21 days, with a range from 2 days to 48 days. This compared to a mean waiting time for routine referrals of 84 days.

INSERT FIGURE 1 HERE

2. Case notes

The random sample of urgent referrals consisted of 22 females and 3 males. The ages ranged from 23 years to 59 years (mean age = 37.6 years). A total of 3 (12%) did not attend for initial appointment, which compares to an overall initial appointment non-attendance rate of 21% within the department. Additionally it was established that 5 (20%) of the random sample of urgent referrals, dropped out of treatment before discharge had been agreed with the psychologist. The rate of treatment drop-out for all referrals to the department was not available.

The presenting problems of the random sample of urgent referrals reflects the problems routinely seen by the psychologists in the department. The most common diagnosis was of anxiety problems. The presenting problems of the sample of routine referrals was

somewhat similar, again the most frequent diagnosis being anxiety problems. This information is illustrated in figures 2 and 3.

INSERT FIGURES 2 & 3 HERE

From the random sample of urgent referrals, 19 of the referral letters included additional criteria in support of the urgent classification. There was a total of 27 additional criteria corresponding to twelve different categories. The two most common factors were, employment being in jeopardy, and family problems as shown in Table 1.

INSERT TABLE 1 HERE

From the matched sample of routine referrals, 18 of the referral letters included additional criteria in support of the referral. There were a total of 25 additional critical corresponding to twelve different categories. The two most common factors were family problems and physical health problems as shown in Table 2.

INSERT TABLE 2 HERE

Analysis of the number of additional criteria in each referral letter for the sample of urgent referrals and the for sample of routine referrals, using the Wilcoxon matched-pairs test, revealed no significant differences between the two samples.

3. Clinical Psychologists

The criteria which the clinical psychologists in the department deemed appropriate to constitute an urgent referral were:

- suicide risk or risk of self-harm
- risk of harm to others
- children at risk
- situation likely to deteriorate
- preventative input to halt development from acute problem to chronic problem
- sudden change in functioning
- medical urgency - psychological assessment of physical symptoms
- pregnancy / illness / surgery
- major life event / acute situation
- relationship breakdown

This list is not intended to be exhaustive nor is it suggested that each of these situations always necessitates an urgent referral.

The above list on comparison with the criteria associated with urgent referral (Table 1) encompasses all factors with the exception of temporary accommodation and substance abuse. It is also noted that this list encompasses all the factors associated with routine referrals sampled (Table 2) with the exception of substance abuse and request for re-referral.

DISCUSSION

This study has provided information on the pattern of urgent referrals to an Adult Mental Health, Clinical Psychology Department in Glasgow. Factors which referrers associate with urgency have been established and compared with corresponding factors for routine referrals, and factors which clinical psychologists associate with urgency.

The initial appointment non-attendance rate for urgent referrals of 12% is substantially lower than the overall department rate of 21%. This lowered rate is consistent with the decreased waiting time for urgent referrals (Dickey & Morrow, 1991) and the increased problem severity (Gerhand & Blakey, 1994), however this non-attendance rate is not insignificant and is perhaps indicative of inappropriate referrals.

Comparison of the presenting problems in urgent and routine referrals reveals few differences except that in this sample PTSD and cognitive assessment are only seen urgently and anger management is only seen routinely. In general within this department, these problems are accepted as urgent referrals and as routine referrals depending on circumstances.

It appears that similar problems are being seen urgently and routinely, and it is thus likely that additional factors are involved in urgent referrals. Analysis of referral letters reveals no significant differences between the number of additional criteria implicated for urgent referrals and for routine referrals. Generally all factors associated with routine referrals were encompassed by the corresponding factors for urgent referrals and furthermore a wider variety of factors were associated with urgent referrals. Although

not readily quantifiable, these additional criteria may be said to be of a more severe nature. Instances of this from the sample include self-harm and the situation pregnancy with a phobia of doctors and hospitals. An example which is less clear-cut is of a referral being classified as urgent because the subject was in temporary accommodation and may soon be difficult to locate.

Criteria supplied by clinical psychologists as being appropriate for an urgent referral, encompass the main criteria which referrers associated with urgency. This would suggest that urgent referrals are not inappropriate. However it is also noted that, depending on circumstances, criteria generally considered for routine referrals may become urgent. Examples of this include certain bereavement reactions or substance abuse problems which are deteriorating or having detrimental effects on others such as children.

It appears very difficult to categorically distinguish problems and related factors into urgent and routine referrals. The criteria produced by the clinical psychologists could perhaps be used as guidelines but these must be accompanied by thorough assessment of individual situations to determine when prompt psychological intervention will indeed be most beneficial and when a waiting period will not have a significantly detrimental effect.

In summary, it appears there is some evidence that some urgent referrals are inappropriate: 12% of urgent referrals do not attend for their first appointment, the same problems are being seen urgently and routinely, and there are no significant differences in the number of additional criteria associated with routine or urgent referral

according to the referral letters. On the other hand there is some evidence that the referrals are not inappropriate because a wider variety of additional criteria are associated with urgent referrals and it can be argued that these are of a more severe nature. Furthermore, the criteria which referrers associate with urgency are consistent with those suggested by the clinical psychologists.

Given that it is unlikely that we can make criteria for an urgent referral more specific, more attention should perhaps be given to ensuring that referrers are more familiar with our service, able to assess more accurately and thus able to refer more appropriately (Trepka, 1986). Also, changes in service delivery may help decrease inappropriate urgent referrals, for example shorter waiting times should help to ensure the system is not used inappropriately to avoid waiting. Changes in working practices are being introduced in attempts to reduce waiting lists (Newnes, 1993) e.g. short therapy contracts. Also attempts are being made to reduce non-attendance rates through a new system for accepting psychological referrals via GPs. This is based on the core idea of psychologists helping GPs to help their patients to reach their own decisions about whether or not to request a psychological consultation (Seager et al,1995).

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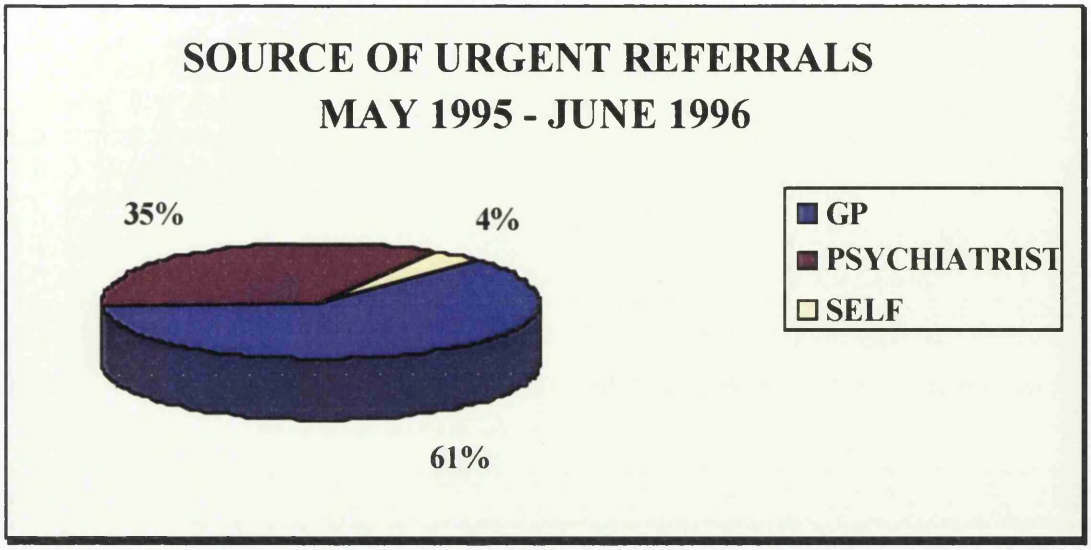
FIGURE 1. SOURCES OF URGENT AND ROUTINE REFERRALS



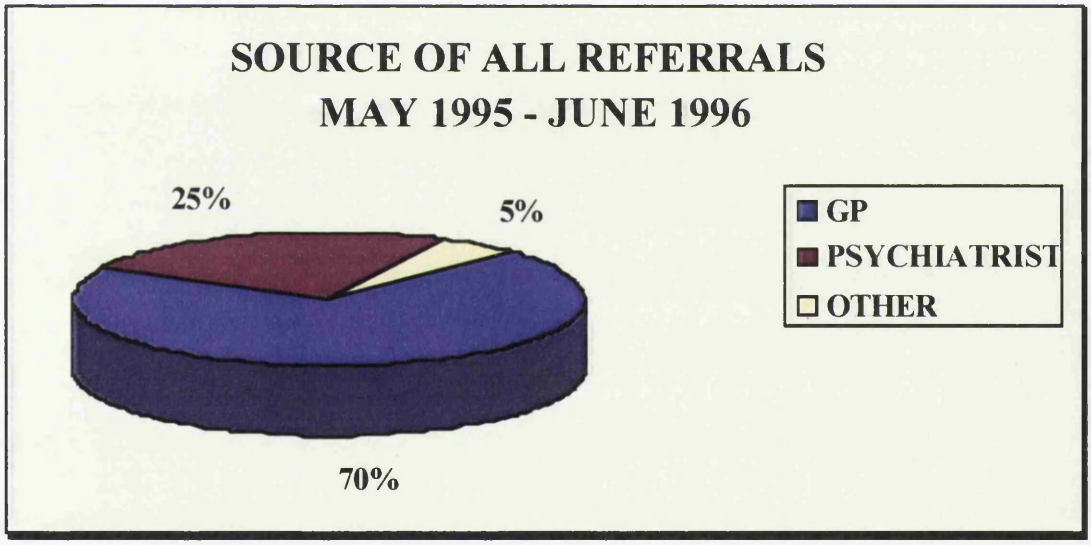


FIGURE 2. PRESENTING PROBLEMS OF URGENT REFERRALS

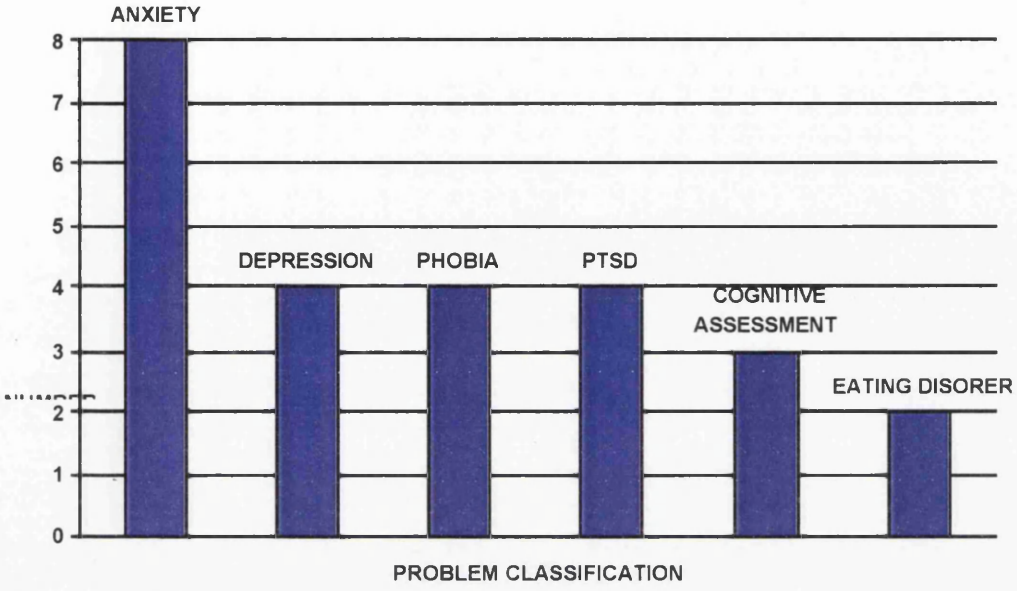


FIGURE 3. PRESENTING PROBLEMS OF ROUTINE REFERRALS

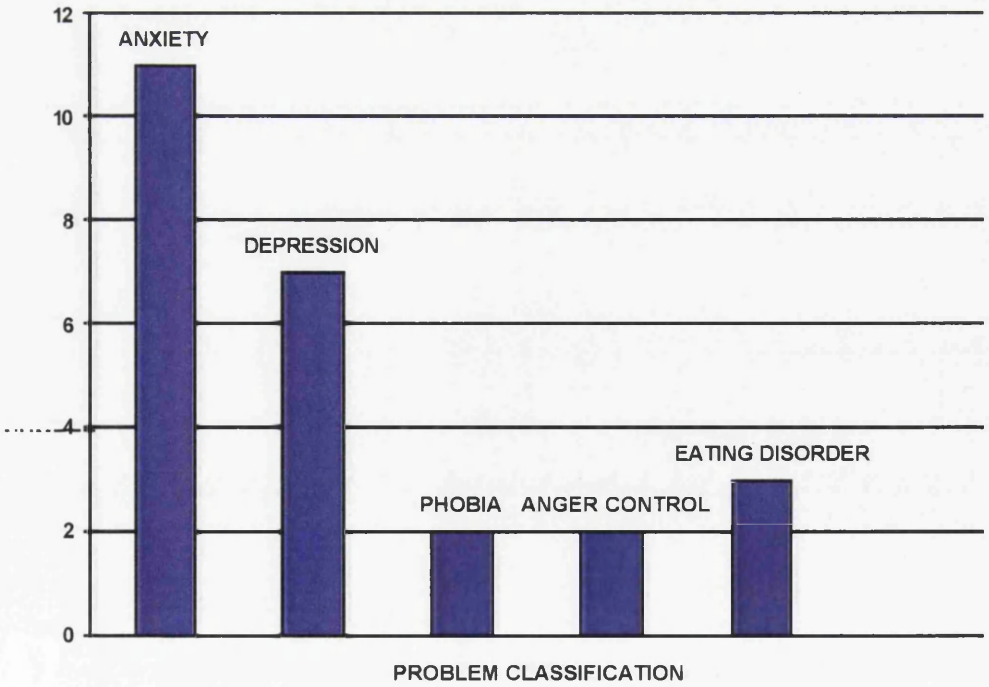


TABLE 1. ADDITIONAL FACTORS IN URGENT REFERRALS

	PRESENTING PROBLEM				
CRITERIA	Anxiety	Depression	Phobia	PTSD	Eating Disorder
Employment in jeopardy		1	2	2	
Family problems	3			1	1
Condition deteriorating	1	1	1		
Critical incident	2			2	
Physical health problems	1		1		
Suicide risk		1	1		
Temporary accommodation	1				
Negative effect on children	1				
Pregnancy			1		
Multiple trauma			1		
Bereavement	1				
Substance abuse	1				

Entries correspond to the number of times a particular criterion is associated with a particular presenting problem from the sample of urgent referrals.

TABLE 2. ADDITIONAL FACTORS IN ROUTINE REFERRALS

	PRESENTING PROBLEM				
CRITERIA	Anxiety	Depression	Phobia	Anger Control	Eating Disorder
Family problems	4	2			
Physical health problems	3			2	1
Critical incident	3	1			
Request re-referral	2	1			
Condition deteriorating	1	1			
Bereavement	2				
Negative effect on children	1				
Substance abuse				1	

Entries correspond to the number of times a particular criterion is associated with a particular presenting problem from the sample of routine referrals.

MAJOR RESEARCH PROJECT LITERATURE REVIEW

PSYCHOLOGICAL ASPECTS OF PAEDIATRIC EPILEPSY

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PSYCHOLOGICAL ASPECTS OF PAEDIATRIC EPILEPSY

ABSTRACT

This review considers current understanding and developments concerning psychological aspects of epilepsy. There is a particular focus on paediatric epilepsy and the impact of the disorder on various aspects of childhood and family functioning. The research literature on cognitive aspects of epilepsy, employed to explain some possible mediating factors for the discrepancy between seizure occurrence and level functioning and adjustment, is reviewed. The development of cognitive interventions, the theoretical constructs behind these and the directions and opportunities for future research, are also discussed.

INTRODUCTION

It has been estimated that there are approximately 350,000 people in the UK with a diagnosis of epilepsy (Brown & Betts 1994). It is the most common neurological disorder in childhood, occurring in 5:1000 children (Cowan et al 1989). Causes of epilepsy are varied but include birth injury, congenital malformations, infections, tumours, neurodegenerative disorders, toxins, or metabolic disorders. However, in up to two-thirds of cases the aetiology is unknown (Lishman 1987). For the majority of people with epilepsy, their symptoms are well controlled, but associated with the disorder is an increased risk of mortality up to two or three times higher than for the general population (Chadwick 1994). There is also a significant morbidity in epilepsy, a range of injuries particularly skull and skeletal fractures which necessitate much in-patient hospital care. Additionally there may be neurological handicaps, learning difficulties and behavioural problems (Brown & Betts 1994). The first line of treatment for epilepsy is pharmacological management, preferably with one anti-epileptic drug (AED) but if necessary with more than one. These drugs can have cognitive side-effects, which increase with polypharmacy (Meador 1994). Even with medication, seizure control is only achieved in 80% of cases and the remainder with intractable seizures have few other options although for some, invasive resective neurosurgery may be appropriate. Evidence suggests that the earlier surgery is done in intractable epilepsy the better the outcome - in children this is due to the neural plasticity and the adverse effects of seizures and AEDs, as well as the negative psychosocial ramifications (Cascino 1995). Novel treatments are also being developed in the area of vagal nerve stimulation. The mechanism for the anti-epileptic effect is not fully understood, but may relate to effects on the reticular activating system (Wilder et al 1991).

For many people the psychological and social implications which frequently accompany epilepsy can cause greater disruption than the actual seizures (Betts 1993). This is evident in the variety of psychological problems which have been associated with a diagnosis of epilepsy - anxiety, depression, low self esteem, poor sense of control, aggression and psychosis (Baker 1997). The explanations for the development of these emotional and behavioural problems have been related to brain damage, side effects of medication, and the stigma and negative social label associated with epilepsy (Scambler & Hopkins 1986). Jacoby (1994) indicated that people with well-controlled epilepsy were still stigmatised by their condition suggesting that the diagnosis and not necessarily the frequency or severity of seizures, is important in understanding the stigma in epilepsy. In addition to this stigma, it is also true that even when seizures are well controlled, their possible recurrence can remain a source of great anxiety. There is a reciprocal relationship between anxiety and epilepsy in that the more anxious the patient is, the more likely they are to have a seizure, and the more seizures they have the more anxious they become. To treat epilepsy only in terms of seizure reduction is clearly inadequate and the disorder cannot be managed without reference to associated psychological factors.

PAEDIATRIC EPILEPSY

It is unsurprising that research has demonstrated that children who have epilepsy have a much higher rate of psychological disorder than healthy children or children with other chronic illnesses (Hoare 1984), and a similar pattern has been demonstrated for self-image and self-esteem (Matthews et al 1982, Hoare & Kerley 1991). There is a growing body of evidence to suggesting that these childhood factors are related to the many of the chronic difficulties experienced by adults with epilepsy (Betts 1993). Seizure control in children has been demonstrated to be predictive of the development of behaviour disorder and it has been recognised that the experience of epilepsy is likely to lead to the development of an external locus of control, which may be associated with behavioural disturbance (Matthews et al 1982, Matthews & Barabas 1986). A multi-aetiological model encompassing neurology, pharmacology and psychosocial aspects, has also been proposed in explanation of the development of psychological problems in children with epilepsy (Herman & Whitman 1991).

Family adjustment and coping with chronic illness have been predicted by the stability and predictability of the child's illness (Eiser 1993). Epilepsy by it's very nature lacks stability and predictability and the experience of having a child with epilepsy in the family is undoubtedly stressful. Stress within the family has been associated with behavioural problems and emotional disturbance in the child with epilepsy (Hoare & Kerley 1991, Austin et al 1992). Other influential factors include, lack of support from relatives and a perceived lack of control over family events and outcomes (Austin et al 1992, Cull 1988). Pianta & Lothman (1994), assert that the quality of the parent-child relationship itself is the most important predictor of behaviour problems and that the

effect of this is independent of epilepsy variables. A good parent-child relationship is also more likely to engender open communication whereby children benefit from frank discussions related to their illness and illness related questions are encouraged. This approach has many strong proponents (Goldstein 1990, Eiser 1992) but unfortunately in families affected by epilepsy a policy of concealment of diagnosis is common (West 1986, Scambler & Hopkins 1988). The promotion of increasing independence and responsibility during childhood are two of the more important maturational tasks that parents have to do for their children. This often problematic for parents of children with epilepsy, who understandably find it difficult to allow their child to become independent in an age-appropriate fashion and also to assert effective control over the child's behaviour (Hoare 1993). It appears that parents have different expectations of a child with epilepsy than of other offspring - in general, these expectations are that the child with epilepsy will be less able, both functionally and socially (Long & Moore 1979, Ferrari 1989). Parenting for children with epilepsy is likely to be more protective, controlling and dominant than for children who do not suffer from epilepsy (Munthe-Kaas 1981, Ritchie 1981, West 1986). Some studies however are more positive with little evidence of over-protection or over-anxiety even when children were still having seizures (Clement & Wallace 1990).

PSYCHOLOGICAL ASPECTS

The psychological and emotional problems encountered by people with epilepsy have been well documented in terms of the frequency of seizures, the reaction of other people and society's attitude to people with epilepsy (Dodrill et al 1983). Necessarily, the

main target for the treatment of epilepsy is a reduction in seizure occurrence but recently there is increased awareness of the importance of improved psychosocial functioning as a major therapeutic goal of treatment. This advance has led to a number of recent studies taking into account measures of Quality of Life (QoL), as well as measures of seizure frequency and severity (Jacoby 1996). QoL encompasses an individual's satisfaction with a broad spectrum of variables which include physical, cognitive, emotional, social and economic functioning (Kendrick 1997). QoL would appear to be a particularly pertinent measure within the study of epilepsy because it is often a disorder where treatment does not result in cure and may indeed be associated with adverse side-effects. It is hoped that the use of measures of QoL will be used to achieve optimal treatment outcome for people with epilepsy - already they are being used to measure the impact of novel medications both in adults and children (Smith et al 1993, Smith et al 1995). For children this is leading to more attention being paid to the adverse effects on the child's adjustment and development, the restrictions on family life and activities, and the side-effects from AEDs.

Increased awareness of the importance of optimal psycho-social functioning in epilepsy treatment has led to the recognition that psychological treatments can complement medication in some cases. This has been demonstrated in behavioural management of seizures where learning and the environment play a significant role in seizure expression. Interventions such as relaxation techniques, differential reinforcement and competing response training have been successfully implemented (Kuhn, Allen & Shriver 1995), and self-control approaches using cognitive behavioural techniques have also proved very useful (Goldstein, 1990). Cognitive-behaviour therapy (CBT) has also been used to treat the anxiety and depression which are commonly associated with

epilepsy (Tan & Bruni 1986, Brown & Fenwick 1989). Psychological therapy of an educational nature aimed at improving coping skills, also produced a reduction in seizure frequency in people with refractory epilepsy. This is likely to be due to a reduction in anxiety through the improvement in coping skills (Gillham 1990). Given these successes, it is unsurprising that research has now reflected the current advances and popularity of cognitive therapy techniques and has focused on cognitive factors and treatment opportunities.

COGNITIVE INFLUENCES

The recognition that physical characteristics of epilepsy do not directly covary with psychopathology has led to a growing awareness in epilepsy research of the importance of patient's perceptions of their condition and their role in psychosocial and medical adjustment. In line with Beck's cognitive model (Beck 1976), it has been suggested that the perceptions the person with epilepsy has about his/her condition and about him/her self are more important predictors of adjustment than more objective measures such as seizure type or frequency (Morrow & Baker 1993). These perceptions have implications for psychosocial well-being and it has been demonstrated that better adjustment is achieved when there is least discrepancy between current self-perception and anticipated self without epilepsy (Collings 1990). Jacoby (1991), argued that patient's feelings concerning the potential social ramifications of being epileptic and specific fears about aspects of their seizure disorder may be as important in helping them cope with their epilepsy as the control of seizures by medication. A number of cognitive processes have been examined in this context and these include patient

perceptions of stigma, perceived physical and social effects of having epilepsy, perceptions of control and knowledge of epilepsy.

There is an extensive literature on the concept of stigma and it has been argued that perceived stigma shapes and distorts interpretations of the experiences of those with epilepsy (Scambler 1989, Scambler & Hopkins 1988). Research has indicated that people with epilepsy learn these negative perceptions through interaction with significant others who act as "stigma coaches" (Schneider & Conrad 1980, West 1992). As many people develop epilepsy in childhood, the family and in particular parental attitudes, are instrumental in the development of these self-perceptions. 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 (Scambler 1993). Many aspects of epilepsy are characterised by a loss of control (Matthews et al 1982), and an individual's sense of loss of control may have serious physiological and psychological consequences including feelings of helplessness, depression, anxiety and low self-esteem (Garber & Seligman 1980, Betts 1988). It has been claimed that people with epilepsy, by virtue of their lack of control over their seizures, tend to develop a fatalistic attitude, or belief in an external locus of control (Herman & Whitman 1991), and that parenting behaviour, the severity and frequency of seizures and the patient's perceptions of themselves and their disorder, are all implicated in this (Baker 1997). Studies by Matthews & Barabas (1986) and Arnston et al (1986), on children and adults with epilepsy, have found significant associations between an external locus of control and psychopathology. Similarly the concept of learned resourcefulness (Rosenbaum 1983), which refers to an individual's response to a series of uncontrollable events, has been related to epilepsy. Rosenbaum & Palmon

(1984) demonstrated that independent of seizure frequency, high levels of resourcefulness in the epilepsy patient were related to low levels of depression and anxiety, high levels of coping and strongest beliefs in control over their health and seizures. A major component in perceived control of epilepsy is knowledge. Jarvie et al (1993) highlighted much ignorance surrounding important areas such as diagnosis, causes and consequences of seizures and the purpose and side-effects of medication. This lack of knowledge is likely to have adverse effects on factors such as treatment compliance, and on the person's coping with the medical and social implications of the condition.

SCOPE FOR COGNITIVE TREATMENTS

As understanding within a cognitive framework increases, so treatment opportunities reflecting these advances are becoming possible. This is highlighted in developments in an understanding of illness in terms of a cognitive model and the possible influences of these models upon treatment outcome. Weinman & Petrie (1997) argue that internal representations or cognitive models are constructed which reflect illness, and that these models help patients make sense of their experience and provide a basis for their own coping responses. A study by Weinman et al (1996) demonstrated great variation within patient models of chronic illness, even among individuals with the same disease severity. These differing models may provide explanations for variation between patients in coping responses, treatment adherence and illness-related disability - factors which have major influences upon treatment outcome (Horne 1997, Moss-Morris et al 1996). To optimise treatment outcome and minimise difficulties such as non-

compliance, it is therefore important to take account of patient models and cognitions such as beliefs about the cause or potential for control/cure of an illness. Cognitive therapies offer the potential for eliciting such cognitions, which may not become evident during medical consultations, and when necessary offer possibilities for challenging and restructuring erroneous or maladaptive beliefs. Related work includes that of Tedman et al (1995) who developed a scale measuring underlying core beliefs generated by the experience of epilepsy in adults. They argued that epilepsy generates specific detrimental core beliefs which affect coping skills in general and the ability to deal with the specific problems of a chronic illness. The epilepsy patient constructs a view of self that is different to a non-epilepsy subject which results in a high level of both depression and anxiety. They discussed this in relation to Bandura's self-efficacy theory whereby thought has a prominent position in its ability to foster belief in self capability and effective actions. Studies indicate that high self efficacy aids both psychological and physical coping responses - core beliefs constructed as a result of having epilepsy will adversely affect the levels of self efficacy specifically related to those areas. Their results supported the assertion of an intimate relationship between core beliefs, self-efficacy and emotional pathology in the form of increased depression, anxiety and low emotional adjustment factors.

Intervention studies in other clinical populations have shown that depression, anxiety and knowledge are all factors amenable to change. For people with epilepsy there is evidence that cognitive retraining can improve self efficacy beliefs and consequently relieve depressive affect (Schwartz & Fish 1989, O'Leary et al 1988) and preliminary examples indicate progress in helping families identify and challenge constraining beliefs about epilepsy (Wright & Simpson, 1988). It is suggested that perceived

improvements may be due to the provision of mastery experiences and improvement in subjective perceived coping skills, which have been implicated as vital components in the development of efficacy beliefs (Craig & Oxley 1988, Gillham 1990). It is insufficient to alter superficial behaviour pattern without attending to the cognitive constructs that underlie them and it has been argued that future interventions may achieve their best results by concentrating on the nature of core beliefs influencing levels of self-efficacy and perceived coping skills, to motivate behaviour change (Tedman et al 1995).

The further development of cognitively-based therapies for people with epilepsy is welcome, and consideration of the role of cognitive factors in terms of constructs such as core beliefs, is an important avenue of investigation. Given that children are the group of the population most commonly affected and often greatly disadvantaged by epilepsy they would appear to be a particularly pertinent group for study. It has been recognised that much cognitive development occurs during childhood and that children are excellent candidates for cognitive interventions (Spence 1994, Ronen 1997). This, in addition to the impact on cognitive development from parental influences, suggests that if interventions for children and their families can be developed, they are likely to prove particularly fruitful.

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MAJOR RESEARCH PROJECT PROPOSAL

CORE BELIEFS AND TREATMENT OUTCOME IN PAEDIATRIC EPILEPSY

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CORE BELIEFS AND TREATMENT OUTCOME IN PAEDIATRIC EPILEPSY

SUMMARY

Recent research has highlighted developments in an understanding of illness in terms of cognitive models and the possible influences of these models upon treatment outcomes. Cognitive factors have previously been recognised as important within the study of epilepsy and given recent successes in the application of other psychological therapies it seems likely that cognitive therapies will be of benefit in enhancing treatment outcomes. Further investigation of the role of cognitive factors within illness is therefore an important avenue of investigation.

This study will focus on children with epilepsy. Children are the group of the population most commonly affected by epilepsy and a group who are often greatly disadvantaged by the disorder - for them the role of cognitive interventions may be of particular benefit. The study aims to measure the core beliefs of children with epilepsy and their parents and to investigate the relationship of these with treatment outcome. Treatment outcome will be measured in psychosocial terms as well as in terms of seizure experience. Comparison will be made across a spectrum of types and degrees of severity of epilepsy and differences will be examined with regards to a series of relevant socio-demographic and medical variables.

It is proposed that the study will be carried out at paediatric out-patient clinics at Law Hospital, Lanarkshire and at the Royal Hospital for Sick Children, Glasgow. Subjects will comprise, as far as possible, a consecutive sample of children aged six years and above attending the clinics. Information will be gathered from hospital records, self-

complete questionnaires and interview. Participation in the study will be voluntary and data collection for individual children should be complete within one hour.

INTRODUCTION

Weinman and Petrie (1997) argue that internal representations or cognitive models are constructed which reflect illness, and that these models help patients make sense of their experience and provide a basis for their own coping responses. A study by Weinman et al (1996) demonstrated great variation within patient models of chronic illness, even among individuals with the same disease severity. These differing models may provide explanations for variation between patients in coping responses, treatment adherence and illness-related disability - factors which have major influences upon treatment outcome (Horne 1997, Moss-Morris et al 1996). To optimise treatment outcome and minimise difficulties such as non-compliance, it is therefore important to take account of patient models and cognitions such as beliefs about the cause or potential for control/cure of an illness. Cognitive therapies offer the potential for eliciting cognitions which may not become evident during medical consultations and when necessary offer possibilities for challenging and restructuring erroneous or maladaptive beliefs.

Within the study of epilepsy, cognitive influences have previously been recognised. Much research has focused on the stigma related to having a diagnosis of epilepsy and the contribution of the patient's perceptions of stigma (Scambler 1989). It has also been claimed that people with epilepsy, by virtue of their lack of control over their seizures, tend to develop a fatalistic attitude, or belief in an external locus of control. Studies by Matthews & Barabas (1986) and Arnston et al (1986) on children and adults with epilepsy, have found significant associations between an external locus of control and psychopathology. The concept of learned resourcefulness (Rosenbaum 1983) refers to an individual's response to a series of uncontrollable events - such as epileptic seizures. A study by Rosenbaum & Palmon (1984) demonstrated that independent of

seizure frequency, high levels of resourcefulness in the epilepsy patient were related to low levels of depression and anxiety, high levels of coping and strongest beliefs in control over their health and seizures. Tedman, Thornton & Baker (1995) developed a scale measuring underlying core beliefs generated by the experience of epilepsy in adults. They argued that epilepsy generates specific detrimental core beliefs which affect coping skills in general and the ability to deal with the specific problems of a chronic illness. This was discussed in relation to Bandura's self-efficacy theory whereby thought has a prominent position in its ability to foster belief in self capability and effective actions. Their results supported the assertion of an intimate relationship between core beliefs, self-efficacy and emotional pathology in the form of increased depression, anxiety and low emotional adjustment factors.

Within epilepsy treatment it is also being slowly recognised that psychological treatments can complement anticonvulsant medication in some cases. This may be manifest through a reduction in seizure frequency but more often through an improvement in psychosocial functioning and quality of life (QoL). This has been demonstrated in behavioural management of seizures whereby studies have found that learning and the environment play a significant role in seizure expression. Interventions such as relaxation techniques, differential reinforcement and competing response training have been successfully implemented (Kuhn, Allen & Shriver 1995). Also it has been shown that psychological therapy of an educational nature aimed at improving coping skills, produced a reduction in seizure frequency in people with refractory epilepsy (Gillham, 1990). Given these successes, it is also hoped that further psychological interventions will be developed, perhaps reflecting the benefits derived

from cognitive therapy models with other populations and the increased understanding of cognitive influences in epilepsy.

Epilepsy is the most common neurological disorder in childhood and even when seizures are well controlled, additional problems are prevalent - parental fears and expectations, stigma associated with the disease, and anxiety regarding the possible recurrence of seizures. It is unsurprising that research has demonstrated that children who have epilepsy have a much higher rate of psychological disorder than healthy children or children with other chronic illnesses (Hoare 1984). Until relatively recently, the main goals for treatment were a reduction in seizure frequency and severity - little attention was paid to the adverse effects on the child's adjustment and development, the restrictions on family life and activities, nor indeed the side-effects from anti-epileptic drugs (AEDs). Now however, within the study of epilepsy, there is increased awareness of the importance of improved psychosocial functioning as a major therapeutic goal of treatment. This advance has led to a number of recent studies taking into account measures of quality of life as well as measures of seizure frequency and severity (Jacoby 1996). When treatment outcome is measured in this way it is more likely that the influence of cognitions and patient beliefs will be evident and may become a target for intervention. Given the difficulties associated with epilepsy in childhood, the evidence supporting the influence of cognitions on treatment outcome and the possibilities of developing cognitive treatments, the cognitions of children concerning their epilepsy appears to be an important area for investigation.

AIMS

The aims of this study are to consider a cognitive model of core beliefs in children with epilepsy and their parents and to establish the relationship of these beliefs with treatment outcome. This will involve measurement of core beliefs about epilepsy in children with the disorder and their parents and comparison of these beliefs with measures of treatment outcome, both medical and psychosocial. The study will attempt to show that good psychosocial functioning and QoL in children with epilepsy, is more strongly correlated with positive and adaptive core beliefs than with low seizure frequency.

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

- measurement of core beliefs about epilepsy in children with the disorder and their parents
- measurement of treatment outcome - epilepsy and psychosocial measures
- investigation of relationship between core beliefs and treatment outcome

PLAN OF INVESTIGATION

Subjects

Subjects shall be recruited from paediatric out-patient clinics at Law Hospital, Lanarkshire and the Royal Hospital for Sick Children, Glasgow. A broad cross-section of degrees of severity of epilepsy is desired with a population sample as large as possible - it is hoped that a minimum of forty subjects shall be recruited over a six

month period. To maximise the validity of this study, subjects should comprise as far as possible a consecutive series of the presenting clinical population. Subjects will meet the following criteria:

- duration of epilepsy for a minimum of 6 months
- age 6 years and above to enable assessment of core beliefs
- no significant cognitive impairment such as to prevent attendance at mainstream school

Measures

It is intended to use a series of questionnaires which have been used previously in epilepsy research. Some of these will require adaptation for children and these adaptations may require some pilot work before inclusion in the study. These measures will provide assessment of core beliefs about epilepsy in children and their parents and of children's treatment outcome in both medical and psychosocial terms.

1. Core Beliefs.

Adaptation of scale developed by Tedman, Thornton & Baker (1995) measuring core beliefs about epilepsy. This self-completion measure will be administered to the children and also to a parent or main carer based on their beliefs about their child.

2. Treatment Outcome.

Measures of seizure frequency and severity based on medical case-notes, seizure diaries and self-report from family.

Measures of QoL - Impact of Childhood Illness Scale (Hoare & Russell 1995), a parental self-complete questionnaire.

Assessment of concerns and worries pertaining to epilepsy, raised by families during semi-structured interview.

3. Demographics.

Information will be obtained from medical case-notes, family interview and when necessary from the medical team, on the following variables: sex, age, age at onset, illness duration, duration of treatment, treatment compliance, drug toxicity, current pharmacological treatment, clinical classification of epilepsy, family history of epilepsy, school attendance, and school attainment.

Procedures and Timescales

The first stage of this study will involve piloting the assessment measures to ensure their suitability and the time necessary for their completion. (September 1997).

The following stage will involve data collection, attempting to ensure a large, consecutive and representative population sample. (October 1997 - April 1998).

Potential subjects will be identified from clinic lists prior to their attendance for an out-patient appointment. Subjects will be approached on arrival for appointment, given a brief explanation of the study and invited to participate. Those subjects willing to participate will be offered an appointment to complete measures that day - while waiting for their medical consultation or immediately following this. If this is not possible or inconvenient to them, another time to complete assessment measures will be arranged to

coincide with their next out-patient visit. It is anticipated that the time needed to collect measures will be less than one hour.

The final stage of the study will involve analysis of the data collected and writing up of the results. (May - July 1998).

Design and Analysis

Data from the assessment measures will be scored manually and analysed on computerised statistical packages to determine the relationship between core beliefs about epilepsy and treatment outcome. This study is a single sample design and analysis will involve factors within the entire group and also factors between subgroups of the sample. Descriptive statistics will be utilised with correlational analysis and difference testing used to identify relationships. Dependent on these results, further analysis may be useful in the form of a multiple regression model.

Ethical Approval

Ethical approval has been obtained for this study from the respective Ethics of Research Committees at Lanarkshire Health Board and Yorkhill NHS Trust.

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Weinman J, Petrie KJ, Moss-Morris R & Horne R (1996). The Illness Perception Questionnaire: a new method for assessing the cognitive representation of illness. *Psychological Health*, 11: 431-446.

MAJOR RESEARCH PROJECT PAPER

CORE BELIEFS AND TREATMENT OUTCOME IN PAEDIATRIC EPILEPSY

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CORE BELIEFS AND TREATMENT OUTCOME IN PAEDIATRIC EPILEPSY

ABSTRACT

This study investigated cognitive models of illness held by children with epilepsy and their parents, and considered these in relation to measures of epilepsy treatment outcome. Cognitive models were assessed through examination of underlying core beliefs and a comprehensive assessment of treatment outcome was obtained through consideration of seizure control and psychosocial variables. It was demonstrated that the core beliefs of children and parents follow a very similar pattern and are highly correlated. It was also shown that although there was a lack of significant relationship between the measure of Quality of Life (QoL) and seizure control or other epilepsy variables, there was a strong correlation between QoL and core beliefs - those with the highest scoring positive beliefs experienced the highest QoL. Common concerns across measures were also identified and most frequently were related to discrimination, medical care and social functioning. It was concluded that there is a case for therapeutically attempting to change these aspects of cognition related to disturbances in the adjustment and functioning of children with epilepsy.

INTRODUCTION

Epilepsy is the most common serious neurological condition, affecting 420,000 people in the UK (Laville 1998). In more than half the cases there is no clearly identifiable cause and risk of premature death in people with epilepsy is three times that of the general population. Epilepsy is particularly common in childhood and has been associated with rates of emotional and behavioural psychopathology higher than those for healthy children or children with other chronic illnesses (Hoare 1984). Similarly, the experience of having epilepsy appears to lead to decreased levels of self-esteem and a negative self image in children with the condition (Matthews et al 1982, Hoare & Kerley 1991). The explanations for these emotional and behavioural problems encompass many different factors including neurological, pharmacological, psychological and psychosocial (Herman & Whitman 1991). Treatment of epilepsy, however, focuses almost exclusively on outcome in terms of seizure frequency and only recently are studies beginning to include psychosocial measures such as quality of life (Jacoby 1996). Drug treatment is but one part of the treatment required by the majority of people with epilepsy - psychological and social aspects warrant attention to some detail in virtually every patient who is subject to recurring attacks, particularly if psychopathology is indicated (Lishman 1998). For children this is leading to more attention being paid to the adverse effects on the child's adjustment and development, the restrictions on family life and activities, and the side-effects from anti-epileptic drugs (AEDs).

The treatment of epilepsy would appear to be highly appropriate for psychological intervention:

"Epilepsy originates in the brain; so do our thoughts, our feelings and our behaviour... ...Epilepsy, therefore, can change the way we think feel and behave; but, equally thought emotion and behaviour can change epilepsy" (Betts 1993, p 397).

Psychological approaches have been important in the treatment of the range of problems associated with a diagnosis of epilepsy, including anxiety, depression, low self esteem, poor sense of control, aggression and psychosis (Baker 1997). Advances have also been made in behavioural management of seizures (Kuhn, Allen & Shriver 1995), and in self-control approaches using cognitive behavioural techniques (Goldstein 1990). There is also a growing awareness in epilepsy research of the importance of patient's perceptions of their condition, their role in psychosocial and medical adjustment, and the potential for appropriate interventions in this (Morrow & Baker 1993).

Recent developments in this area include the understanding of illness in terms of cognitive models and the possible influences of these models upon treatment outcome. Weinman and Petrie (1997) argue that internal representations or cognitive models are constructed which reflect illness, and that these models help patients make sense of their experience and provide a basis for their own coping responses. A study by Weinman et al (1996) demonstrated great variation within patient models of chronic illness, even among individuals with the same disease severity. These differing models may provide explanations for variation between patients in coping responses, treatment adherence and illness-related disability - factors which have major influences upon

treatment outcome (Horne 1997, Moss-Morris et al 1996). To optimise treatment outcome and minimise difficulties, it is important to take account of patient models and cognitions such as beliefs about the cause or potential for control/cure of an illness. As has been demonstrated in other fields such as the treatment of affective disorders, cognitive therapies offer the potential for eliciting maladaptive cognitions and possibilities for challenging and restructuring erroneous or maladaptive thoughts, attitudes and beliefs. Furthermore, the recognised role of developmentally appropriate cognitive therapies in the treatment of children (Spence 1994, Ronen 1997) provides a very real potential for development of novel treatments for paediatric difficulties including the behavioural and emotional problems identified in children with epilepsy.

The aims of this study were to investigate cognitive models held by children with epilepsy and to determine the relationship of these to epilepsy treatment outcome. Cognitive models were assessed through examination of underlying core beliefs generated by the experience of epilepsy, adapted from a scale measuring these core beliefs in adults (Tedman et al 1995). A comprehensive assessment of treatment outcome was obtained through consideration of seizure control, QoL and psychosocial functioning. The following research questions were considered:

- Which core beliefs are scored most highly in the positive direction by children with epilepsy and their parents and what are the relationships between these?
  It is hypothesised that there will be a strong positive correlation between parent and child core beliefs.
- Which aspects of QoL are most compromised in children with epilepsy, and how does QoL vary with experience of epilepsy?

It is hypothesised that there will be a lack of significant relationship between QoL and seizure occurrence.

- What is the relationship between core beliefs, QoL and epilepsy experience?

  It is hypothesised that there will be a positive correlation between core beliefs and Qol. Also, the aspects of QoL identified as compromised are expected to be related to the psychosocial concerns raised and to the lowest scoring core beliefs.

METHOD

SUBJECTS

The children with epilepsy in this study were recruited from out-patient paediatric clinics at Law Hospital, Lanarkshire and the Royal Hospital for Sick Children, Glasgow.

The sample comprised, as far as possible, a consecutive series of the presenting clinical population attending on selected dates. The clinics on these selected dates (approximately two days per week over five months) were similar to such clinics held on other days and thus this sample was likely to be broadly representative of children with epilepsy in the region. For inclusion in this study, children had a minimum of six months prior to diagnosis of epilepsy, they were between six and sixteen years of age, they attended mainstream schooling and they presented at the out-patient clinics accompanied by a parent.

The major characteristics of the 47 children in the study group are summarised in Table 1. The average age was 9.9 years (range = 7-16 years) and there were almost twice as many boys as girls. The age at onset of epilepsy varied widely from infancy to 13

years. Similarly, although the mean duration of illness was 2.9 years, this ranged from six months to 13 years. Clinical classification of epilepsy showed a wide diversity of seizure pattern, with partial seizures the most common. The frequency of seizure occurrence varied widely, with 27 children experiencing one or more seizures per month. The majority of children (39) were taking a single AED, and of the entire group 43 had experienced an improvement in seizure occurrence.

Descriptive information regarding the sample of parents involved in this study was not formally collected. However, it was noted that in over 40 cases children were accompanied by only their mother. In four cases fathers completed the parental measures and in three cases, when both parents were present, one set of measures was completed jointly.

INSERT TABLE 1 HERE

ASSESSMENTS

Core Beliefs Scale

An eight-item scale (see Appendix 1) was adapted from the core beliefs scale for adults with epilepsy (Tedman et al 1995). Each core belief was presented as a statement, e.g. "You are relaxed and confident when you go out / Your child is relaxed and confident when he/she goes out". This was then scored on a five-point likert scale, according to how true it was believed to be. Senior colleagues in Clinical Psychology and Speech and Language Therapy, with experience of a paediatric epilepsy population were consulted on the appropriateness and wording of items and a final draft was used in a pilot study with four children. Corresponding versions for parents and their children

were developed and administered to allow comparison of the patterns of core beliefs held.

Impact of Childhood Illness Scale (ICIS)

The ICIS (see Appendix 1) is parental self-completion questionnaire which provides a comprehensive assessment of the quality of life of children with chronic illness and their families, and has been developed and validated on a Scottish paediatric epilepsy population (Hoare & Russell 1995). It consists of thirty questions divided into four sections (impact of illness and its treatment, impact on the child's development and adjustment, impact on parents, impact on family). For each question, the parent is asked to make a rating on two dimensions: frequency and importance. The former refers to how often a particular problem or situation arises and the latter to the amount of concern it produces. The two dimensions for each question are scored 0, 1 or 2.

Semi-Structured Interview

A semi-structured interview schedule (see Appendix 1) was developed for administration with child and parent. The primary purpose of this was to obtain data on the child's psychosocial functioning and to explore concerns or worries that the child or family had regarding the impact of the illness. Additionally this interview served as an opportunity to check information on the child's demographics and epilepsy status and history, and supplemented information from medical case-notes.

Pilot Study

A pilot study was undertaken with four children primarily to determine the time necessary to obtain the assessment information and also to ensure there were no

difficulties with the clarity or terminology of measures. The pilot study indicated that all measures could be collected within one hour and that families did not encounter problems with these measures.

PROCEDURE

Prior to each paediatric clinic attended, the author conducted a review of the medical case-notes of all children scheduled to attended and identified those children who met the criteria for inclusion in the study. Upon arrival for the clinic these children and their families were approached by the author who explained the nature and purpose of the study and supplied information sheets (see Appendix 1). Those families who consented to participate in the study completed the assessment measures either while waiting for their medical appointment, immediately following their medical appointment or were offered an appointment coinciding with their next clinic attendance. For the entire period of the study, only two families refused to consent to participation. All measures were completed with the author present with the Core Beliefs scales and the ICIS administered before semi-structured interview was conducted.

RESULTS

The three measures of assessment were analysed to determine information relating to the research questions raised: the most highly scored core beliefs of parents and children and the relationships between these, the overall outcome and highest scoring items on the ICIS, and the concerns raised regarding psychosocial functioning. The relationships between these variables were investigated using correlational and regression analyses, and difference testing as appropriate. The majority of analyses

involved non-parametric methods but when variable distributions were normal or approaching normal, parametric methods were employed.

Core Beliefs Scale

Scoring and relationship of core beliefs held by children with epilepsy and their parents

The Core Belief Scales completed by parents and children were scored according to how highly the belief was rated as being true in the positive direction. Table 2 shows the rank order and scoring of these core beliefs. The two most highly scored core beliefs are the same for both parents and children (i.e. CB1 achievement, CB4 sociability). Across the eight items in the scale there is a strong positive correlation between the scoring of beliefs held by parents and their children ($r_s = 0.706$, $p < 0.05$). In addition to the relationship between the overall scores for beliefs held by parents and children, the pattern of agreement for individual scale items was also investigated. This was achieved by means of contingency coefficients generated from parent and child scoring patterns. These contingency coefficients, reported in Table 2, indicated a positive and significant association between parent and child scores for each item (range of values 0.61 - 0.76, all $p < 0.01$).

INSERT TABLE 2 HERE

Although there was a strong positive correlation between the pattern of scoring of beliefs held by parents and children, it was also noted that the mean score of each core belief is greater for parents than for children. Difference testing (Wilcoxon test) indicates that this was a significant difference ($p < 0.05$) for three of the core beliefs

(CB1 independence, CB6 decision-making, CB7 coping) and for the total of all eight core beliefs. This is illustrated in Figure 1.

INSERT FIGURE 1 HERE

Given the similarities from a statistical perspective between the parent and child versions of this measure, initial analyses with other measures involved consideration of parent and child core beliefs together.

Impact of Childhood Illness Scale (ICIS)

Aspects of QoL most compromised through experience of epilepsy

The ICIS, completed by parents, was analysed across the two scales of frequency and severity. There was a strong positive correlation between these two dimensions (mean $r_s = 0.801$, range = 0.514 - 1.00, see Appendix 1 Table 1 for individual item values). This suggests that these two dimensions are highly dependent on each other and were not interpreted as discrete measures. Conceptually, therefore, consideration of these dimensions together is likely to provide the most representative of measures. Additionally, these very similar distributions were examined and it was determined that the sum scores most closely approximated normal distribution and would be the more useful measure for further analyses.

These values were analysed across the whole scale, and the 10 items ranked most highly have been listed in Table 3. Similarly these values were considered within the four sub-scales of the ICIS and the highest rated items within each sub-scale are listed in Table 4.

INSERT TABLES 3 & 4 HERE

Psychosocial functioning

Concerns raised regarding psychosocial functioning

The semi-structured interviews indicated that for the majority of children, no problems with psychosocial functioning were reported. Thirty-seven children had good peer relations, 46 children had hobbies and interests they enjoyed and 34 children were involved in peer group activities outside the home. Similarly most children achieved satisfactorily at school. For 38 of the children no problems were reported with school attendance and for 39 children there were no problems with school attainment.

The concerns and worries which the families raised were examined by the author and categorised according to type. These comprised seven discrete categories, the proportions of which are illustrated in Figure 2. (See Appendix 1, Table 2 for examples of items within each category). The most commonly raised concerns and anxieties were those regarding to discrimination and those pertaining to medical problems.

INSERT FIGURE 2 HERE

Relationships between variables

Nature of the relationships between core beliefs, QoL and epilepsy experience

Table 5 summarises the results of statistical analyses performed across the Core Beliefs Scale, the ICIS and the range of demographic and epilepsy variables (see Appendix 1 Table 3 for details of categorisation of epilepsy and demographic variables). It is indicated that there are no significant relationships between either of the scales and the

variables studied. This was further confirmed through multiple regression analyses which indicated a lack of predictive power between these variables and the two scales considered.

INSERT TABLE 5 HERE

In particular, the lack of a significant relationship between the ICIS and seizure experience is noted. Similarly there is a lack of significant relationship between core beliefs and seizure experience. In contrast correlation of the Core Beliefs Scale and the ICIS indicated a strong negative correlation ($r_s = -0.881$, $p < 0.005$). Similarly each of the four sub-scales comprising the ICIS were negatively correlated with the Core Beliefs Scale (see Appendix 1 Table 4). Finally, Figure 3 illustrates links between the highest scoring items on the ICIS, the most commonly raised psychosocial concerns and the lowest scoring core beliefs. In particular the themes of medical concerns and concerns about being treated differently from others appear to be common.

INSERT FIGURE 3 HERE

DISCUSSION

Summary of results

This study aimed to investigate the core beliefs of children with epilepsy and their parents, and the relationships between these and measures of epilepsy experience, QoL and psychosocial functioning. It was demonstrated that the core beliefs of children and parents follow a very similar pattern and that the core beliefs scored most highly in the positive direction by both parents and children pertain to the potential for high

achievement and the ability to interact well socially. The QoL of the children in this study is most affected through difficulties in explaining illness, the need for supervision and long-term medication, and the risks of injury. The most frequently raised concerns were those regarding discrimination, medical care and social functioning. It was also shown that although there was a lack of significant relationship between QoL and seizure control or other epilepsy variables, there was a strong negative correlation between QoL and core beliefs. Those with the highest scoring positive beliefs experienced the highest QoL as measured on the ICIS.

Limitations of study

Although it was anticipated that there would be a relationship between core beliefs and QoL in this study, the very strong positive correlation obtained was unexpected. This raises the possibility that there was a high degree of parallel measurement in these scales. Conceptually, core beliefs as a means of investigating cognitive models might be expected to be independent from QoL measures, the latter generally encompassing an individual's feelings of satisfaction with a complex amalgam of areas of functioning (Kendrick 1997). However, it would appear that the scales used are not entirely achieving their conceptual ends and given the strong focus in both scales on illness, it recognised that there is a degree of overlap in item content and domain of reference (eg CB1. Your child could get to the top of the ladder if given the opportunity; ICIS 12. My child is less clever because of his illness). It is acknowledged that although the ICIS is advocated as a measure of QoL for children with epilepsy and their families, it is in fact a very much more focused measure than other generic QoL scales. This focus on the experience of illness suggests that the ICIS cannot be readily equated with the more multidimensional concept of QoL, and should perhaps be interpreted only as a measure

of the experience of living with a chronic illness such as epilepsy. This is of course an important element of the QoL of children with epilepsy but it is not sufficient as an exclusive measure. It is also noteworthy that the version of the Core Belief Scale used for this study was adapted from a scale originally developed for an adult population. There may be therefore, features of epilepsy in childhood which are unique, and this scale may lack sensitivity to these factors. The potential remains for the development of such a scale exclusively with a child population.

Much of the information in this study was obtained through self-report and although some data was corroborated through medical case notes, there is certainly the potential for additional sources of independent information such as school reports. It is also acknowledged that although the categorisation of concerns raised by families would appear to comprise discrete groupings, some concerns may be interpreted as influencing more than one category. This suggestion of some inter-dependence may merit further investigation through consideration of the inter-rater reliability of a sub-set of the concerns raised. It is also recognised that although this sample was broadly representative of children with epilepsy, it is does not generalise to the entire population. Children not attending mainstream schooling were not included and they are a group more likely to have significant additional difficulties and have their QoL more severely impacted through the experience of having epilepsy. Also, this study did not attempt to focus on particular forms of epilepsy in childhood although in the analysis of results, classification of type and seizure experience was utilised. It is recognised that there is enormous variation in childhood epilepsy - in type, severity and association with other conditions. This raised the question whether generalised statements are appropriate and whether a more profitable line of future inquiry may be to focus within more specific and similar epilepsy experiences.

Conclusions

Given the results of this study, particularly in relation to the correlation between core beliefs and QoL, it would appear that there is further justification for the development of cognitive techniques for children with epilepsy. There should be attempts to modify the underlying core beliefs that people have about their condition which may cause psychological impairments. Families should also be considered as important targets for modifying beliefs about the epilepsy, its cause and its management. It is necessary to correct misperceptions and prejudices and to enable these children to regard themselves in as normal a light as possible, to foster social and emotional development. In some instances epilepsy remains a stigmatised and unnecessarily over-protected condition, but, while many fears and restrictions are unnecessary, the reality is that people with epilepsy are always subject to a higher degree of risk and are likely to be discriminated against. However, it is encouraging to consider the relatively low level of impact that many of the families studied here are allowing this disorder to have on their lives - the majority of children were functioning well both psychosocially and educationally. This may reflect reported emerging trends to more positive and open attitudes towards people with epilepsy (Richards and Reiter 1990), and may enable some fulfilment of the potential benefits and enrichment that can occur when the child and family adapt successfully to a condition such as epilepsy (Hoare 1993).

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TABLE 1.

SUMMARY OF DESCRIPTIVE DEMOGRAPHIC AND EPILEPSY VARIABLES OF THE STUDY GROUP

SUBJECTS			
AGE (mean)	9.9 YEARS		
SEX			
MALE	30 CHILDREN	64%	
FEMALE	17 CHILDREN	36%	
EPILEPSY VARIABLES			
SEIZURE TYPE			
GENERALISED	10 CHILDREN	21%	
GENERALISED (Absence)	9 CHILDREN	19%	
PARTIAL	17 CHILDREN	37%	
MIXED	11 CHILDREN	23%	
ONSET AGE (mean)	6.9 YEARS		
ILLNESS DURATION (mean)	2.9 YEARS		
FAMILY HISTORY OF EPILEPSY	13 CHILDREN	28%	
AED			
MONOTHERAPY	39 CHILDREN	84%	
POLYTHERAPY	4 CHILDREN	8%	
NONE	4 CHILDREN	8%	
SEIZURE FREQUENCY (monthly)	MEAN	MEDIAN	RANGE
CURRENT	12.80	1.25	0-300
CURRENT (excluding absences only)	4.64	0.75	0-60
PREVIOUS	71.27	30	1-900
PREVIOUS(excluding absences only)	26.84	8	1-150

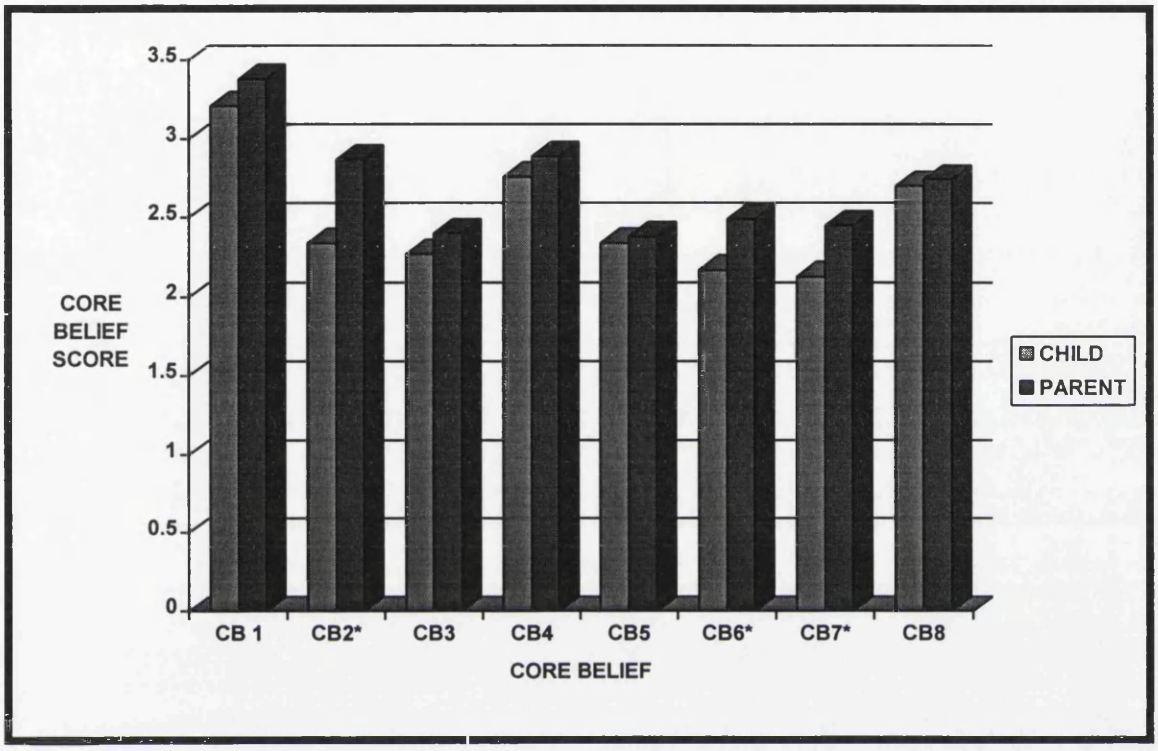
TABLE 2.

CHILD AND PARENT RANKING AND MEAN SCORE OF CORE BELIEFS AND CONTINGENCY COEFFICIENTS OF PARENT AND CHILD SCORING PATTERNS

	RANKINGS				PARENT x CHILD
	CHILD		PARENT		
BELIEF	RANK	MEAN (SD)	RANK	MEAN (SD)	CONTINGENCY COEFFICIENT
CB1 Achievement	1	3.21 (0.72)	1	3.38 (0.68)	0.686, $p < 0.001$ df = 9
CB2 Independence	4	2.34 (1.26)	3	2.87 (1.08)	0.661, $p = 0.002$ df = 16
CB3 Difference	6	2.27 (1.38)	7	2.40 (1.47)	0.704, $p < 0.001$ df = 16
CB 4 Sociability	2	2.76 (1.38)	2	2.89 (1.15)	0.732, $p < 0.001$ df = 16
CB 5 Perceptions	5	2.32 (1.09)	8	2.38 (1.31)	0.685, $p < 0.001$ df = 16
CB 6 Decisions	7	2.17 (1.25)	5	2.49 (1.36)	0.664, $p < 0.002$ df = 16
CB 7 Coping	8	2.13 (1.39)	6	2.45 (1.41)	0.607, $p < 0.004$ df = 16
CB 8 Confidence	3	2.70 (1.18)	4	2.74 (1.37)	0.756, $p < 0.001$ df = 12

FIGURE 1.

DIFFERENCES BETWEEN MEAN SCORE OF PARENT AND CHILD CORE BELIEFS



* $p < 0.05$ (Wilcoxon)

TABLE 3.

TEN HIGHEST RANKED ITEMS FROM THE ICIS BASED ON TOTAL OF FREQUENCY AND SEVERITY SCORES

RANK	VALUE	ITEM
1	94	19. IT IS DIFFICULT TO EXPLAIN MY CHILD'S ILLNESS TO OTHERS
2	91	14. BECAUSE OF HIS ILLNESS MY CHILD MUST BE MORE CLOSELY WATCHED THAN OTHERS
3	90	21. MY CHILD MAY HAVE TO TAKE MEDICATION FOR YEARS
4	81	2. THERE IS A RISK HE MAY INJURE HIMSELF
5	80	20. IT IS DIFFICULT TO EXPLAIN MY CHILD'S ILLNESS TO HIM
6	69	6. MY CHILD IS MORE MOODY BECAUSE OF HIS ILLNESS
7	60	7. HE IS SHY AND EASILY EMBARRASSED
8.5	56	4. THE MEDICATION MY CHILD TAKES MAKES HIM LESS ALERT
8.5	56	29. MY CHILD IS MORE DIFFICULT TO MANAGE BECAUSE OF HIS ILLNESS
10	50	13. MY CHILD MAY NOT FIND A JOB WHEN HE LEAVES SCHOOL

TABLE 4.

SUBSCALES AND HIGHEST RATED ITEMS WITHIN EACH ON ICIS

SUBSCALE AND MOST IMPORTANT ITEMS

IMPACT ON PARENTS
19. IT IS DIFFICULT TO EXPLAIN MY CHILD'S ILLNESS TO OTHERS
20. IT IS DIFFICULT TO EXPLAIN MY CHILD'S ILLNESS TO HIM

IMPACT OF EPILEPSY AND ITS TREATMENT
2. THERE IS A RISK HE MAY INJURE HIMSELF
4. THE MEDICATION MY CHILD TAKES MAKES HIM LESS ALERT

IMPACT ON DEVELOPMENT AND ADJUSTMENT
14. MY CHILD MAY HAVE TO TAKE MEDICATION FOR YEARS
6. MY CHILD IS MORE MOODY BECAUSE OF HIS ILLNESS

IMPACT ON FAMILY
21. BECAUSE OF HIS ILLNESS MY CHILD MUST BE MORE CLOSELY WATCHED THAN OTHER CHILDREN
29. MY CHILD IS MORE DIFFICULT TO MANAGE BECAUSE OF HIS ILLNESS

FIGURE 2.

CATEGORISATION OF CONCERNS AND ANXIETIES RAISED BY FAMILIES

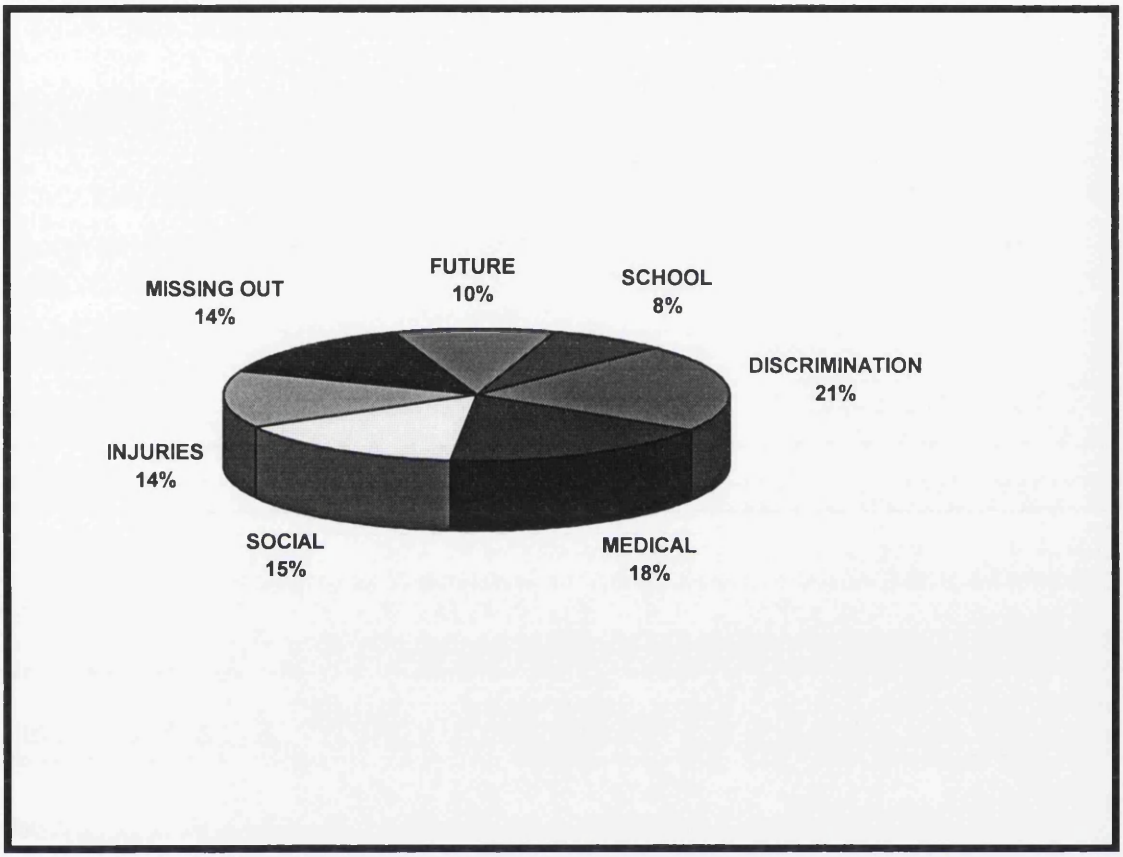


TABLE 5.

SUMMARY OF CORRELATIONAL AND DIFFERENCE ANALYSES ON CORE BELIEF SCALE AND ICIS WITH DEMOGRAPHIC AND EPILEPSY VARIABLES

DEMOGRAPHIC / EPILEPSY VARIABLES	CORE BELIEF SCALE	ICIS
SEX	$U = 196, p = 0.191$	$U = 238, p = 0.706$
AGE	$r_s = 0.253, p = 0.086$	$r_s = -0.193, p = 0.200$
ONSET AGE	$r_s = 0.146, p = 0.328$	$r_s = -0.160, p = 0.283$
ILLNESS DURATION	$r_s = 0.146, p = 0.327$	$r_s = -0.050, p = 0.736$
EPILEPSY FAMILY HISTORY	$U = 218, p = 0.943$	$U = 220, p = 0.981$
SEIZURE TYPE	$KW = 2.802, p = 0.423$	$KW = 3.894, p = 0.273$
CONTROL	$U = 246, p = 0.613$	$U = 220, p = 0.286$
SEIZURE FREQUENCY	$r_s = -0.144, p = 0.167$	$r_s = 0.211, p = 0.155$
SEIZURE FREQUENCY (EXCLUDING ABSENCES)	$r_s = -0.152, p = 0.309$	$r_s = 0.218, p = 0.141$
PREVIOUS SEIZURE FREQUENCY	$r_s = 0.118, p = 0.431$	$r_s = -0.164, p = 0.272$
PREVIOUS SEIZURE FREQUENCY (EXC. ABSENCES)	$r_s = -0.062, p = 0.677$	$r_s = 0.153, p = 0.304$
MULTIPLE REGRESSION	Adjusted $R^2 = -0.013$	Adjusted $R^2 = 0.083$

(Mann-Whitney test, Spearman correlation, Kruskal-Wallis test, Multiple Regression analysis)

FIGURE 3.

LINKS BETWEEN HIGHEST SCORING ITEMS ON THE ICIS, MOST COMMONLY RAISED PSYCHOSOCIAL CONCERNS AND LOWEST SCORING CORE BELIEFS.

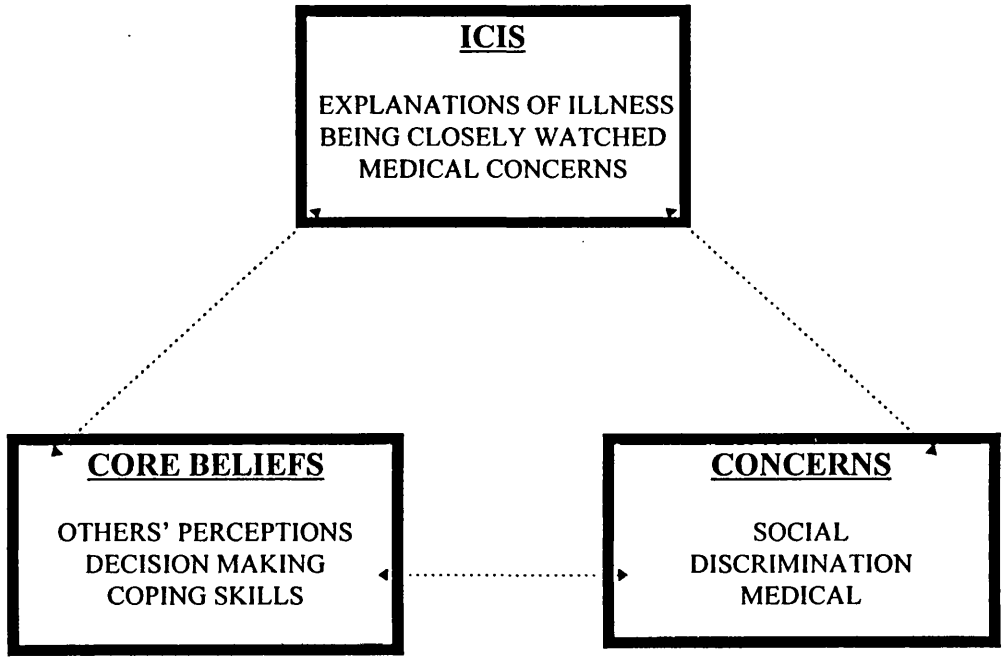
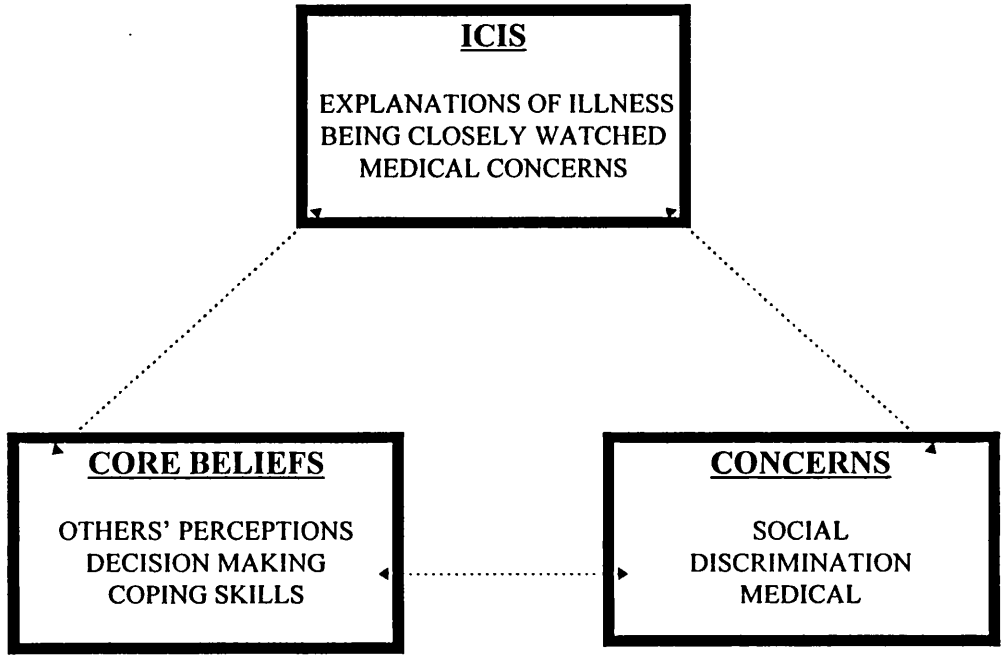


FIGURE 3.

LINKS BETWEEN HIGHEST SCORING ITEMS ON THE ICIS, MOST COMMONLY RAISED PSYCHOSOCIAL CONCERNS AND LOWEST SCORING CORE BELIEFS.



APPENDIX 1

MAJOR RESEARCH PROJECT PAPER

CORE BELIEFS AND TREATMENT OUTCOME IN PAEDIATRIC EPILEPSY

- Core Beliefs Scale (child)
- Core Beliefs Scale (parent)
- Impact of Childhood Illness Scale
- Semi -Structured Interview Schedule
- Information Sheet (child)
- Information Sheet (parent)
- Tables 1 - 4

CORE BELIEFS AND SELF EFFICACY SCALE (CHILD VERSION)

Please mark the scale below according to how much you believe the following statements to be true or untrue.

1. You could be the best at what you want to do if you are given the chance.

0	1	2	3	4
NOT TRUE				VERY TRUE

2. You can do as much as you want on your own.

0	1	2	3	4
NOT TRUE				VERY TRUE

3. You feel different from others of your own age.

0	1	2	3	4
NOT TRUE				VERY TRUE

4. You can go out and mix with others as much as you want to.

0	1	2	3	4
NOT TRUE				VERY TRUE

5. You are not sure how others think and feel about you.

0	1	2	3	4
NOT TRUE				VERY TRUE

6. You rely on others to help you make decisions.

0	1	2	3	4
NOT TRUE				VERY TRUE

7. You worry about how you'll cope as you get older.

0	1	2	3	4
NOT TRUE				VERY TRUE

8. You are confident and relaxed when you go out.

0	1	2	3	4
NOT TRUE				VERY TRUE

CORE BELIEFS AND SELF EFFICACY SCALE (PARENT VERSION)

Please mark the scale below according to how much you believe the following statements to be true or untrue for your child.

1. Your child could get to the top of the ladder if given the opportunity.

0	1	2	3	4
NOT TRUE				VERY TRUE

2. Your child has as much independence as he/she wants.

0	1	2	3	4
NOT TRUE				VERY TRUE

3. Your child feels different from others of a similar age.

0	1	2	3	4
NOT TRUE				VERY TRUE

4. Your child can go out and mix with others as much as he/she wants.

0	1	2	3	4
NOT TRUE				VERY TRUE

5. Your child is not sure how others think and feel about him/her.

0	1	2	3	4
NOT TRUE				VERY TRUE

6. Your child relies on others to help make decisions.

0	1	2	3	4
NOT TRUE				VERY TRUE

7. Your child worries about coping as they grow older.

0	1	2	3	4
NOT TRUE				VERY TRUE

8. Your child is confident and relaxed when he/she goes out.

0	1	2	3	4
NOT TRUE				VERY TRUE

IMPACT OF CHILDHOOD ILLNESS SCALE

This questionnaire is for completion by parents of children with long-standing illnesses. All questions refer to the effect that the illness has had on your child, on you as a parent or to your family as a whole. It should be answered with reference to the past year.
Each question consists of a statement followed by two sets of answers (0,1,2 and A,B,C). The first set of questions refers to how frequently the problem occurs. You should reply by circling: **never or rarely true = 0; sometimes true = 1; often or really true = 2.**
The second set of questions refers to how much concern it causes. You should answer by circling: **A = a lot of concern; B = a bit of concern; C = not much concern.**

1. Because of my child's illness he may stop breathing	**0 1 2**	**A B C**
2. There is a risk he may injure himself	**0 1 2**	**A B C**
3. There is a risk he may be brain damaged or even die	**0 1 2**	**A B C**
4. The medication my child takes makes him less alert	**0 1 2**	**A B C**
5. The medication makes his behaviour worse	**0 1 2**	**A B C**
6. My child is more moody because of his illness	**0 1 2**	**A B C**
7. He is shy and more easily embarrassed	**0 1 2**	**A B C**
8. Because of my child's illness, he is teased and bullied	**0 1 2**	**A B C**
9. Because of my child's illness, he has few friends	**0 1 2**	**A B C**
10. Because of my child's illness, he has fewer interests	**0 1 2**	**A B C**
11. Because of his illness, my child has special problems with reading or maths	**0 1 2**	**A B C**
12. My child is less clever because of his illness	**0 1 2**	**A B C**
13. My child may not find a job when he leaves school	**0 1 2**	**A B C**
14. My child may have to take medication for years	**0 1 2**	**A B C**
15. My child may not marry or have a family	**0 1 2**	**A B C**
16. My child makes a fuss about taking his medicine	**0 1 2**	**A B C**
17. Because of my child's illness it is difficult for him to use public transport	**0 1 2**	**A B C**
18. He is less able to care for himself	**0 1 2**	**A B C**
19. It is difficult to explain my child's illness to others	**0 1 2**	**A B C**
20. It is difficult to explain my child's illness to him	**0 1 2**	**A B C**
21. Because of his illness my child must be more closely watched than other children	**0 1 2**	**A B C**
22. It is difficult to give my other children enough attention	**0 1 2**	**A B C**
23. My child's illness limits what his brothers and sisters can do	**0 1 2**	**A B C**
24. We have to restrict our holidays	**0 1 2**	**A B C**
25. His illness means we have fewer friends round	**0 1 2**	**A B C**
26. My child's illness limits how often we go out as a family	**0 1 2**	**A B C**
27. We have more arguments at home	**0 1 2**	**A B C**
28. We go out less often in the evening as a couple	**0 1 2**	**A B C**
29. My child is more difficult to manage because of his illness	**0 1 2**	**A B C**
30. Because of his illness we turn down opportunities at work	**0 1 2**	**A B C**

SEMI-STRUCTURED INTERVIEW

DEMOGRAPHIC

age -

sex -

EPILEPSY HISTORY

age at onset -

family history of epilepsy -

clinical classification -

current seizure control (frequency and severity) -

previous seizure control (frequency and severity) -

current treatment (poly/mono pharmacy) -

drug toxicity -

treatment compliance

PSYCHO-SOCIAL

peer relations, hobbies, activities -

school attendance and attainment -

anxieties, worries, concerns -

INFORMATION SHEET (CHILD)

This is to tell you about a project which we would like you to take part in.

WHAT THE PROJECT IS ABOUT

We want to find out more about children like yourself, who have epilepsy. We are interested in asking you about how you feel about having seizures and what difference this makes to your life. This will help us when we talk to other children about what might be worrying them about epilepsy.

WHAT WE WOULD LIKE YOU TO DO

You don't have to do anything if you don't want to! If you would like to take part in this project then someone will speak to you when you come to the clinic for one of your appointments. They will ask you to fill in a sheet with eight questions (there are no right or wrong answers to these questions - they are about how you feel). If your mum or dad is with you, they will be given some questions to answer too. Once you have done this, someone will spend a few minutes talking to you about what it is like to have epilepsy. This is all you will be asked to do, you don't have to talk about anything you don't want to and all the answers you give will kept private. Please ask if you have any questions.

INFORMATION SHEET (PARENT)

AN INVESTIGATION INTO THE RELATIONSHIP BETWEEN CORE BELIEFS, TREATMENT OUTCOME AND QUALITY OF LIFE IN CHILDREN WITH EPILEPSY

WHAT IS THIS ALL ABOUT?

You are being invited to take part in a research study. The aim of the study is to investigate psychological influences on the outcome of epilepsy treatment in children. Specifically this means looking at the beliefs and attitudes of children with epilepsy and their parents, and comparing this with seizure control and the impact that epilepsy is having on their life overall. Ultimately it is hoped that this study will aid in the development of psychological treatments to complement medical treatments in epilepsy, to improve seizure control and treatment outcome. Your participation in this study may not be of direct benefit to you at this point in time but will help in the development of treatment for future patients and perhaps for you in the future.

WHAT WILL THIS INVOLVE?

If you agree to participate then you will be approached during one of your routine clinic appointments and while you are waiting or perhaps after your appointment, a researcher will collect some information from you. You will be asked to fill in some short questionnaires (one for your child and two for you as parent/carer), you will also be asked for some background information about your child's medical history and current health. This will only take place once and should take no longer than an hour to complete. A researcher will be available throughout to answer any queries you may have.

DO I HAVE TO TAKE PART?

This study is entirely voluntary. If you do not wish to take part or wish to withdraw at any time after commencing, you may do so without the need to give an explanation and your care will not be affected in any way. Also you are assured that if you do take part, all the information you supply is entirely confidential. Information is stored anonymously and cannot be traced back to individuals.

Sheenagh Macdonald
Department of Clinical Psychology

TABLE 1.

CORRELATIONS BETWEEN FREQUENCY AND SEVERITY SCORES ON ICIS

ITEM	SPEARMAN'S CORRELATION	ITEM	SPEARMAN'S CORRELATION
1	0.951	16	0.668
2	0.896	17	0.629
3	0.659	18	0.736
4	0.811	19	0.701
5	0.846	20	0.716
6	0.837	21	0.903
7	0.917	22	0.874
8	0.817	23	0.807
9	0.958	24	0.744
10	1.0	25	0.815
11	0.894	26	0.606
12	0.899	27	0.913
13	0.860	28	0.797
14	0.514	29	0.722
15	0.734	30	0.836

TABLE 2

EXAMPLES OF CONCERNS RAISED WITHIN DESCRIPTIVE CATEGORIES

CATEGORY	EXAMPLES
DISCRIMINATION	"people hold this (epilepsy) against him" "is labelled as handicapped" "people make too much of a fuss about it (epilepsy)"
MEDICAL	"has to go to the doctor all the time" "will have to take medication long-term" "his condition may deteriorate"
SOCIAL	"very shy and quiet" "becoming more self-conscious as she gets older" "rejected by friends"
INJURIES	"doesn't recognise limitations - may get hurt" "may get injured if he has a fit while alone" "unaware of the danger he may be in"
MISSING OUT	"stopped from doing things I want" "not allowed to play football" "broken-hearted when not allowed to go to Brownies"
FUTURE	"others may not be as understanding in the future" "won't cope when older and we (parents) have less control" "may not grow out of this"
SCHOOL	"worried about the move to High School" "missing lots of school work" "mum has to come on school trips"

TABLE 3

CATEGORISATION OF EPILEPSY AND DEMOGRAPHIC VARIABLES USED IN ANALYSIS

VARIABLE	CATEGORISATION
SEX	MALE/FEMALE
AGE	CONTINUOUS (7-16)
ONSET AGE	CONTINUOUS (0-13)
EPILEPSY FAMILY HISTORY	POSITIVE/NEGATIVE
SEIZURE TYPE	GENERALISED, GENERALISED (ABSENCE), PARTIAL, MIXED
SEIZURE CONTROL	POOR/WELL CONTROLLED - BASED ON MORE THAN ONE SEIZURE PER MONTH OVER PAST SIX MONTHS
SEIZURE FREQUENCY	CONTINUOUS
SEIZURE FREQUENCY (EXCLUDING ABSENCE SEIZURES)	CONTINUOUS
PREVIOUS SEIZURE FREQUENCY	CONTINUOUS
PREVIOUS SEIZURE FREQUENCY (EXCLUDING ABSENCE SEIZURES)	CONTINUOUS

TABLE 4.

CORRELATION BETWEEN ICIS SUB-SCALES AND CORE BELIEFS SCALE

ICIS SUB-SCALE	CORRELATION
IMPACT ON PARENTS	$r_s = -0.529, p < 0.05$
IMPACT OF EPILEPSY AND ITS TREATMENT	$r_s = -0.698, p < 0.05$
IMPACT ON DEVELOPMENT AND ADJUSTMENT	$r_s = -0.530, p < 0.05$
IMPACT ON FAMILY	$r_s = -0.731, p < 0.05$

APPENDIX 2

SINGLE CLINICAL CASE RESEARCH ABSTRACTS

SINGLE CLINICAL CASE RESEARCH STUDY - 1

OBSESSIVE-COMPULSIVE DISORDER IN PRADER-WILLI SYNDROME

Summary. This study presented the successful treatment of Obsessive-Compulsive Disorder in a twenty-six year old woman with Prader-Willi syndrome (PWS). Treatment involved exposure and response prevention techniques but also included psycho-education and cognitive strategies. Previously documented evidence indicated effectiveness of such an approach for the treatment of OCD in the learning disabled population and the treatment of food obsessions in PWS, but this study pointed to an additional role for reducing non-food compulsions in PWS. It was also suggested that underlying concerns about weight were implicated in this case and that such concerns may be pertinent in the increased risk of OCD in PWS. Additionally it was argued that this information added to the body of research on the PWS behavioural phenotype, which is important in accurate diagnosis and treatment.

SINGLE CLINICAL CASE RESEARCH STUDY - 2

COGNITIVE-BEHAVIOURAL TREATMENT OF CHILDHOOD FOOD PHOBIA

ABSTRACT

This study described assessment and treatment of a ten year old boy with chronic refusal of solid food resulting in weight loss and malnutrition. Psychological, behavioural and medical assessments indicated no other significant disorders. The eating problem was conceptualised as a phobic disorder maintained by family factors reinforcing the avoidant behaviour, and was also considered as food avoidance emotional disorder (FAED). Cognitive-behavioural interventions targeting behavioural, social , nutritional and developmental components were utilised in treatment. Outcome of treatment was successful reintroduction of solid foods, a balanced and nutritionally adequate diet and weight gain.

Key Words: phobia, eating disorders, food-avoidance-emotional-disorder (FAED).

SINGLE CLINICAL CASE RESEARCH STUDY - 3

FAMILY WORK WITH OBSESSIVE-COMPULSIVE DISORDER

ABSTRACT

This study presented the successful treatment of a fifteen year old boy with Obsessive-Compulsive Disorder (OCD). The treatment approach encompassed anxiety-management training and cognitive behavioural (CBT) techniques including exposure and response prevention. The treatment context remained family based throughout and issues pertinent to the whole family became a major focus of treatment. Treatment gains were achieved not only in OCD symptomatology but also in the reported functioning of other family members. These results indicate that this is a useful approach for treating this disorder when family issues are contributory. It is argued that in this case the role of the family in treatment goes beyond that of merely facilitating CBT interventions and provides an opportunity for intervention on the impact of common anxieties and distress.

Key Words: obsessive-compulsive disorder, children and adolescents, treatment, families, cognitive-behaviour therapy.

APPENDIX 3

NOTES FOR CONTRIBUTORS

Notes for contributors for *The British Journal of Medical Psychology*

NOTES FOR CONTRIBUTORS

1. The *British Journal of Medical Psychology* is an international journal with a traditional orientation towards psychodynamic issues. Whilst maintaining a broad theoretical base and insisting upon sound and sensible methodology its objective is to avoid the more simplistic approaches to psychological science.

The Journal aims to bring together the medical and psychological disciplines and this is reflected in the composition of the Editorial Team. Collaborative studies between psychiatrists and psychologists are especially encouraged.

Original theoretical and research contributions are invited from the fields of psychodynamic and interpersonal psychology, particularly as they have a bearing upon vulnerability to, adjustment to and recovery from both medical and psychological disorders.

The Journal aims to promote theoretical and research developments in the fields of subjective psychological states and dispositions, interpersonal attitudes, behaviour and relationships and psychotherapy. Clinical or case studies will be considered only if they illustrate unusual forms of psychopathology or innovative forms of therapy which carry important theoretical implications. In all studies concise and clear presentation is essential and it is strongly recommended that the patient's permission to publish is sought.

2. The circulation of the Journal is world-wide. There is no restriction to British authors: papers are invited and encouraged from authors throughout the world.

3. The readers are medical psychologists, in particular those concerned with psychotherapy, from the disciplines of psychology, sociology and medicine. Thus they include clinical psychologists, psychiatrists and social workers.

4. Papers should be as short as is consistent with clear presentation of the subject matter; in general they should not exceed 5000 words. The title should indicate as briefly as possible the subject of the article. A 200 word summary should be provided but, with experimental papers, should specify hypotheses, methods, results and conclusions.

5. Brief Reports limited to 1000 words may include research studies and theoretical, critical or review comments whose essential contribution can be made briefly. They also include research studies whose importance or breadth of interest are insufficient to warrant publication as a full article or case reports making a distinctive contribution to theory or technique. A summary of not more than 50 words should be provided.

6. The Code of Conduct of The British Psychological Society requires psychologists 'Not to allow their professional responsibilities or standards of practice to be diminished by considerations of religion, sex, race, age, nationality, party politics, social standing, class or other extraneous factors'. The Society resolves to avoid all links with psychologists and psychological organizations and their formal representatives that do not affirm and adhere to the principles of the clause of its Code of Conduct. In cases of doubt the Journals Office asks authors to sign a document confirming their adherence to these principles.

7. Publication is speeded by care in preparation.

(a) Contributions should be typed in double spacing with wide margins and only one side of each sheet. Sheets should be numbered. The top copy and at least three good duplicates should be submitted and a copy should be retained by the author.

(b) This journal operates a policy of blind peer review. Papers will normally be scrutinized and commented on by at least two independent expert referees as well as by the editors or an associate editor. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to a removable front page and the text should be free of such clues as identifiable self-citations ('In our earlier work...'). The paper's title should be repeated on the first page of the text.

(c) Tables should be typed in double spacing on separate sheets. Each should have a self-explanatory title and should be comprehensible without reference to the text. They should be referred to in the text by arabic numerals. Data given should be checked for accuracy and must agree with mentions in the text.

(d) Figures, i.e. diagrams, graphs or other illustrations, should be on separate sheets, numbered sequentially 'Fig. 1' etc., and each identified on the back with the author's name and the title of the paper. They should be carefully drawn, larger than their intended size, suitable for photographic reproduction and clear when reduced in size.

(e) Bibliographical references in the text should quote the author's name and the date of publication thus: Jones (1989). They should be listed alphabetically by the author at the end of the article according to the following format:

Herbert, M. (1993). *Working with Children and the Children Act*, pp. 76–106. Leicester: The British Psychological Society.

Smith, P. B., Petersen, M. F. & Misumi, J. (1994). Event management and work team effectiveness in Japan, Britian and the USA. *Journal of Occupational and Organizational Psychology*, 67, 33–44.

Particular care should be taken to ensure that references are accurate and complete. Where books are available in both hardback and paperback please give references to both editions and publishers. Give all journal titles in full.

(f) SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses. A guide to SI Units is given in the BPS *Style Guide*, available at £3.50 per copy from The British Psychological Society, St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK.

(g) Authors are required to avoid the use of sexist language.

(h) Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the editors together with the article, for simultaneous refereeing.

8. Proofs are sent to authors for correcting of print, but not for introduction of new or different material. They should be returned to the Press Editor as soon as possible. Fifty complimentary copies of each paper are supplied to the senior author; further copies may be ordered on a form supplied with the proofs.

9. Submission of a paper implies that it has not been published elsewhere and is not currently under submission for publication elsewhere. Authors are responsible for getting written permission to publish lengthy quotations, illustrations, etc., of which they do not own the copyright.

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Notes for contributors for *Clinical Child Psychology and Psychiatry*

CLINICAL CHILD PSYCHOLOGY AND PSYCHIATRY

AIMS AND SCOPE

Clinical Child Psychology and Psychiatry brings together clinically oriented work of the highest distinction from an international and multidisciplinary perspective, offering comprehensive coverage of clinical and treatment issues across the range of treatment modalities.

Clinical Child Psychology and Psychiatry is interested in advancing theory, practice and clinical research in the realm of child and adolescent psychology and psychiatry and related disciplines.

The journal directs its attention to matters of clinical practice, including related topics such as the ethics of treatment and the integration of research into practice.

Multidisciplinary in approach, the journal includes work by, and is of interest to, child psychologists, psychiatrists and psychotherapists, nurses, social workers and all other professionals in the fields of child and adolescent psychology and psychiatry.

INSTRUCTION TO AUTHORS

The Editor apologizes for the apparent pedantry of these instructions, but emphasizes that adherence to them will ensure rapid and efficient processing of your contributions, and will enhance the article itself.

Submission of MSS. Four copies of each manuscript, **typed in double spacing throughout**, and on one side only of white A4 or US standard size paper, should be sent to the Editor at the address given below.

Format of MSS. Each manuscript should contain the following, in the correct order.

(a) Title page to include the title of the paper, full name of each author, current professional position and work context, and indicators of which author will be responsible for correspondence. A word count should also be included.

(b) Abstract page: the abstract itself not to exceed 200 words (150 for preference), and up to 5 key words to be listed on the same page. This page should carry the title of the paper but not the author name(s).

(c) Main text: not usually to exceed 7500 words and to be clearly organized, with a clear hierarchy of headings and subheadings (3 weights of heading maximum).

(d) References: Citation of references follows APA (American Psychological Association) style. References cited in the text should read thus: Brown (1955: 63–64); (Brown, 1995, pp. 63–64; Green & Brown, 1992, p. 102, table 3). The letters a, b, c, etc., should distinguish citations of different works by the same author in the same year (Black, 1989a, 1989b). All references cited in the text should appear in an alphabetical list, after the Notes section.

(e) Figure, tables, etc.: should be numbered consecutively, carry descriptive captions and be clearly cited in the text. Keep them separate from the text itself, but indicate an approximate location on the relevant text page.

(f) Author biographies: On a separate sheet provide a one-paragraph bio-bibliographical note for each author – up to 100 words for a single author, but none to exceed 65 words in a multi-authored paper.

Style. Use a clear and readable style, avoiding jargon. If technical terms must be included, define them when first used. Use plurals rather than he/she, (s)he, his or hers: 'If a child is unhappy, he or she...' is much better expressed as 'When children are unhappy, they...'.

Spelling. British or American spellings may be used (the 'z' versions of British spellings are preferred to the 's' versions, as given in the Oxford English Dictionary).

Punctuation. Use single quotation marks, with double inside single. Present dates in the form 9 May 1996. Do not use points in abbreviations, contractions or acronyms (e.g. DC, USA, DR, UNESCO).

Covering letter. Attach to every submission a letter confirming that all authors have agreed to the submission and that the article is not currently being considered for publication by any other journal. The name, address, telephone and fax number of the corresponding author should always be clearly indicated, and an email address would be very welcome.

Disks. On acceptance of your MS for publication you will be asked to supply a diskette (IBM-compatible or Mac) of the final version.

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Mailing. Address MSS to the Editor: **Dr Bryan Lask, Consultant Psychiatrist, Department of Psychological Medicine, Great Ormond Street Hospital, Great Ormond Street, London WC1N 3JH, UK.**

Books for review should be sent to: **Bernadette Wren**, 177 Brooke Road, London E5 8AB, UK.

Guidelines for Major Research Project Proposal

1.1 Applicants - names and addresses including the names of co-workers and supervisor(s) if known.

1.2 Title - no more than 15 words.

1.3 Summary - No more than 300 words, including a reference to where the study will be carried out.

1.4 Introduction - of less than 600 words summarising previous work in the field, drawing attention to gaps in present knowledge and stating how the project will add to knowledge and understanding.

1.5 Aims and hypothesis to be tested - these should wherever possible be stated as a list of questions to which answers will be sought.

1.6 Plan of investigation - consisting of a statement of the practical details of how it is proposed to obtain answers to the questions posed. The proposal should contain information on Research Methods and Design i.e.

1.6.1 Subjects - a brief statement of inclusion and exclusion criteria and anticipated number of participants.

1.6.2 Measures - a brief explanation of interviews/observations/ rating scales etc. to be employed, including references where appropriate.

1.6.3 Design and Procedure - a brief explanation of the overall experimental design with reference to comparisons to be made, control populations, timing of measurements, etc. A summary chart may be helpful to explain the research process.

1.6.4 Settings and equipment - a statement on the location(s) to be used and resources or equipment which will be employed (if any).

1.6.5 Data analysis - a brief explanation of how data will be collated, stored and analysed.

1.7 Practical applications - the applicants should state the practical use to which the research findings could be put.

1.8 Timescales - the proposed starting date and duration of the project.

1.9 Ethical approval - stating whether this is necessary and, if so, whether it has been obtained.