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An investigation into the effects of childhood atopic eczema on parental stress

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Award date:
1996

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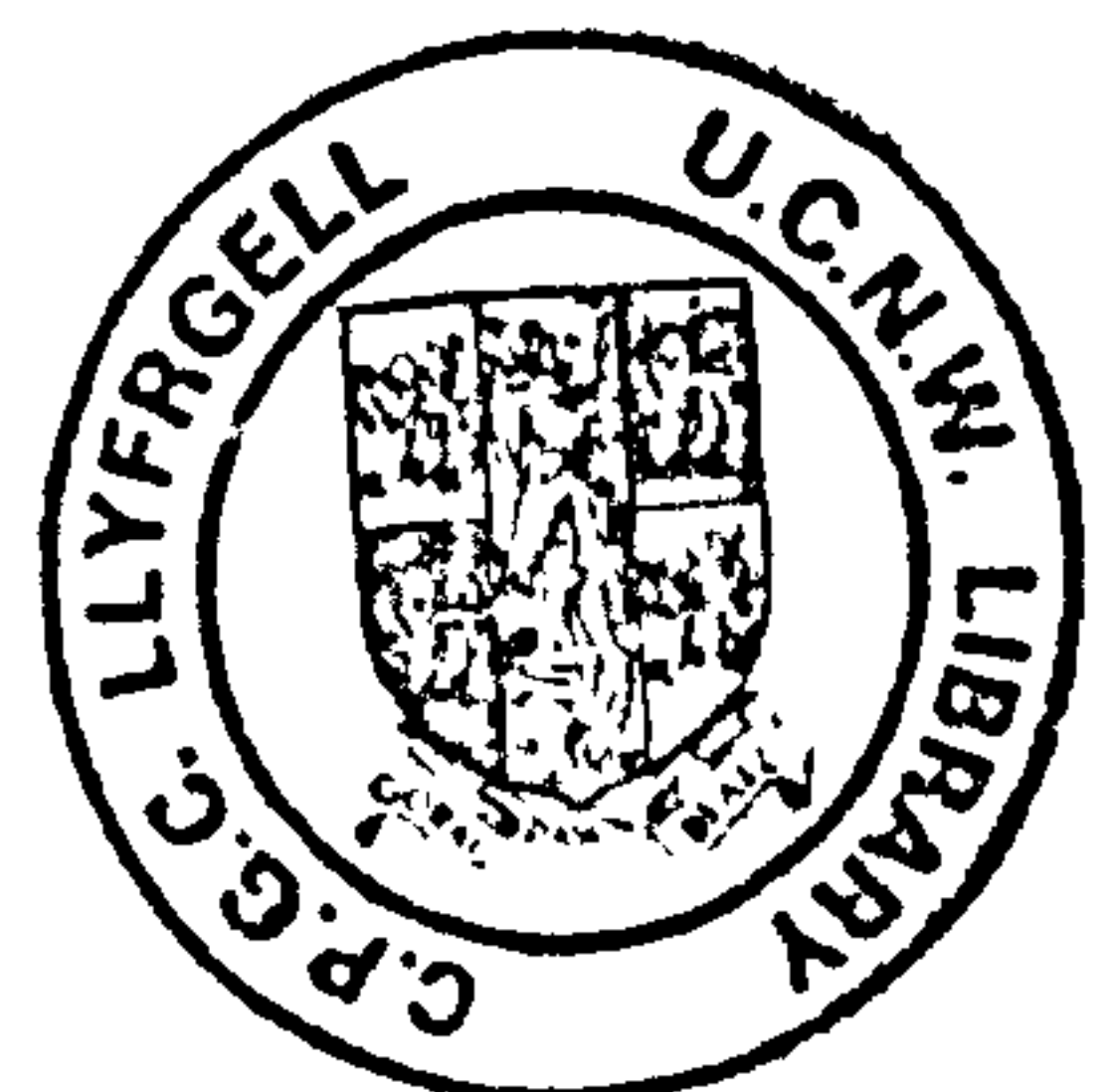
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An investigation into the effects of childhood atopic eczema on parental stress

Thesis submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D. Clin. Psy.)

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Summary

Very little research has examined stress among parents of children with atopic eczema, though stressful events are widely implicated in its aetiology. This study investigated reported stress among 38 parents of children with atopic eczema who had received hospital out-patient treatment within the previous 12 months. Responses of parents on the Parenting Stress Index were compared with published norms. Significantly elevated levels of stress among the study sample were found on the Difficult Child subscale. Total stress scores showed significant positive correlations with parental reports of illness severity. The majority of parents reported problems in relation to the symptom of scratching by their child with eczema. Recent problems with scratching were also found to correlate significantly with parenting stress.

A rating scale was developed to allow parents to report on situational variables they associate with increased scratching by their child with eczema. The scale was found to have good test-retest reliability over a one-to-four week period. Three of its subscales (Environmental Sensitivity, Psychological Sensitivity and Negative Coping) showed acceptable internal consistency. A fourth subscale (Positive Coping) showed poor internal consistency. Ratings on the Negative Coping subscale correlated significantly with parenting stress. A near-significant positive correlation was also found between parenting stress and the Psychological Sensitivity subscale. The methodological limitations of the study are discussed and implications for clinical practice and future research are outlined.

The thesis also includes three small-scale research projects completed during placements in Adult Mental Health, Learning Disabilities and Child and Adolescent services.

Acknowledgements

I would like to thank Steve Manley, Caroline Eayrs and Jill Everett for their assistance with the small scale research projects contained in this thesis. Thanks also to Rob Jones, Mark Williams, Mike Startup, Dr Lewis-Jones and Peter Appleton for their help at various stages of the large scale research project.

My special thanks are due to Peter Reid who could not have been more supportive and helpful throughout the last three years, particularly during his supervision of the large scale research project.

Finally I would like to thank all the participants who were involved in these projects.

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LARGE SCALE RESEARCH PROJECT

Title : An investigation into the effects of childhood atopic eczema on parental stress

Word Count: 11,967 words

INTRODUCTION

Overview

A number of psychological phenomena have been implicated in the aetiology, symptomatology and management of the skin condition, atopic eczema. The present study focussed on the psychological impact of childhood atopic eczema on parents. The main aim of the study was to investigate whether parents of children who have received hospital-based treatment for atopic eczema experience significantly elevated levels of parenting stress compared with published norms. An additional aim was to begin to identify some possible sources of stress among this group of parents. Of particular interest was the symptom of scratching among children with this condition. The study explored parental perceptions of factors which affect this symptom and investigated possible links with reported levels of stress.

This introduction begins with a summary of what is known about the psychological impacts on parents of childhood chronic illness. The specific features of atopic eczema are then outlined, with an emphasis on psychological perspectives on the condition, particularly on the symptom of scratching. Theories of stress and coping are reviewed and their possible relevance to childhood eczema discussed. Finally the scope and purpose of the study is explained.

Psychological effects of childhood chronic illness on parents and children

As Eiser (1985) points out, estimates of the incidence of childhood chronic disorder vary considerably, depending on the criteria for determining what conditions are included. Stewart (1967) included visual and hearing impairments, speech, learning and behaviour disorders as well as chronic physical conditions, producing an estimate of 30-40% of children below 18 years experiencing one or more chronic disorder. Estimates based solely on chronic physical conditions suggest that 7 - 10% of children are affected (e.g. Jennison, 1976; Rutter 1970).

Research into the psychological effects of chronic illness on children was traditionally dominated by 'the search for global deficits' (Eiser, 1990, p86). The premise on which this search was based was that chronic illness has an adverse and diffuse effect on children's development and on the functioning of their families. In an early literature review, Pless and Pinkerton (1975) presented evidence of problems in the intellectual and social functioning of children with a chronic illness. A number of epidemiological studies have also suggested that children with a chronic illness show an increased risk for behavioural and emotional problems compared with children without an illness. Results from the National Survey (Douglas & Bloomfield, 1958), the Rochester Survey (Roghman & Haggerty, 1970) and the Isle of Wight Survey (Rutter, Tizard & Whitmore, 1970) are summarised by Eiser (1985). Each study used parent estimates of child adjustment and showed significantly higher rates of maladjustment among children with a chronic illness. Rates of maladjustment varied according to the type and severity of disorder, but children with mild disorders were still at greater risk of maladjustment than healthy children.

The risk appears to increase for children who have illnesses affecting the central nervous system or who have a physical disability. Younger children appear to be affected more in school (Rovet, Ehrlich, & Hoppe, 1987), while social adjustment problems are more apparent in older children (Ungerer, Horgan, Chaitow, & Champion, 1988).

Eiser (1990) presents a more recent review of the psychological effects of chronic illness on children. She describes a general shift in the research away from definitions of maladjustment and deviance towards an interest in identifying the ways children cope with their illness and associated procedures.

Traditionally, research into the impact of a child with a chronic illness on the family has focussed on a range of negative outcomes, including marital disruption, divorce, distress, or psychopathology in parents and children (reviewed in Eiser, 1985). Much of this work was based on maternal reports, the role of fathers being generally neglected in the research. Mothers appear more likely than fathers to react to the illness and its treatment by showing depressive symptoms, particularly in the absence of a supportive relationship (Walker, Ford and Donald, 1986). Some family-focussed studies have shown negative effects of a child with a chronic illness on family functioning (e.g. Gustafsson, Kjellman, Ludvigsson, & Cederblad, 1987). It has been suggested that ecological family-based models, which explore the demands of chronic illnesses in specific situations, are needed to predict parenting behaviour more accurately (Eiser, 1990).

A number of studies have specifically examined stress among parents of children with chronic illness. For example, Goldberg, Morris, Simmons, Fowler & Levison (1990) compared the levels of stress

experienced by parents of children with Cystic Fibrosis or congenital heart disease with a matched control group (parents of healthy children). The study used the Parenting Stress Index (Abidin, 1986) which measures stress according to perceived source: life events, parent factors and child factors. The three groups did not differ on measures of life event stress but parents of chronically ill children consistently reported higher levels of stress than those of healthy children. Differences were most consistent in the child domain. The highest overall stress levels were reported by parents of children with heart disease, while parents in the Cystic Fibrosis group reported more stress in the domain measuring child demandingness. The authors suggest this is consistent with the increased parental care required by children with Cystic Fibrosis relative to children with heart disease. Parents of both groups of ill children showed increased depression and lower sense of competence compared with the comparison parents.

Some studies have shown that negative impacts are not inevitable for parents of children with a chronic illness (e.g. Spaulding & Morgan, 1986). Indeed the link between parenting stress and potential child-related stressors, such as disability or chronic illness, is now widely viewed as complex and multi-dimensional. Before discussing models which can help to inform research in this area, the specific stresses associated with the chronic condition, atopic eczema, will be outlined.

Atopic Eczema

Symptoms and prevalence

Atopic eczema (sometimes referred to as atopic dermatitis or neurodermatitis) is a chronic health condition, the main symptom of which is severe itching and inflammation of the skin. This leads to scratching which causes further problems, both physical (e.g. skin damage, bleeding and infection) and psychosocial (e.g. irritation to onlookers) (Daud, Garralda & David, 1993).

The prevalence of atopic eczema appears to be increasing, though prevalence estimates have been difficult to establish since most studies have been based on hospital rather than general community-based samples. One exception was the study by Kay, Gawkrödger, Mortimor & Jaron (1994), based on a socially and ethnically mixed general practice population in England (age range 3-11 yrs). This provided lifetime occurrence figures of 20% for boys (12% in the year preceding the study) and 19% for girls (11% in the preceding year). Atopic eczema had developed during the first 12 months of life in 60% of children with the condition.

Aetiology

The aetiology of atopic eczema is unknown. Increasingly, evidence indicates a multifactorial aetiology, including both physical and psychological factors. There is general agreement that heredity plays an important role in the condition's aetiology. A family history of 'atopic' or allergic conditions, such as asthma or hay fever is frequently found in patients with eczema. Faulstich & Williamson (1985), for example, report on a study in which 62% of patients with atopic eczema had a family history

of allergic rhinitis or asthma. Abnormal immunological and allergic reactions have been found in studies of the condition (e.g. O'Loughlin (1977), McGeady & Buckley (1975)). Eczema flares have also been associated with a variety of environmental trigger factors such as foods, pets, woollen clothes, and soap (e.g. Daud et al, 1993).

Psychological perspectives on eczema

A number of authors writing from a psychodynamic perspective have attributed the cause of eczema symptoms to unconscious conflicts. Several papers written during the 1950s and 60s suggested that eczema and scratching were a reflection or representation of sexual conflict. Scratching was seen as the symbolic gratification of repressed sexual expression which has been inhibited through guilt and insecurity (e.g. Alexander, French, & Pollock (1968), Kepecs, Rabin, & Robin (1957). As Faulstich & Williamson (1985) state, this view was based on methodologically problematic research. Projective tests of questionable validity were used, along with inadequate or absent control conditions in many studies. The studies also suggested a direction of causality without justification, since the hypothetical traits they described could be a result rather than a cause of eczema.

Other psychodynamic perspectives on eczema have focussed on specific personality traits of mother and child and on the quality and quantity of maternal touching (reviewed in Solomon & Gagnon, 1987). Mothers of children with eczema are variously reported to be hostile and aggressive, rejecting, and highly anxious. The same traits have been described in the children themselves. As Solomon & Gagnon(1987) point out, however, these psychodynamic theories of eczema aetiology can be contradictory.

'On the one hand, we have a series of writers who hold that these mothers and children have a disturbed and rejecting relationship with one another and, on the other hand, we have writers who hold that the relationship between mother and child is too close'(p219)

The research evidence in support of these views has also been criticised on methodological grounds. Solomon & Gagnon (1987) attempted to test reported differences between mothers of very young children with eczema and mothers of healthy children under controlled, direct-observation conditions. They found only subtle differences between the two groups of mothers and these did not match those reported in the literature. The two groups of children they studied also did not behave as the literature reported. In the light of their observations, the authors caution against 'hasty and premature conclusions about the causes and/or psychomaintenance of eczema.'(p219)

The search for psychological causative factors has included studies on the possible impact of stress on the initiation or exacerbation of eczema. Life events (Brown, 1972), daily hassles (Schubert, 1989) and stressful communication with important others (Ehlers, Stangier, & Gieler, 1995) have all been linked with atopic eczema symptoms. There is considerable agreement that stressful stimuli exacerbate the symptoms of atopic eczema (e.g. Ehlers et al 1995).

Behavioural perspectives on eczema have tended to focus on the situational variables, such as emotional stressors or social consequences, which may affect eczema-related symptoms and behaviours. These variables may be functionally related to individual children's eczema so that symptoms are brought on, maintained or reduced in response to them. The symptom of

scratching, for example, has been viewed as a learned behaviour. Using operant reinforcement principles, scratching behaviour can be thought to be negatively reinforced by the relief from itching. As a consequence, a number of behavioural techniques have been employed in an attempt to inhibit scratching (e.g. Melin, Frederiksen, Noren & Swebilius, 1986).

Social environment is also thought to play a role in precipitating and/or maintaining scratching behaviour. Gil, Keefe, Sampson, McCaskill, Rodin & Crisson (1987) investigated the impact of family environment on symptoms (including scratching) of children with Atopic Eczema, arguing that the family might act either as a stress buffer, reducing its impact, or as a significant source of stress. Participants in their study were 44 children with severe atopic dermatitis, recruited from a tertiary care hospital. The study examined the relationship between stress and family environment and a number of measures of symptom severity among participating children. The study assessed two types of stress: 'major life events', such as moving home, and chronic stress. The latter was further subdivided into 'everyday stress' (i.e. the common daily problems typically experienced by children, such as 'having too much homework') and problems specifically associated with having a skin condition (such as 'putting on creams'). Family environment was assessed using the Family Environment Scale (Moos, 1974), a 90 item questionnaire composed of ten subscales reflecting constructs such as cohesion, independence and family conflict. The study found that measures of stress and family environment were significant predictors of eczema severity among the children sampled. Two of the Family Environment Scale subscales were significantly correlated with symptom severity, namely Independent/ Organised and Moral/ Religious.

Several possible explanations for this relationship are suggested by Gil et al.

The psychosocial impacts of eczema on parents and children

There has been very little research into the psychosocial impacts of eczema on young children and on their families. Research conducted recently in South Clwyd (Lawson, Lewis-Jones, Owens, Reid & Finlay, 1995) suggests that childhood atopic eczema has a considerable impact on many areas of family functioning. Intensive qualitative interviews identified 11 problem areas, including practical care, life-style restrictions, sleep disturbance and psychological effects on parents. Seventy one percent of parents reported psychological pressures associated with caring for a child with eczema. Specific self-reported symptoms included mental and physical exhaustion, guilt feelings about the possibility that eczema is inherited, and generalised resentment that the "world is not fair". Parents reported feeling upset at their child's discomfort and distress and their own perceived inability to control the condition effectively.

In another study which looked at the impacts of childhood eczema on parents, Daud, Garralda and David (1993) found that significantly more of a sample of mothers of children with eczema felt highly stressed in relation to their parenting compared with a matched control group of mothers. The study indicated that the children's social development and the quality of the attachment relationship were not adversely affected, though significantly more of the mothers of children with eczema reported feeling tired and 'fed up'. Nearly half of the mothers (43%) felt that their child's atopic eczema had had a negative influence on their marriage, while 83% reported detrimental effects on family life.

Relatively few studies have explored the psychological impacts of atopic eczema on children. Children attending paediatric dermatology clinics have been shown to have levels of psychosocial dysfunction similar to those seen among children attending other specialty clinics (Rauch et al,1991). A recent study (Lewis-Jones & Finlay, 1995), showed children with atopic eczema scoring highly on a measure of the negative effects of a skin condition on quality of life. In the study by Daud et al (1993), children with atopic eczema showed significantly greater psychopathology than control children although the majority of children with eczema were psychiatrically well adjusted. Approximately one third of the children with eczema had behavioural screening questionnaire scores at or above the clinically significant level. This frequency of disturbance matched levels found for children with other severe physical problems. These studies suggest that atopic eczema can have significant negative psychosocial impacts on children and may be a risk factor for the development of behaviour problems in children, particularly in the areas of dependency, fearfulness and waking.

Interventions

Specifically psychological interventions to treat atopic eczema fall into two main types. One form of intervention uses some form of relaxation training or hypnosis. This may involve non-specific relaxation to reduce the levels of patients' stress or the use of specific hypnotic suggestion, to effect changes in skin condition or the reduction/ cessation of scratching. In a recent, small-scale uncontrolled study, Stewart & Thomas (1995) used hypnosis to treat 20 children with severe eczema. Nineteen of them reported immediate improvement, which was maintained

at two follow-up clinic appointments. Longer term effects (over 18 months) were reported on by only twelve of the original sample. Ten indicated improvements in itching and scratching, and 7 reported better sleep patterns and mood.

The second form of psychological treatment is focused directly on scratching behaviour. Habit-reversal techniques, based on those originally developed by Azrin & Nunn (1973), have been used to reduce scratching behaviour in both adults and children with atopic eczema. A variety of procedures are described in the literature, including extinction (Walton, 1962), differential reinforcement for other (non-scratching) behaviour (Allen and Harris, 1966; Bar and Kuypers, 1972), self-recording (Rosenbaum and Ayllon, 1981), aversive responses to scratching (Bar and Kuypers, 1972) and replacing scratching with stroking or patting (Watson et al, 1972). (For reviews, see Ehlers, Stangier & Gieler (1995), and Rosenbaum & Ayllon (1981))

The physiological and psychological mechanisms which affect eczema symptoms are not mutually exclusive and one recent study of adults with atopic eczema has looked at the combined effects of medical and psychological treatments (Ehlers, Stangier & Gieler, 1995).

Models of Stress and Coping

As Rutter (1981) points out, the term stress is frequently used without a clear definition of its meaning, despite its widespread usage. 'Stress' can be viewed as a response to difficult situations or, alternatively, as the stimulus itself. Much of the research into stress has sought to identify the

characteristics of particular circumstances which make them stressful. Studies of parental stress have sought to identify the adverse impacts on parents of a wide range of difficult life circumstances. A key assumption underlying this work has been that 'sources of stress' (such as poverty, single parenting, child psychopathology and major life changes) can have a significant impact on parental behaviour and can both directly and indirectly influence children's development. Although much research has focussed on the impact of major life events on parental stress, these have been shown to be relatively low-frequency events for most families. Lazarus and his colleagues (e.g. Kanner, Coyne, Schaefer, & Lazarus, 1981) have suggested that models which focus exclusively on major life events may be less useful in predicting parental stress than those which explore the cumulative impact of relatively minor daily stresses or 'hassles'.

Daily hassles are defined as the 'irritating, frustrating, distressing demands that to some degree characterise everyday transactions with the environment'(Kanner et al, 1981). Evidence suggesting that they may have an adverse impact on parent-child relationships can be found in studies by Patterson (1983) and Dumas (1986). Crnic and Greenberg (1990) found that minor stresses associated with 'normal' parenting events were more predictive of maternal, child and family adjustment than was major life stress.

This has lead some authors to investigate whether the daily hassles associated with parenting a child with a chronic illness have a significant effect on parental stress. A study by Thompson, Gustafson, Hamlett & Spock (1992) looked at the psychological adjustment of mothers of children and adolescents with cystic fibrosis. Approximately one third of their sample showed overall poor maternal adjustment, with illness and demographic

parameters accounting for only 13-15% of the variance in maternal distress. Among a number of hypothesised mediating variables, the stress reflected in daily 'hassles' was most strongly related to maternal depression and anxiety. Though this might be expected to have been influenced by the day-to day caring tasks associated with parenting a child with cystic fibrosis, there was only 25% shared variance in stress associated with illness tasks and mothers' appraisals of the stress of daily hassles.

Another area of interest to researchers into stress has been the ways in which individuals think about stressful events. Clearly the same event may be perceived by different individuals in different ways. Lazarus and Launier (1978) use the term 'primary appraisal' to describe an individual's perception about whether an event is generally positive or negative in its impact on them. An additional 'secondary appraisal' is thought to involve an individual's perception about what he or she can do about the event. In postulating the concept of 'learned helplessness', Seligman (1975, 1978) suggested people vary in the extent to which they anticipate positive outcomes, expect to be able to change or influence events and attribute failure. Brown and Harris (1978) suggest that 'vulnerability' factors, such as lack of social support, lead to feelings of low self-esteem and a sense of being unable to deal with stressful events. These cognitive appraisal models can be seen to be applicable to studies of stress among parents of children with a chronic illness. In the study of mothers of children with Cystic Fibrosis, for example (Thompson et al, 1992), maternal adjustment was significantly affected by low maternal expectations of efficacy for the task of maintaining their child's emotional well-being.

The impact of chronic and acute stressors on parental adaptation is therefore no longer seen as directly causal but as mediated by a range of

intervening variables. In a typical model (such as that of McConachie, 1994), these mediating variables include resources, such as social support, family interactional style, and practical resources. In addition parents' coping style, such as their general and specific beliefs about their child's illness or disability, may reduce or amplify the effects of stressors.

Research into other chronic illnesses suggests that the relationship between childhood eczema and parental stress is likely to be complex and multi-dimensional. The present study aimed to explore this relationship by examining the level of stress among this group of parents. The study also aimed to identify whether other variables, such as illness/ symptom rating and perceived influences on child scratching, were significantly correlated with reported stress.

Hypotheses

1) The present study predicted that parents of children with atopic eczema would show elevated levels of parenting stress compared with published norms. As in the Goldberg et al (1990) study, these increases were expected to be primarily in the Child domain. Since clinical experience suggested that parent-child interactions can be adversely affected by scratching among children with eczema, elevated stress in the Parent-Child Dysfunctional Interaction domain was also expected.

2) It was predicted that parents' stress levels would be related to their perceptions of their child's illness severity as this has been found to be related to stress among parents with other chronic conditions.

3) Clinical observation and previous research suggests that parents of children with eczema find scratching irritating and often difficult to deal with on a day-to-day basis. Since irritating, distressing everyday transactions with the environment (i.e. daily hassles) have been associated with poorer maternal adjustment, a further hypothesis was that mothers' ratings of their problems coping with scratching by their child would be related to parental stress.

By devising and field testing a questionnaire for parents to rate variables affecting their child's scratching, it was hoped that the present study would help identify some of the ways parents view and respond to this symptom. On the basis of research into other chronic conditions, the following additional hypotheses were generated:

4) Higher ratings of environmental and psychological factors perceived by parents to make their child's scratching worse (perceptions of low control) would be associated with greater parenting stress,

5) Higher ratings of positive strategies which parents report they use to reduce their child's scratching (perceptions of greater control) would show a negative correlation with parenting stress,

6) Negative responses to scratching reported by parents in response to their child's scratching would be associated with higher stress.

METHOD

Approval by the ethics committees of the local Health Care Trust and the university was obtained prior to the commencement of this research.

Participants

Participants for this study were originally drawn from a list of children with a diagnosis of atopic eczema who had been seen in the hospital dermatology clinic during the previous two years. Medical notes on each of these children were scrutinised to identify children who had been seen within the dermatology clinic in the last 12 months. A small number of this cohort were excluded on the advice of the Consultant Dermatologist due to their involvement in another project or because they had left the area. Each child's G.P. was consulted to ensure there were no objections to the child or parent's involvement in the project. A total of 42 participants were contacted, of whom 38 (90%) agreed to take part. The age profile of the sample is shown in figure 1. Sample characteristics are shown in Table 1.

Figure 1. Histogram showing Age profile of participants' children

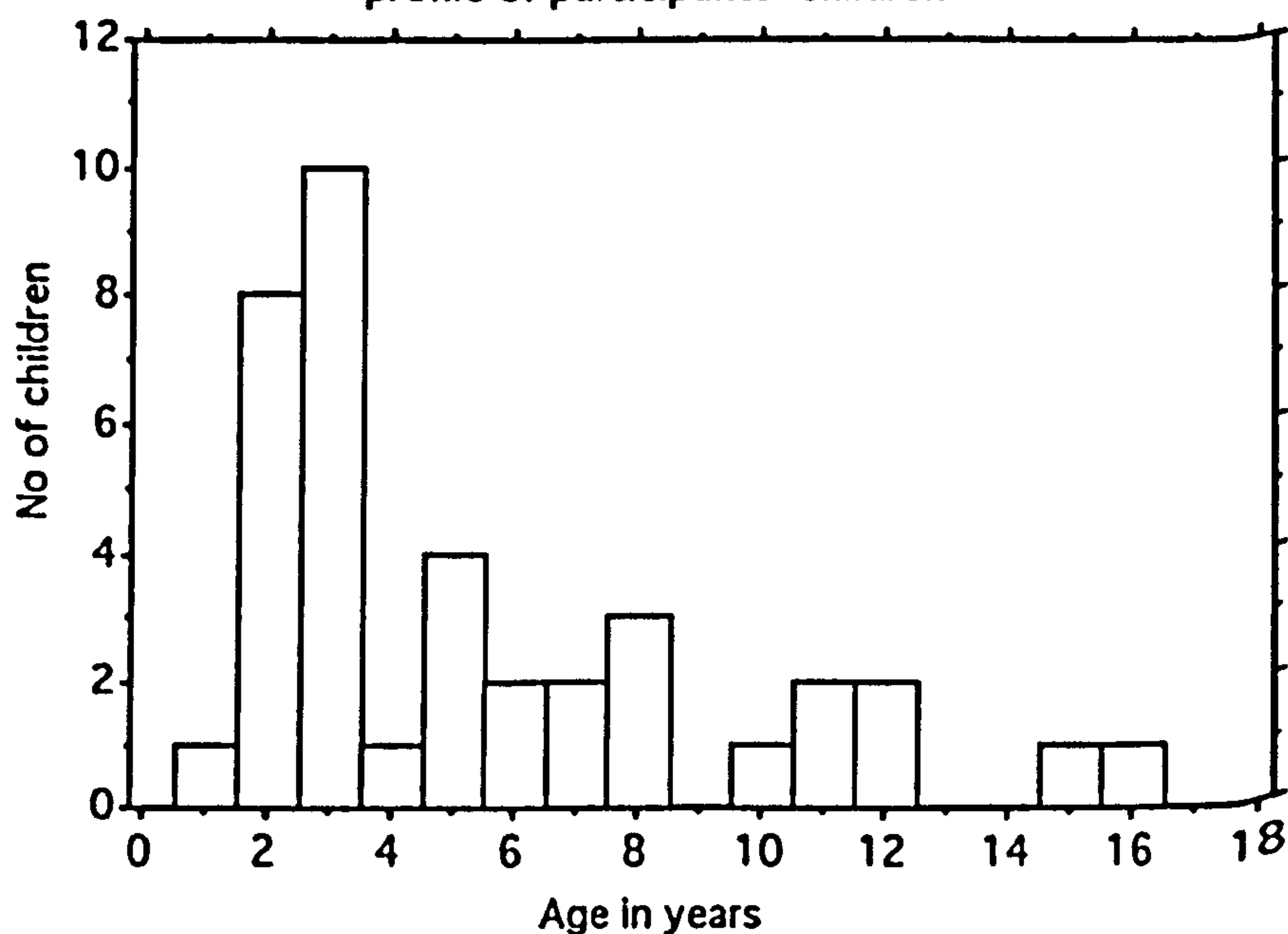


TABLE 1.SAMPLE CHARACTERISTICS

Characteristic	n	%
Child's age		
0-5 yrs	24	63%
5-11 yrs	10	26%
11-16 yrs.	4	10%
Duration of eczema according to parent		
< 12 months	3	8%
1-2 yrs	11	29%
2-3 yrs	5	13%
3-4 yrs	6	16%
4-5 yrs	1	3%
5-11 yrs	9	24%
> 11 yrs	3	8%
Child's gender		
Male	22	58%
Female	16	42%

Procedure

Parents were initially informed in writing about the project (see letter 1, appendix). An information sheet (see appendix) outlining the nature of the project was sent with the initial contact letter.

Within a week of the initial letter, parents were contacted again, either by phone or by letter and invited to take part. Questionnaires were posted to parents who agreed on the phone to take part and a collection visit proposed. A second letter was sent to parents who were not on the phone,

enclosing the questionnaires and proposing a collection visit. Parents who did not wish to take part were invited to return a numbered card which enabled them to be identified and their names taken off the participant list.

During the collection visit, parents were asked about any problems they had completing the questionnaires. A follow-up appointment was arranged for parents agreeing to complete an eczema questionnaire re-test. The re-test questionnaire was posted to this sub-sample (N=22) a few days before the follow-up visit.

Measures

Illness/ symptom severity

Parents taking part in the study were asked to rate the severity of their child's eczema 'over the last week' and 'over the last 12 months' on a 3-point scale, mild, moderate, and severe. In addition they were asked to indicate how much of a problem their child's scratching had been 'over the last week' and 'over the last 12 months', also on a 3-point scale ('not a problem', 'a bit of a problem', and 'a big problem').

Eczema scale

In order to obtain a profile of factors which parents perceived to be related to their child's scratching symptoms, a suitable instrument was required. Since no applicable measures were found in the literature on childhood

eczema or scratching, it was necessary to develop and field-test a questionnaire for this study.

A review of measures used for other recurrent childhood complaints identified a questionnaire on environmental and psychosocial variables associated with headache activity, the Children's Headache Assessment Scale (CHAS), developed by Budd and Kedesdy (1989). Items on this scale were divided into six conceptual categories; Stress Antecedents, Physical Antecedents, Attention Consequences, Escape Consequences, Coping Responses and Medication Use which were modified following a follow-up study (Budd, Workman, Lemsky, and Quick, 1994). Adequate test-retest stability, content validity and internal consistency was found for the revised scale. Though there are clear differences between childhood eczema and childhood experiences of headaches, it was felt that a number of items from this scale could be adapted to measure parental perceptions of scratching-related variables.

Of the 44 CHAS items, 3 items were rejected immediately as being of no obvious relevance to scratching among children with eczema (items relating to bright lights, eye strain and loud noises).

The next stage involved revision of items on the basis of clinical observation, as suggested in Streiner and Norman (1989). Clinicians working with children who have eczema were shown the preliminary scale and asked to indicate which items they thought were of limited relevance to this population, to indicate any additional/alternative items they thought could be used and to comment on any unclear items. A number of adaptations were made in the light of these comments. For example, the item "Thinking about a calm or pleasant scene helps my child

to reduce his/her scratching" became "I try to help my child to think about a calm or pleasant scene when he/she scratches". Items about not completing homework, choosing quiet activities, hunger, and completing household chores were omitted.

Finally, comments on the item content as well as the layout and readability of the scale were invited from 3 parents of children with eczema. On the basis of these, a number of further modifications were made to the items. Two parents reported some confusion with the phrase 'non-prescribed medication' which was changed to 'creams or medication which a doctor has not prescribed'. The item 'My child stays in bed in the morning if his/her scratching is worse' was problematic for one parent who reported her child often stays in bed whether or not her scratching is worse. The word 'longer' was therefore added after 'bed'.

On the final version of the, parents were asked to indicate how often each situation or event occurs in relation to their child's scratching using a seven-point response scale, in accordance with the CHAS. Ratings choices were 'never'(0), 'almost never'(1), 'seldom' (2), 'half the time' (3), 'usually' (4), 'almost always' (5), and 'always' (6).

For the purposes of this study, the majority of items were grouped into 4 conceptually-derived subscales; Psychological Sensitivity, Environmental Sensitivity, Positive Coping strategies and Negative Coping strategies. As the sample size was insufficient to factor analyse parents' responses to the questionnaire, Cronbach's alpha was used to give an indication of the homogeneity of items within each subscale. These are given in the results section.

Parenting Stress Index (short form)

In addition to the questionnaire on parental perceptions of variables affecting their child's scratching, the study used the Parenting Stress Index (Short Form) (Abidin,1990). This is derived from a fuller length measure of parenting stress, the Parenting Stress Index, which contains 120 items. Both of these measures reflect two key assumptions about the nature of stress, namely that sources of stress are additive and that stressors are multi-dimensional. Three major domains of stress form the underlying structure of the full-length PSI; 1) Child characteristics, 2) Parent characteristics, and 3) Situational/ Demographic- Life Stress. Abidin's original stress model (Abidin,1976) suggested that child and parent characteristics could each be subdivided into interrelated variables, six for the child domain ('demandingness' , 'mood' , 'adaptability', 'acceptability', 'distractibility/hyperactivity' and 'reinforces parent') and seven for the parent domain ('depression' , 'parental attachment', 'role restriction', 'sense of competence', 'social isolation', 'relationship with spouse' and 'parent health').

The short form version of this scale, which this study uses, contains 36 items drawn from the full length scale domains and with identical wording.

It was specifically developed to enable clinicians and researchers to administer a valid measure of parenting stress in less than 10 minutes.

A series of replicated factor analyses suggested three factors as the best description of the short form data; Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. These corresponded with the

suggestion by Castaldi (1990) and others that three factors are the best way to describe the information collected using the long-form.

For the present study, parents were asked to consider each of the items in relation to their child with atopic eczema. Each item consists of a statement, such as *I often have the feeling that I cannot handle things very well*. Parents respond by circling a number from 1 to 5 which correspond with the verbal descriptors, Strongly agree (1), Agree (2), Not sure (3), Disagree (4), Strongly Agree (5). Scores for the twelve items in each subscale are reversed and summed to provide a subscale raw-score in the range 12-60, with higher scores indicating greater stress. The three subscale scores are summed to provide a total stress score in the range 36-180.

The PSI shows good internal consistency, with alpha reliability coefficients of .8 to .87 for the subscales and .91 for the total score. Test-retest reliability coefficients over a six month interval are between .68 and .85 for the subscales and .84 for the total score, suggesting reasonable stability over this period. Though independent validity research for the short form is not yet available, there is extensive evidence in support of the validity of the long-form PSI. As total scores for the two versions correlate very highly (.94), it is likely that the short form's empirical validity will closely match that of the long-form.

RESULTS

Responses to Parenting Stress Index: comparing parents of children who have eczema with a normative sample (Hypothesis 1)

Parental responses to the Parenting Stress Index are shown in table 2.

Table 2. Comparison of mean scores on PSI for normative sample and study sample

Stress subscales	Mean (S.D) for normative sample of mothers (Abidin ,1990) (N=800)	Mean (S.D.) for study sample (N=38)
Parental Distress	26.4 (7.2)	24.4 (6.8)
Parent-Child Dysfunctional Interaction	18.7 (4.8)	20.7 (7.2)
Difficult Child	26 (6.7)	31.4 (11.5)*
TOTAL SCORE	71 (15.4)	76.5 (21.7)

*Difference in means is significant at <.01 level

Of the 3 PSI subscales, the study sample mean raw score was significantly elevated ($p < .01$) compared with the normative sample mean on only the Difficult Child subscale. Though mean raw scores were higher for the Parent-Child Dysfunctional Interaction and lower for the Parental Distress subscales, these differences were not statistically significant. The mean total stress score was higher for the study sample than the normative sample but the difference did not reach a level of significance. A greater dispersion of scores (higher s.d.) among the eczema sample compared with the normative sample was noted for the total stress score. This reflected higher standard deviations for both the Parent-Child Dysfunctional Interaction and the Difficult Child subscales, compared with the normative sample.

To test for possible age-effects, a median-split procedure was used to divide the sample into two groups by age. Though higher mean total stress scores were found for the older group, the difference between mean scores was not significant. No significant differences between the younger and older group were found in subscale means for the three subscales.

The frequency distribution of parental scores on the Parenting Stress Index are shown in Figures 2-5 on the following pages. Scores for the normative sample at the 50th, 90th and 99th centile are included for comparison. On the basis of the PSI manual's criterion which defines a 'high score' as equal to or above the 90th centile scores for the normative sample:

- i) High total stress scores (raw score=90+) were reported by 10 (27%) of the parents in the study sample,
- ii) High Parent Distress scores (raw score= 36+) were reported by 2 (5.5%) of the sample,
- iii) High Parent-Child Dysfunctional Interaction scores (raw score = 27+) were reported by 6 (16%) of the study sample.
- iv) High Difficult Child scores (raw score=36+) were reported by 12 (32%) of the study sample.

Figure 2. Frequency distribution of Parental Distress subscale scores for eczema sample (N=38)

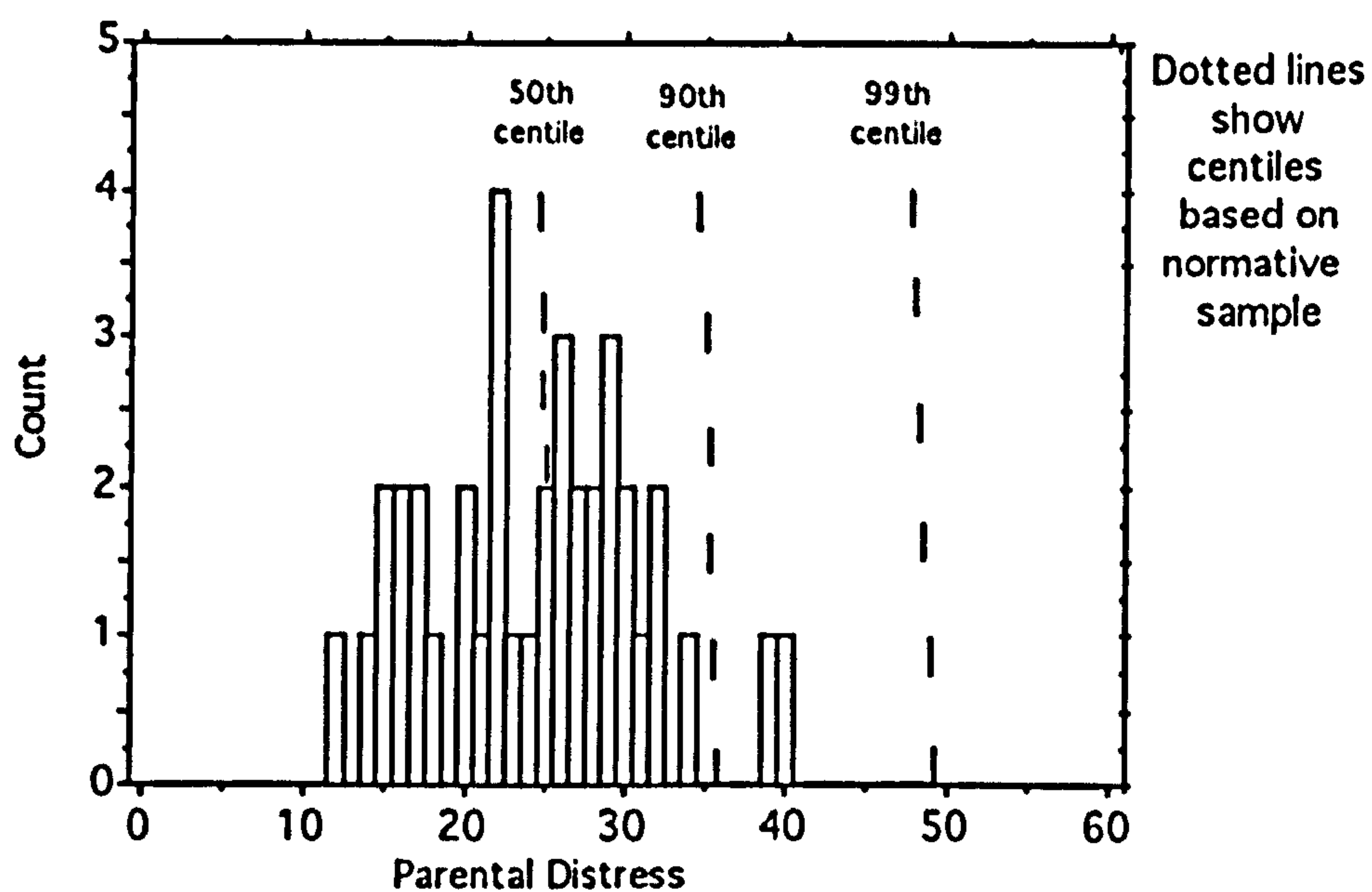


Figure 3. Frequency distribution of Parent-Child Dysfunctional Interaction subscale scores for eczema sample (N=38)

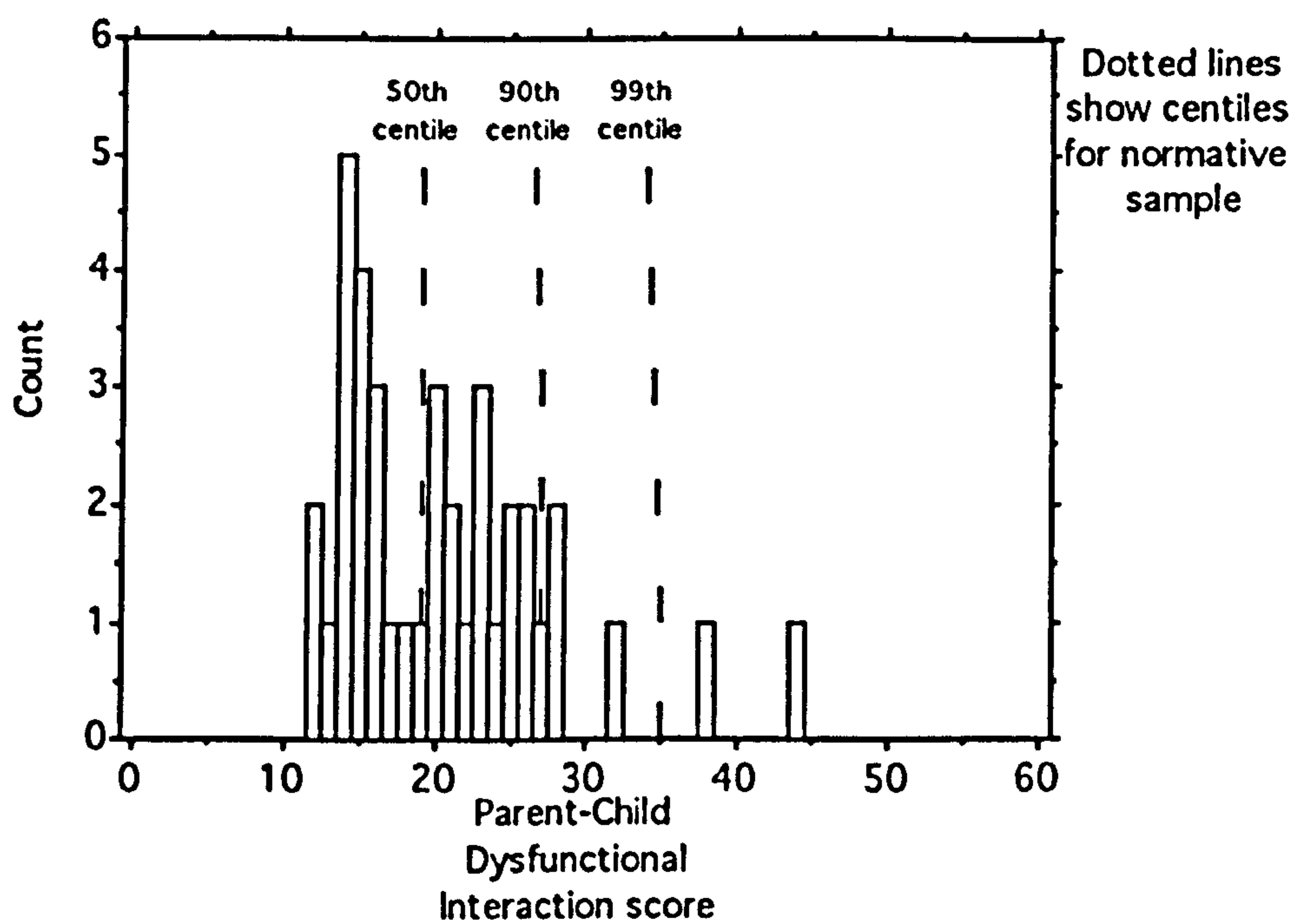


Figure 4. Frequency distribution of Difficult Child subscale scores for eczema sample

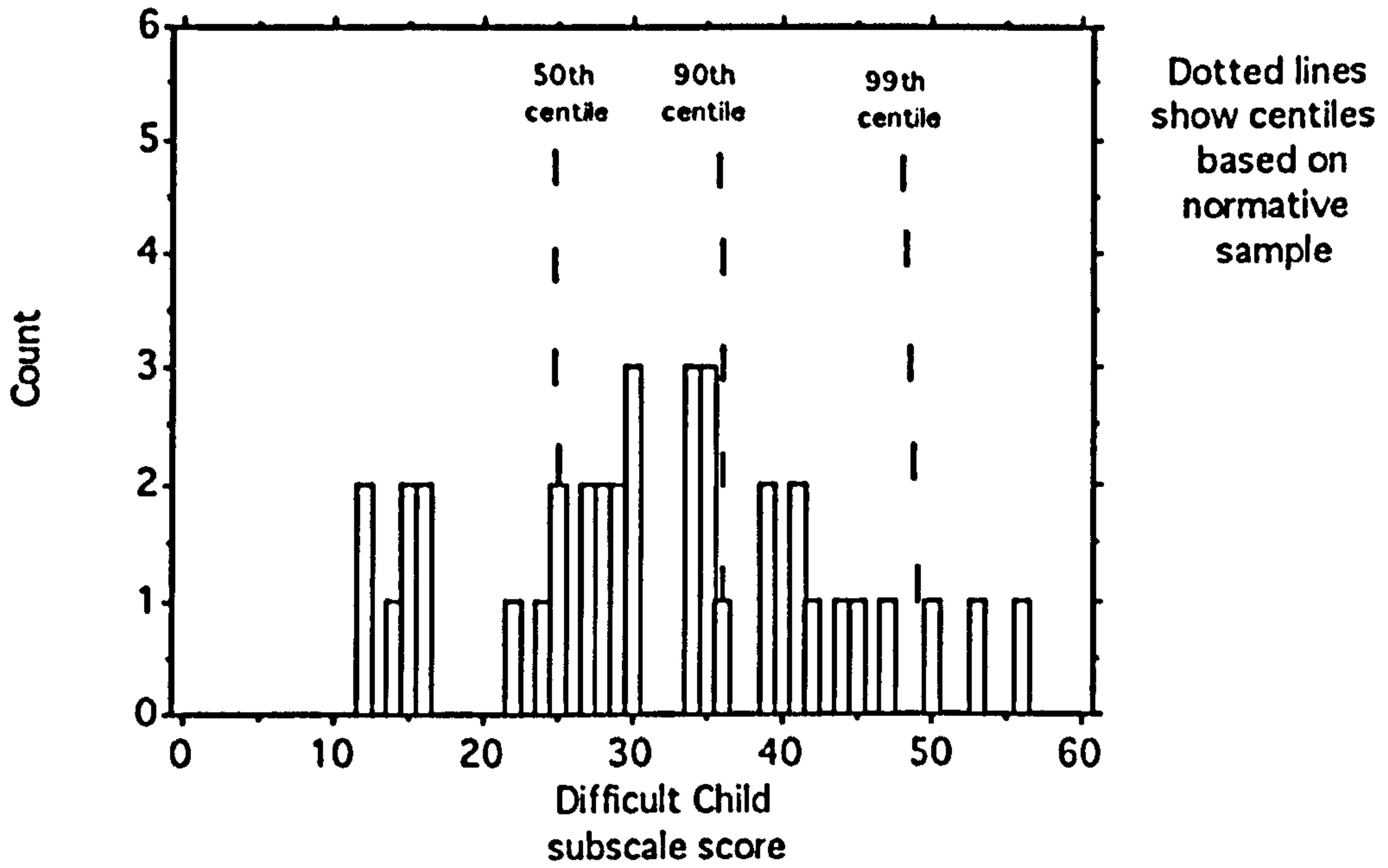
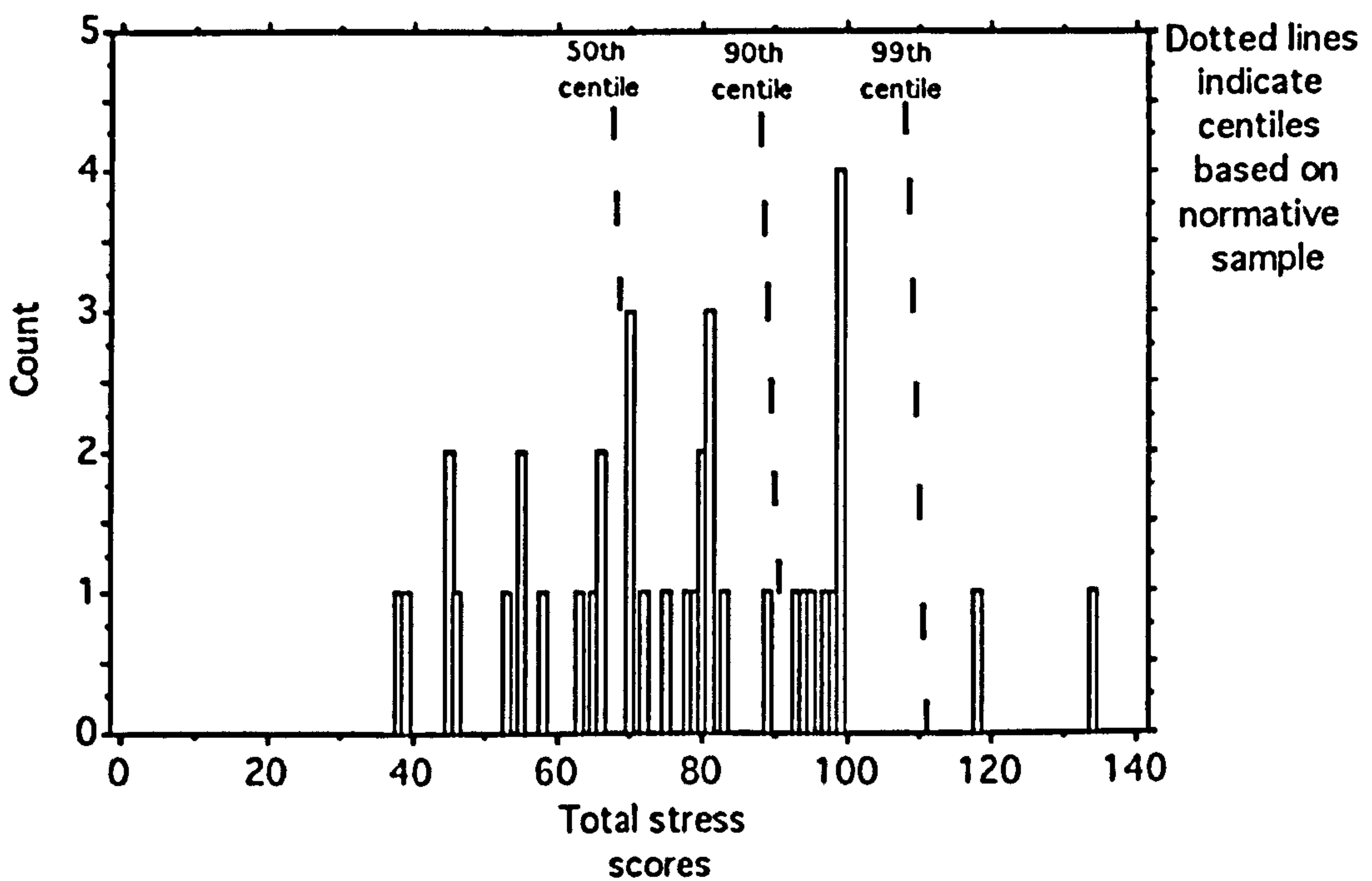


Figure 5. Frequency distribution of Total Stress scores for eczema sample



Parental stress and ratings of eczema severity (Hypothesis 2)

In order to test the second hypothesis, that parental stress would be related to perceptions of illness severity, mean total stress scores were computed for each of the three possible eczema severity ratings (mild, moderate, and severe). These are shown in table 3. (As only one parent rated eczema over the previous week as severe, combined stress scores for current eczema ratings >1 are given.).

The degree of association between total stress scores and illness ratings was assessed using Spearman rank-order correlations. A correlation of .31, $p < .05$ was found between parenting stress and ratings of eczema severity over the last year. The correlation between Parenting stress and parental ratings of eczema severity over the previous week was .36, $p < .02$.

Total stress scores for the three groups of parents who rated their child's eczema during the previous year as mild ($N=4$), moderate ($N=19$) and severe ($N=15$) were compared, using a one-factor ANOVA. A significant difference in stress scores [$F(2,35)=4.84$, $p < .01$] was found between the three groups.

A t test for unrelated pairs was used to assess whether there were significant differences in total stress scores between parents rating their child's eczema over the previous week as mild ($N=19$) and parents who rated it moderate or severe ($N=19$). A significant difference in stress scores between the two groups was found ($t= 2.23$, $p < .02$).

Table 3. Effects of parental ratings of child's eczema severity on mean total stress scores

Parent rating of eczema during previous year	Parental Stress Index: Mean total score (S.D.)	Parent rating of eczema during previous week	Parenting stress Index Mean total score (S.D.)
Mild(1) (N=4)	48(15)	Mild(1) (N=19)	69(21)
Moderate(2) (N=19)	78(16)	Moderate or severe(2 or 3) (N=19)	84(20)
Severe(3) (N=15)	82(25)		

Parental stress and problems with child's scratching (Hypothesis 3)

In order to test hypothesis 3, that parental stress levels would be related to ratings of problem with scratching, separate mean total stress scores were computed for each of the three possible ratings. These are shown in table 4. Since only one parent rated scratching in the last year as 'not a problem', mean stress scores for long-term scratching ratings of 1('not a problem') and 2 ('a bit of a problem') are given. A Spearman correlation of .24 ($p < .1$, n.s.) was found between parenting stress scores and rating of difficulty with child's scratching over the last year. The correlation between parent ratings of difficulty with scratching over the last week and parenting stress was .44. ($p < .005$).

A t test for unrelated pairs was used to assess whether there were significant differences in total stress scores between parents rating their child's scratching over the previous year as 'not a problem' or 'a bit of a problem' (N=14) and parents who rated it as 'a big problem' (N=24). A non-significant difference in stress scores between the two groups was found ($t = 1.48$, $p < .1$).

Total stress scores for the three groups of parents who rated their child's scratching during the previous week as 'not a problem' (N=10), 'a bit of a problem' (N=23) and 'a big problem' (N=5) were compared, using a one-factor ANOVA. A significant difference in stress scores [$F(2,35)=3.78$, $p < .02$] was found between the three groups.

Table 4: Effects of parents rating of problems dealing with child's scratching on mean total stress scores

Parent rating of problems with child's scratching during previous year	Parenting Stress Index Mean total stress score (S.D.)	Parent rating of problems with child's scratching during previous week	Parenting Stress Index Mean total stress score (S.D.)
Not a problem(1) or a bit of a problem (2) (N=14)	70 (20.3)	Not a problem(1) (N=10)	62.5 (17)
A big problem(3) (N=24)	80 (22)	A bit of a problem (2) (N=23)	79.7(22.3)
		A big problem(3) (N=5)	90 (14)

Parental responses to eczema scale

Parents' responses to each of the eczema scale items are shown in Table 5, which lists items in descending order of mean rating. Mean, standard deviation and median responses for each item are included.

Nine of the 40 items showed very positively skewed responses, defined as >50% of responses being 0 (never), 1 (almost never) or item omitted. These responses identify situations which very few parents associate with scratching by their child with eczema (such as staying in bed longer in the morning) or describe strategies they are unlikely to adopt (such as the use of deep breathing / relaxation techniques).

Six items showed very marked negatively skewed responses, with >50% of responses being 5 (almost always) or 6 (always). These responses appear to identify situations which most parents either associate with scratching in their children with eczema (such as the child going to bed) or describe strategies they are likely to use to try to control it (such as the use of prescribed creams/medication).

Several items show a more even distribution of responses. On the basis of this study sample, these items appear to be the most clinically useful items, since parent responses to them are less predictable. The age of the child may have influenced parental responses to some of these items (such as telling the child it will soon get better).

Some of the items with highly skewed responses showed outlier responses, which contrast sharply with those of the majority of parents. For example, all but one parent indicated they seldom/ almost never/ never have to

leave the room when their child scratches. However, one parent responded that they always have to leave the room at these times.

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Psychometric properties of Eczema scale

The test-retest reliability of the eczema scale over a 1-4 week interval is shown in Table 6. Coefficients between .8 and .9 were obtained for the four subscales, indicating good stability over this period of time.

Alpha reliabilities were determined for each of the subscales of the eczema scale. These are presented in Table 6. A high degree of internal consistency was found for both the two Sensitivity subscales and for the Negative Coping subscale. In line with expectations, lower internal consistency was found for the Positive Coping subscale.

Table 6. Internal consistency and test retest reliability of eczema questionnaire subscales

Subscale	Items included	Cronbach's alpha	Test-retest reliability
Psychological sensitivity	7,13,16,19,25, 27,29,30,34,40	.87	.84
Environmental sensitivity	1,2,14,20,32, 37,38,39	.73	.87
Positive coping	5,9,15,26,31, 33,36	.56	.8
Negative coping	3,8,10,11,35	.75	.9

Relationships between eczema questionnaire subscales and parenting stress (Hypotheses 4-6)

Pearson product-moment correlations were computed to evaluate the relationships between total stress scores, eczema questionnaire subscales and child's age. Age and illness duration were very highly correlated ($r=.98$), since most parents reported their child's eczema started during their first year. Illness duration did not show a significant correlation with total stress scores ($r= .14$)

Negative coping subscale scores showed a significant positive correlation with total stress scores ($r= .48$, $P <.005$). The other subscale score correlations with total stress scores were as follows:

Psychological sensitivity, $r=.27$

Environmental sensitivity, $r= .15$

Positive strategies, $r=.03$

None of these latter correlations were statistically significant.

DISCUSSION

Parental stress: comparing parents of children who have eczema with a normative sample (Hypothesis 1)

The findings of this study support the hypothesis that parents of children with eczema would show elevated levels of stress compared with the normative sample. In this study, more than 25% of the parents showed total stress scores in the clinically significant range. The difference in mean stress scores between the total study sample and the normative sample reached significant levels for the Difficult Child subscale only, though the Parent-Child Dysfunctional Interaction and Total Stress scores were also elevated. In contrast, the mean Parental Distress score was slightly lower than the normative sample mean.

The Parenting Stress Index (Short Form) manual provides some guidelines for beginning to interpret stress scores in relation to norms. Firstly, by comparing parental stress subscale scores, it was possible to identify the major sources of stress for parents in this sample. None of the parents in the study sample showed the pattern of scores which Abidin sees as indicative of personal adjustment problems partially independent of the parent-child relationship (i.e. high Parent Distress relative to Difficult Child scores). In the case of two parents, however, the percentile level of Parental Distress was higher than that of the other two subscales, suggesting the need for 'further exploration of the parent's personal adjustment' (Abidin,1990.p20).

Six of the study sample parents (16%) had scores for the Parent-Child Dysfunctional Interaction domain which Abidin suggests indicate that the

parent-child bond is threatened or has never been adequately established. Three of these had scores above the 95th centile in this domain, which Abidin sees as suggesting the potential for child abuse. This interpretation has greatest credibility in the case of two of these parents, whose scores on all three subscales were close to or above the 90th centile.

Four of the parents in the study sample show high Parent-Child Dysfunctional Interaction and Difficult Child subscale scores (close to or above the 90th centile) but Parental Distress scores below the 75th centile. The Index manual suggests that parents with this pattern of scores are coping with exceptionally difficult child behaviour or characteristics.

Scores on the Difficult Child subscale are thought to focus on 'some of the basic behavioural characteristics of children which make them easy or difficult to manage' (Abidin,1990, p21). The manual suggests that high scores on this subscale may reflect age-dependent processes. High scores for parents of very young children (<18 months) are thought to be related to the child's temperament or to physiological problems. For parents of older children (> 2 years), scores on this subscale relate to general measures of child behavioural adjustment. Since slightly higher mean scores on this subscale were found for parents of older children, the elevated scores on this subscale compared with the normative sample do not merely reflect physiological/ temperamental difficulties in the youngest children whose parents were sampled. Daud et al (1993) found increased behavioural adjustment difficulties among their sample of children with eczema, compared with a matched control group. Significantly more parents of children with eczema also reported their children's behaviour to be generally difficult compared with control group parents. The results of the present study appear to support those findings, since study sample

parents showed significantly elevated mean Difficult Child subscale scores compared with the normative sample.

Twelve (32%) of the parents in this study had scores in the Difficult Child subscale which the manual sees as indicating the likely need for professional assistance. Nine of these (24% of the entire sample) had Difficult Child subscales scores in the range which Abidin (1990) describes as 'extreme cases' (raw scores above 39), indicating a need for further diagnostic investigations to rule out significant psychopathology. In the case of 3 parents (8% of the sample), scores on this subscale were above the 99th centile.

The results show some similarities with the findings of Goldberg et al (1990). Their study showed elevated stress levels among parents of children with Cystic Fibrosis and congenital heart disease. As in the present study, these were most apparent in the Child Domain. Greenberg et al argue that the care demands on parents of children with Cystic Fibrosis are reflected in the elevated scores on the child demandingness subscale. It is possible that Difficult Child scores for parents of children with eczema similarly reflect the care demands of this condition. In the study by Lawson et al (1994), 74% of parents of children with eczema reported a general burden of extra care. In the present study, the item 'My child turned out to be more of a problem than I had expected' could have been interpreted by the study sample parents as referring to problems with managing the illness (i.e. more of a problem *to look after*).

Though the short form Parenting Stress Index contains identical items to the long-form, it does not allow for comparison of scores on items within the three domains. It is therefore not possible to identify whether high

scores on the Difficult Child subscale are the result of a general perception of 'child difficulty' or of one or more specific concerns, such as the child being perceived as more 'demanding', less 'adaptable', or less 'acceptable'. Further research into parenting stress among this population could be conducted using the PSI long-form. This would help to identify more clearly whether perceptions of the child as more difficult is a generalised perception or one confined to specific child characteristics as perceived by the parent.

As well as showing differences in parenting stress between the study sample and normative sample, there were clear within group differences in the parenting stress scores of the study sample. This discussion now focusses on some of the variables which seem to have influenced reported parenting stress within the study sample.

Parental stress and perceptions of illness severity (Hypothesis 2)

In line with expectations, the results appear to have been influenced by the status of the child's illness severity, as perceived by the parent. Parents reporting their child's eczema was moderate or severe during the previous week showed mean total stress scores between the 80 and 85th centile (.84 standard deviations above the normative sample mean). In contrast, the mean total stress scores for parents reporting their child's current eczema was mild corresponded to the 50th centile (.12 standard deviations below the normative sample mean). Moderate positive correlations were found between ratings of both current and twelve-month illness severity and parenting stress. This study therefore supports previous findings for other chronic illnesses in suggesting that reported stress is linked to parental perceptions of illness severity.

Parenting stress and problems with child's scratching (Hypothesis 3)

The study's findings suggest that dealing with scratching by children with atopic eczema is a considerable problem for parents. A majority of the study sample parents (63%) reported finding their child's scratching over the previous year 'a big problem'. Only one parent reported scratching had not been problematic. Although only 13% of parents reported that their child's scratching during the previous week had been 'a big problem', 74% of the sample reported some problems with scratching during the previous week. As half of the sample reported their child's eczema was 'mild' during that time, some parents appear to experience difficulties in relation to their child's scratching during times when they feel the eczema is mild.

Parental ratings of difficulties with scratching over the year showed a non-significant, positive correlation with stress. Ratings of current difficulty in relation to scratching, however, were significantly correlated with reported stress levels. Although only a small sub-sample (N=5), those who reported current scratching during the last week as 'a big problem' showed mean total stress scores above the 85th centile (1.23 standard deviations above the normative sample mean). These findings support the hypothesis that parent perceptions of problems in relation to scratching by their children with atopic eczema are associated with parental stress.

The relatively high correlation between parental stress and perceptions of problems with the child's scratching during the last week may indicate significant sleep problems. Children with eczema frequently experience sleep problems due to scratching at night when their skin is flaring. A large majority of children with eczema in the study by Lawson et al were reported to have experienced sleep problems. In a study by Reid and Lewis-

Jones (1994), the parents of 39 preschool children with atopic eczema reported sleep disturbance on 86% of nights when their child's skin was flaring. The toll on parents was shown by an average of 2.7 wakings per night and mean parental sleep loss of 2.6 hours per night. It is not difficult to envisage the impact on parental stress and on child difficulty of this pattern of sleep disruption and deprivation.

Association between factors which parents perceive make their child's scratching worse and parenting stress (Hypothesis 4)

This study did not show a strong link between parenting stress and 'environmental'/'psychological' factors perceived by parents to make scratching worse. However a weak positive correlation was found for both of these factors, suggesting there may be some link with parenting stress. Neither factor was empirically derived from parent responses and their validity and reliability must therefore be questioned. Future studies need to focus more narrowly on exploring parents' perceptions of psychological/environmental variables which affect their child's scratching. It would be particularly interesting to look at parental attributions about such variables. Do parents who see their child's scratching as heavily influenced by 'psychological' or 'environmental' variables attribute this to within-child characteristics or to situations they feel they can influence? The assumption that high ratings of these variables lead to feelings of low control over scratching may not be justified for all parents.

*Association between positive coping strategies and parenting stress
(Hypothesis 5)*

The results of this study failed to support the hypothesis that parents reporting more strategies for dealing with scratching would show lower parenting stress compared with parents who use fewer strategies (i.e. they would show a significant negative correlation). This hypothesis was based on the premise that parents endorsing a greater number of strategies would feel they had greater control over their child's scratching. The absence of a significant correlation between these variables indicates that this premise may not have been justified.

Firstly, parents indicated only how frequently they use various strategies to reduce their child's scratching and not whether they find these strategies effective. The lack of a negative association between positive coping strategies and parenting stress may therefore reflect the real or perceived utility of strategies they are employing. Some parents may be employing a number of 'positive' strategies, such as distracting or comforting the child, which do not influence (or which they perceive not to influence) their child's scratching significantly. They may simply not know any effective strategies for dealing with scratching. In this case, high endorsement of these strategies could reflect a perception of low control over this symptom. Alternatively, some parents may perceive they can reduce scratching most effectively by consistently using one positive strategy.

In addition, the low Cronbach's alpha (.56) for the Positive Coping subscale suggests relatively low internal consistency within this subscale. A cumulative 'positive strategies' subscale score may not therefore represent

a meaningful measure of parental coping with scratching. The results do not necessarily rule out the existence of a link between parents' stress and perceptions of control over their child's scratching.

Association between negative responses to scratching and parenting stress (Hypothesis 6)

The results of this study support the hypothesis that negative responses to their child's scratching would be associated with increased parenting stress. The evidence for this link suggests the risk of a vicious circle developing. Negative responses to the child in reaction to scratching (such as telling off/ getting cross with the child) may inadvertently be positively reinforcing this behaviour (through increased attention and the child's awareness of the powerful effect of scratching on his parents). This would make the behaviour more likely to re-occur, leading to increased parental stress, worsening skin condition and further positive reinforcement of the undesired behaviour.

Before considering some of the clinical implications of this study, a number of methodological limitations need to be addressed.

Lack of local matched comparison group

The present study relies on published norms to compare levels of stress among the study sample with those of a normal population. The study by Goldberg et al (1990) found significantly elevated stress in parents of children with Cystic Fibrosis and congenital heart disease compared with a local comparison group. However significant differences between their study sample's stress scores, including those of parents whose children have a chronic illness, and those of the normative sample were

not found. The authors suggest that this may have reflected regional differences between Canada and the USA in health care delivery systems. The significantly elevated Difficult Child stress scores reported in the present study may also reflect cultural differences. The use of a local matched comparison group would help to identify whether regional differences are influencing the reports of parenting stress. However the close match between study and normative sample Parental Distress mean scores and standard deviations suggests that regional differences did not exert a general effect on parenting stress reports in this study.

Generalisability of findings

The present study sample included only parents of children with atopic eczema who had received treatment on a hospital out-patient basis. Although children are referred for a variety of reasons, they are likely to represent more severe and/or intractable cases of atopic eczema. The results can not therefore be generalised to parents of the wider population of children who receive community-based treatment for this condition.

Although the study refers to parenting stress, it should be emphasised that the sample included only mothers, since the families reported they were the principal carer for the children concerned. Fathers have been reported to show significantly lower stress scores on the Parenting Stress Index compared with mothers (Abidin,1990). In the study by Goldberg et al (1990), however, fathers reported more stress than mothers on two subscales from the Child Domain of the Parenting Stress Index (long form). Though the absence of fathers from the study may have influenced the findings, the likely direction of influence is unclear. Since the normative data for the short form is based solely on mothers, the comparison of stress

scores between the study and normative samples was not affected by gender.

Other relevant variables

Although the sample parents showed elevated parenting stress compared with the normative sample, the majority of the sample did not show Parenting Stress scores in the clinically significant range on any of the subscales or on the total score. The study provides an indication of some of the variables which may help to predict the impact of childhood atopic eczema on parental stress levels. Previous research suggests there is a strong likelihood that other variables, which were not measured in the present study, also affect parental stress. For example 'resource' variables (McConachie,1994), such as social support and family functioning, are likely to have accounted for some of the variance in parenting stress among the study sample.

Absence of objective illness measures

Another limitation of the present study concerns the validity and reliability of the illness and symptom ratings. As parents rather than professionals served as informants, objective medical assessments of the children's current eczema severity were not available. Parents' ratings may not have been objectively accurate measures of illness severity. The relationship between parenting stress and objectively measured changes in illness/symptom severity was not therefore examined in this study. However, in the study by Daud and Garralda (1993), a link between objectively measured eczema severity and both child psychiatric morbidity and maternal distress was found. Only 14 children from their original

sample were severely affected by eczema at the time of their study (>10% of skin area affected). Seven of these children (50%) had Behavioural Screening Questionnaire scores in the clinically significant range, compared with 12.5% of the children who were less severely affected. High maternal distress was reported by 85% of mothers of severely affected children, compared with 31% of the less severely affected group.

Validity of eczema scale

The eczema scale developed for this study showed good test-retest reliability and three of the four subscales showed reasonable internal consistency. However evidence supporting the validity of the eczema scale devised for this study was limited. Comparison with other measures of scratching-related variables (such as diary-recording) are needed to establish clearly what is being measured by the scale developed in this study.

Type of data

As the only source of data used in this study was cross-sectional parental self-report, it is possible that the same domain or construct is being tapped by the different measures used. For example, the Difficult Child domain contains an item which asks parents to rate how hard they have found 'getting my child to do something or stop doing something'. It is possible that parents in this study were thinking of their child's scratching when responding to this item. Also in the Difficult Child domain, responses to the item 'There are some things my child does that really bother me a lot' could have been influenced by parental perceptions of their child's scratching. This could have been clarified by asking parents to say what they had in mind when responding to specific items on the PSI.

Future research needs to address this issue by employing more varied measures. Where parents report finding their child with atopic eczema 'difficult', a clearer understanding of precisely what this means to them is needed, together with a closer look at how this interacts with other variables to affect their management of their child and his/her condition.

Correlational design

This study presents correlational data and does not therefore provide evidence in support of a causal relationship between parental stress and associated variables, nor of the direction of any causal influence which may exist. It is not clear, for example, whether parental perceptions of greater problems with 'current' scratching by the child lead to greater parental stress or vice versa.

Clinical Implications

This study adds to a growing awareness of the complex and interrelating processes which are involved in childhood atopic eczema. The findings suggest that parents of children who receive hospital outpatient treatment are at risk of experiencing elevated levels of stress compared with a normative sample. Treatment of the child needs to be complemented by a careful and sensitive exploration of the impact on the parent of the child's condition. In the case of parents who do report greater stress, some form of psychological intervention may be helpful. The nature of this intervention needs to follow from a detailed assessment of the sources of stress for the parent.

There are no published controlled studies which investigate the impact of interventions focussed on improving the relationship between children with eczema and their parents. Case-studies, such as Koblenzer & Koblenzer

(1988), suggest such treatment may lead to improvements in behaviour and skin symptoms. In the light of the present study's findings, an exploration of the parents' perceptions about problems with the child's scratching should be included in treatment of this sort. Since negative parental behaviour, such as telling the child off, is associated with parenting stress, a detailed behavioural assessment of parent-child interactions before, during and immediately after scratching is advised.

Conclusion

This study builds on the work of Lawson et al (1994) which identified a range of ways in which eczema among children affects families and which called for further work to evaluate and quantify the extent of the problem. The findings suggest that parents of children who receive out-patient hospital-based treatment for eczema are significantly more likely to experience parental stress than a normative population sample. Increased stress is most likely to arise from a perception of the child as difficult. The child's symptom of scratching is problematic for most parents and greater parenting stress is associated with current perceived problems with this symptom. Parent perceptions of greater illness severity are also associated with increased parenting stress. A range of environmental and psychological conditions are reported by parents to influence their child's scratching. The findings of this study suggest there may be an association between parenting stress and parents' perceptions of psychological factors which increase their child's scratching. The link between parenting stress and perceptions of low or high control over the child's scratching remains to be established.

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APPENDICES

Appendix 1: Introductory letter

Appendix 2: Information sheet (English version)

Appendix 3: Information sheet (Welsh version)

Appendix 4: Follow-up letter (Phone)

Appendix 5: Follow-up letter (No phone)

Appendix 6: Eczema questionnaire

***** Children's Centre

Ext ****

Mr and Mrs ****,
 48 ***** Way,
 *****,

Date as Postmark

Dear Mr and Mrs *****,

Scratching among Children with Eczema

Parents of children with eczema often report how difficult it is to control their child's scratching. This can be frustrating and stressful for parents. I am currently carrying out a research project into these aspects of childhood eczema. I am writing to parents of children with eczema who have been seen at the hospital to tell you about the project and to ask if you would like to take part. The Information Sheet which is enclosed tells you what is involved.

I will be contacting you again shortly, either by phone or by letter, to ask if you are willing to help. In the meantime, if you have any questions or would like any more information about the project, I would be delighted to hear from you.

Yours sincerely,

Graeme Gillespie

(Paediatric Psychologist : ***** Children's Centre)

CHILDREN WITH ECZEMA PROJECT INFORMATION SHEET FOR PARENTS

What is the project?

Parents and professionals report a wide range of factors which affect the symptoms of childhood eczema. As parents know their children better than anyone else, they are particularly valuable in informing professionals about their children's illness. This project aims to develop and use a simple rating scale to help all parents of children with eczema to identify the factors which seem most to affect their children's scratching. The project also looks at how these factors affect parental stress.

Why have I been contacted?

We are approaching the parents of children with eczema who attend hospital-based Dermatology Clinics.

What will I be asked?

If you agree to take part, you will be given a questionnaire to complete. It lists the main factors which are associated with childhood eczema. You will be asked to say how often (from 'never' to 'always') you think they are present when your child's skin gets worse and also when your child's scratching increases. You will also be asked a few basic factual questions about your child's illness (such as how long it has lasted) and your family.

How long will it take?

It is anticipated that it will take about 20-30 minutes in total.

Who is carrying out the research?

The main researcher is Graeme Gillespie, a Psychologist working in the hospital Paediatric Department. He has a special interest in the difficulties of children who have eczema. He is being helped in this project by Dr L*****, Consultant Dermatologist at the hospital as well as by other staff working with children with eczema.

What if I choose not to take part?

You are under no obligation to take part. If you choose not to take part, it will not in any way affect your child's rights to have whatever treatment he/she needs.

Who benefits from this project and how?

By helping parents to identify the factors which are associated most frequently with their children's eczema symptoms, it is hoped that professionals will be able to target and evaluate treatment more effectively.

What if I agree to take part but afterwards feel unhappy about the way the research was conducted?

If you do decide to help with this project, we hope you enjoy it and find it interesting. However if you do not like the way the research is carried out, you are entitled to complain to Prof F. Lowe, School of Psychology, University of Wales Bangor, Bangor, Tel (01248) 382211 and to Mrs I***** , ***** Hospital, (Tel) *****.

Other questions?

If you would like to know any more about this project, either before or after agreeing to take part, please feel free to contact G.Gillespie, c/o ***** Children's Centre, ***** Hospital, Tel (***** (Ext ****))

PROJECT PLANT A CHROENLID
TAFLEN WYBODAETH I RIENI

Beth yw'r project?

Mae rhieni a phobl broffesiynol yn sôn am amrywiaeth eang o ffactorau sy'n effeithio ar symptomau croenlid plentyndod. Gan fod rhieni yn adnabod eu plant yn well nag unrhyw un arall, maen nhw'n hynod werthfawr pan fyddan nhw'n egluro salwch eu plant i'r bobl broffesiynol. Nod y project hwn yw datblygu a defnyddio graddfa cyfraddiad syml i helpu rhieni pob plentyn â chroenlid i ganfod y ffactorau sy'n effeithio fwyaf ar gosi'r plant. Mae'r project hefyd yn edrych ar sut y mae'r ffactorau hyn yn effeithio ar straen rhieni.

Pam maen nhw wedi cysylltu â mi?

Rydyn ni'n cysylltu â rhieni plant â chroenlid sy'n mynychu Clinigau Dermatoleg mewn ysbytai.

Beth fyddan nhw'n ei ofyn i mi?

Os byddwch chi'n cytuno i gymryd rhan, byddwch chi'n derbyn holiadur i'w gwblhau. Mae'n rhestru'r prif ffactorau sy'n gysylltiedig â chroenlid plentyndod. Byddan nhw'n gofyn i chi ddweud pa mor aml (o 'byth' i 'bob amser') y byddan nhw'n bresennol 'pan fydd croen eich plentyn yn gwaethygu' a phan fydd cosi'r plentyn yn cynyddu. Hefyd, byddan nhw'n gofyn rhai cwestiynau ffeithiol syml i chi am salwch eich plentyn (e.e. pa mor hir mae'n para) ac am eich teulu. Yn olaf, byddwn ni'n gofyn i chi gwblhau holiadur byr am straen rhieni.

Pa mor hir fydd hyn yn para?

Rhagwelir fydd hyn yn para am tua 20 - 30 munud.

Pwy sy'n cynnal yr ymchwil?

Y prif ymchwilydd yw Graeme Gillespie, Seicolegydd sy'n gweithio yn Adran Baediatreg yr ysbyty. Mae ganddo ddiddordeb arbennig mewn anawsterau plant â chroenlid. Mae'n cael ei gynorthwyo yn y project hwn gan Dr ******, Ymgynghorydd Dermatoleg yn yr ysbyty ynghyd â staff eraill sy'n gweithio gyda phlant â chroenlid.

Beth os na fydda i'n dymuno cymryd rhan?

Nid oes yn rhaid i chi gymryd rhan o gwbl. Os byddwch chi'n dewis peidio â gwneud, ni fydd yn effeithio mewn unrhyw ffordd ar hawliau eich plentyn i ba bynnag driniaeth sydd ei angen arno/arni.

Pwy fydd yn elwa o'r project hwn a pham?

Drwy helpu rhieni i ganfod y ffactorau sy'n gysylltiedig amlaf â symptomau croenlid eu plant, gobeithir y bydd pobl broffesiynol yn gallu targedu a gwerthuso triniaeth yn fwy effeithiol. Hefyd, dylai'r project ein helpu i ddysgu mwy am y straen sy'n wynebu rhieni plant â chroenlid.

Beth os bydda i'n cytuno i gymryd rhan ond yna'n anhapus ynglŷn â'r dull o ymchwilio?

Os byddwch chi'n penderfynu helpu gyda'r project hwn, gobeithio y byddwch chi'n ei fwynhau ac yn ystyried ei fod yn ddiddorol. Fodd bynnag, os na fyddwch chi'n hapus â'r dull o ymchwilio, gallwch gwyno i'r Arthro F Lowe, Ysgol Seicoleg, Prifysgol Cymru Bangor, Ffôn (01248) 382211 ac i Mrs ******, Ysbyty ****** (*****) *****.

Cwestiynau Eraill?

Os hoffech wybod mwy am y project, naill ai cyn neu ar ôl cytuno i gymryd rhan, gallwch gysylltu â G. Gillespie, d/o Canolfan Blant ******, Ysbyty ******, Ffôn (*****)(Est *****).

***** CHILDREN'S CENTRE
EXT ****

Mrs *****,
1 ***** Cottage,
*** **** Lane,

7th September 1995

Dear Mrs *****,

Scratching among children with eczema

Many thanks for agreeing to take part in this project. I enclose the project booklet for you to have a look at. You might like to fill it in as you read through it. I hope it is easy to understand and that you find it interesting to work through.

As agreed, I will call at your home on Wednesday 13th September at 6 P.M. to collect the booklet and to answer any questions you may have. I look forward to meeting you.

Yours sincerely,

Graeme Gillespie
(Paediatric Psychologist)

***** CHILDREN'S CENTRE
EXT 5153

Mrs *****,
53 ***** Street,
*****,

6th September 1995

Dear Mrs *****,

Scratching among children with Eczema

Recently I wrote to tell you about this project. I am enclosing the project booklet which I hope you find interesting.

If you do not wish to take part, simply post the enclosed numbered card to me. This allows me to know who does not wish to take part in the project, whilst maintaining confidentiality. As stated on the information sheet, this does not in any way affect your right to receive a service either now or in the future.

If you would like to take part, you simply fill in the booklet as you read it. I am able to visit you at your home to collect the booklet on Thursday 14th September at 2 P.M. Please let me know if that is not a good time for you, so we can arrange a better day or time. If I am not available to speak to personally, you are welcome to leave a message with the secretary. You might like to indicate a preferred day/time. (I can visit at any time during the day or evening, to suit you). If I do not hear from you, I will assume that the day and time indicated is acceptable to you and look forward to seeing you then.

Thank you for your help.

Yours sincerely,

GRAEME GILLESPIE
(Paediatric Psychologist)

PAGE/PAGES
EXCLUDED
UNDER
INSTRUCTION
FROM
UNIVERSITY

ADULT MENTAL HEALTH

SMALL SCALE RESEARCH PROJECT

Title: An investigation into patient reactions to a pre-treatment information sheet and questionnaire used by an Adult Clinical Psychology Department

Word count: 3436 words

ABSTRACT

Since November 1992, the department in which this project was carried out has sent patients a pre-appointment information sheet and questionnaire. The aim of this project was to identify patient reactions to these and highlight specific areas for quality improvement.

A sample of 10 former patients were interviewed, using largely open-ended questions. Nine of the respondents found the information sheet helpful, either because of specific information or due to affective reactions to it. The questionnaire caused mixed feelings which are discussed in the context of therapeutic factors. None of the responses indicated the questionnaire put patients off attending. Specific quality improvement suggestions included changes in language, question order and layout.

INTRODUCTION

Over the last decade, there has been an increased emphasis in the N.H.S. on the cost-effectiveness and marketing of services. This has led to growing interest in the effects on patients of pre-treatment written information.

Jackson and Fell (1992) highlight the particular importance of giving patients information about clinical psychology services, given its relatively diffuse boundaries and low profile within the N.H.S. A number of papers have specifically evaluated the impact of informational material on patient attendance rates. Spector (1988) reports increased attendance rates following the provision of information about the service. Others have combined the use of such material with a procedure which allows patients to 'opt in' for treatment. Balfour (1986) and Adams et al (1989) both report reduced DNA rates after introducing pre-appointment information sheets combined with returnable questionnaires/forms on which patients describe the presenting problems.

The effect of a pre-appointment questionnaire alone has been studied by O'Loughlin (1990). Rather than provide explicit information about the service, O'Loughlin aims to encourage patients to begin to 'think psychologically', by responding to a 12-page psychodynamically-formulated pre-appointment questionnaire. The intuitive sense that the size, intimacy and open-ended nature of the questionnaire might have a negative impact on attendance rates is disconfirmed in O'Loughlin's study. The improved contact rates he reports suggest the questionnaire may act as a facilitator.

Webster (1992) points out that these approaches to improving attendance rates are becoming widely used, though the mechanisms by which they increase attendance are still not clear. In his study, an improvement in attendance rate from 57 to 82 % compares with that found by Spector(1988). Webster suggests the impact of the information sheet is mediated by increased levels of satisfaction, as measured by a patient satisfaction questionnaire.

The study described below was conducted in a service which has used a combination of service information sheet and pre-appointment questionnaire since November 1992. The project aimed to help the service identify patient responses to this preparatory material. It was anticipated that patient responses would reflect considerable qualitative differences which the project could begin to describe and evaluate. It was hoped that this could clarify some of the ways in which these materials impact on patients and identify possible improvements in content, style, layout etc.

METHOD

Subjects

The original subject pool consisted of patients who had been contacted by the Adult Clinical Psychology Department with the offer of a first appointment between November 1992, when the information sheet and questionnaire were first introduced, and July 1993. Referrals to the department come from a variety of sources, the majority being from G.P.s and Consultant Psychiatrists. It was decided subjects should also meet the following criteria;

- (a) not continuing to receive treatment from this department,
- (b) no prior contact with the researcher,
- (c) not especially high problem/treatment sensitivity (as rated by the psychologist who provided treatment).

This provided a subject pool of 33 subjects. The adoption of criteria (a), (b) and (c) reduced the potential subject pool from over 100 to 33 subjects.

Initial subject contact was by letter, including a return slip and stamped addressed envelope, (N = 23) or by telephone (N = 10). Those contacted by letter (see appendix) were also sent a question and answer sheet describing the project (see appendix). Subjects contacted by telephone were read a prepared standard telephone script (see appendix) and those agreeing to take part were sent a follow-up letter, enclosing the question and answer sheet.

Following this initial contact, the responses were as follows;

Agreed to take part N = 11(F=10,M=1)

Declined to take part N = 7

Nil response N = 11

Miscellaneous (e.g. changed address/left area) N = 4

One of the subjects who agreed to take part subsequently withdrew due to giving birth, leaving a final sample of 10 subjects (F=9,M=1).

Data collection and analysis

In order to obtain subject responses to the information sheet and questionnaire, a standardised, largely open-ended interview schedule was used (see appendix). The questions were phrased in such a way that subjects were encouraged to generate responses in their own words in order to express their own personal perspectives. The subjects' spoken answers were written down by the interviewer on an interview prompt sheet. This method of data collection allowed the interviewer to hand the subjects a copy of the information sheet/questionnaire and direct their attention to specific sections for detailed comment as the interview progressed.

In order to present the complex patient responses obtained in this study in a coherent and meaningful way, a form of content analysis has been

carried out. This technique, described in Patton (1987) and Coolican (1990), essentially involves looking for themes and patterns in the data and organising it into manageable categories.

RESULTS

Patient responses to the information sheet

All the respondents remembered receiving and reading the information sheet. Their responses have been divided into 2 sections; key themes and aspects of the sheet found to be helpful.

(Word-count restrictions prevent the inclusion in this report of all interview responses. These are available from the author on request.)

Key themes

1) Need to improve readability/language

Five respondents referred to the sheet's language, readability or tone. Responses which advised improvements included;

'you have to be fairly literate to understand what it says'(A)

'it's the wording of it...it could be improved'(D)

'things like insight-orientated don't mean a lot to me..'(J)

'it sounds a bit like a teacher-pupil relationship...we are laying down the ground-rules for how you will comply...I think it's really a question of tone'(A)

'it's rather bogged down in words..symptom-focussed..insight-orientated..'(A)

However one respondent may have been reflecting on the sheet's language-style when she stated;

'it's not patronising...it doesn't make you feel stupid'(C)

2) Impact of section B of information sheet (two contrasting psychological models)

Six respondents commented on this section of the information sheet specifically. Three were positive about its impact;

'I thought the bit about the two different approaches was helpful...I knew which one I would go for and how long it would take'(G)

'the bit on the two different approaches was good'(C)

'Section B1 and 2 was useful...all of section 2...very useful'(H)

Four respondents specifically criticised the language used in this section, e.g.

'the symptom-focussed, insight orientated bit is difficult'(D)

'the bits about symptom-focussed and insight-orientated approaches....the bits about anxiety and depression are all right...it's just those headings.'(J)

3) Difference between psychologist and psychiatrist

Three subjects felt it was important to be clear about the difference between a psychologist and a psychiatrist. Two felt the differences could be described more clearly ;

'It doesn't actually specify there is a difference between a psychologist and psychiatrist..it doesn't explicitly make the difference clear' (A)

'I think it could be clearer on the difference between psychologist and psychiatrist.....(later in interview)..I don't know if there's a difference between a psychologist or psychiatrist' (E)

Another felt re-assured after reading the information sheet;

'I think I was pleased it wasn't a psychiatrist'(F)

4) Knowing more about what to expect from the treatment

Four respondents referred to the sheet helping them know what to expect in the sessions with the psychologist e.g.

'at least you knew what was going to happen when you went there...it puts your mind at rest'(I)

5)Relationship between patient and psychologist

Two respondents spoke of the sheet describing the participative nature of the relationship between psychologist and patient e.g.

'This is also what I mean by a contract...if they're going to help me, I've got to help them too...'(F)

What did patients find most helpful about the information sheet?

Nine of the respondents felt the sheet had been helpful. Their responses to question 6, about what they found helpful about the information sheet fall into two broad categories. The first was about being more informed about some aspect of the service. Specific information found to be helpful was;

- _ the two contrasting approaches in section B,
- _ waiting-times,
- _ what a psychologist is,
- _ what to expect in the sessions,
- _ the difference between a psychologist and a psychiatrist.

The second category of responses was less easy to define, but seemed to reflect the perceived emotional benefits derived from the information sheet. These included,

- 'it was obvious that an effort had been made'(A),*
- 'I knew that other people were going through it as well'(B),*
- 'it did make you feel that it mattered...that you mattered'(F)*
- 'it puts your mind at rest...the first time you're told you've got to see a psychologist you think oh God...once I'd read it it 's not that bad at all'(I)*
- 'it just put me at ease that I would just be talking to another human-being'(J)*

Patient responses to the pre-treatment questionnaire

All the respondents remembered receiving and completing the questionnaire.

Perceived purpose of the questionnaire

Several respondents perceived the questionnaire as a way of informing/helping the psychologist gain a clear understanding of their problem. One expressed surprise that the questionnaire was to be brought to the first session, rather than posted in advance for the psychologist to read before the session. Other responses described the questionnaire assisting the process of the first session, through focussing on their problems, and on the benefits of writing down their problems.

Perceived audience

Five respondents thought only the psychologist would read their completed questionnaire. Five thought other staff within the department (e.g. secretary, psychiatrist) would be able to read it.

Feelings about completing the questionnaire

Three respondents expressed generally positive feelings/thoughts about completing it (e.g. *'good idea'(C)*, *'it..concentrated the mind(A)*). Three expressed some negative feelings/thoughts (e.g. *'I'm not happy with form-filling at the best of times(D)*, *'I think it made me more angry'(E)'*). One respondent (G) described mixed feelings, hating questionnaires due to low confidence in her writing ability but feeling glad in the first session that

she had written it down. Another spoke with feeling about the painful therapeutic process involved in writing about her problems (*'I found it quite difficult because of having to go back over it all....I picked out all the easiest questions first...left the difficult ones till the night before'*(H)). Another mixed reaction was described by respondent J, *' I felt that it was good in one way...I think it was necessary...but it did make me feel a bit vulnerable as well'*.

Influence of the questionnaire

Five respondents said the questionnaire did not influence their decision about whether to come for their first appointment. Of those who felt it did influence their decision, five indicated they were more likely to attend after completing it. Their reasons included;

'I couldn't put down exactly how I felt so I felt I had to speak to the person face to face'(D)

'I'd waited so long I wondered if it was worth going...when I read through the questionnaire I realised it probably would help to talk'(F)

One respondent indicated the questionnaire nearly put her off attending as she felt her problem looked *'rather pathetic on paper'*(A).

Completing the questionnaire

Three of the ten respondents had discussed it with someone else. The time taken to complete it varied from less than 10 minutes(N=1) to more than 60 minutes(N=4), with 3 people filling it in as soon as they received it, 2 just before their first appointment and three completing it in stages. One

patient said she had spent *'absolutely hours on it'*(A), deliberately removing a phrase which she later felt could be compromising if taken out of context. Five patients had found it quite easy/ not very difficult to complete. Four found some of the questions quite difficult, very difficult or distressing. One had sought help from his wife and this had led to some conflict as, *'my wife didn't know the full extent of the problems...she said why didn't you tell me'*(D).

Suggested alterations / other comments about the questionnaire

Page 1

Review space for address compared with space for telephone number (currently the same)

Page 2

More friendly, informal tone for Q.1 (e.g. 'could you' or 'would you' rather than 'please describe briefly')

Q.1 possibly difficult to start with

It doesn't say whether or not to put physical problems

Page 3

Qs1 and 2 felt to be difficult for some patients. Might help to include adjectival prompts

Lines would help keep writing straight

Relevance of information on parents not clear to 3 respondents

Page 4

One respondent not clear on what information was wanted about relationship with parents. Another felt this question could cause some discomfort .

Page 5

Four respondents suggested or implied improvements, such as increased question specificity, less white space. Difficulties with ' knowing where to start'(F) were raised by one.

Page 6

One respondent felt Q,1 could come earlier. Two mentioned the wording of Q,2 invites a yes/no response. Q,3 received some critical comment from 2 respondents. One felt it could deter someone with a specific problem, such as a phobia. Another *'wasn't too happy with answering that...I couldn't see the relevance'(D)*. Another respondent found it *' a little bit hard to put down on paper'(J)*.

Page 7

One respondent felt the order of questions would be improved if this came before Q3, page 6. The same respondent mentioned difficulties the questionnaire would present to a Welsh-speaker.

Perceived helpfulness overall of the questionnaire

Five of the respondents thought the questionnaire was helpful. Others found it helpful to a degree(1),fairly helpful(1), very helpful(1), most helpful(1) and unhelpful(1). Additional comments included one who felt her problem looked 'puny' on paper and that printing the questionnaire double-sided would halve its 'dauntingness'.

DISCUSSION

Methodology

The major weakness of this project is its small sample size. Though the relatively time-consuming data-collection method limited the scope of the study, interpretations and conclusions have to be extremely cautious given such a small sample. Clearly a larger sample would have been possible had the original subject pool been greater. The decision to exclude from the subject sample those patients who were continuing to receive treatment was taken on ethical and methodological grounds. It was felt that their inclusion might have interfered with the therapeutic process, leading to some confusion in their minds about the nature of this investigation. Also they might have felt under implicit pressure to consent to take part against their will and to have provided positive-biased responses. Further research into patient responses to the information sheet and questionnaire will be possible as more patients complete their treatment under this protocol.

It is not clear why volunteer rates reflected such a noticeable gender imbalance, which far exceeded the small imbalance in the original sample of 33. It raises the possibility that responses to the sheet are themselves affected by gender.

Volunteer rate was also affected by the initial means of contact. Of the 10 subjects who were contacted initially by telephone, 5 volunteered to take part and a further one was willing to take part but indicated he was shortly returning for further treatment from the department and was therefore not included. This 60 % volunteer rate contrasted with a volunteer rate of 27% in response to initial contact by letter. It is possible that the effort

required to complete and return a tear-off slip acts as a counter-incentive to volunteering behaviour. However initial contact by telephone may apply covert pressure on subjects who feel uncomfortable about saying no and therefore raises ethical concerns. Indeed one subject who was contacted by telephone subsequently contacted the department to express her concerns about being contacted in this way.

A recent paper by John (1992) raises the issue of whether the hospital experience itself might influence patient willingness to respond to surveys about their experience. One interesting hypothesis suggested by the findings in this paper is that patients who have been less satisfied with their hospital experience might be more likely to respond to surveys. It is claimed that this is supported by literature on complaining behaviour (e.g. Day and Boder 1978). John's paper goes on to suggest that patients may also be more likely to respond to surveys conducted by someone not directly associated with the hospital. The paper emphasises that these are tentative research hypotheses, based on small samples of patients who had stayed in hospital for at least one night. However they highlight some of the complex variables which might have affected patient responses to this research project. Though it was made clear that the present research study was being carried out as part of a University doctorate degree, it was also made clear that the researcher is currently employed at the same hospital, albeit in a different department, and that the results of the research would be communicated to the psychologists who treated them.

The self-selected nature of the sample poses a threat to validity. It is possible that those who agreed to take part had more positive views about the information sheet and questionnaire than those who declined. Though patients who had not attended for treatment were included in the original

sample, all those who agreed to take part had received treatment and had completed the questionnaire. It is possible that some patients are put off attending for treatment by the preparatory information and questionnaire, and such patients might feel reluctant to express their views.

An interest in focussing on the diversity of individual patient responses led to a desire to personalise the evaluation process, through research methods which emphasised relatively informal, face-to-face contact. A further practical consideration guided the choice of data-collection method. It was felt that patients could potentially become confused if asked to respond in writing, through for example a response questionnaire. This would of necessity require them to receive simultaneously two questionnaires (i.e. the original pre-treatment questionnaire to remind them of its contents and a project questionnaire to complete and return). Subjects might have been uncertain in these circumstances about precisely what they were expected to complete. However the face-to face interview approach may have increased a positive response bias.

Recording subject responses in writing, as they were spoken, proved difficult. Some responses could not be recorded quickly enough and were consequently missed. Also the process of writing seemed non-verbally discouraging and this may have inhibited some respondents. The use of a tape-recorder would have helped record responses more accurately.

Patient responses: what was learned?

The themes which were identified in response to the information sheet suggest that it is generally well received. Patient descriptions of what was found helpful suggest the sheet does more than simply provide

information. The benefits described by some patients indicate a positive emotional impact, due to feeling valued by the therapist, reducing anxiety and recognising other people have psychological problems. A number of respondents commented on the need to clarify the difference between a psychologist and psychiatrist, although this is specifically addressed in the sheet.

Improvement suggestions indicate a need to review the information sheet's readability and tone. Section B, particularly the headings, was specifically commented on, though this section was felt to be particularly helpful by some.

The responses to the questionnaire raise some complex issues which can only be briefly addressed here. Perhaps the most interesting issue concerns patients' emotional reactions to it. A number of respondents indicated they had experienced some uncomfortable feelings in response to the questionnaire. Some of these were due to not liking writing/ form-filling, a problem with any approach inviting patients to write. It is possible that the questionnaire deters those with poor reading/writing skills or those for whom English is a second language. The problem of poor writing skills could possibly be alleviated through inviting patients to record rather than write their responses, if preferred.

Other uncomfortable emotions were due to a feeling of resurrecting problems, feelings of vulnerability, or increased anger in one respondent who had not wished to be referred. These feelings seem to relate closely to the feelings which can surface during therapy. It is possible that these responses illustrate the beginnings of a therapeutic process prior to attending. Clearly if this produced an increased likelihood of not attending,

this would be reflected in increased non-attendance subsequent to the questionnaire's introduction and would contra-indicate its use. However none of the respondents were less likely to attend as a result of it, though one felt it nearly put her off attending. A review of attendance patterns following the introduction of the questionnaire is recommended.

Other responses demonstrate considerable differences in the time taken to complete the questionnaire, possibly reflecting variation in the importance attached to it by patients.

Only half the respondents identified the questionnaire as a confidential document which is seen only by the psychologist. This is likely to affect patient responses and may need emphasising more clearly.

A number of suggested specific alterations are provided. It is hoped that these could inform a review of the questionnaire's language, content and layout.

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APPENDICES

Appendix 1: Information sheet

Appendix 2: AMH Clinical Psychology Department: Pre-treatment questionnaire

Appendix 3: Telephone contact script

Appendix 4: Introductory letter

Appendix 5: Question and answer sheet

Appendix 6: Patient survey

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UNDER
INSTRUCTION
FROM
UNIVERSITY

Dear «Name»,

I am writing to you to see if you could help me with a patient survey I am doing. I have been asked by the Adult Psychology Department in ***** to find out how patients feel about the information sheet and questionnaire they send out before their first appointment. It is hoped that this will help to prepare future patients better.

I am therefore writing to every patient who was contacted after November 1992 and who is not now receiving treatment from the Psychology Department. The enclosed Question and Answer sheet explains the survey in more detail.

I would be grateful if you could let me know by August 27th whether or not you are willing to help, by completing the tear-off slip below, or by phoning the secretary on the above number. Your decision about whether or not to take part does not affect any treatment you may have either now or in the future. If you do decide to take part, however, I will contact you again to arrange to visit you at a convenient time. Your responses will be extremely helpful to the Department. I look forward to hearing from you.

Yours sincerely,

GRAEME GILLESPIE
(Chartered Psychologist)

Adult Clinical Psychology; *** Hospital Patient Survey
Consent Form**

(Please return in the enclosed stamped addressed envelope)

Please tick one box

I am willing to take part in this survey.

I am not willing to take part in this survey.

Most convenient appointment time(s) are usually; (please ring)

MONDAY	A.M.	P.M.	EVENING
TUESDAY	A.M.	P.M.	EVENING
WEDNESDAY	A.M.	P.M.	EVENING
THURSDAY	A.M.	P.M.	EVENING
FRIDAY	A.M.	P.M.	***
SATURDAY	A.M.	P.M.	***

Tel. no. I can be contacted on_____

Signed_____

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LEARNING DISABILITIES
SMALL SCALE RESEARCH PROJECT

**TITLE : An evaluation of a training approach for carers of
a person with challenging behaviour and multiple
impairments**

WORD COUNT : 3437 words

Abstract

This report describes a carer training intervention aimed at reducing the challenging behaviour (pinching) of a young man with multiple impairments, through altering handling and feeding approaches. An AB research design is used to evaluate the effects of training on frequency of pinching and overall difficulty rating. Reductions in mean and median pinch frequencies and overall difficulty ratings are noted, though data instability raises questions about the validity of the baseline comparison. The study suggests multiple behavioural determinants may be affecting the frequency of challenging behaviour in this case.

INTRODUCTION

Challenging, disturbed or inappropriate behaviours are widely acknowledged to affect a significant minority of individuals with learning disability and to present major stresses to their carers (Jones and Eayrs, 1993). The term 'challenging behaviour' reflects a move away from perceiving such problems as solely individual towards a recognition of the interactive nature of problematic behaviour. Broderick (1988) points out the term challenging behaviour shifts service goals away from the elimination of disturbed behaviour to attempting to 'meet the needs of the person despite the difficulties his behaviour represents'.

Challenging behaviours take a variety of forms, including physical attacks on others, self injury, destructive behaviour, noninjurious stereotyped behaviours and bizarre, psychotic speech. Durand(1990) highlights the need to understand and manage these behaviours, citing a number of their negative consequences, such as;

interference with family life,

interference with employment and education,

physical threat to the persons themselves and those with whom they relate,

frequently cited obstacle to placement in community setting.

Jones and Eayrs (op cit) identify the difficulties in establishing meaningful estimates of the prevalence and incidence of challenging behaviours,

given wide variations in operational definitions and service responses. However they identify some general trends which emerge from prevalence studies, namely;

challenging behaviour is more common in residential services than in day services,

the majority of challenging behaviours are seen in people with profound or severe disabilities,

it is more common for individuals to display more than one challenging behaviour than to engage in only one,

challenging behaviour is most common between the ages of 15 and 30.

Attempts to understand and reduce challenging behaviours over the last 25 years have frequently incorporated the defining characteristics of Applied Behaviour Analysis, as described by Baer, Wolf and Risley (1968). Woods and Blewitt (1993) describe the developments in this approach to interventions focused on challenging behaviours. Early studies aimed to manipulate the environmental consequences of behaviour, experimentally assessing the impacts of techniques such as extinction, punishment and differential reinforcement of incompatible or other behaviour. These techniques were themselves derived from laboratory research on the experimental analysis of behaviour (Skinner, 1953).

With the development of the concepts of social validity (Kazdin 1977) and normalisation (Wolfensberger, 1972) and an increased focus on ethical

considerations, the public acceptability of procedures began to be debated as much as the effectiveness of specific techniques. The role of aversive techniques became highly controversial, leading to close public scrutiny in the United States and what has been termed 'the intense politicisation of treatment decisions' (Sturmey, Ricketts and Goza, 1993, p.118).

In the light of criticisms of over-simplified rules of environmental control over behaviour, the influences of complex physiological, verbal and ecological variables have begun to be accepted in the literature on challenging behaviour (Jones and McCaughey, 1993). These complex variables are particularly relevant when considering challenging behaviour in the context of brain damage and associated sensory impairment.

METHOD

Participant

The main participant in this research study was Mr D, a 21 year old man living with his family. He had developed normally until the age of 14 years, when he contracted subacute sclerosing panencephalitis, a condition related to the measles virus. The initial prognosis was of a life expectancy of up to one year, though a number of cases of long-term survival are reported. Mr D now has a profound learning disability, has no expressive language, and is cortically blind. He has a generalised physical weakness down the left side of his body and regularly has localised fits involving his left side, for which he receives medication (Lamotrigine 25mg bd. at the time of this study). During weekdays, Mr D was spending the daytime in the

company of one of two 'good neighbours' funded by the Independent Living Fund.

Mr D was referred to the Clinical Psychology Service by the team leader of a Community Living Service, the presenting problem being 'aggression towards family members'. This problem was reported to have escalated in the time leading up to referral.

Preliminary investigations

In order to clarify the presenting problem, a number of preliminary investigations were carried out prior to the main research intervention. These steps included the following;

i) Mr D was observed informally within the family home, while out walking with a day carer and while being taken horse riding,

ii) Mr D was videotaped while being fed by his mother and, separately, by each of his two daytime carers. This activity was specifically chosen as it involves a relatively high level of physical contact and prompting and because it had been identified as particularly problematic. The videotape was subsequently analysed for frequency of behaviour, antecedent/ consequent conditions and to guide behavioural definition of the target problem,

iii) Mr D's mother and one of his daytime carers completed the Motivation Assessment Scale (Durand, 1988),

iv) a series of meetings involving Mr D's parents and his day carers took place at the family home. The original aim of these meetings was to share observations about the presenting problem in the context of Mr D's history, to begin considering possible functions of the behaviour and to pilot and review data collection methods.

Problem Definition

The target of analysis and intervention was Mr D's pinching of family members and carers. Through detailed interviewing of Mr D's parents and daytime carers, a precise behavioural description was agreed. Pinching was defined as a discrete touch in which the right hand is applied to another person's body, usually with an open palm, and significant pressure applied with the finger-ends/fingernails and thumb. This behaviour was frequently accompanied by a bite of the bottom lip.

Preliminary Findings

Initial investigations revealed the following;

a) the family and the two day care staff perceived Mr D's pinching to be deliberate, intentional acts whose main function was to inflict pain on them. He was described as 'having a go at me', 'thinking to himself I'll get her', and as, at times, 'vicious' or 'crafty'.

b) observed and reported behavioural antecedents could be categorised into 3 main types, carer-initiated physical contact (C), removal of or threat of removal of tangible (T), lack of direct carer attention (A).

c) typical consequences of the behaviour included verbal reprimands or 'commentaries', (such as "Don't", "That hurts...and that does", "What are you doing that for?"), spontaneous laughing or yelps of pain, and physical prompts such as moving/ slapping Mr D's hand away.

d) Mr D had a very limited ability to control his environment, virtually all activities being mediated through others. Mr D had a very restricted repertoire of physical and social skills and would frequently engage in stereotyped, repetitive movement patterns, such as standing and sitting back down.

e) Following his illness, Mr D had experienced a therapeutic programme based on 'patterning', on the advice of a specialist centre in the South West. This programme involved a very high degree of physical manipulation, such as passive limb movements and being spun upside down.

f) the frequency and intensity of Mr D's pinching appeared to vary considerably. During one period of videotaped observation, Mr D pinched approximately 50 times in one hour, about 50% of pinches being preceded by direct physical contact from a carer. Instances of the target behaviour were not distributed evenly throughout the period of observation. Some occurred in relative isolation and appeared to be of higher intensity. Others occurred in rapid succession and appeared to be of much lower intensity. This was reported to be 'a good night'. Much of the pinching was in response to deliberate, mild provocation by Mr D's carer (e.g. taking away and

returning a toy). Subsequently it was explained that this had been done in order to demonstrate the behaviour to the author.

Problem formulation

The preliminary investigations suggested this behaviour might be serving a number of functions. The Motivation Assessment Scale suggested tangible consequences were most influential but that social attention and escape from demands might also be influencing the behaviour. Observations suggested that the most intense, usually sustained single pinches appeared to follow situations involving unpredictable touching, difficult, more complex movements (such as getting in or out of the car or dismounting from a horse), or unpredictable trips or stumbles. Less intense, more rapid 'bursts' of pinching appeared to be more likely when Mr D's hands were unoccupied or he did not have full carer attention (such as sitting in the car). Three possible functions were hypothesised on the basis of these investigations.

Possible functions of behaviour

One possible function of pinching was felt to be to reduce or alter physical contact by a carer. An activity involving a high level of handling/touch or which involved handling associated with aversive prior experiences might act as an antecedent for pinching which in turn might reduce handling or change its characteristics in some way. This hypothesis assumes the behaviour is maintained by negative reinforcement.(e.g.Iwata,1987)

An alternative hypothesised function was that pinching might represent a panic/anxiety response in which increased physiological arousal and internal discomfort was dissipated or reduced by pinching.

A third function might be to increase the level of interaction with/attention from a carer. It was hypothesised that the verbal/physical responses of carers to pinching might be positively reinforcing this behaviour.

It was recognised that each of these functions might be operational. It was also recognised that the same topographically defined behaviour may serve different functions for different people (e.g. Carr and Durand, 1985). It is also often the case that one defined behaviour may serve a number of different functions for an individual. (e.g. Carr, 1977)

Intervention

Programme Design

Following discussion with the main carers, it was agreed that intervention would focus specifically on measuring the impact on pinch frequency of changes in handling, thereby testing the first hypothesised function. It was felt that handling techniques could be reviewed specifically in the context of Mr E's visual impairment. As this fell outside the researcher's own professional expertise, advice was sought from a specialist in visual impairment. A regional representative from the Royal National Institute for the Blind was contacted and met with the researcher and community nurse to discuss possible ways of assisting. With the consent of Mr D's parents, she conducted independent observations of Mr D, using both the

available videotapes and direct, informal observations. Subsequently it was decided with Mr D's parents and carers that the RNIB representative would run a series of awareness-raising training sessions, looking at a variety of handling techniques, using blindfolds in simulation role-plays.

The training sessions took place in Mr D's home, without him being present. Session 1 focused on leading/guiding techniques. Carers took turns at guiding one another while the person being guided was blindfolded. Open-ended questions were asked about the experience, both as guide and guided. Key points were noted and summarised at the end of the session and included the following;

(1) importance of being talked to in a reassuring voice and warned about potential obstacles such as steps,

(2) indicating if steps/slopes are up or down and if doors are push or pull,

(3) need to pause before an obstacle,

(4) importance of maintaining contact and not leaving the visually impaired person 'standing in space',

(5) sense of reassurance gained through having hand placed on door or on chair before being sat down,

(6) sense of reassurance through being able to feel edge of chair against back of legs before being sat down,

(7) importance of preceding instructions and comments with the person's name.

Session 2 focused on feeding and drinking techniques. Again the day care staff took turns at being fed and being given a drink while wearing a blindfold. The subsequent discussion raised the following points;

(8) drinking without a sense of control was highly aversive. It was felt that Mr D would benefit from increased opportunities to learn how to use a straw,

(9) there had been some indications that Mr D could have some peripheral vision in his left visual field. Feeding from that side was recommended, in addition to attempts to maximise illumination and contrast,

(10) the need to tell Mr D what the food is prior to feeding him was emphasised,

(11) discussion took place about trying to encourage independent finger-feeding, initially through the use of chocolate buttons with which some recent success had been observed.

Experimental Procedure

The procedure was conducted according to an AB design, where A represents the baseline phase and B the intervention phase. Though the limitations of this type of design are well documented (e.g. Kazdin, 1982), a number of clinical considerations were taken into account in the design. These are outlined in the discussion section of this report.

Phase 1: Baseline

Prior to the first awareness-training session, Mr D's parents and his two daytime carers were assigned the task of maintaining a record of the frequency and intensity of pinches. Following piloted recording systems, it was agreed that pinch intensity would be rated according to one of three

categories, high, moderate and low intensity. Verbal descriptions of these levels were generated by carers, as follows;

High intensity Nails dug in for several seconds, leaving marks on the skin, and causing distinct pain.

Moderate intensity Relatively quick but hard pinch, without nails dug in

Low intensity Quick, light touch usually accompanied by laugh from Mr D.

A hand held tally counter was provided to assist in recording the frequency of pinches and daily record sheets provided, divided into hourly units and with spaces to record activity if felt particularly relevant (see appendix). In addition to pinch frequency, a daily rating of overall 'difficulty' was included, utilising a 10 point rating scale (1=least difficult, 10 = most difficult). Ten days' baseline data were kept.

Phase 2: Intervention

The second phase commenced with the first awareness training session, as described above. A second training session was scheduled for 3 weeks after the first session, with telephone contact in the intervening period. Unfortunately the second training session had to be postponed due to the trainer's sickness. The researcher visited at that time to collect data and discuss the programme. The second awareness-training session was completed 3 weeks later and a follow-up session provided 20 days later. Sixty days' data were kept over the intervention period.

Inter-observer reliability

In order to maximise inter-observer reliability, a session was spent prior to the baseline phase in which a videotape was watched by the four experimental observers and the researcher. Independent assessments were made of the overall pinch frequency and intensity and subsequently compared. Four of the five raters gave a frequency count of 15(n=2) or 17(n=2), producing a frequency ratio of 88% agreement (Kazdin, 1982). One observer's rating of 22 led to a discussion about the difficulties in accurately observing all pinches. A subsequent viewing of the videotape showed that 'under the table' assumed pinches had been counted in that case only. The videotape encouraged discussion about what looked like high vs. moderate or low intensity pinches and a consensus view was agreed.

Following the training, the researcher observed Mr D with his parents and the remaining daytime carer. This offered the opportunity for further checks on inter-observer agreement. 100% agreement was established, though at the time of the observations there were relatively few instances of pinching.

RESULTS

The results demonstrate considerable fluctuations in pinch frequency, during both baseline and intervention phases. Total daily pinch frequency (see figure 1) during baseline ranges from 6 to 36, with a mean of 15.8 and a median of 13.5. During the entire intervention phase, total daily pinch frequency ranges from 0 to 28 with a mean of 6.25 and a median of 4. These

figures, together with separate means and medians for high, moderate and low intensity pinches are presented in figure 1.

The results show a reduction in mean daily rating of difficulty from 4.5 in baseline phase to 3.14 during the intervention phase and a reduction in median from 4.5 to 2.2.

Figure 1. Table showing mean and median reported pinch frequencies and difficulty ratings during baseline and intervention phases

Total pinches (per day)			
	Range	Mean	Median
Baseline	6-36	15.8	13.5
Intervention	0-28	6.25	4
High intensity pinches (per day)			
	Range	Mean	Median
Baseline	0-13	5.4	2.2
Intervention	0-16	1.9	0.6
Moderate intensity pinches (per day)			
	Range	Mean	Median
Baseline	2-20	8.2	7
Intervention	0-21	3.7	1.8
Low intensity pinches (per day)			
	Range	Mean	Median
Baseline	0-18	6.7	3
Intervention	0-5	1	0.6
Daily difficulty rating			
	Range	Mean	Median
Baseline	1-8.5	4.5	4.5
Intervention	1-10	3.14	2.2

Figure 2 presents daily total pinch ratings in graph form. Visual inspection shows marked fluctuations in total pinch ratings, both in baseline and intervention phases. Particularly high ratings during the intervention phase are apparent during days 26 and 27 and during days 49-56. Possible reasons for these high ratings are advanced in the discussion section.

Figure 2. Graph showing total number of pinches per day over the baseline (days 1-10) and intervention period (days 11-70)

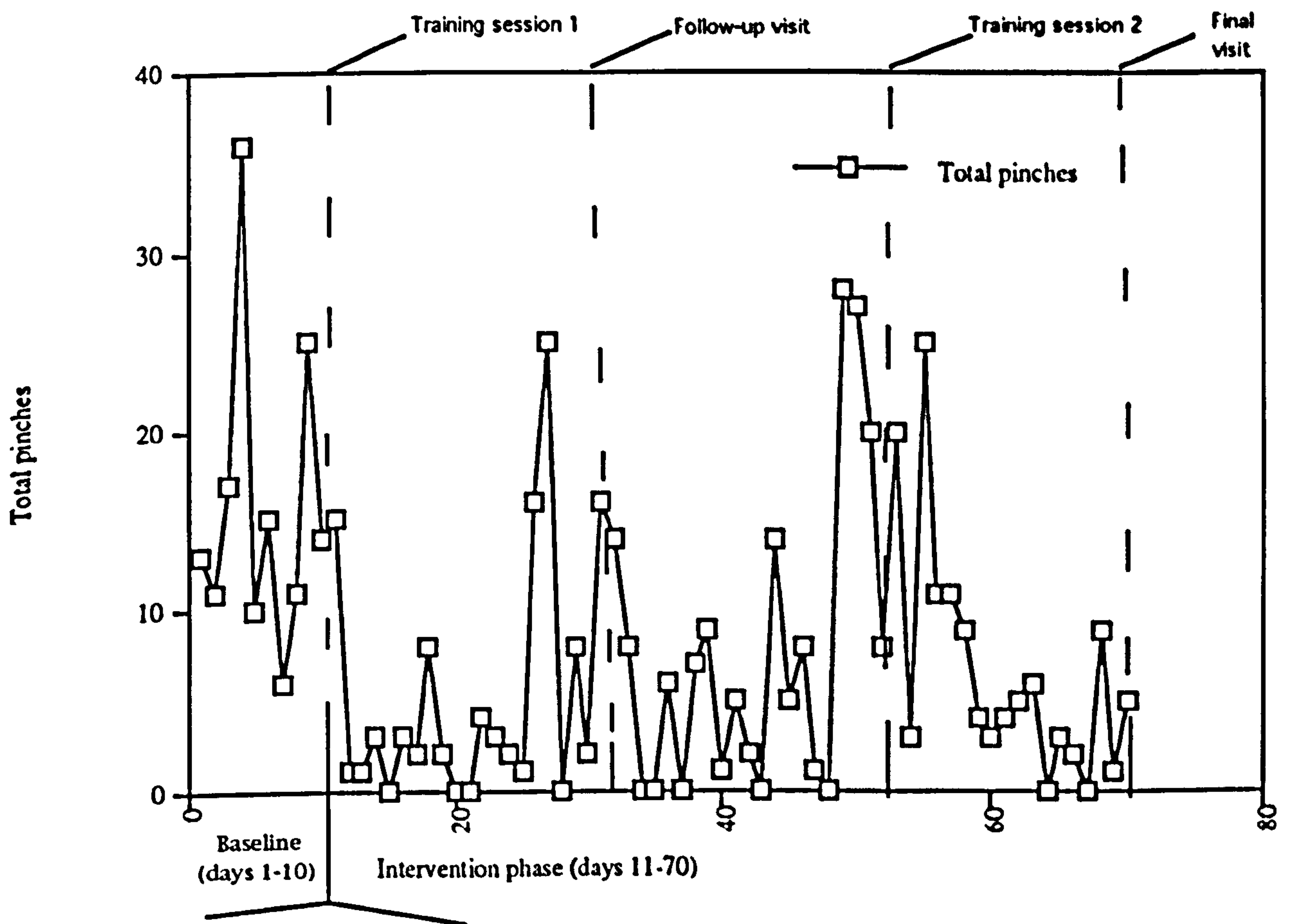
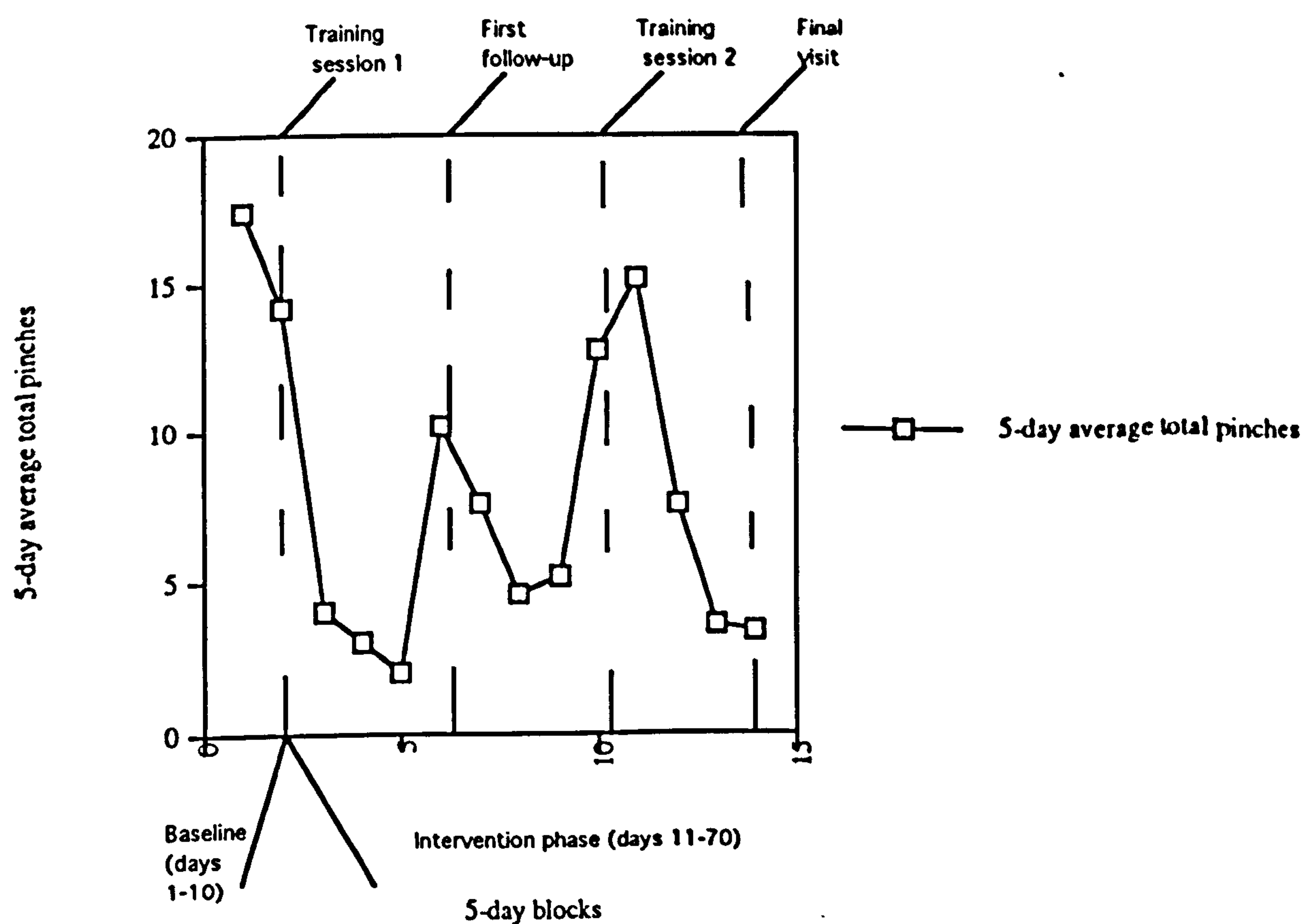


Figure 3 presents 5-day averages for total pinch ratings. Visual inspection of figure 3 fails to identify stable trends in the data but indicates a marked reduction in level of pinch frequency during the 15 day period immediately following baseline.

Figure 3. Graph showing 5-day mean total pinches over baseline and intervention phases



DISCUSSION

Impact of intervention

The results of this study suggest that the intervention achieved partial success. Though wide variations in pinch frequency are noted, the reduction in mean and median frequencies comparing baseline with intervention phases indicates an overall reduction in total pinches. These reductions are noted across all pinch intensity ratings. The reductions in mean and median overall ratings also suggest improvements and decrease the likelihood that a reduction in pinch frequency led to increased topographically different challenging behaviour. However a number of factors suggest the need for these results to be viewed very cautiously.

Variability in the data

The fluctuations in pinch frequency throughout the baseline and intervention phase casts doubt on the reliability of the findings. As Sidman(1960) points out, excessive variability in the data during intervention indicates a lack of experimental control over the behaviour and therefore an incomplete understanding of the factors which may be exerting influence on that behaviour.

Figure 3 represents an attempt to identify changes in level by averaging data for 5 day periods (as described in Kazdin, 1982). These suggest the possibility of periods of fluctuating but relatively high rates of pinching, lasting for 5-10 days, followed by periods of relatively low rate pinching, lasting for approximately 15 days. This would invalidate the baseline phase as a valid comparison, since this phase may have corresponded with a period of high rate pinching. This research lacks sufficient data points to establish this long-term periodicity with any degree of confidence and

there are a number of other possible explanations for the degree of evident variability in the data.

Inter-observer reliability

It is possible that Mr D's behaviour was consistent and that variations in the data reflect inconsistent recording. Although efforts were made to ensure inter-observer agreement and accuracy, the behaviour being recorded was 'felt' rather than observed. This inevitably introduces a considerable element of subjectivity in the recording. The verbal descriptions used to rate pinch intensity rely heavily on subjective impression, such as perception of pain/pressure. These subjective impressions might be affected by 'observer' mood, leading to recording bias.

A further source of recording bias results from the observers' awareness of the experimental hypothesis and basic design.

Uncontrolled conditions

The record sheets provided an opportunity for observers to note activities where they thought this was relevant. Additional qualitative comments were also at times included on completed record sheets and were discussed during the training/follow-up sessions. These indicated high rates of pinching during the intervention phase may have been associated with specific external and internal conditions. The high ratings at days 26 and 27 corresponded with an unsuccessful attempt to take Mr D camping. This is likely to have resulted in considerable changes in routine and possibly necessitated unfamiliar or unusual handling. The period between days 49 and 56 corresponded with Mr D experiencing a mouth infection which led to him eating little. Fluctuations in the data do not therefore invalidate the

experimental hypothesis but highlight the complexity of the behaviour and the factors which may influence it.

Validity of baseline comparison

The possible sensitivity of the target behaviour to a variety of conditions casts further doubt on the validity of the baseline as a comparison since unrecognised internal or external conditions may have been affecting pinch frequency at that time. Ideally the baseline period could have been extended. However there were valid clinical reasons for intervening with this behaviour as soon as possible.

Design Limitations

The AB design of this study poses threats to internal validity. The absence of a reversal phase prevented the conditions in baseline being restored in order to test predictions about impact on target behaviour. However the effects of training could not be withdrawn since maintenance of changes in carer behaviour was ethically necessary. Changes resulting from repeated assessment may also have affected the findings, though the fluctuations in frequency recorded during the intervention phase suggest observations remained sensitive to behavioural changes.

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APPENDIX

Example record sheet

RECORD SHEET

DAY :
 CARER :

Time	Activity	Pinch frequency	High intensity	Mod intensity	Low intensity
7.00-8.00					
8.00-9.00					
9.00-10.00					
10.00-11.00					
11.00-12.00					
12.00-1.00					
1.00-2.00					
2.00-3.00					
3.00-4.00					
4.00-5.00					
5.00-6.00					
6.00-7.00					
7.00-8.00					
8.00-9.00					
9.00-10.00					
10.00-11.00					
11.00-12.00					

Overall rating for day 1 2 3 4 5 6 7 8 9 10
 1=least difficult 10=most difficult (please circle)

**CHILD AND ADOLESCENT BLOCK
SMALL SCALE RESEARCH PROJECT**

**Title : The use of a questionnaire to identify needs in
families in which a child has epilepsy**

Word count : 3399 words

ABSTRACT

This paper describes the second stage of a study to identify the needs of families with a child who has epilepsy. A total of 31 families were interviewed, using a needs assessment questionnaire developed in part 1 of the study. A high level of interest was shown by carers and young people in receiving more information about epilepsy, particularly its nature, causes, future implications, medication and effects. The child version of the questionnaire was less successful in identifying needs. The implications for service development are discussed.

INTRODUCTION

The prevalence rates for children with epilepsy range from 2.5 to 121 per 1000. (Leviton and Cowan, 1982) This variability is thought to reflect differences in age ranges included in prevalence studies, differing definitions of epilepsy and methods of case ascertainment, or population differences in frequency of childhood. Nevertheless most frequently cited prevalence rates for childhood epilepsy fall in the range 4 - 6 per 1000 (or approximately 1 in 200) (Cowan et al, 1989). Slightly increased prevalence in males is reported (M:F = 1.1), and prevalence is reported to be highest in children aged 1-4 years.

The classification of epilepsy into types is complex and is frequently being revised. The International League Against Epilepsy classification system (Commission, 1981) proposes the following seizure types;

Partial, including simple, complex and partial secondarily generalised seizure types,

Generalised, including simple (or petit mal) and atypical absences, myoclonic, atonic/ akinetic, and tonic, clonic, or tonic-clonic (or grand mal) seizures,

Unclassifiable seizure types.

A recent review article by Laybourn and Hill (1994) highlights the difficulties in generalising about childhood epilepsy, given its enormous variability in type, severity and association with other conditions. They draw on a recommendation from the National Child Development Study (Ross and Peckham, 1983, Kurtz et al. 1987) which suggests it is practical to divide children with epilepsy into two main groups:

1 'Epilepsy - only' i.e. those children for whom epilepsy is the main problem (approximately two thirds of children with epilepsy)

2 'Epilepsy-plus' i.e. those children with associated mental and physical disabilities or intractable seizures (approximately one third of children with epilepsy)

A number of studies point to adverse psychosocial effects of epilepsy on children . These include higher rates of emotional and behavioural disturbance among children with epilepsy (in both 'epilepsy- only' and 'epilepsy - plus' groups) than among healthy children and children with other chronic illnesses (Rutter et al, 1970, Bagley, 1971, Long & Moore, 1979, Matthews et al, 1982). Studies comparing children who have epilepsy with children who have other chronic conditions such as diabetes or asthma suggest particular features of epilepsy (e.g. brain-behaviour relationships, specific medication effects) lead to increased emotional/behavioural vulnerability, rather than this simply being due to the effects of chronic illness. (Hoare, 1984a and b, Austin, 1988).

A higher incidence of learning difficulties among children with epilepsy compared with peers is found in studies which do not differentiate between those with 'epilepsy - plus' and those with 'epilepsy - only' (Penry, 1986). However Laybourn and Hill (op cit) point out that separate analysis of the two groups shows performance may be slightly depressed as a result of medication or reduced expectations but the majority of children with epilepsy do not present impaired intellectual impairment when social variables are controlled for.

Studies of the effects of childhood epilepsy on families have presented mixed findings. The increased risk of emotional/ behavioural disturbance among children with epilepsy has been attributed to parental over-protectiveness and impaired family functioning (Suurmeijer 1980, West

1986, Ferrari 1989). Other studies report little evidence of parental over-anxiety or over-protection (Ward and Bower 1978, Clement and Wallace 1990). Laybourn and Hill (op cit) refer to the 'common belief' that parents of children with epilepsy experience bereavement reactions to the diagnosis, anxieties about the condition and fears about other people's reactions. However, Hoare (1984c) shows no increased risk of psychological problems. Positive parental coping is reported in some studies (e.g. Ward and Bower, 1978) and Austin (1988) suggests that a positive parental attitude towards the condition is predictive of successful coping. An increased risk of psychological disturbance in the siblings of children with epilepsy is reported, with greatest risk among the siblings of children with 'epilepsy - plus'(Hoare 1984c, Goldin et al, 1971).

The literature on services for children with epilepsy is reviewed by Laybourn and Hill (op cit). They argue that much of the thinking about services for this population has taken place 'largely without reference to the views of families themselves' (p 11). They consider it an urgent priority to seek the perceived needs and service priorities of this group, in order that services can develop on an appropriate basis.

This paper describes the second stage of a project to identify the needs of families with children with epilepsy. Stage 1 involved the development of a needs assessment tool to be used by this population(see Clerkin, 1994). Stage 2 involved using this assessment tool with a group of carers and children in order to clarify needs and provide 'a framework of need' within which service planning could take place.

METHOD

Participants

The participants in this study were selected from a list of children with a diagnosis of epilepsy living within Clwyd South. This list, supplied by the area's Senior Clinical Medical Officer, was cross-referenced with Wrexham Maelor Hospital records to identify children with epilepsy who were receiving treatment at the hospital.

The following exclusion criteria were adopted;

1) Children for whom epilepsy was, as far as was known by the S.C.M.O., a secondary diagnosis (e.g. children with profound or severe learning disabilities)

2) Children excluded on the advice of their G.P. or S.C.M.O.

Initial contact

A total of 66 families were initially contacted by a research assistant, using one of two bi-lingual letters. Letter A (see appendix) was sent to parents who were not able to be contacted by telephone (N= 20). The letter briefly outlined the nature of the project and invited parents to indicate if they were willing to take part by returning a tear-off slip in an enclosed stamped addressed envelope. Letter B (see appendix) was sent to parents who could be contacted by telephone (N=46). After describing the project, the letter explained that a researcher would be contacting the families by telephone to ask if they would be willing to take part. A total of 31 families agreed to take part in the survey and were visited at home and interviewed by a research assistant using the needs assessment questionnaire described below.

Needs Assessment Questionnaire

The research instrument used in this study was a needs assessment questionnaire devised by a former trainee clinical psychologist (Clerkin,1994). Three versions of the questionnaire were developed to allow its use with Carers, Young People (aged 11-18), and Children (aged < 11) (see appendix). Items were drawn from a study of the literature on problems associated with children with epilepsy and from discussions involving professionals working with people who have epilepsy. Six domains of need (based on Bailey and Simeonsson, 1988) formed the original organising structure for questionnaire items. These domains were Information, Family and Social Support, School Issues, Explaining to others, Professional Support and Community Services.

Each questionnaire is in two parts. Part 1 contains an introductory page, providing a brief outline of its purposes and explaining the anonymous nature of this part of the survey. This is followed by a section for background details, including the perceived severity and type of epilepsy experienced by the child/ young person. The main body of the survey uses a 3-point scale format, in which respondents indicate whether they would/ would not/were 'not sure' if they would like, to know more about a given topic. The carer version contains 54 items, the young person's version 56 items and the child's version 29 items. Following the administration of Part 1 of the questionnaire, participants were encouraged to illuminate their responses to items they have indicated they would like to know more about. Non-directive questioning was used to prompt responses (e.g. "You indicated you would like to know more about..*item read out*... Could you say a bit more about this item?"). It was felt that this would provide useful

qualitative information about the meanings of items for the participants. A complete set of qualitative data is available from the author.

Part 2 of the survey invites participants to list any specific queries they would like to discuss further. This information is recorded on a separate, detachable sheet on which names and addresses are recorded, to allow a member of staff to follow up concerns.

A copy of the questionnaires is enclosed in the appendix.

(See Clerkin (1994) for a fuller description of the development of the needs assessment instrument)

RESULTS

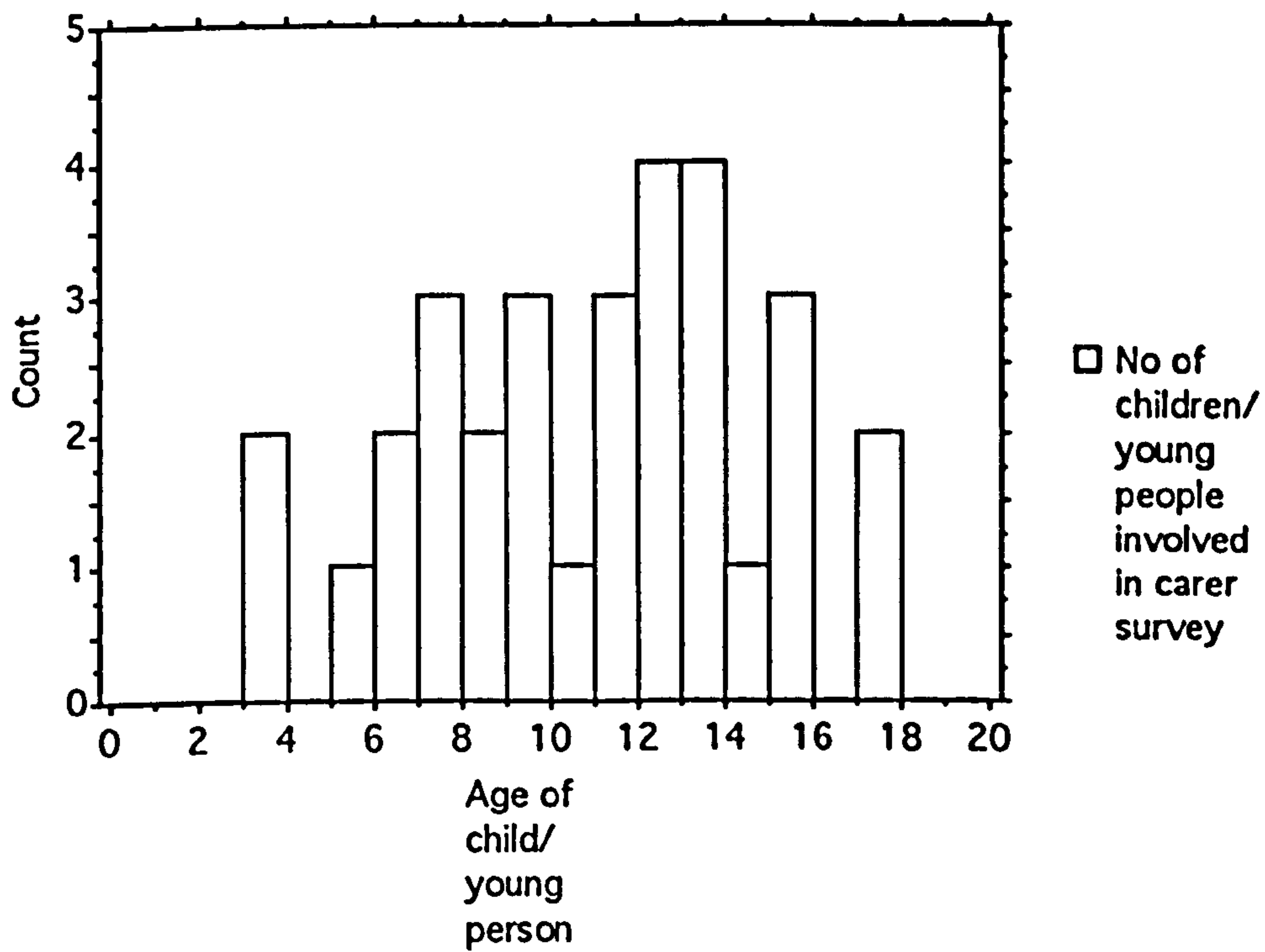
Background details

Eight (26%) of the carer questionnaires were completed jointly by mothers and fathers, the remaining 23 (74%) being completed by mothers only.

The frequency distribution of their children's ages is shown in figure 1. A total of 18 young people (M=7, F=11) and 13 children (M=5, F=8) were also interviewed.

FIGURE 1

FREQUENCY DISTRIBUTION OF AGES OF CHILDREN INVOLVED IN SURVEY



Carer responses

Rating of severity of child's epilepsy

Parents were asked to rate the perceived severity of their child's epilepsy on a scale of 1(not severe) to 10 (very severe). The mean severity rating was 4.1, with a standard deviation of 3.1.(range 0-10; one parent rated the severity as 0 as she reported her child was no longer having fits)

Total no. of items receiving a 'Yes' response (i.e.'would like to know more about this')

Out of 54 parent questionnaire items, the total number of 'Yes' responses ranged from 0 to 32, with a mean of 14 (S.D.= 8.19). Figure 2 illustrates the frequency distribution of questionnaire items selected by carers.

FIGURE 2:

FREQUENCY DISTRIBUTION OF QUESTIONNAIRE ITEMS SELECTED BY CARERS

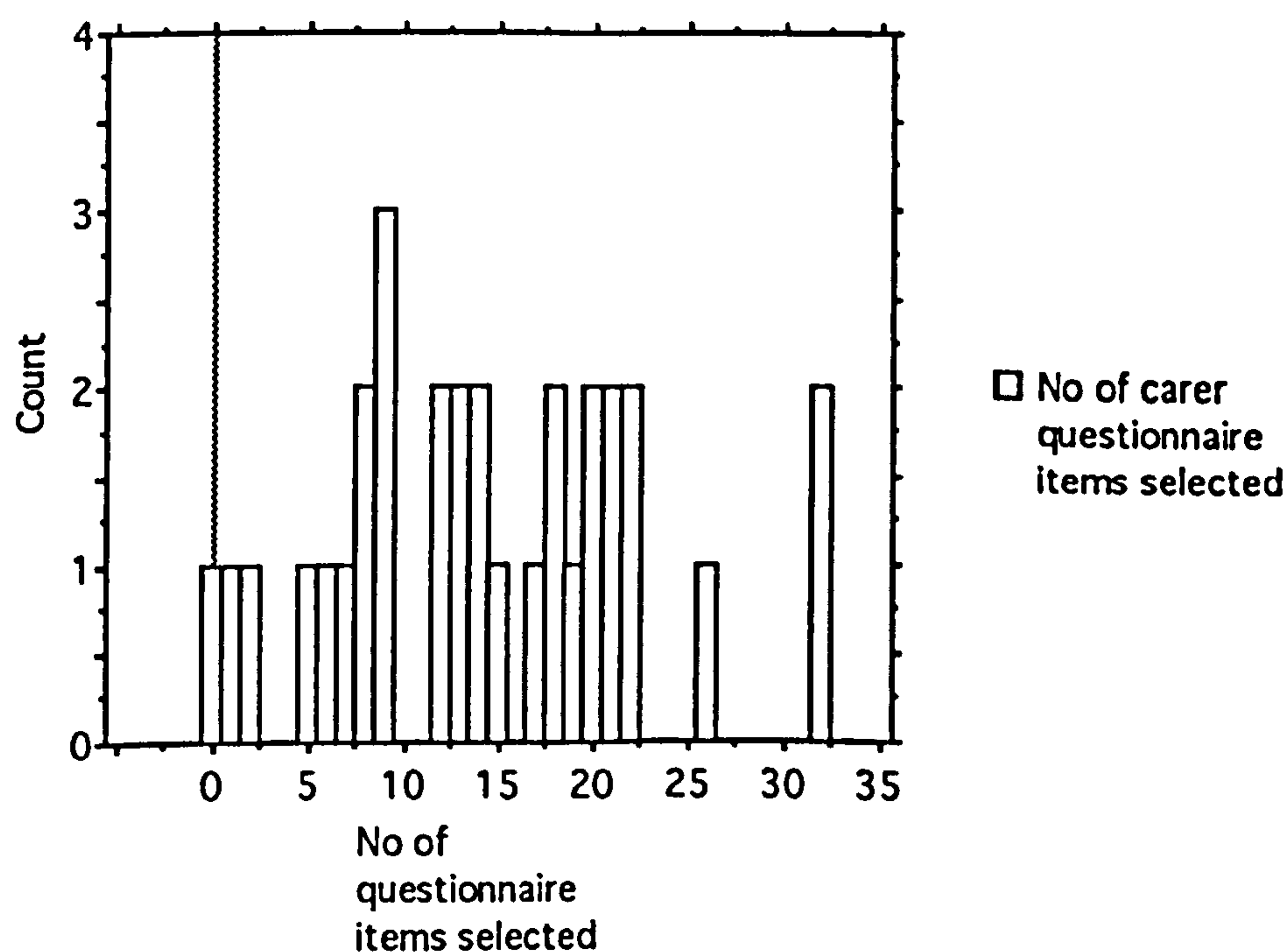
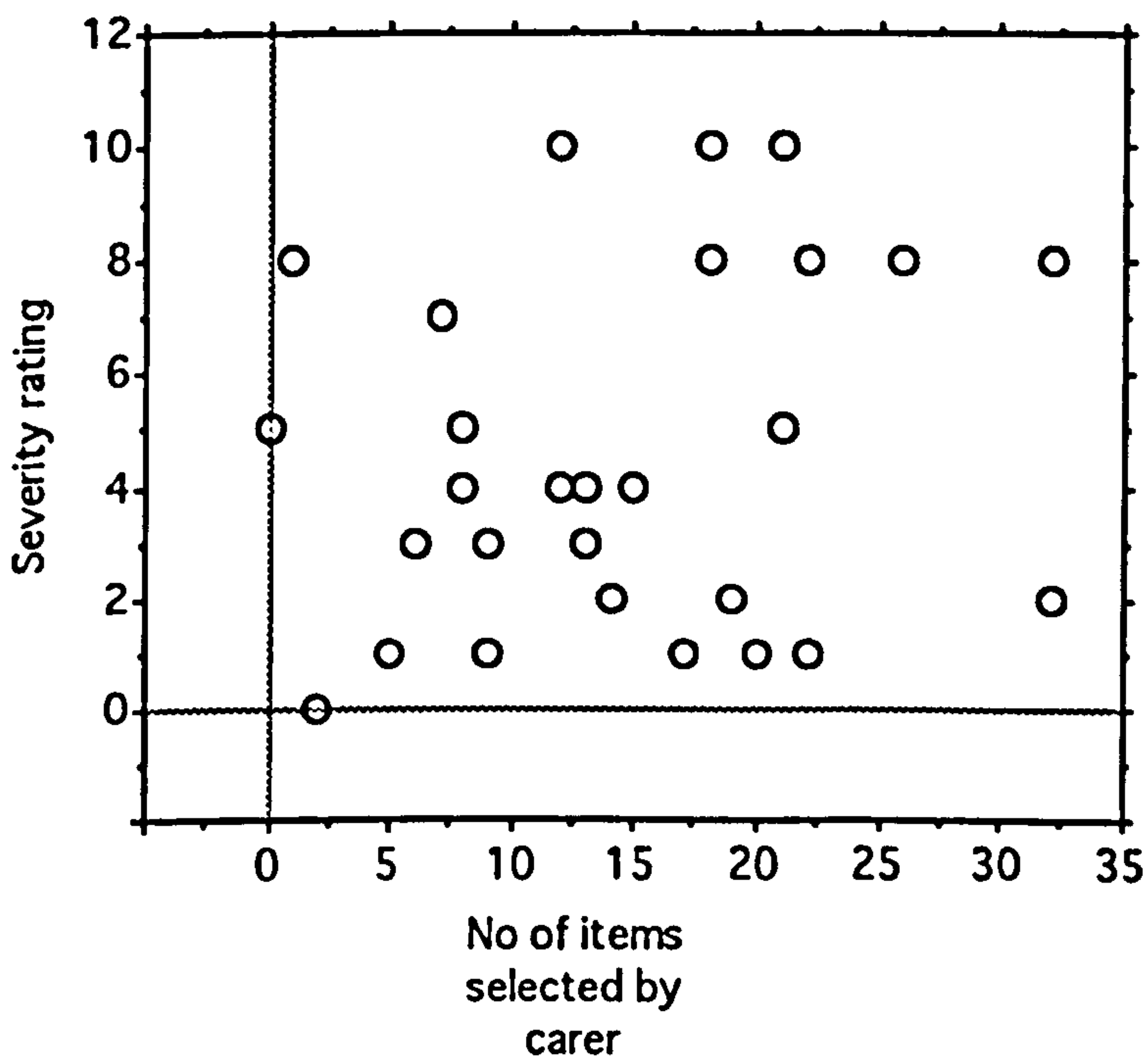


Figure 3 shows there was no significant correlation between carers' perceptions of illness severity and the number of items they selected.

FIGURE 3
SCATTERGRAM SHOWING RELATIONSHIP BETWEEN CARERS' RATING OF THE
SEVERITY OF THEIR CHILD'S EPILEPSY
AND NUMBER OF QUESTIONNAIRE ITEMS SELECTED



Carer responses: Most/ least popular domains

The responses of carers to the survey show a high level of interest in specific items. Nine items were selected by 50% or more of the respondents.

Substantial interest in the Information domain was shown by carers, with 15 (out of 18 possible) Information items in the 20 most frequently

requested items (ratings >30%). The next most popular domain was School Issues, with 3 (out of 7 possible) items in the 20 most frequently requested items. Two items from the Family and Social Support domain (from 13 possible items) were selected in the 20 most popular items. Items about Explaining epilepsy to others received limited support, with 4 of the 5 items in this domain receiving less than 15% yes responses. The least popular domain was Professional Support, with no items (from 6 possible) receiving more than a 16% Yes rating.

The following five items did not receive a 'Yes' rating by any of the participants;

*helping my family support each other,
finding a G.P. who understands my child's needs,
explaining epilepsy to family members,
talking to a social worker,
talking to a minister or other religious figure.*

The most popular themes requested in Part 1 were also reflected in responses to Part 2 of the survey, which 17 of the carers (55%) elected to complete. These were organised into specific themes which are shown in the appendix.

Young Persons Responses

Of the 56 items on the young person's questionnaire, the total number of items young people wanted to know more about ranged from 5 - 35, with a mean of 12.7 (S.D. = 7.2). Ratings of the severity of their epilepsy (from 1 - 10) provided a mean of 3.9 (S.D. = 3.1).

Young People's responses : most/ least popular domains

The complete set of Young People's responses is shown in the appendix. As was the case with carers, the responses of young people showed greatest interest in the Information domain. Within the twenty most requested items (out of a total of 56 items), 15 items from the Information domain were selected. Three items from the Professional Help domain and one item each from Family and Friends and Telling Others were also selected within the twenty most frequently requested items.

In contrast to the responses of their parents, young people showed little interest in school-based issues. Only 11% (N=2) of the young people interviewed said they would like to know more about *Getting help with my epilepsy in school* and *Getting help with my schoolwork*. Five items about 'helping the family' received very little interest, with only one item (*helping my family talk about problems*) receiving a Yes response from one young person, the other four (*helping my family understand/ accept/ cope with my epilepsy/support each other*) receiving no 'Yes' responses. Items about 'telling others about my epilepsy' also received relatively little interest generally, with 2 young people giving a Yes response to the items *telling my friends about my epilepsy* and *telling my brothers and sisters about my epilepsy*. The items *Telling my teacher/ doctor about my epilepsy* each received a Yes rating by one young person only.

Of the 18 young people who completed Part 1 of the questionnaire, 6 (33%) elected to complete Part 2. Their responses reflect the priorities identified in part 1 and are shown in the appendix.

Child responses

A total of 13 children were interviewed. The research assistants reported that a number of difficulties were encountered during the child interviews. Some of the children found the questionnaire format/ items difficult to understand or quickly lost concentration. The parents of one child subsequently explained that the child had not been told she has epilepsy.

The child version of the questionnaire is not organised into separate domains. Their responses are shown below under Key Themes. Of the 29 items in the child version of the questionnaire, only 7 items were selected by more than 25% of the children interviewed. Seventeen items received a 'Yes' response from only one child or were not selected. Only 2 of the children interviewed elected to complete Part 2 of the survey. Their responses are shown in the appendix.

Key themes selected by Carers, Young People and Children

The items most frequently selected by survey participants have been organised under thematic headings which are shown below.

(Figures in brackets indicate % of sample expressing interest in item. Ca= Carer, YP = Young Person , Ch = Child))

Information about the future e.g. effects of epilepsy in the future (Ca =77%, YP = 61%, Ch = 25%), job prospects (Ca = 64%, YP =

56%,), services in the future (Ca = 59%), possibility of child having a driving licence (Ca = 50%, YP = 67%, Ch = 25%)

Information about the nature/ causes/ management of epilepsy e.g. What is epilepsy? (Ca = 71%, YP = 39%, Ch = 31%), Why has my child/ have I got epilepsy? (Ca = 61%, YP = 67%, Ch = 46%), My child's condition now (44%), Dealing with my child's epilepsy attacks/ What happens during a fit? (Ca = 42%, YP = 47%, Ch = 27%)

Information about medication e.g. what other effects might medication have? (Ca = 65%), what should medication do?/ Why do I have to take medicine? (Ca = 55%, YP = 24%, Ch = 42%) When can I stop taking medicine? (YP = 39%, Ch = 50%)

Information about other possible effects of epilepsy How does epilepsy affect my child's behaviour? (Ca = 61%) How my epilepsy affects me now (YP = 39%)

Education e.g. Getting help with problems with school work (Ca = 40%, YP = 11%, Ch = 27%), getting appropriate care for my child in school (37%), problems my child can have with school work (35%).

DISCUSSION

Unmet need

The relatively high level of interest in specific questionnaire items suggests a high level of unmet need within this group. The pattern of responses shows a high level of interest in receiving more information about epilepsy, particularly its nature, causes,

future implications, medication and effects on behaviour and education. These results match those of Hoare and Kelly (1992) who also found that parents expressed an interest in receiving more information about epilepsy and its management.

Some of the qualitative responses of parents in the current study suggest that, in several cases, they have found it difficult to access information when they felt they needed it and this has caused considerable stress. This has implications not only for parents' own ability to manage their children's epilepsy but also for their child's, since parents are the main sources of information for the child (see, for example, Eiser, 1985). The interest in understanding the causes of epilepsy suggests that the concept of illness causality is important for this group. Since causal ambiguity is highly aversive for people, this unmet need places the survey participants at risk of developing self-blaming explanations for the child's epilepsy (see e.g. Wortman, 1976, LaBorde and Seligman, 1983).

Over the last twenty years, one approach to meeting the needs of parents of children with a chronic illness has been the provision of a range of different parent support groups. As part of their project involving children with epilepsy and their families, Hoare and Kerley (1992) asked parents if they were interested in meeting to discuss problems relating to their child's epilepsy. Although, at an initial interview, 103 parents expressed interest in attending, only 14 (<14%) of them attended the first session, with high attrition rates for subsequent sessions (36% attendance attrition for session 2, 86% for sessions 3 and 4). Parents who accepted the intervention programme were the few whose children had severe intractable epilepsy and additional educational or family problems. This study highlights some factors which may adversely affect participation in

groups for parents of children with epilepsy and suggests that many parents prefer individual counselling, particularly in the months following diagnosis .

Questionnaire utility

The questionnaire appears to be successful in identifying aspects of epilepsy which carers and young people are interested to know more about. The child version was less successful and may need modifying to reflect the communicative competence of children in this age group.

There was no clear relationship between the number of items chosen and ratings of illness severity. However the number of items chosen can not be considered an accurate measure of perceived need as perceived importance was not measured. Some participants may have chosen a small number of items which they consider extremely important, while others may have chosen several items which interest them but which they consider only slightly important. Part 1 of the questionnaire in its current form is therefore suited to population-based screening rather than as a means of comparing individual levels of need, which can be more reliably assessed using Part 2.

Possible sources of response bias

The response rate following initial contact was less than 50%. It is possible that a degree of self- selection may have operated, such that carers with lower levels of interest or need opted not to take part. The participants in this survey were all receiving hospital - based services. For these reasons, the results can not safely be generalised across the entire population of families with a child who has epilepsy.

It is possible that the responses of participants were affected by their perceptions of the researchers' purposes. Although the research assistants were 'independent', the project was managed and co-ordinated from a local hospital. This may have led to a bias towards expressing higher levels of interest in items which seemed more medically oriented, rather than, for example, items about financial needs/ family support.

The responses to the Carer and Young Persons' questionnaires also show a higher level of interest overall in Information items compared with other domains. This may reflect the wording of the introductory question, i.e. 'Would you like to know more about any of the following topics?' This wording, particularly the phrase 'know more about' may have encouraged responses towards more knowledge-based items, possibly at the expense of items about emotional needs and individual/family coping.

A further possible source of response bias is the effect of item order. Information items appear first on the questionnaire. A 'Yes' response-attrition effect would result in an apparent reduction of interest in later items. Random ordering of the questionnaire domains would clarify whether order effects were biasing responses.

Conclusion

This project successfully identified a high level of interest among participating families in knowing more about specific aspects of epilepsy. This provides a useful context for considering the development of services for this population.

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APPENDICES

Appendix 1: Initial contact letter

Appendix 2: Questionnaire (Carer version)

Appendix 3: Questionnaire (Young People version)

Appendix 4: Questionnaire (Child version)

Appendix 5: Carer responses

Appendix 6: Young People's responses

Appendix 7: Child responses

Appendix 8: Responses to part 2 : Key themes

8th July 1994

Mr and Mrs *
***** Street

Dear Mr & Mrs *****

Epilepsy in Children Survey

We are contacting you to ask if you can help us with a survey on epilepsy. We hope the survey will help us provide better services for families where children have or have had epilepsy. There may not always be enough time to discuss broader issues and concerns during visits to the doctor at the hospital. This survey can help us to learn what issues and concerns there are.

We have research workers who would like to visit you at home to find out your views and, if possible, those of your child who has or has had epilepsy. Your comments would be completely confidential. We expect that the interviews will take between half an hour to an hour. You are under no obligation to take part in this survey and any decision you make will not affect the service your child is receiving now or in the future. However, the more people we can talk to, the more we will know about the services people will want.

Please indicate whether you are willing to take part in the survey, by ticking the appropriate boxes on the attached form and returning it in the enclosed pre-paid envelope within the next seven days.
Many thanks for your help.

Yours sincerely

Dr G. *****, Consultant Paediatrician, ***** Hospital
on behalf of Chronic Illness Working Party

I am willing to take part

I am not willing to take part

Preferred day for interview:

Mon	Tues	Wed	Thur	Fri	Sat	Sun
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Preferred time for interview

AM PM

Print Name

Signature

7th July 1994

Mr a Mrs G
2 Street

Dear Mr & Mrs *****

Epilepsy in Children Survey

We are contacting you to ask if you can help us with a survey on epilepsy. We hope the survey will help us provide better services for families where children have or have had epilepsy. There may not always be enough time to discuss broader issues and concerns during visits to the doctor at the hospital. This survey can help us to learn what issues and concerns there are.

We have research workers who would like to visit you at home to find out your views and, if possible, those of your child who has or has had epilepsy. Your comments would be completely confidential. We expect that the interviews will take between half an hour to an hour. You are under no obligation to take part in this survey and any decision you make will not affect the service your child is receiving now or in the future. However, the more people we can talk to, the more we will know about the services people will want.

One of our research workers will be contacting you by phone during the next week or so, to see if you would be able to help us.

Many thanks for your help.

Yours sincerely

Dr G. *****, Consultant Paediatrician, ***** Hospital
on behalf of Chronic Illness Working Party

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Responses to Part 2: Key themes

Figures in brackets indicate the number of respondents who wanted to know more about the following aspects of their child's epilepsy;

Carers

Career/Jobs (8)
Behaviour (7)
School Performance (6)
Relapse/Prognosis (6)
Medication/main and side effects (5)
Benefits (4)
Driving (3)
Why does my child have E? (2)
Current/new services (2)
How to explain E. to my child (1)
Parent support groups (1)
What triggers a fit? (1)
E. generally (1)
Temporal Lobe E. (1)
Effects of med'n on EEG (1)
Support for siblings (1)
Respite care (1)
Is there a link between E. and Bowel function? (1)
Is there a S.W. advice line? (1)

Four carers expressed a wish to talk to a specific professional, namely;

Dietician (2)
School Nurse (1)
Psychologist (1)

Young People

Careers/ Job prospects (4)
Benefits (2)
Driving (2)
Why do I have E? (1)
What happens during a fit? (1)
Support group (1)
Medication (1)
Contraception (1)
Telephone contact (1)
Private issues (1)
Likelihood of relapse due to exam pressures (1)

In addition to the above, 2 young people expressed a wish to talk to a *male counsellor (1)* and a *careers advisor (1)*.

Child Responses

Driving (2)

E. in general (1)

What happens to me when I have a fit? (1)

Why do I have to take medicine? (1)

Will I need an operation? (1)

Playing on computers (1)

Meeting other children with Epilepsy(1)