

**EVALUATION OF THE SERVICES
FOR CHILDREN WITH EPILEPSY
AND THEIR FAMILIES IN THE
BOROUGH OF BEXLEY
WITH SPECIAL EMPHASIS ON
PARENTAL PERCEPTION**

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ABSTRACT

Epilepsy is the most common serious neurological condition, affecting 350,000 people in Great Britain, of whom at least 70,000 are children. It is a disorder characterised by brief recurrent usually unprovoked, stereotyped disturbance of consciousness behaviour, emotion, motor function or sensation which results from cortical neuronal discharge.

Children with epilepsy face the challenge of growing up healthy with barriers that few of their peers encounter. Many studies have demonstrated the impact seizure disorders have had on children's academic achievement, emotional growth, development, and resulting low self-concept, in-appropriate levels of dependency and behavioural problems, both at school and at home. Health surveys of school children have indicated that children with epilepsy have a greater prevalence of psychiatric morbidity, do not appear to outgrow their behavioural disturbances and even show a higher risk of taking their own lives.

Epilepsy has important **socio-economic costs** to a population. Longitudinal cost profile studies have shown that in the UK the total annual costs of established epilepsy is around £1930 million, over 69% of which was due to indirect costs (unemployment and excess mortality).

The development of services in the UK over the years has been disappointing, this despite a succession of government reports for better care of those with epilepsy, spanning more than three decades. A few local services, for example in Doncaster have achieved good results in improving delivery of care but nationally, rather like the case of diabetes thirty years ago, epilepsy has tended to fall through the net of conventional clinical and service organisations.

The last few years have seen the profile of epilepsy and its care rise rapidly. This has been due to a number of factors, notably the launch of new anticonvulsants replacing older ones, some of which introduced as long ago as 1912, newer techniques of neuro-imaging which have a powerful capacity to improve accuracy of diagnoses, and an increasing recognition that more needs to be done as regards psycho-social and educational aspects.

Over the years many people had come to accept their seizures and ceased using hospital care and in some cases even general practice care. Although the studies that demonstrate this have been on adult populations, this could be equally true of children. Parental attitudes towards their children's epilepsy and their coping patterns are aspects that have also emerged as key factors that influence the care of children with epilepsy. Childhood epilepsy, like many other chronic disorders, causes long-term stress for the entire family. Maladaptive coping by parents is often cited as a major reason for the increased incidence of emotional problems in children with epilepsy.

It is generally accepted that health care systems should provide not only treatments of confirmed efficacy but that the **provision should take place with the maximum effectiveness and efficiency**. In the UK as elsewhere there has been an increasing emphasis in recent years on evaluation and audit. There has been little systematic work in developing comprehensive means of assessing quality of care in epilepsy.

Assessments of the **process** of care in epilepsy should particularly focus on issues of communications and the interpersonal aspects of care. In this respect **patient's (in the case of children, parents or carers) satisfaction may be seen as representing one important outcome of care, and it also speaks to the management of the process of care**.

Previous research suggests that patient's satisfaction makes a direct contribution to other important outcomes. Thus patients who are less satisfied with care are less likely to comply with treatment regimes and are less likely to re-attend for treatment - both factors that are important in achieving good management and control of epilepsy.

In 1993, the Epilepsy Needs Document was produced at the suggestion of the Department of Health by six leading epilepsy specialists. The **Epilepsy Task Force** set up subsequently, **produced service specifications with input from a wide range of clinical, consumer, public health and purchaser representatives**.

In the **evaluation of the local epilepsy services in Bexley, for children with epilepsy**, the relevant Task Force recommendations were chosen as **criteria for good practice**.

The standards recommended by the Epilepsy Task Force specific to the topic area covered here are in relation to The Epilepsy Register, Staffing and access to specialists, investigations, treatment and follow-up, provision of information, and with respect to rehabilitation - liaison with primary care, with the school health service, with voluntary services and self help groups and provision of counselling and support.

In the evaluation of the organisation and provision of services against these criteria, special emphasis was placed on **parental perceptions as a key measure**. A semi-structured interview protocol was used to elicit information from parents.

The key findings in the study were as follows.

There is no register of those suffering from epilepsy in Primary Care Services, in Community Child Health Services, nor in the Hospital Paediatric Services. With the help of this study the compilation of a Register has already begun in Bexley.

Eighty eight children with epilepsy between the ages 0-11 were identified. This is only about 63% of the number expected even on a conservative estimate of 4.1/1000 of prevalence. This highlights the problem in relation to the absence of a register. Also of the eighty eight children, it was possible to obtain consent from parents of only 47.

There is a possibility of a degree of selection bias in this study because of the under reporting of cases and because of those identified a high proportion (38%) came from the special needs module.

With respect to responder bias of the 88 children identified, despite repeated efforts, consent for interview was obtained from the parents of only 53% of our sample.

A comparison of the basic demographic data of responders and non responders reveals that a high proportion of non responders came from the socially disadvantaged areas of the Borough. This may in fact be the group that requires more of the service input.

Despite the level of bias in this study, general conclusions could be made and underpinned with evidence from the relevant literature review a number of key recommendations in line with Task Force guidelines can be made for further consideration.

Although almost all the children have had access to a specialist, it was found that there is no Paediatrician with a special interest in epilepsy, there is no specialist epilepsy clinic, or the services of an Epilepsy Specialist Liaison Nurse.

There were major deficiencies noted with respect to **provision of information** to the parents. There were no consistent sources of information, with parents reporting a number of different **sources** other than the professional dealing with the child reported and some reported that they had not been given **any** information by clinicians. In rating the **adequacy**, 74% reported the information to be inadequate. With regard to the **timing of receipt of information**, nearly 30% reported not receiving any information at the time of the diagnoses, about how fits could be managed at home.

With respect to the **School Health Service**, 90% of the parents felt that the school was aware of the child's epilepsy and 72% of the parents felt that the school was adequately informed.

Only 10% of the parents reported being introduced to the British Epilepsy Association, or a voluntary organisation. 79% felt that it would be useful to have a support group locally and 64% were willing to be involved themselves.

There were a number **major areas of concern for the parents**. The most important one being a worry about the child's future followed by progress at school, restrictions in activities, medication and side effects. When asked **what they thought** their child's main concerns about epilepsy were. They gave worries about school work, feeling unsafe and restricted as major concerns. These areas point to the importance of providing facilities for counselling and support to the families either through local statutory or voluntary agencies.

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INTRODUCTION

The history of epilepsy can be summarised as 4000 years of ignorance, superstition and stigma followed by 100 years of knowledge, superstition and stigma. Knowing that seizures result from sudden, excessive, abnormal electrical discharges of a set of neurons in the brain has done little to dispel misunderstanding epilepsy in most of the world. Epilepsy remains a hidden disease associated with discrimination in the work place, school and home, says a recent BMJ Editorial (Kale 1997).

Epilepsy is the most common serious neurological condition, affecting 350,000 people in Great Britain, of whom at least 70,000 are children. Every day in Britain about 80 new families face the fact that their child has epilepsy (Brown 1994).

The development of services for Epilepsy in the UK over the years has been disappointing. This is despite recommendations in a succession of government sponsored reports spanning more than 30 years. (Taylor et al 1994).

The Epilepsy Task Force set up in 1994 produced a comprehensive document with specifications for epilepsy services.(Epilepsy Task Force 1994). According to the Task Force, epilepsy costs the UK about £2 billion per year, of which around £600 million is spent on direct costs of care. It is estimated that in a UK Health District population of around 250,000, there are approximately 2000 patients with epilepsy. Of these 1600 will have the potential to be seizure -free but it is known that many continue to have

frequent fits or suffer from unacceptable drug-related side-effects, thus making disproportionate demands on health service resources.

In 1995 the National Association of Health Authorities and Trusts (NAHAT) highlighted the continuing problems in the care of those with epilepsy. “In the past 25 years there have been six National enquiries and Reports in the UK on Epilepsy but there are as yet no authoritative national guidelines for the organisation and provision of epilepsy services nationwide.”(Update 1996).

The last five years have seen the profile of epilepsy and its care rise rapidly. This had been due to a number factors; the launch of new anti-epileptics, the establishment of an all party parliamentary group, the publication of an Epilepsy Needs Document and the increasing profile of epilepsy voluntary organisations, to name but a few. (Anon 1996). However, the view expressed in nineteen ninety three, in the Epilepsy Needs Document that “Services for people with Epilepsy are poor in quality, fragmented and poorly organised”, still appears to be largely true. The NAHAT document too refers to recent evidence showing the ‘lottery’ of care for epilepsy in the UK as being due mainly to the unsatisfactory way services are provided and co-ordinated locally.

BACKGROUND

6. WHAT IS EPILEPSY?

An epileptic seizure is a brief, usually unprovoked stereotyped disturbance of consciousness, behaviour, emotion, motor function or sensation which on clinical grounds results from cortical neuronal discharge. The disorder may be present from birth or be caused by one of a variety of later events, such as head injury, infection or stroke.

The concept of recurrence of attacks is central to any definition of epilepsy. To apply the term to children who have had a single attack especially when associated with clear provoking factors, is inadmissible and can be harmful in many ways. (Brett 1991).

Brett also quotes the great Swedish proto-paediatrician, von Rosenstein (1776) who in his rather optimistic prognosis for early convulsions, showed remarkable insight, not only to the concerns of parents, but also to the tendency towards spontaneous improvement. He had clearly recognised the distinction to be made between those young children who are subject to seizures for a limited period, and those who showing a tendency to recurrent attacks somewhat later, justify the use of the word 'Epilepsy'. Even the classical definition of Hughlings Jackson (1888) - 'epilepsy is the expression of occasional, sudden, excessive rapid local discharge in the grey matter' - is of little practical use to the Paediatrician involved in the problem of childhood

seizures. Time is a major factor in any history, and only the passage of time will show whether a clear pattern of unprovoked attacks will emerge or not.

CLASSIFICATION OF EPILEPSY

The classification of epilepsy has been an issue that has been debated for decades. Over 20 years ago Marsden (1976) outlined the difficulties in devising a single code to cover three basically incompatible systems of classification relating to the

- a) classical features of the fit
- b) the anatomical and electrophysiological evidence of the source of the fit.
- c) its aetiology when known

There are two classifications of epilepsy in current use. The first is the **International Classification of Seizures produced in 1981**, which recognises three main groups, partial, generalised, and an unclassified group.

In the last fifteen years, neurologists have found it helpful not only to distinguish the **different types of epileptic seizures, but also different epileptic syndromes, best defined as disorders characterised by clusters of signs and symptoms customarily occurring together.**

The signs and symptoms may be not only clinical; ancillary investigations such as EEG are invoked in the International Classification of Epilepsy and Epileptic Syndromes (Aicardi 1986). A syndrome diagnosis may give clues to aetiology and prognosis that has implications for the choice of treatment.

Classification of epileptic seizures (International Classification of Seizures 1981)

1. Partial seizures

- a). Simple partial - consciousness not disturbed,
e.g. simple motor seizure.
- b). Complex partial - consciousness disturbed,
e.g. with a sense of distortion of time or reality;
such seizures used to be called 'temporal lobe' seizures.
- c). Either simple or complex partial seizures may evolve to a secondary generalised tonic-clonic seizure.

2. Generalised seizures

- a). Absence seizures - with 3c/s spike-wave EEG
- b). Primarily generalised tonic-clonic seizure.
- c). Other types: Myoclonic seizures.

3. Unclassified group

Classification of epilepsy and Epileptic Syndromes syndromes (1986)

1. **Localisation-related epilepsies**
 - a) Idiopathic, e.g. benign focal epilepsy of childhood.
 - b) Symptomatic, e.g. seizures due to a temporal lobe lesion.
2. **Generalised epilepsies**
 - a) Idiopathic, e.g. absence epilepsy of childhood.
 - b) Sometimes idiopathic, sometimes symptomatic,
e.g. infantile spasms, Lennox Gastaut syndrome.
 - c) Symptomatic, e.g. epilepsy complicating recessively inherited metabolic disorders of childhood.
3. **Epilepsies undetermined**, whether focal or generalised,
e.g. grand mal occurring during sleep, without evidence for more accurate classification.
4. **Special syndromes**
 - a) Febrile convulsions

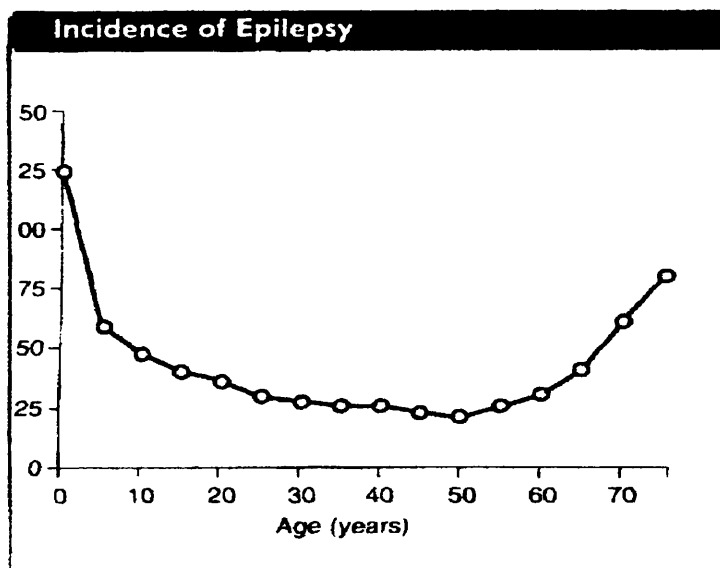
NB Although inserted here in the International Classification, most clinicians do not refer to these as 'epileptic'.
 - b) Epilepsies characterised by specific modes of precipitation,
e.g. photosensitive epilepsy, reading epilepsy.
 - c) Epilepsies characterised by status-like EEG activity,

Epidemiology

The **Incidence** of epilepsy is about 50-70 cases per 100,000 per year, excluding febrile seizures which have a similar incidence. **Age specific incidence** rates are greatest in children and the elderly and lowest in young and middle aged adults. (Brown et al 1993). In a study of epilepsy in the first 10 years of life Verity et al (1992) report an incidence of 4.3/1000. An earlier study by Ross et al (1980) as part of the National Child Development Study found the incidence of non febrile epilepsy to be 4.1/1000.

The incidence of seizures has been reported to be highest of all in the newborn.

Almost all the most serious forms of epilepsy, the malignant syndromes with bad prognoses make their first appearance before the age of five and often, before the age of three. (Appleton 1995).



Demographic and Secular Trends

The pattern of incidence described in earlier studies might be changing as some interesting shifts have been seen recently. In south east England, the incidence of epilepsy in children declined from 152/1000 000 in the period of 1974 to 1983 to 61/1000 000 in the years from 1984 to 1993 while increasing in elderly people over the same period. Similarly in Rochester, Minnesota, the incidence of seizure disorders has decreased in children over time whereas it increased in elderly people to a point that the highest peak is now seen in people over the age of 75.

No clear explanation for these changes has yet been advanced. In children speculation has centred on the role of improved prenatal care and the adoption of healthier lifestyles by expectant mothers, leading to a decrease in defects in neuronal migration and to a reduction in the incidence of birth hypoxia. In elderly people it is presumed that an increase in life expectancy allied to cerebrovascular diseases is responsible for the increase. This seems paradoxical, however, as the incidence of cerebrovascular diseases has decreased in the community over the past two decades. (Sander & Shorvon 1996).

The Prevalence

Epilepsy is the most common serious neurological condition, with a prevalence rate ten fold higher than that of multiple sclerosis and 100 times higher than that of motor neuron disease.

The prevalence is about 5-10 per 1000 persons in the population, and this is relatively constant throughout late childhood and adult life. Lifetime Prevalence is between 2-5% of the population. Most statistics suggest that epilepsy is slightly more common in males than females. The rates are slightly higher in lower social classes. (Brown et al 1993).

Following an analysis of a number of cross-sectional prevalence studies carried out in USA, Iceland and North West Europe, a prevalence rate of 4.1/1000 by the 11th birthday has been found (Ross et al 1980).

An average General Practitioner will care for about 10 patients on active treatment for epilepsy. Another 15-25 patients are likely to have had seizures in the past, but have not been treated or have stopped or defaulted from treatment..(Brown et al 1993).

Prevalence of seizure types and syndromes

Approximately 60% of patients have tonic-clonic seizures (including 20% with secondarily generalised seizures), 20% complex partial seizures, 12% mixed tonic-clonic and partial seizures about 3% simple partial seizures, and less than 5% absence seizures, myoclonic seizures and other seizure types.

About one third of cases have less than one seizure a year, one third have between one and twelve seizures per year, and the remainder more than one seizure per month (20% of these have more than one seizure per week).

Up to 60% of people with active epilepsy have additional neurological or neuropsychological handicaps, e.g. learning difficulties, behavioural disturbances, discrete cognitive impairment, focal neurological deficit.

Fifteen per cent of patients seen by a paediatrician will have severe epilepsy.

West Syndrome (infantile spasms) accounts for at least 3% of childhood epilepsy, the Lennox-Gastaut Syndrome (a condition in which refractory epilepsy often occurs in the context of learning difficulties and cognitive deterioration in childhood) up to 6%, and childhood absence epilepsy 8%.

Thus in the general population, epilepsy occurs in a range of people from those who are otherwise normal to those with profound mental handicap. One third of people with mental handicap have seizures. Similarly, the epilepsy will range from a very mild occasional seizure to patients having many seizures every day.

Aetiology

Approximately 60% of all cases have no clearly identifiable cause, and these are best referred to as cryptogenic epilepsies. (Brown et al 1993). Many of these probably have minor congenital anomalies, and many more have a genetic basis. With improvements in techniques and availability of scanning techniques this proportion will diminish.

Ten to twenty per cent have primary generalised epilepsy, a well-defined genetic syndrome, while other patients with cryptogenic epilepsy may also have genetic contributions.

Improved perinatal care may reduce the incidence of epilepsy.

Much of the secondary handicap of epilepsy however, whether physical, psychological or social, ought to be eminently preventable by appropriate medical management.

Mortality

The overall mortality rate for individuals with epilepsy is two to four times that of the population without epilepsy. The excess mortality is greatest amongst children and young adults, and the standardised mortality rate is highest in the first 10 years after diagnosis.

Management of Epilepsy

Pharmacotherapy for reduction or suppression of seizures is the basis of treatment in epilepsy. However, social and cultural problems are as likely to distress patients as continuing seizures. **For this reason, treatment of the epileptic patient requires much more than the administration of antiepileptic drugs, and prognosis does not depend on seizure control alone. Dealing with these environmental and psychosocial problems is an essential part of the management of epileptic patients.** (Tatterborn & Kramer 1992).

Although most people see it as a physical condition, almost all of the handicaps and sequelae of having epilepsy are psychosocial: Most are unnecessary, preventable, and treatable. One of the major goals of total patient care should be to lead the epileptic

patient toward a normal lifestyle, unless this is prevented by additional mental retardation or cognitive dysfunctions.

Pharmacological treatment of epilepsy

The pharmacological treatment of epilepsy has made considerable progress during the last decade, due to improved knowledge of the clinical pharmacology of individual drugs, acquisition of new information on the factors affecting response and need for drug treatment, and development of promising new agents. Once a clinical diagnosis of epilepsy has been made (which generally requires the occurrence of more than one seizure), treatment is started with a single drug selected on the basis of seizure type and tolerability profile. Although there are important regional differences in prescribing patterns and individual circumstances may dictate alternative choices, carbamazepine is generally regarded as the preferred treatment for partial seizures (with or without secondary generalisation) while valproic acid (sodium valproate) is usually the first choice in most forms of generalised epilepsies. (Berghi and Perniccia 1995).

Although overall about 70% of patients can be completely controlled, response rate is influenced by a number of factors, the most important of which are seizure type and syndromic form. **The importance of a correct syndromic classification for rational drug selection has been poorly assessed and represents a major area for future research.** Patients who do not respond to the highest tolerated dose of the initially prescribed drug may be switched to monotherapy with an alternative agent or may be

given add-on treatment with a second drug. Appropriate prospective trials are required to assess the merits of either strategy. If add-on therapy is selected and the patient becomes seizure free, it may be possible to discontinue the drug prescribed initially and reinstate monotherapy. **Only a minority of patients are likely to require multiple drug therapy**, and it remains to be established whether specific drug combinations are more effective than others.

Until further information becomes available, the new agents should be reserved for patients failing to respond to the conventional treatments of first choice. Patients whose seizures cannot be controlled by available drugs should be reassessed, and polytherapy should be maintained only when there is clear evidence that benefits outweigh possible adverse effects. In many patients who have been seizure free for at least 2 years it may be possible to gradually discontinue all medications. The decision to withdraw treatment is determined largely by the risk of seizure relapse which, in turn, is primarily dependent on the syndromic form.

Although other forms of treatment such as neurosurgery or biofeedback techniques may be of value to individual patients, antiepileptic drugs remain the mainstay for the management of epilepsy in the 1900s. However, the approach to pharmacological treatment of epileptic disorders has changed substantially in the past 30 years for several reasons: (I) the clinical pharmacology of anti-epileptic drugs has been extensively investigated, with improved knowledge of the efficacy and tolerability of

available products; (ii) the contribution of plasma drug concentrations has proved invaluable for a more correct monitoring of the risk/benefit ratio in individual patients; (iii) results of observational studies and clinical trials allow more rational therapeutic decisions for patients with a first unprovoked seizure, early epilepsy and prolonged remission of seizures; and (iv) new agents have been introduced which, although not shown to be superior to the old, time-honoured products, offer alternative options for difficult-to-treat patients. (Bergh & Pernicca 1995)

Despite the advent of newer drugs many children are reported to still receive standard older treatments. Brown(1994) refers to the only major UK study of children conducted by the British Epilepsy Association, which uncovered that two thirds of one thousand children surveyed complained of a disturbing burden of side effects.

The advent of four new drugs for epilepsy in the last decade with the anticipation of many more novel compounds reaching the marketplace means that the clinician treating the patient with epilepsy will need a far greater knowledge of each of the compounds, the disadvantages, advantages, pharmacokinetics and drug interactions. Many of the new drugs appear to have a good side effect profile and although not more effective they have the opportunity to replace our current first-line drugs in the next decade.

Social, behavioural and educational problems

Epilepsy can be socially stigmatising. Appropriate encouragement of the parents and the child and education of family and social contacts improve integration.

With the exception of an increased tendency to catastrophic rage outbursts in children with temporal lobe epilepsy (Ounsted et al, 1966), the behavioural problems of children with epilepsy are not necessarily different from those of other children, particularly if cognitive difficulties are also present. Thus treatment as for other children with behavioural difficulties is appropriate.

Children with epilepsy often have specific education difficulties. Attention and therefore attainment may be affected by subclinical seizure discharges. Sympathetic and understanding handling in school can help children with epilepsy to make the most of their education. (Wallace 1991).

School Environment

Most children with epilepsy can go to regular schools. In 1974, the Epilepsy Foundation of America completed a report entitled "A Preliminary Exploration of Awareness of Epilepsies among Educators." This study revealed that 90% of all children with chronic seizure disorders were able to attend state schools, and only 10% needed special education either at home or in special classes (Kaufman et al., 1982). Harrison and Taylor (1976) published the results of a 25-year follow-up study that also showed that about 10% of all children with epilepsy needed special education. The

report also stated that individuals with ongoing seizures generally fared much less well than those with seizures under control. However, it should not be assumed that children with well controlled epilepsy have no difficulties at school. They suffer the negative effects which impacts on their quality of life (Wildrick et al 1996). Almost 20% of adults with epilepsy considered themselves illiterate.

A child with seizures has to face many social problems in school. All too often, they are jeered at by classmates. Only the emotionally very stable and well-adjusted child will be able to handle this situation. Unfortunately, teachers often do very little to alleviate the problem. Therefore, it is necessary to educate the teachers involved about the specific features of a child's seizure disorder and about the restrictions that may or may not be necessary. Again, overprotection should be avoided, and in most cases the child should be allowed to take part in important social activities with the school, such as excursions or holiday camps. The diagnosis of epilepsy as such should not represent a major handicap: teachers as well as classmates should be "desensitised" and guided toward acceptance. If the seizure disorder is associated with cerebral impairment with low intelligence, learning disabilities, speech problems, and cognitive dysfunctions, then the child belongs in a special class for more severely handicapped children. (Tetterborn & Kramer 1992).

Sports and Epilepsy

A further restriction on children with epilepsy that is often a topic of discussion concerns the area of sporting activities. Participation in sports, and even in athletic competition, should be encouraged, but should be done with some moderation; sports should not be engaged in to the point of exhaustion. Common objections such as increased clumsiness, slower performance, fear of accidents or injuries, or the assumption that sport increases the frequency or severity of seizures are without foundation, except in refractory patients with associated cerebral impairment. Epileptic children were found to have the same rate of sports accidents as their healthy schoolmates (Tettenborn & Kramer 1992).

Parental Counselling

Identification of epileptic syndromes makes it possible to predict a good outcome for those with childhood absence and benign partial epilepsies. In other idiopathic epilepsies, parents can be reassured that control of seizures is likely but continuance of therapy may be necessary. In early infantile epileptic encephalopathy, early myoclonic encephalopathy, and the West and Lennox-Gastaut syndromes, the poor prognosis for both epilepsy and intellectual development should be acknowledged. Children with the Landau-Kleffner syndrome continue to have language difficulties even if the epilepsy remits. (Wallace 1991).

Sociocultural Aspects

In a study of 157 school children between 4.5 and 13 years in Los Angeles, California, examining Psychosocial behavioural and medical outcomes in children with epilepsy it was found that while seizure history was the best predictors of ongoing medical difficulties, the **most important causes of ongoing parental anxiety and negative attitudes** towards epilepsy were **sociocultural**. The study advocated care programmes for epilepsy should be tailored to the sociocultural background of the family.

Clinical Audit in Epilepsy

It is generally accepted that health care systems should provide not only treatments of confirmed efficacy but that the provision should take place with the maximum effectiveness and efficiency. Donabedian (1966) has defined three constituents of the quality of care; structure (the instruments of care of their organisation); process (the activities of care); and outcome (the end results of care). In the United Kingdom as elsewhere there has been an increasing emphasis in recent years on the need for medical audit, defined as “the systematic critical analysis of the quality of medical care ...”. Kessner et al (1997) have listed a number of criteria that should be met if a condition is to be a useful tracer for an audit:

- (1) It should have a definite functional impact (so conditions that are self-limiting and for which there is no specific treatment are not useful).
- (2) It should have a prevalence sufficiently high to allow collection of adequate data.
- (3) It should be well defined and easy to diagnose.
- (4) Its natural history should vary with the utilisation and effectiveness of medical care.
- (5) Techniques of medical management should be well defined for at least one of prevention, diagnosis, treatment, or rehabilitation.
- (6) The effect on the condition of non-medical factors should be understood.

Epilepsy represents as appropriate condition for audit as it fulfils the first two of these criteria wholly and the next three partially. We know little about the last criteria in relation to epilepsy, but can assume that it is considerable.

There has been little systematic work in developing comprehensive means of assessing quality of care in epilepsy. In the United Kingdom, government reports on services for people with epilepsy have emphasised the importance of the primary health care services, specialist epilepsy clinics, and assessment centres in the management of epilepsy, in both its medical and psychosocial dimensions. The report of the working group on services for people with epilepsy state that whereas general practitioners should normally refer all their patients with seizures to a hospital consultant for diagnosis, initial assessment and recommendations for treatment, patients should

thereafter be cared for by the general practitioner, except in specific cases where problems persist, recur, or develop.

Assessments of the process of care in epilepsy should particularly focus on issues of communications and the interpersonal aspects of care. **In this respect patient's satisfaction may be seen as representing one important outcome of care, and it also speaks to the measurement of the process of care.**

Previous research suggests that patients' satisfaction makes a direct contribution to other important outcomes. (Fitzpatrick 1990). Thus patients who are less satisfied with care are less likely to comply with treatment regimens and are less likely to reattend for treatment - both factors that are important in achieving good management and control of epilepsy. With this in mind a model for the audit of care in epilepsy can be proposed, particularly examining adequacy of diagnosis, ongoing care, information provision, and psychosocial adjustment. A structure should exist that provides primary care services with the specialist expertise, investigational, and treatment facilities necessary for the population in question.

BOROUGH OF BEXLEY

Bexley is an Outer London Borough with a population of 218,000 (OPCS 1991).

15,300 (7%) of the population is under 4 years of age and 34,066 (16%) are under the age of 11 years.

Bexley is a mixed area in social class terms, with areas of affluence in the South in the commuter belt of Sidcup and Old Bexley, and areas of deprivation in the North in Erith and Belvedere. A part of Thamesmead, a new town, lies within the Borough. In general the more deprived North of the Borough includes a high proportion of very young people, while the South includes a high proportion of the elderly. 4.3% of Bexley residents are from ethnic minority groups.

EPILEPSY TASK FORCE AND ITS RECOMMENDATIONS

The epilepsy Task Force was formed in Spring 1994 to improve the care of people with epilepsy by raising awareness of the condition, lobbying for appropriate service provision, and establishing a model of care which is sensitive to the needs of the patient at the same time as taking account of new developments in care. The Epilepsy Task Force believes that the goal of epilepsy management should be optimum control of seizures with minimal side effects.

In 1993, the Epilepsy Needs Document, was produced at the suggestion of the Department of Health by six leading epilepsy specialists, identifying specific areas where major improvements are required.

This epilepsy service specification has been drawn up by The Epilepsy Task Force, with input from a wide range of clinical, consumer, public health and purchaser representatives. It outlines the aspects of an epilepsy service which purchasers should now aim for when agreeing a service specification with their providers. The Task Force recommendations cover all aspects of the care of epilepsy across all ages. In the evaluation of the local services in Bexley, for children with epilepsy the relevant Task Force recommendations have been chosen as criteria for good practice.

There are a number of methods that could be used to evaluate services. We have used an interview protocol with emphasis on parents perceptions.

“The quality and relevance of much clinical research fall short of patients needs ... another reason is that research priorities do not flow from a transparent process where the **views of all the relevant stakeholders** are equally considered. The challenge is now for the medical profession to accept this message and develop alliances with consumers to move forward toward a wider recognition of the uncertainty and weaknesses in medicine and the biases in the process of setting research priorities.” (Liberati 1997). These views expressed in a recent BMJ leader apply equally to the evaluation of health care.

The standards recommended by the Epilepsy Task Force specific to the topic area covered by this study are given below.

I Register

Each provider should have a Register of children with Epilepsy to assess, meet and monitor their needs.

II Staffing Access to specialists.

All new paediatric patients suspected of having Epilepsy should be referred to a Paediatric Neurologist or Paediatrician with a special interest in Epilepsy.

There should also be access to an Epilepsy Specialist Nurse where available.

III Investigations Treatment/Follow up

a) every newly diagnosed case will require at least one standard EEG.

b) all children presenting with partial Epilepsy should have neuro-imaging investigations (estimated 50-60%).

c) the proportion of children taking more than one anti-epileptic drug should be less than 30%.

IV Information

A protocol for information and advice for people with Epilepsy should be established.

V **Rehabilitation**

a) **Liaison with Primary Care**

- 1) each primary care practice should have a register of children with epilepsy.
- ii) guidelines for the clinical management of Epilepsy shared between I^{ty} and II^{ty} care should be established.
- iii) a system of liaison between I^{ty} and II^{ty} health care teams should be set up, usually through an Epilepsy specialist nurse.

b) **Liaison with School Health Service**

Liaison should be maintained with schools and school health service with regard to management and rehabilitation of children with Epilepsy

c) **Liaison with Voluntary Services and Self Help Groups.**

Liaison should be maintained with voluntary and self help groups.

d) **Counselling and Support.**

Protocols must be established to promote access to Counselling.

METHODOLOGY

Aim of the Study

To look at the effectiveness of the health service in meeting the needs of children with epilepsy aged 0-11 years in Bexley.

Objectives

- I** To establish a Register of children with Epilepsy in Bexley.
- II** To evaluate the health services currently available to children (0-11 years) with Epilepsy in Bexley.
- III** Compare current practice against recommended standards.
- IV** To produce an integrated strategy to improve services for children with epilepsy in Bexley.

Objectives in detail

- I** **To establish a Register of children with epilepsy in Bexley.**
 - a) To estimate the prevalence of epilepsy in children aged 0-11 in Bexley
 - b) To identify the number of children known to
 - 1) Special Needs Module
 - 2) Primary Care Services only.
 - c) To estimate the prevalence of additional handicaps in children with epilepsy.

II To evaluate the health services currently available to children (0-11yrs) with epilepsy in Bexley.

1. Staffing :- Access to Specialists:

To establish the proportion of children who have seen

- a) Hospital Paediatrician
- b) Paediatric Neurologist
- c) Epilepsy Specialist Nurse.

2. Investigations, Treatment and Follow up

Specialised Investigations:

To establish the proportion of children who have had specialised investigations:

- a) EEG
- b) CT/MRI Scans

Drug Treatment:

To establish the proportion of children on

- a) single anti convulsant.
- b) more than one anti convulsant.

3. **Information:**

To establish

- a) what proportion of parents of children with epilepsy received information regarding the condition.
- b) the sources from which the parents received information
- c) a view of the parents perception of the adequacy of the information given

4. **Rehabilitation**

a) **Liaison with Primary Care**

- 1) To establish whether primary care practices have a register of children with Epilepsy.
- 2) To establish whether there are agreed guidelines for the clinical management of Epilepsy shared between I^{ty} and II^{ty} care.

b) **Liaison with School Health Service**

To establish the proportion of school going children with epilepsy, and

whether -

1. the parents perception of schools awareness of their child's epilepsy.
2. the parents are satisfied with the level of awareness of the school regarding the child's condition.
3. the parents are confident that the school is able to deal with the medications or any seizures if they occur.

c) **Liaison with Voluntary Services and Self Help Groups**

1. To consider what proportion of parents were introduced to the British Epilepsy Association.
2. To determine the timing of the provision of information from the British Epilepsy Association.
3. To establish the level of interest among parents regarding introductions to self help groups.
4. To establish the level of interest in forming a local support group for epilepsy.

d) **Counselling**

1. To establish the areas of concern the parents have in relation to the child's epilepsy.
2. To establish areas which the parents felt their child with epilepsy is concerned about.
3. To establish areas of concern where parents felt they needed further help.

Study Populations

All the children up to and including the age of 11 years in the Borough of Bexley who have been diagnosed as having epilepsy. (see Table 1).

Study Design

The Project was conceived during my Paediatric Neurology attachment at Guy's Hospital, UMDS University of London under the direction of Professor Richard Robinson.

An interview protocol, (questionnaire - Appendix) was prepared to be used in the interviews with parents to obtain their views about the services for the management of epilepsy in Bexley. This was based on a questionnaire recommended by Professor Robinson.

a) **Working Party**

A working party was formed by inviting colleagues in the different disciplines involved in the services for children with epilepsy. We felt that a representative from Primary Care too was essential and secured the help of a GP.

A panel of interested colleagues was convened for the Study.

Members: Myself as Consultant Community Paediatrician

General Practitioner Representative

Clinical Medical Officer

School Nurse Representative

Health Visitor

Audit facilitator

The Hospital Paediatric Consultants were contacted for their views and support.

The interview protocol (questionnaire) was discussed by the Working Party and further modifications made taking into consideration the Task Force recommendations and local views and feasibility.

Letters for contacting GPs to identify children with epilepsy and, to parents inviting them to participate were drafted. (Appendix).

b) **Ethics Committee Approval**

Approval was obtained from the Bexley Ethics Committee.

c) **Preparation of the Register**

- i Letters were sent to all General Practitioners in Bexley asking them to submit names of children between 0 - 11 years who they believed had Epilepsy.

The response to the initial letter was poor. A further reminder letter was sent to the non responding General Practitioners. The rate of response improved only slightly. The practice managers were contracted wherever possible, on the telephone as a third attempt to locate all the names of children with epilepsy.

When we cross checked with available records and contacted parents, some of the names turned out to be of children **not** suffering from epilepsy. We finally managed to identify 37 children with epilepsy from the names gathered from General Practitioners.
- ii Names of children with Epilepsy from the Oxleas Special Needs module were obtained.
- iii Names from the Queen Marys Hospital, of children with known Epilepsy were obtained.
- iv Members of the Working Party were asked to contact colleagues in their respective disciplines to submit names of children known to have Epilepsy.

All names were collated, cross-checked to avoid duplication and a master list was prepared.

d) Training of Interviewers

Semi-structured interviews. The type of interview used was ‘semi-structured’ (‘semi-standardised’), where the interviewer asks certain major questions the same way each time but is free to alter their sequence and probe for more information. The interviewer can thus adapt the research instrument to the respondent’s level of comprehension, and can handle the fact that in responding to questions, people often provide answers to questions that may be asked later. It has advantages in that it allows, researchers to ‘talk around’ the major questions, thus exploring more dimensions of the topic, and it offers respondents more of a feeling that their particular perspective is being taken into account.

Communication in interviews

Two principles inform research interviews. First, questioning should be as open-ended as possible, so as to gain spontaneous information rather than a rehearsed position.

Second, the questioning techniques should encourage respondents to communicate.

Views recommended by Karen Rose (1994) on Interviewing Techniques, formed the basis of our training of interviewers. **Interviewers attended training sessions, this was aimed at bringing about some uniformity in their technique to minimise interviewer bias.**

e) **Pilot Study**

A pilot of the interviewing protocol was carried out by randomly selecting 15 names from the master list. A letter explaining the purpose of the study and seeking consent was sent to the parents. Only four consents were received. All four sets of parents were interviewed. The interview protocol (questionnaire) was then slightly modified with the experience gained from the pilot interviews. Despite this as the study progressed, we found that we had been over inclusive in the preparation of the interview protocol with some of the questions proving difficult for the parents to provide reliable information; for example, our questions with reference to the classification of epilepsies and syndromes was a non-starter. We recognised that the classifications of epilepsy is a subject of constant debate and the problems of uncertainties of classifications are one of the main reasons why even the physicians give epilepsy such a wide berth (Appleton 1995)

MAIN STUDY

f) **Interviews of Parents**

Letters were sent to the parents of the rest of the study group with stamped self addressed envelopes, seeking their consent to be interviewed for the study. The response rate was poor, and the responses were slow in coming.

Reminders again, with stamped self addressed envelopes, were sent to non-responders. Attempts were made by members of the Working Party to contact parents by telephone who had not responded even to the reminder. This again was a very difficult task, with insufficient or wrong information from GPs and other sources and with families having moved.

In all parents of 47 children out of 88 were identified (59%). (see Table 1). The interviews were conducted in the child's home and the interview results entered into a database.

g) **Checking the validity of the interviews**

The information obtained at the interview was cross checked with the available school health records to assess validity. The contents of every 5th interview was compared with the school or child health record of the individual.(see Table 1)

h) **Non responders**

It was felt that the characteristics of the non responders was an important aspect to study. As far as possible basic characteristics of the non-responders was obtained manually from school health and child health records. Once again these records were far from complete and we were able to extract information on age, location and to some extent ethnic and seizure pattern. The results were entered into the database for comparison. (see Tables 21,22,23).

Table I

RESULTS

STUDY POPULATION AND SAMPLE

SUMMARY

1. Total Population of the Borough of Bexley	218,000
2. Total of number of children less than 11 years of age	34,066
3. Estimated prevalence of Epilepsy at 4.1/1000 <11yrs	140
4. Total number of children with Epilepsy identified	88(58%)
5. Total number known to special needs module	49
6.Total number known to General Practitioners	37
7. Total no. of children whose parents interviewed-respondent	47(53%)
8. Total no. of notes of respondents perused for validity check	5
9. Total number of non-respondents	41
10. Total number of notes of non-respondents perused	20

Table 2

Distribution by location of respondents

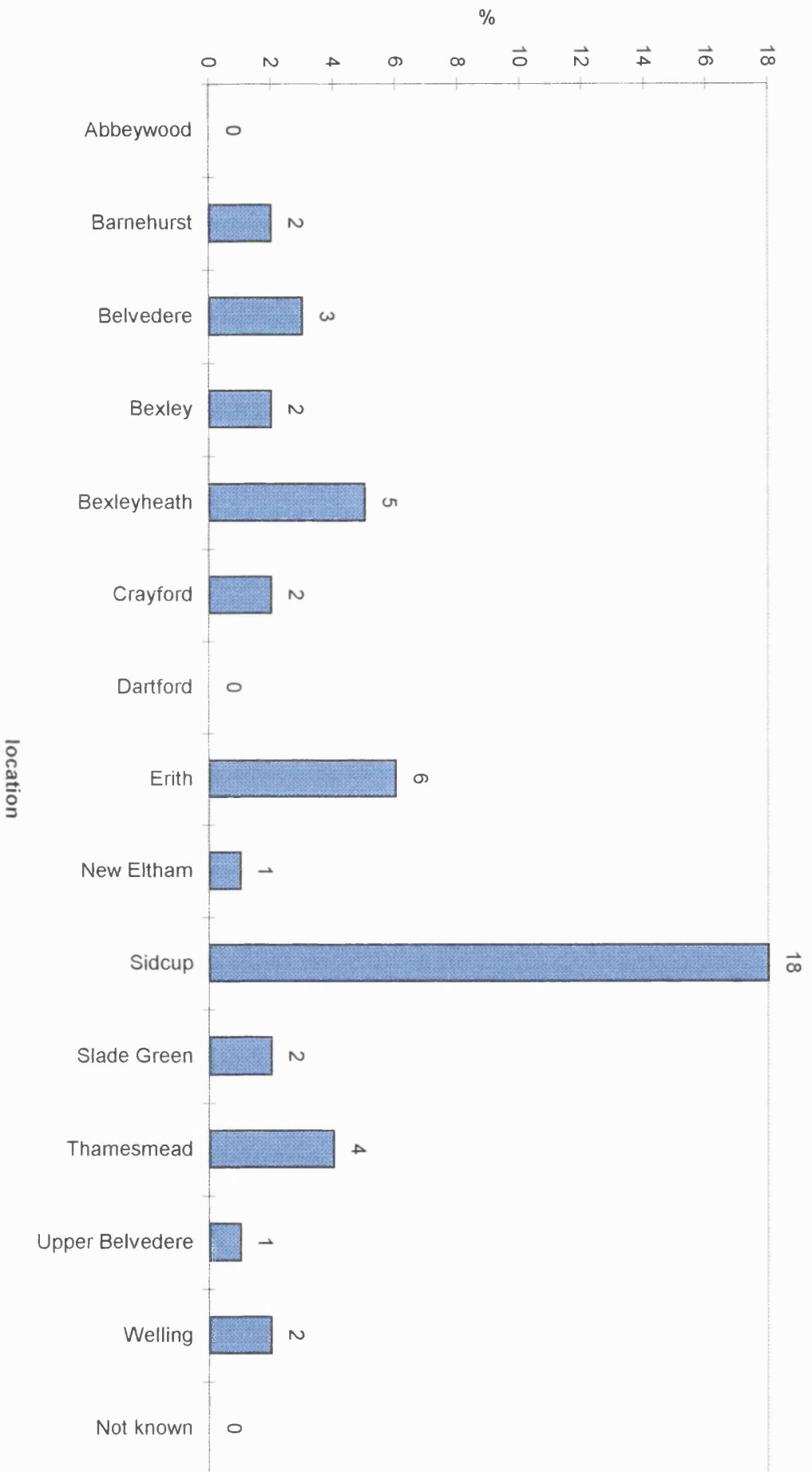


Table 3

Distribution by age group of responders

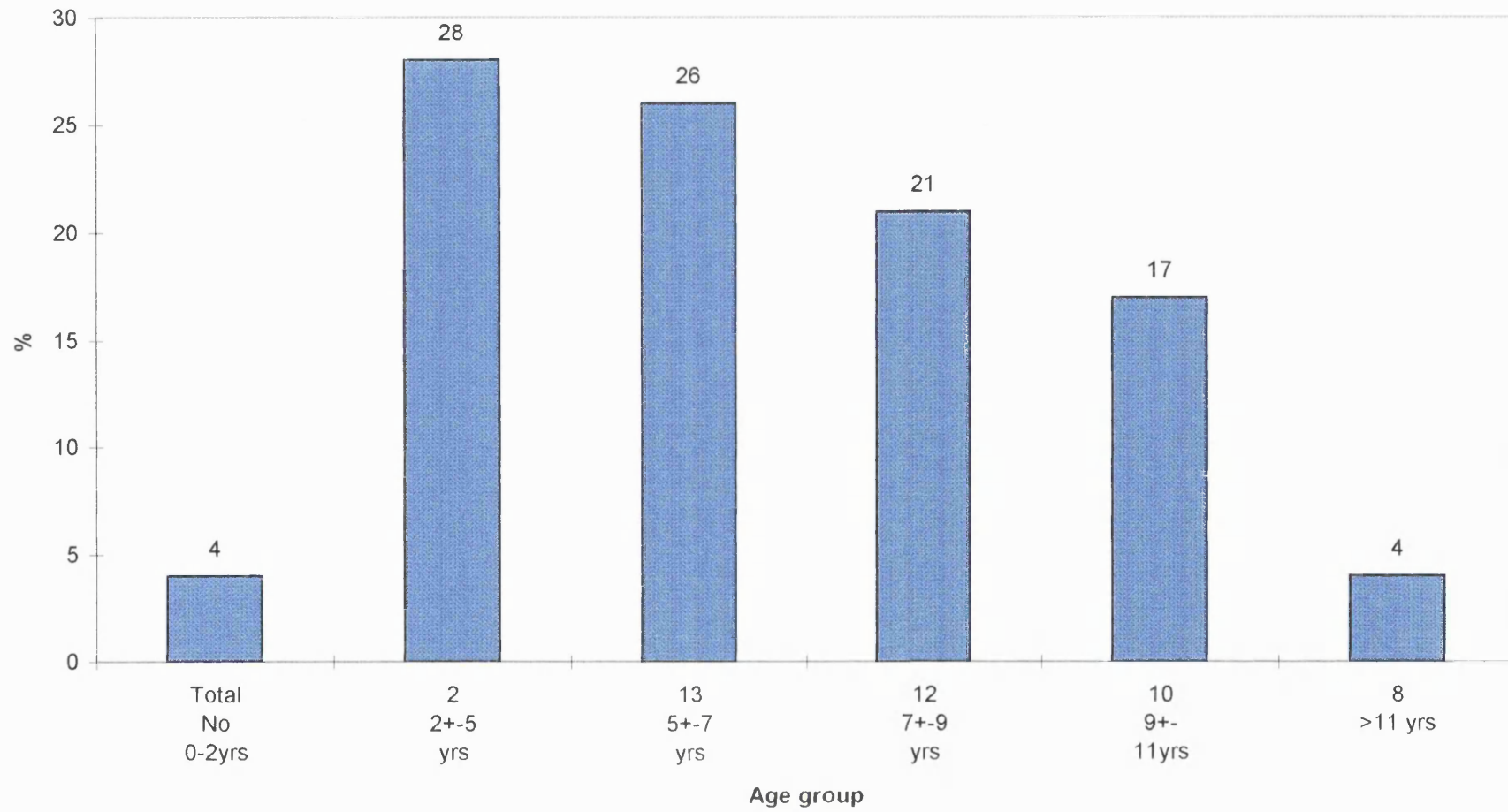
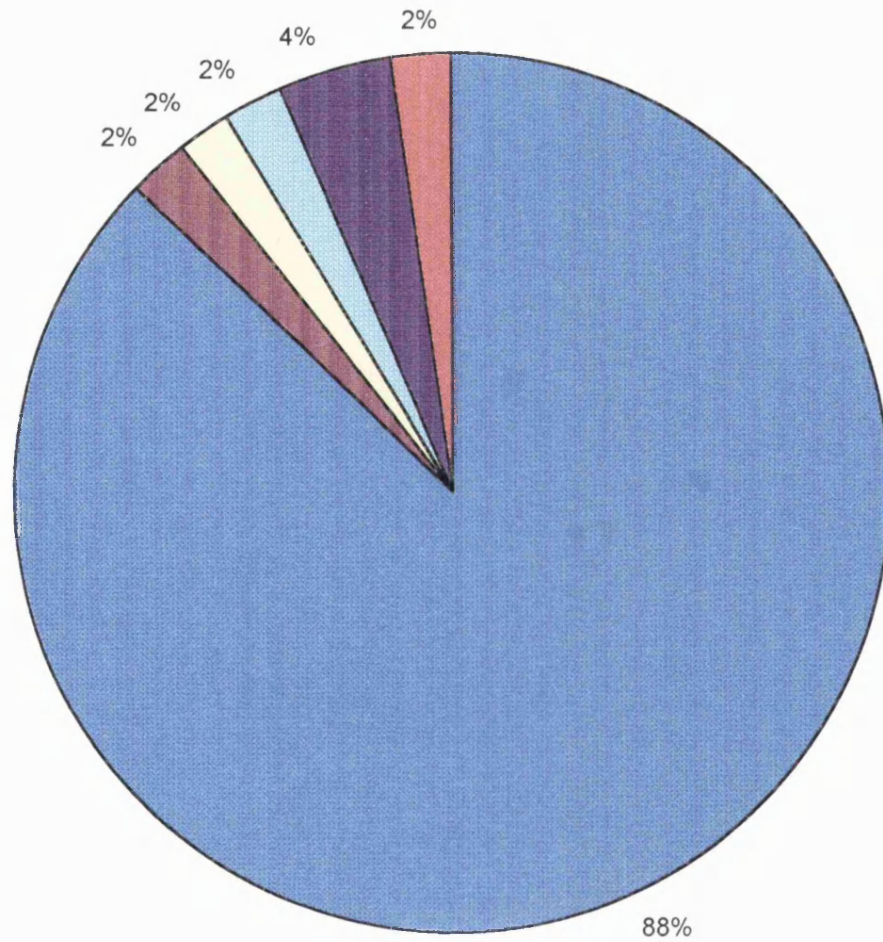


Table 4

Ethnic origin of respondents



- White
- Bangladesh
- Black-African
- Chinese
- Indian
- Others

Table 5

Distribution by seizure type (respondents)

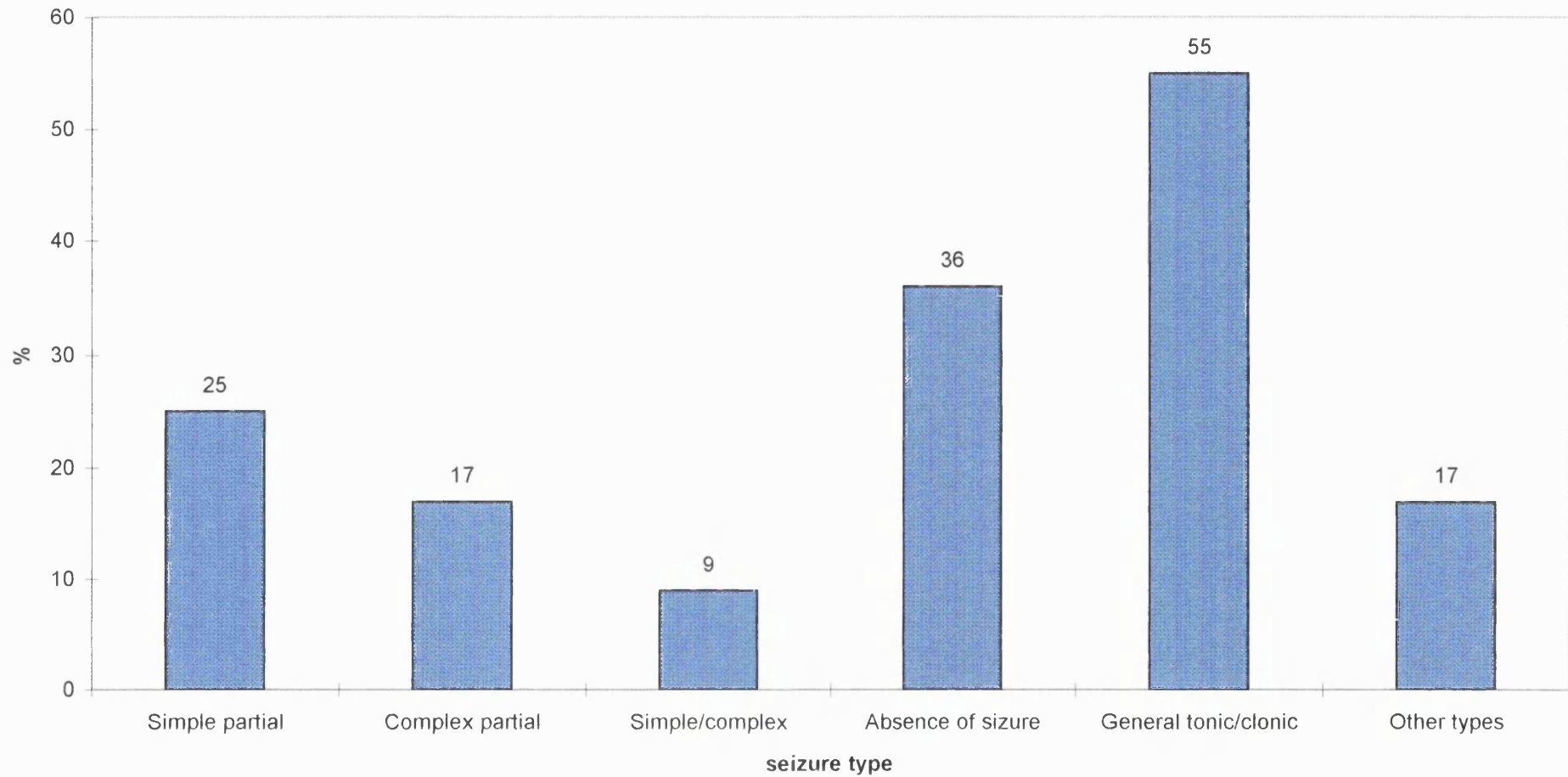


Table 6

Children with epilepsy distribution by pre school and school age (respondents)

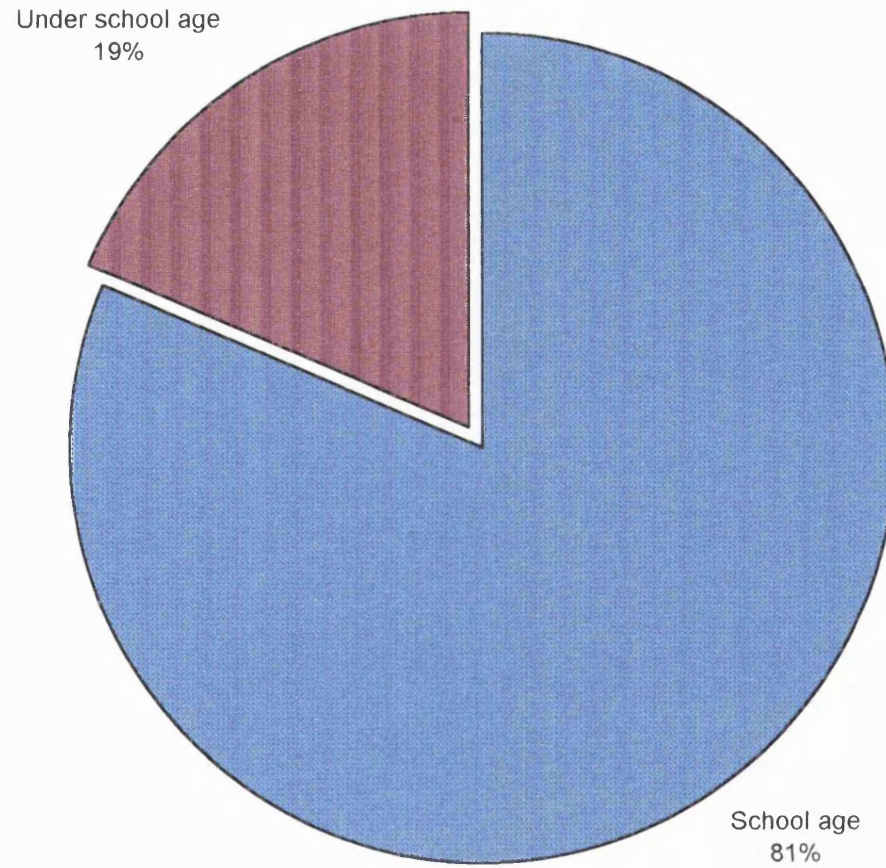


Table 7

Distribution by school (repondents)

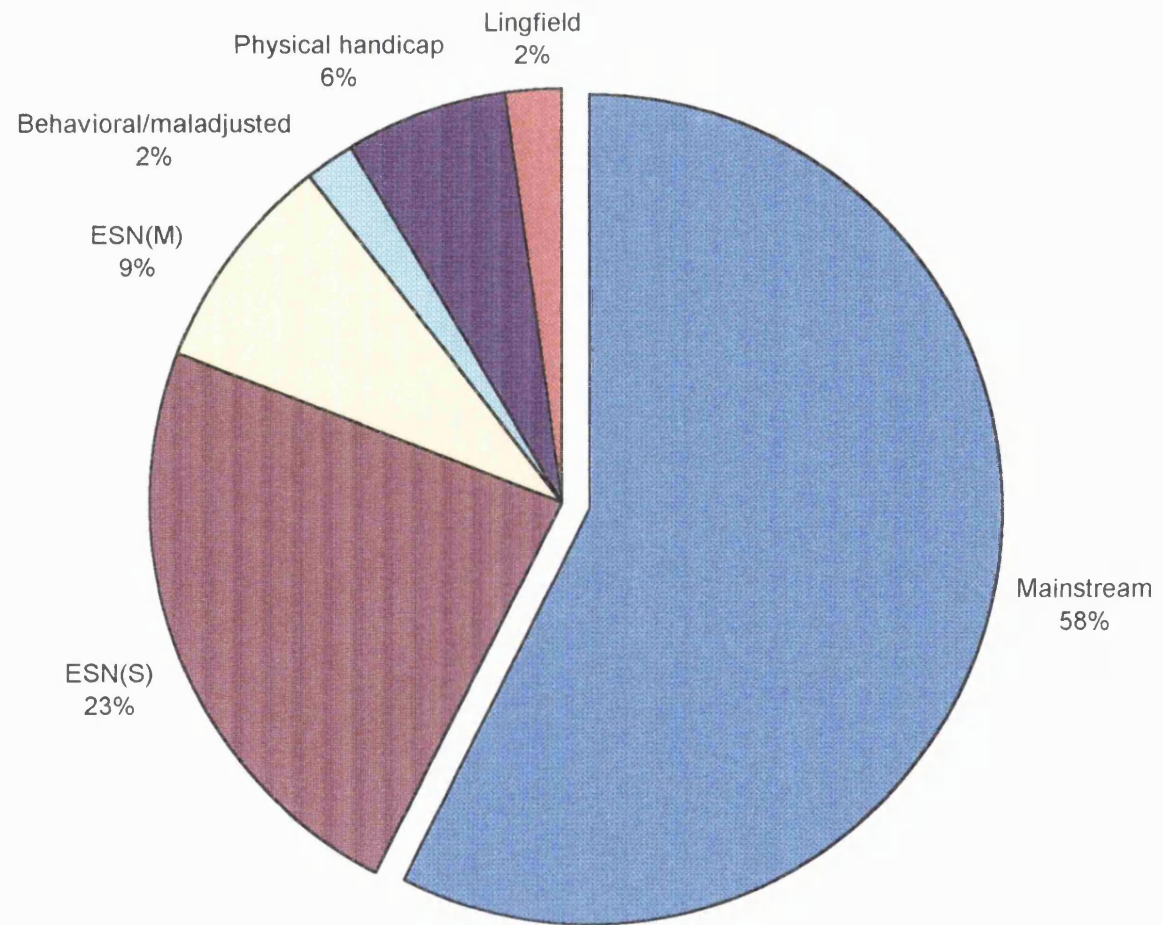


Table 8

Other health problems in children with epilepsy (respondents)

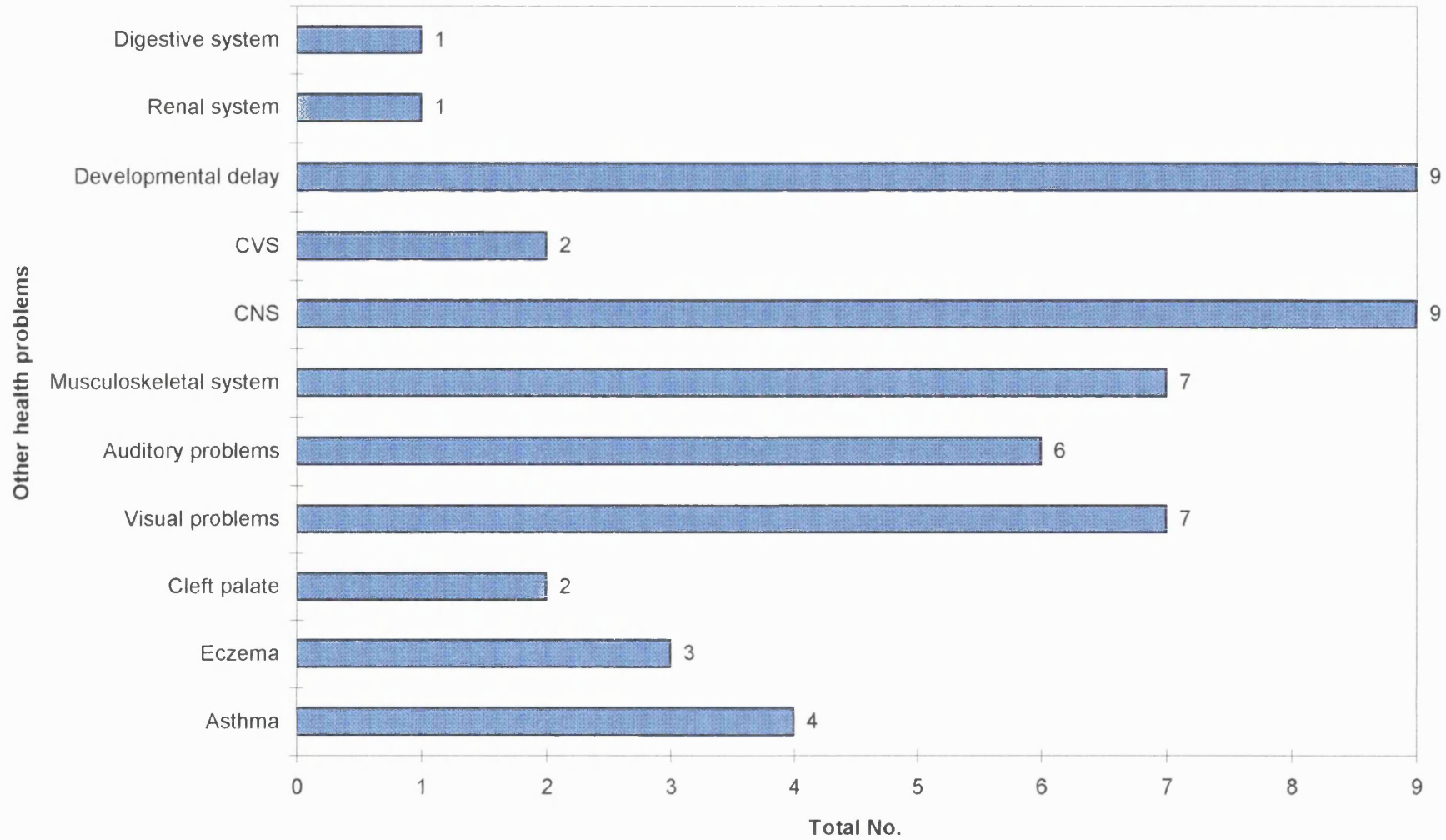


Table 9

Professionals seen to monitor the epilepsy

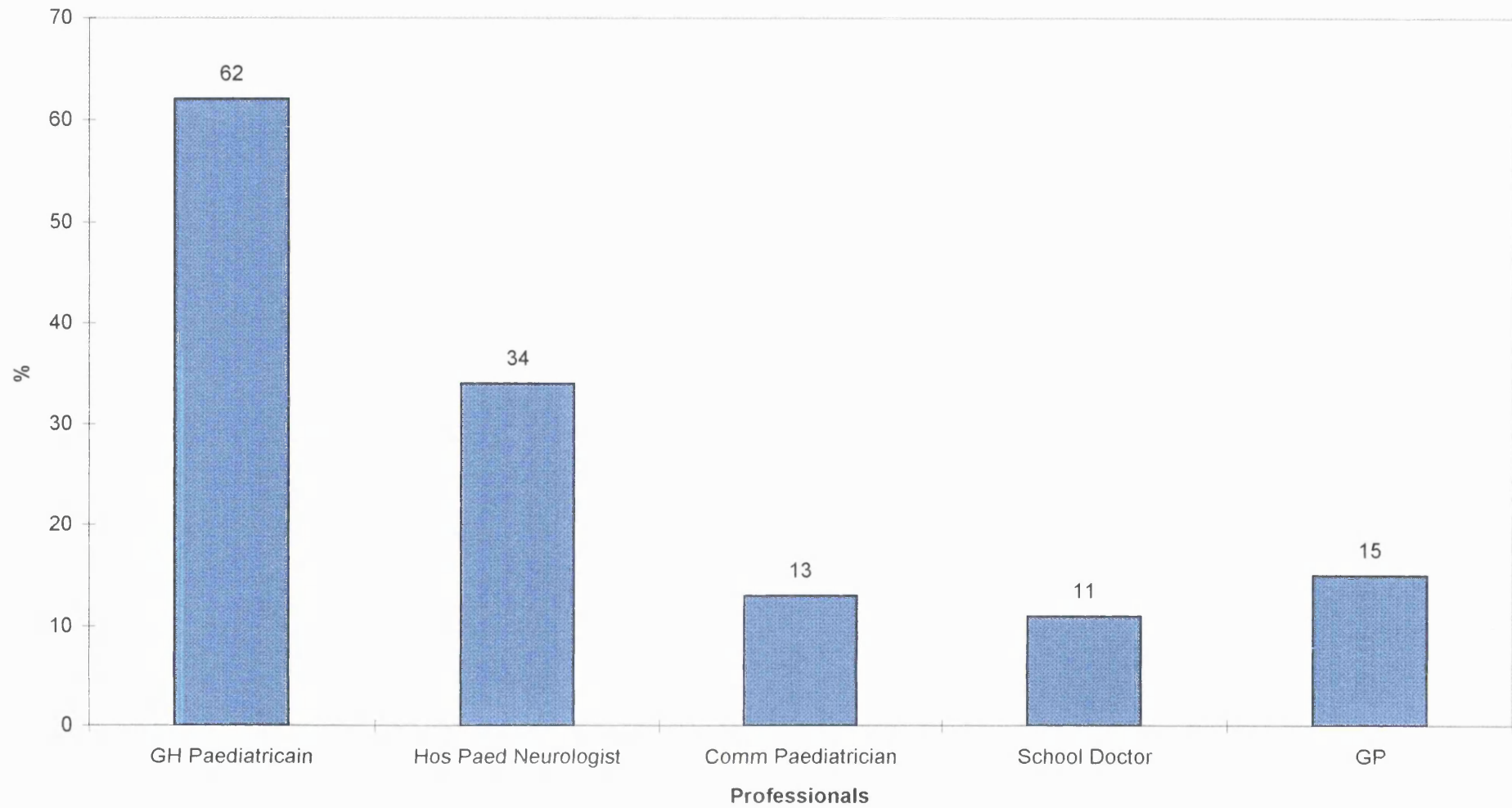


Table 10

Percentage of children with epilepsy who had specialised investigations (respondents)

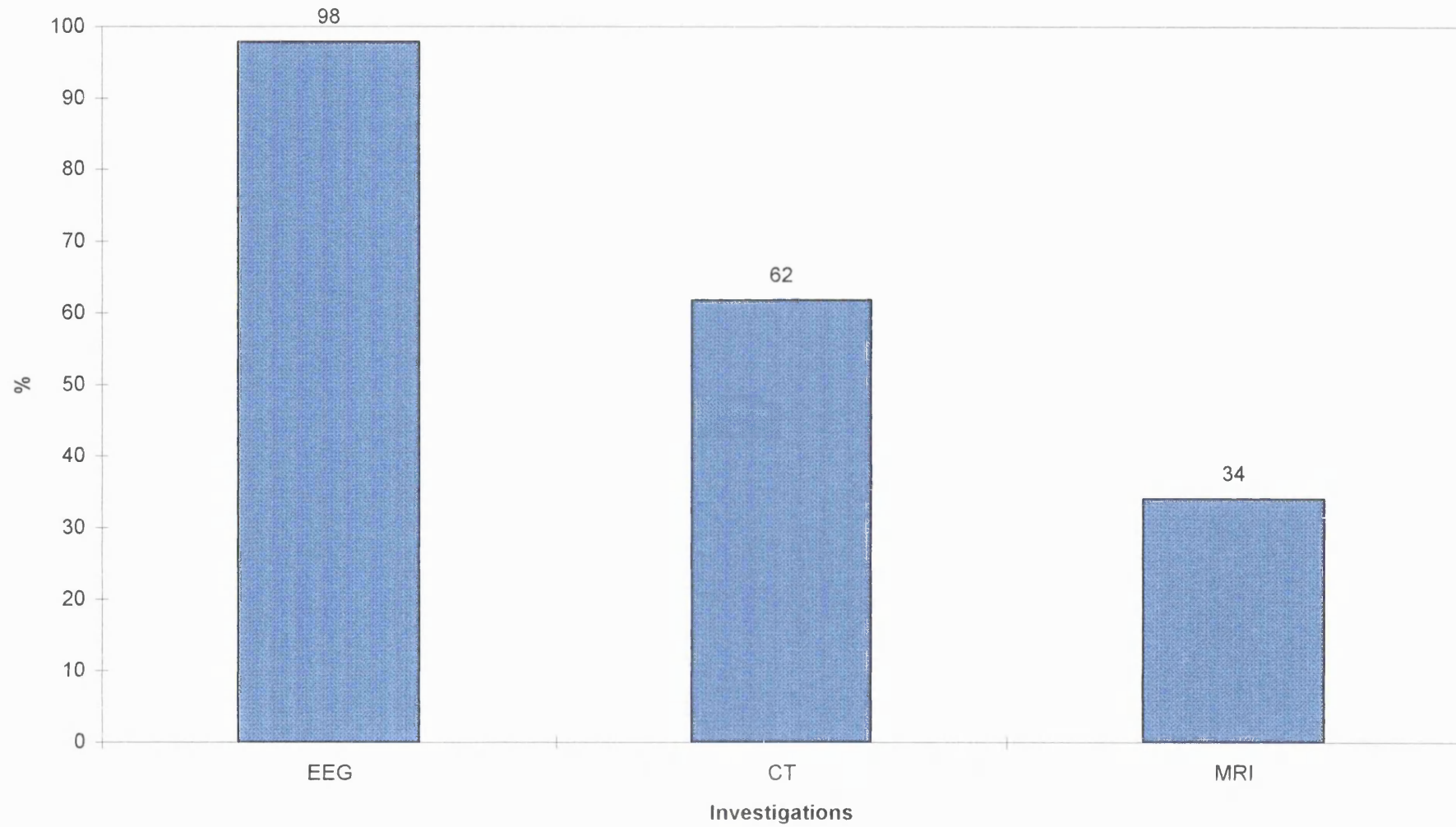


Table 11

Percentage of children on anti-convulsant medication at time of interview (respondents)

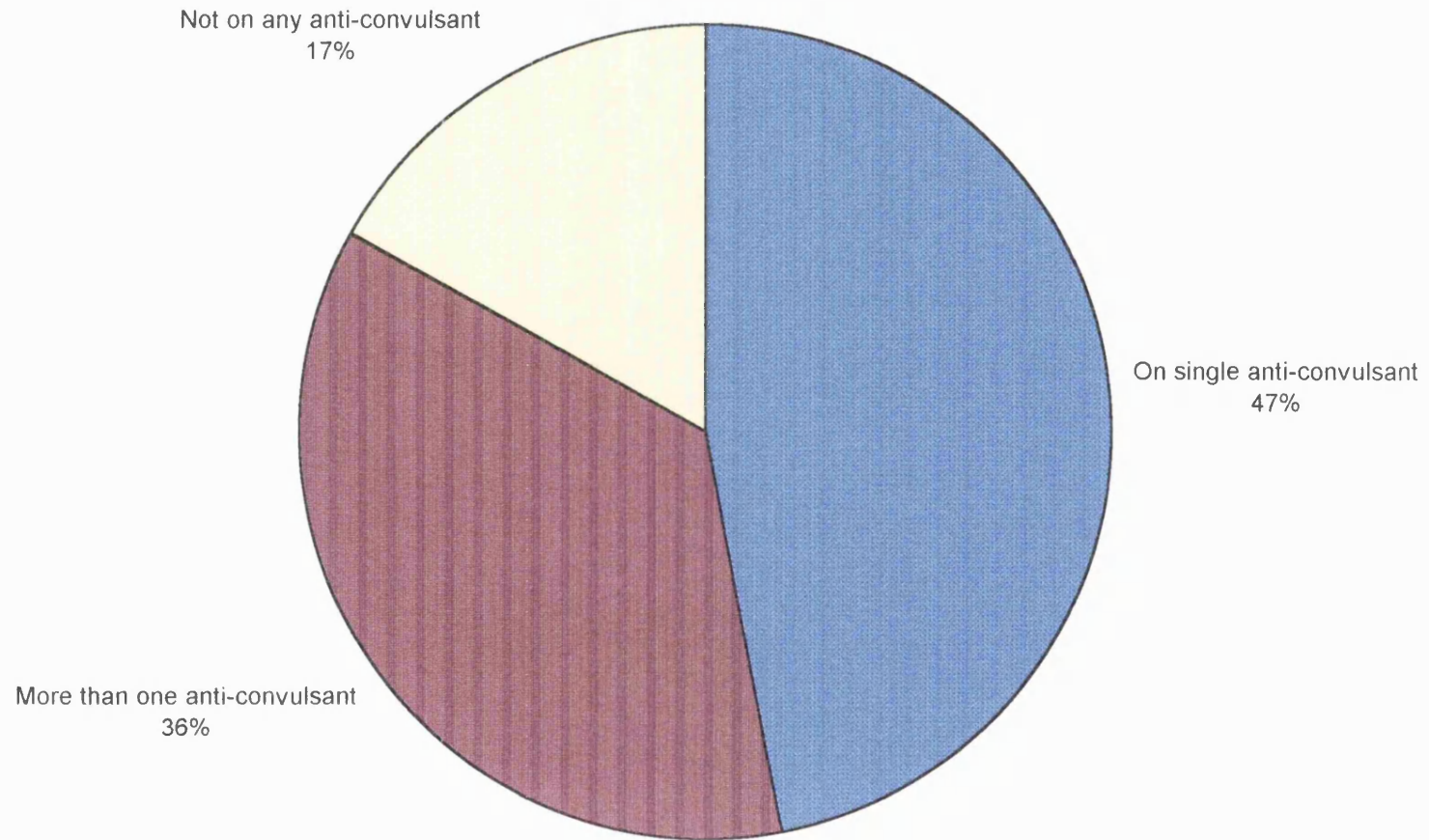


Table 12

Seizure frequency during the last year (respondents)

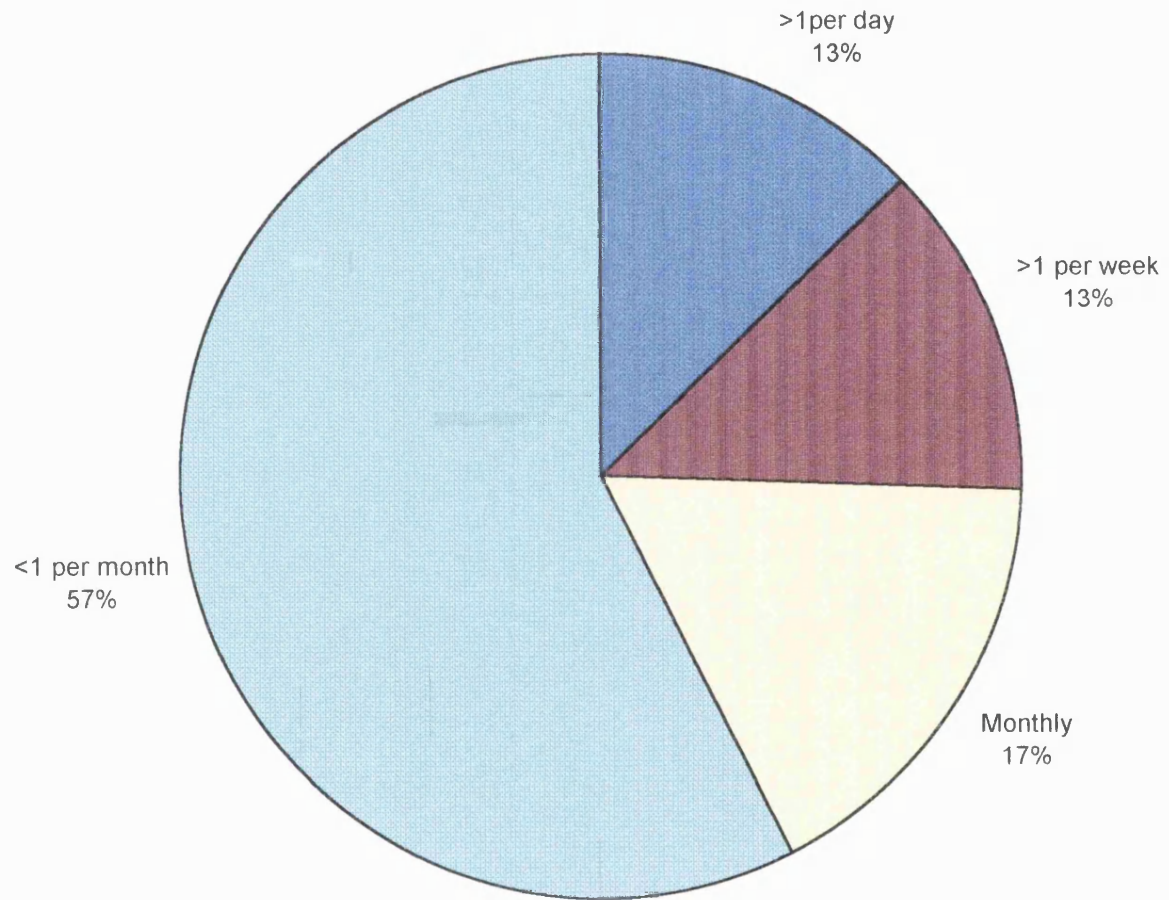


Table 13

Parents perception on the adequacy of information on epilepsy (respondents)

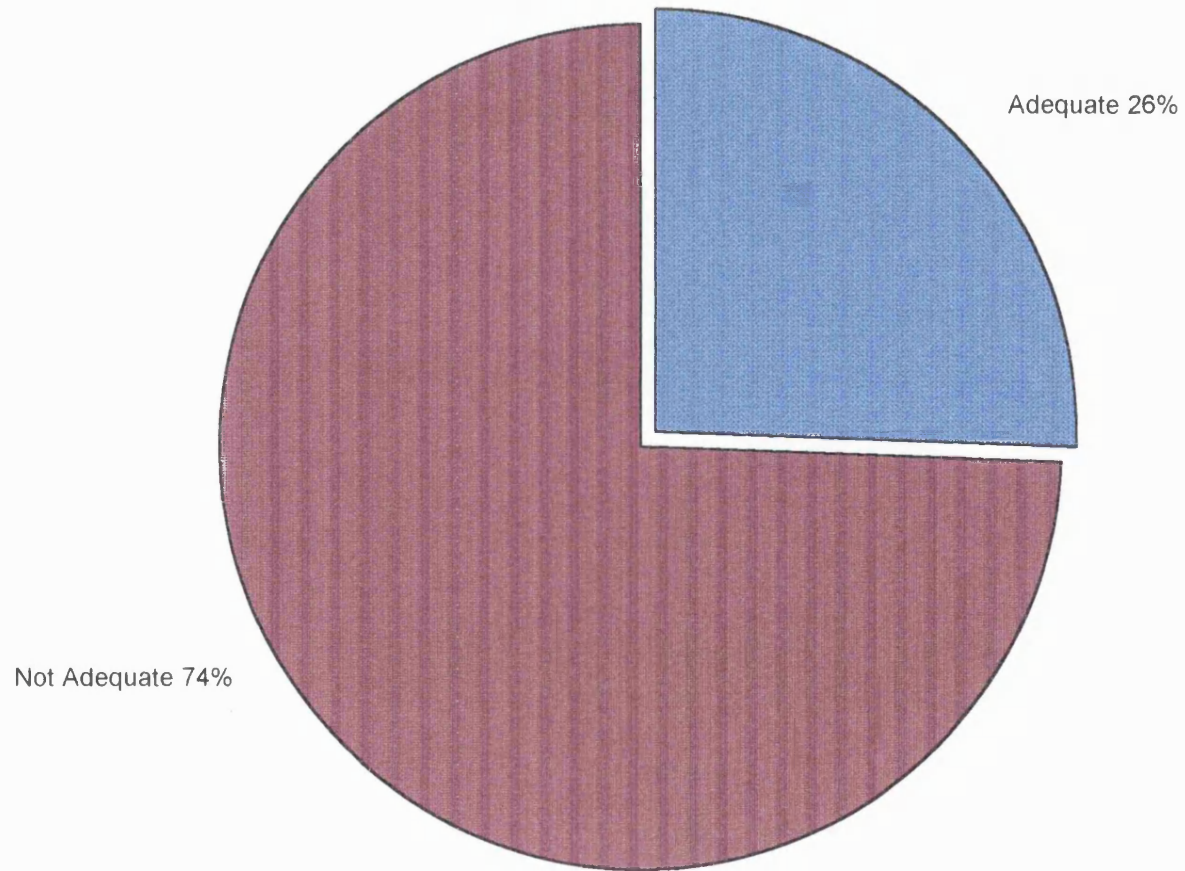


Table 14

Source of Information (respondents)

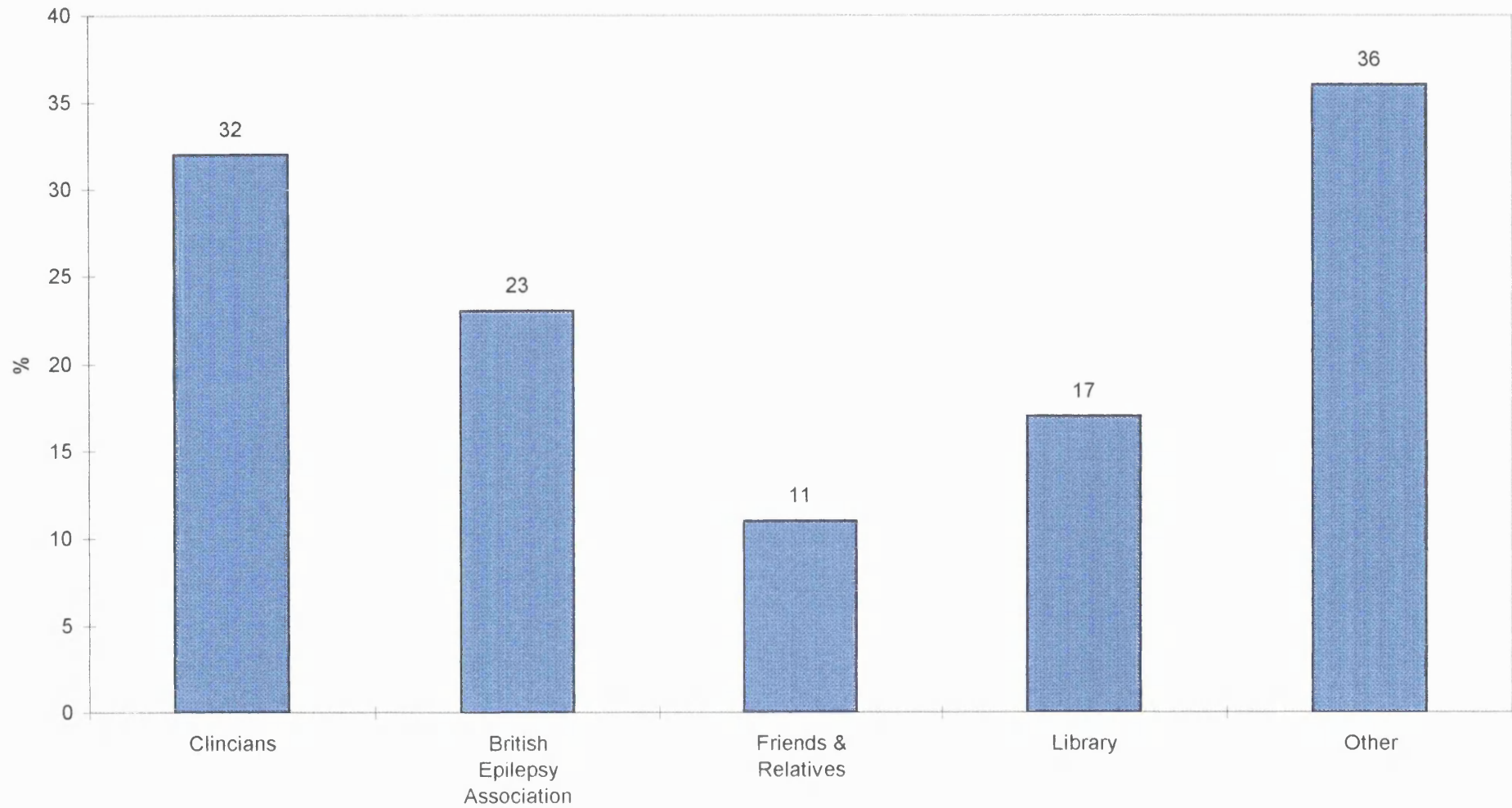


Table 15

How well were parents informed on epilepsy management on their own

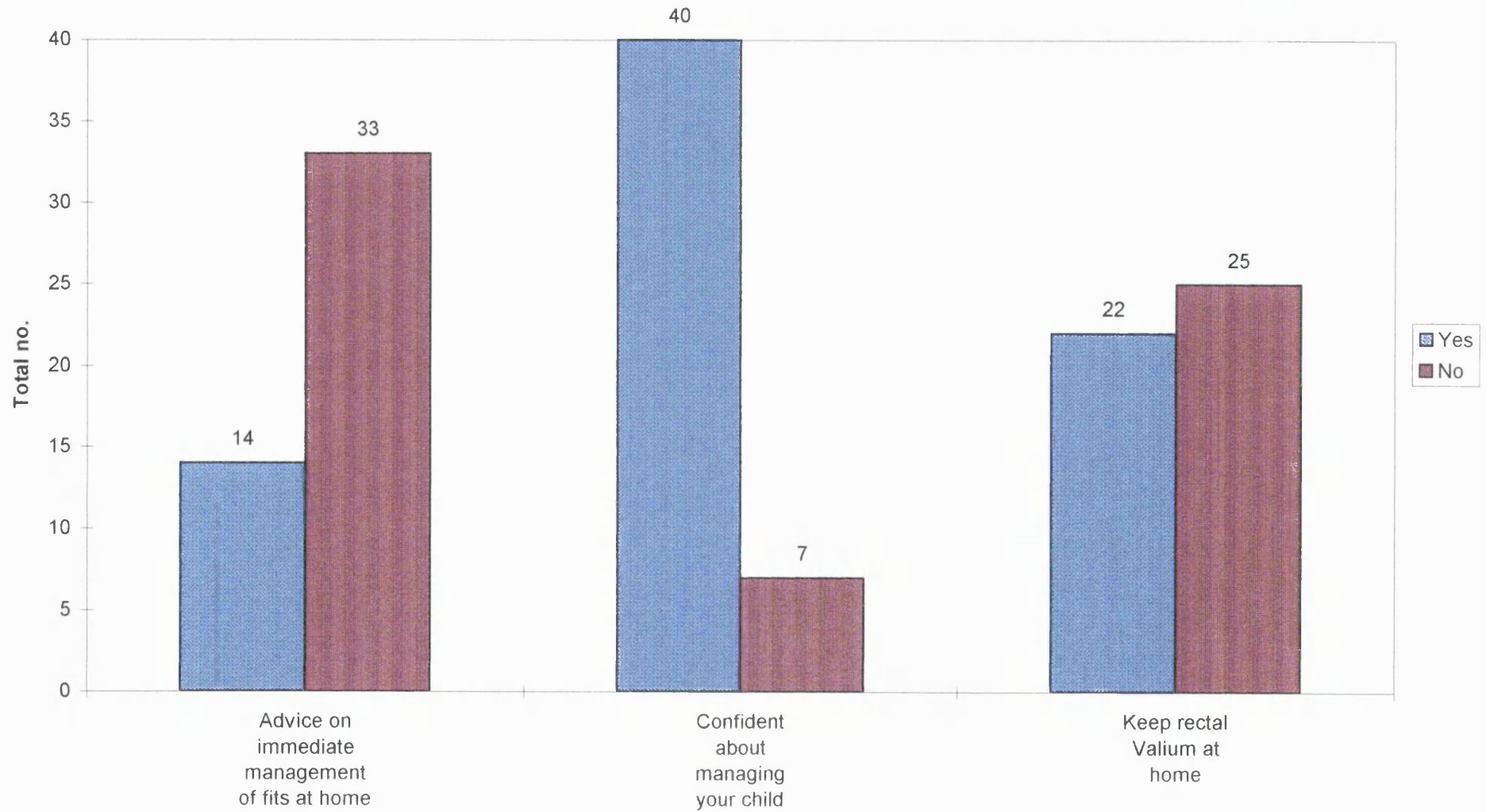


Table 16

Parents rating of the adequacy of the information (respondents)

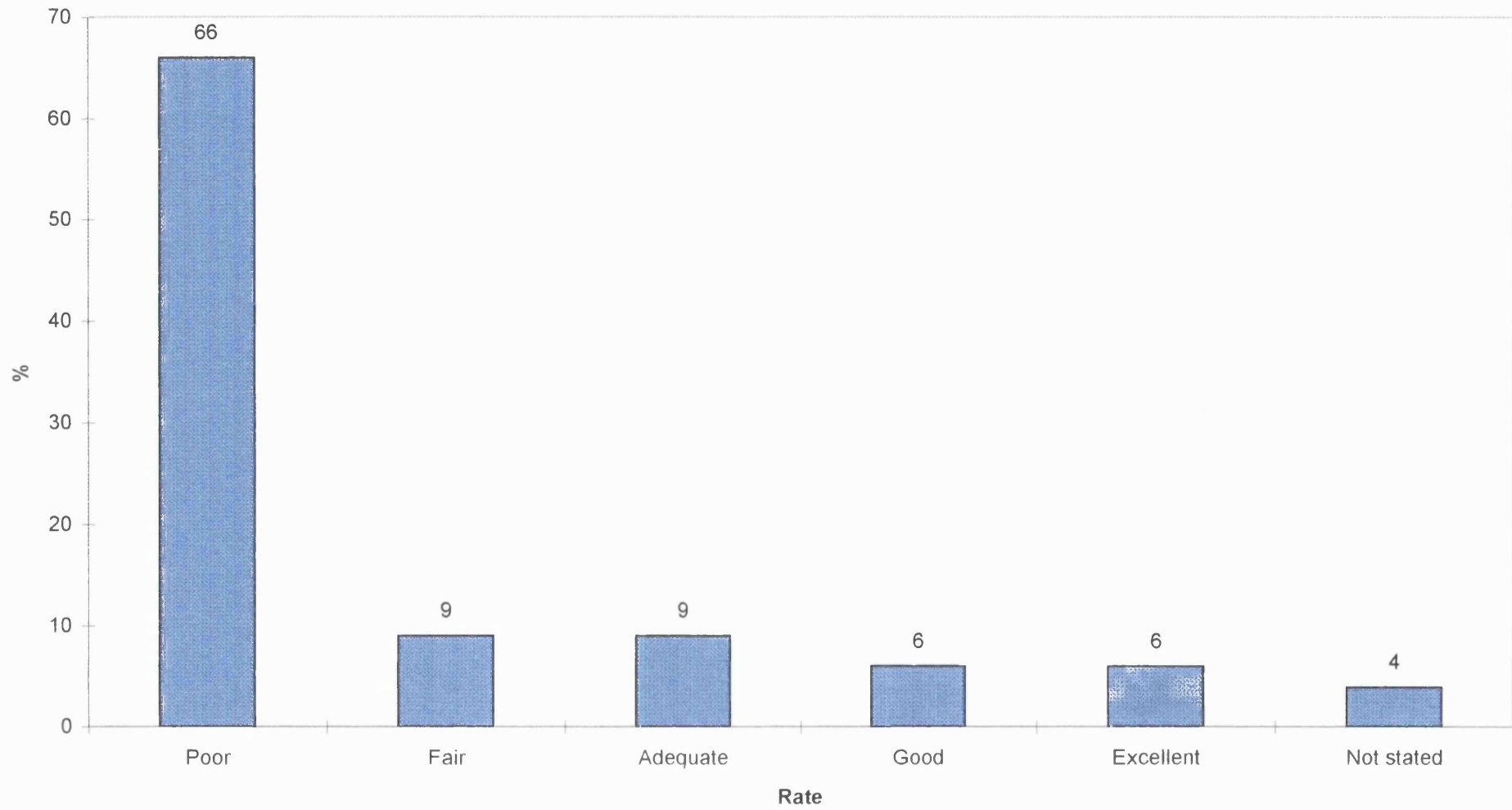


Table 17

Parental perception of schools awareness of child's diagnoses

School aware of diagnoses

Yes	42(90%)	No	5(10%)
Special Schools	19(95%)	Special Schools	1(5%)
Main Stream	23(85%)	Main Stream	4(15%)

Parental Perception of adequacy of information to school

Is the school adequately informed about the child's epilepsy

Yes	34(73%)	No	13(27%)
Special Schools	16(80%)	Special Schools	4(20%)
Main Stream	18(67%)	Main Stream	9(33%)

Table 18

The proportion of respondents introduced to British Epilepsy Association/
Voluntary Organisation

Yes	5(10%)	No	42(90%)
If yes, when was information given		If no, would it be helpful	
At time of diagnosis	1	Yes	28
Within 6 mths of diagnosis	2	No	14
More than 6 mths of diagnosis	1		
Not stated	1		

Parents perception of usefulness of local support

Yes	37(80%)
No	10(20%)

Proportion of parents prepared to be involved in the group.

Yes	30(64%)
No	17(36%)

Table 19

Concerns of Child with Epilepsy as perceived by the Parents compared with their own concerns (respondents)

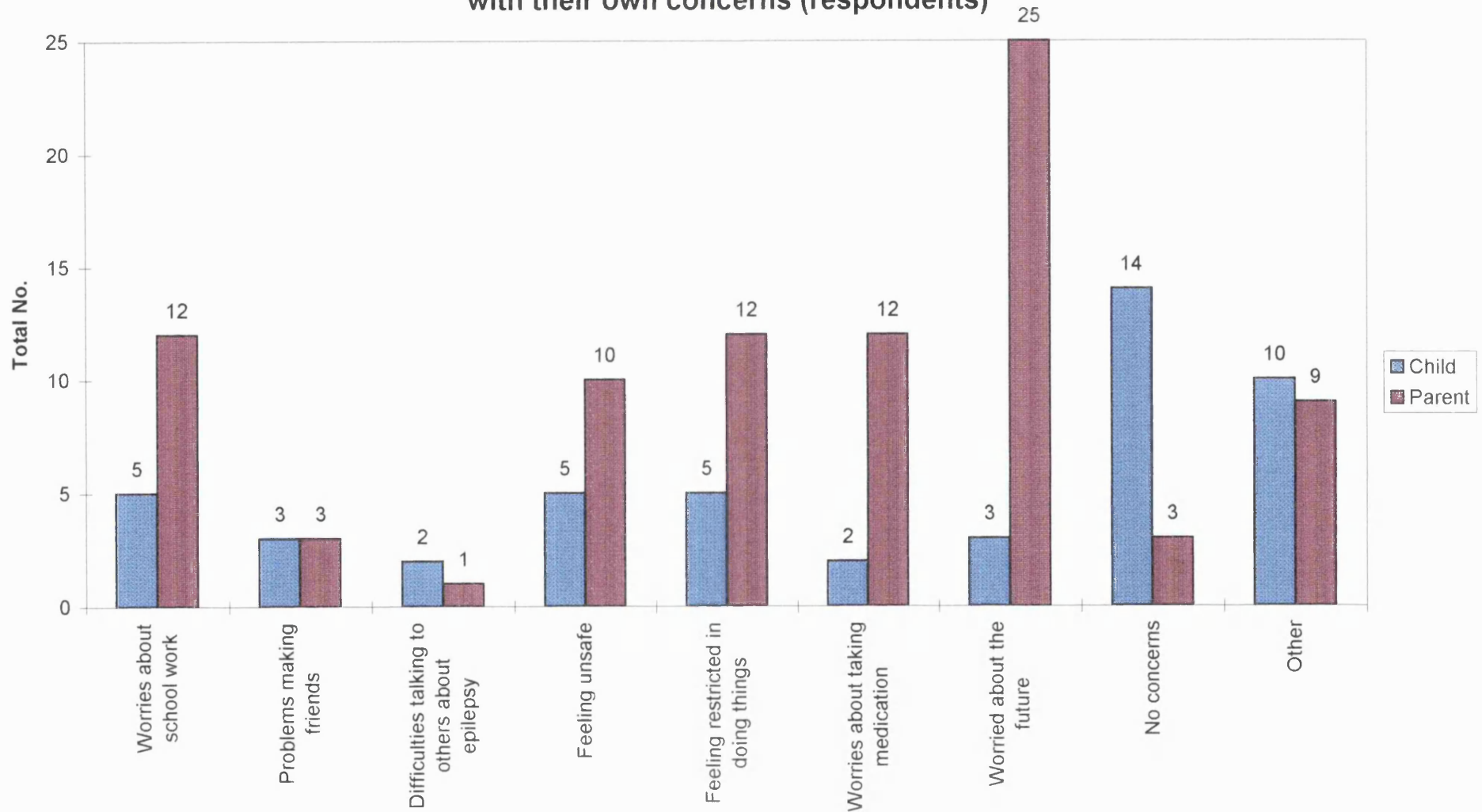


Table 20

Level of satisfaction with the overall management the child's epilepsy (respondents)

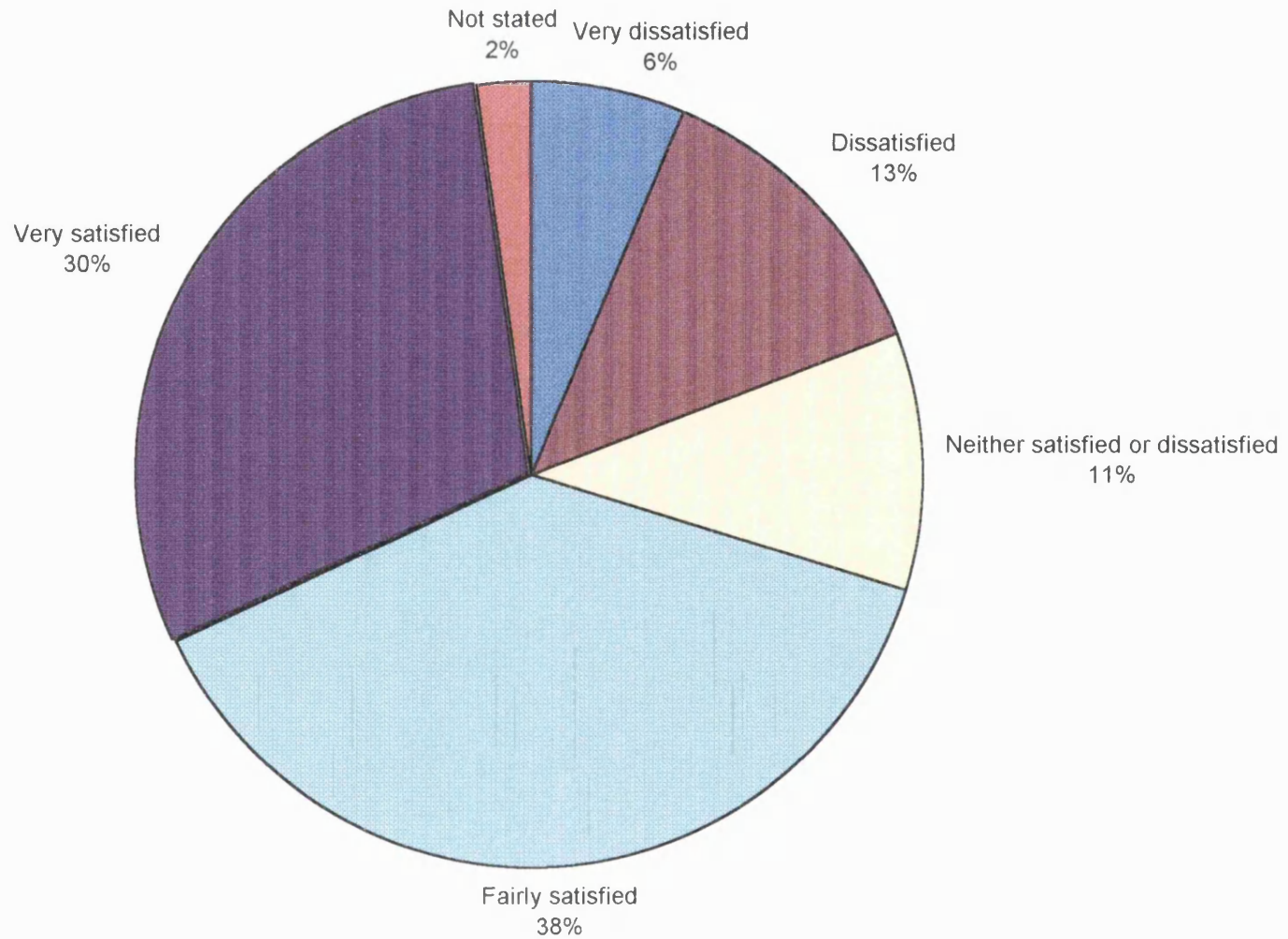


Table 21

Distribution by locality of non-respondents

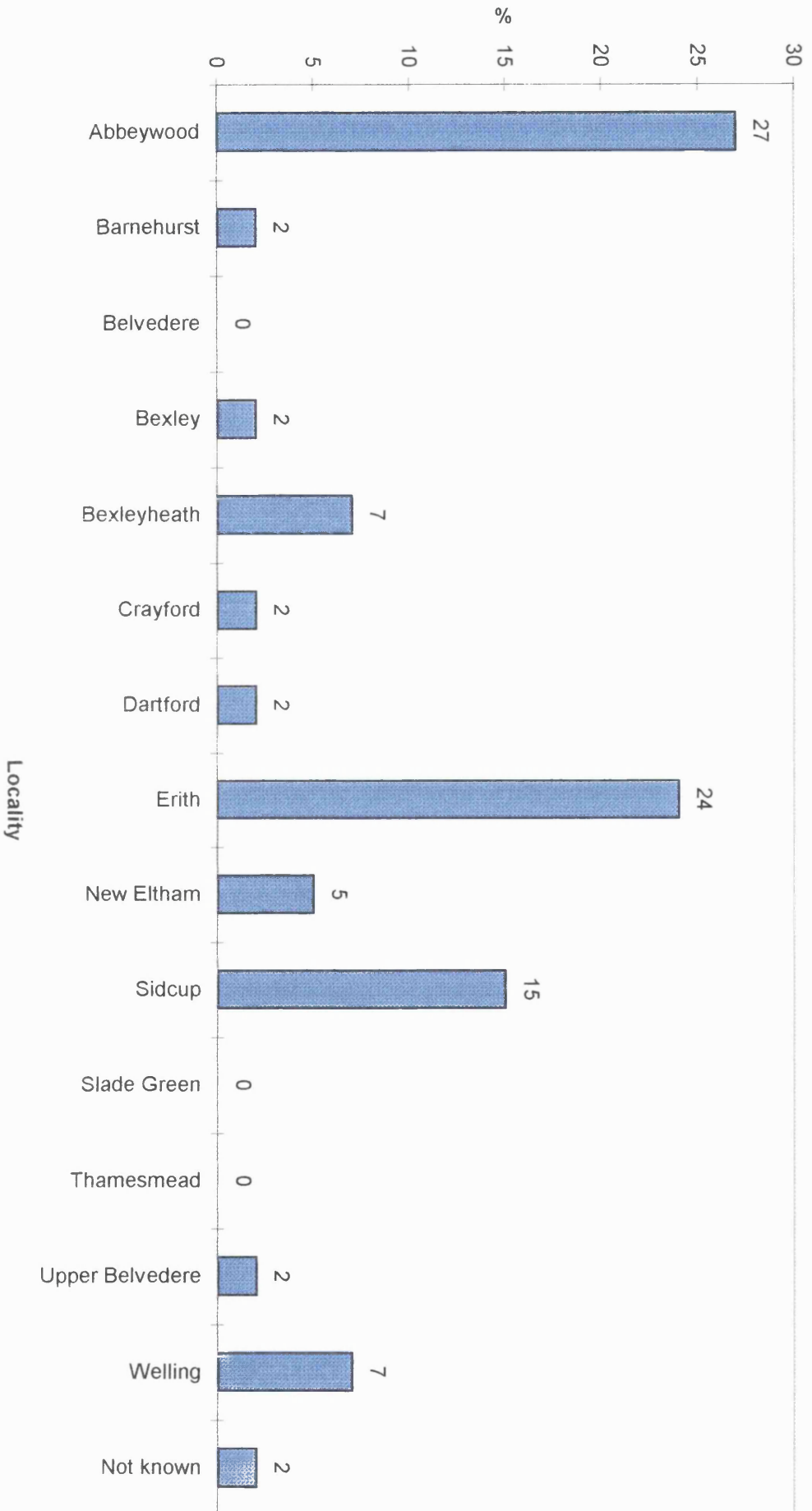


Table 22

Distribution by age group of non-responders

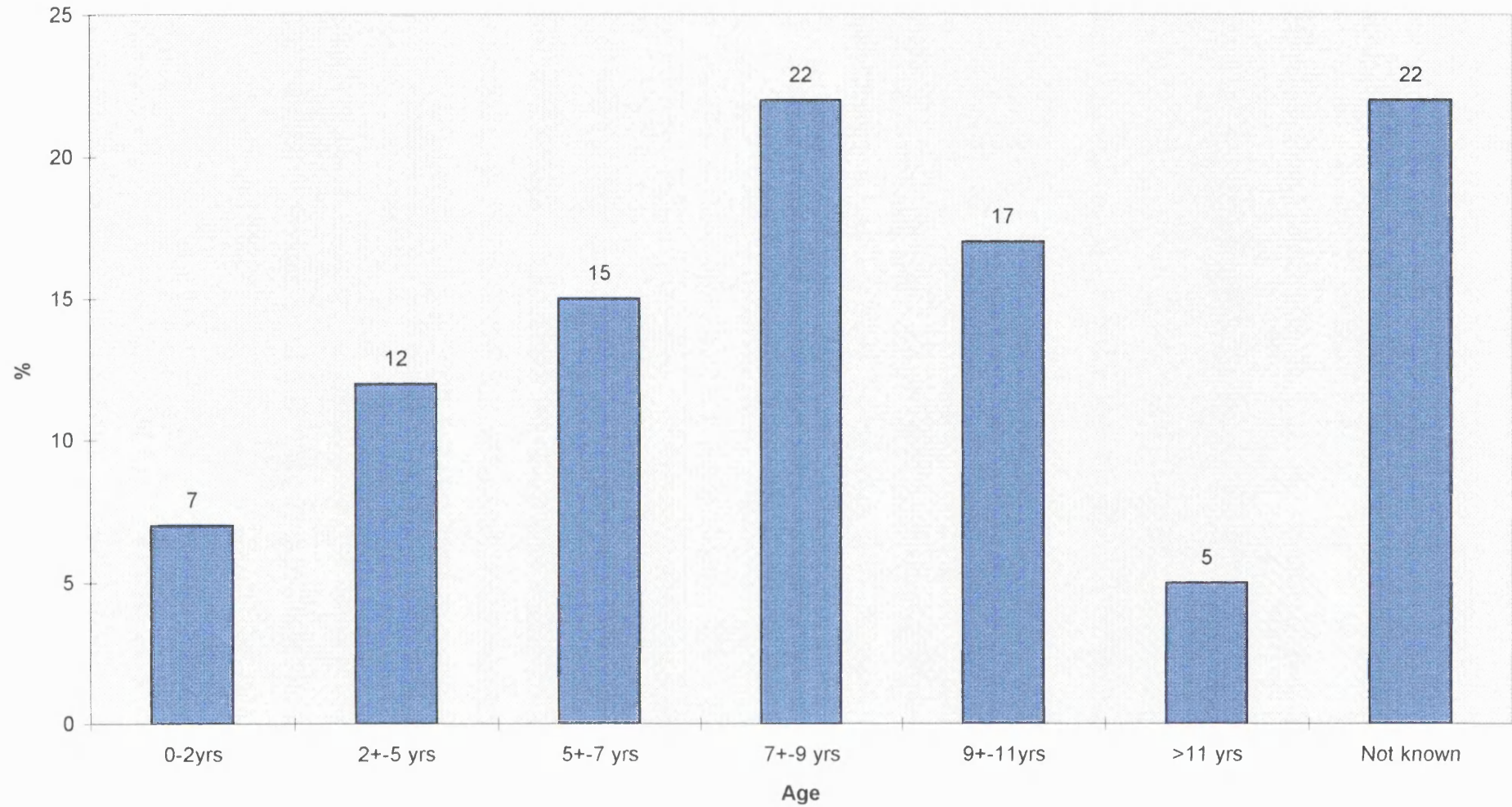


Table 23

Ethnic origin of non-respondents

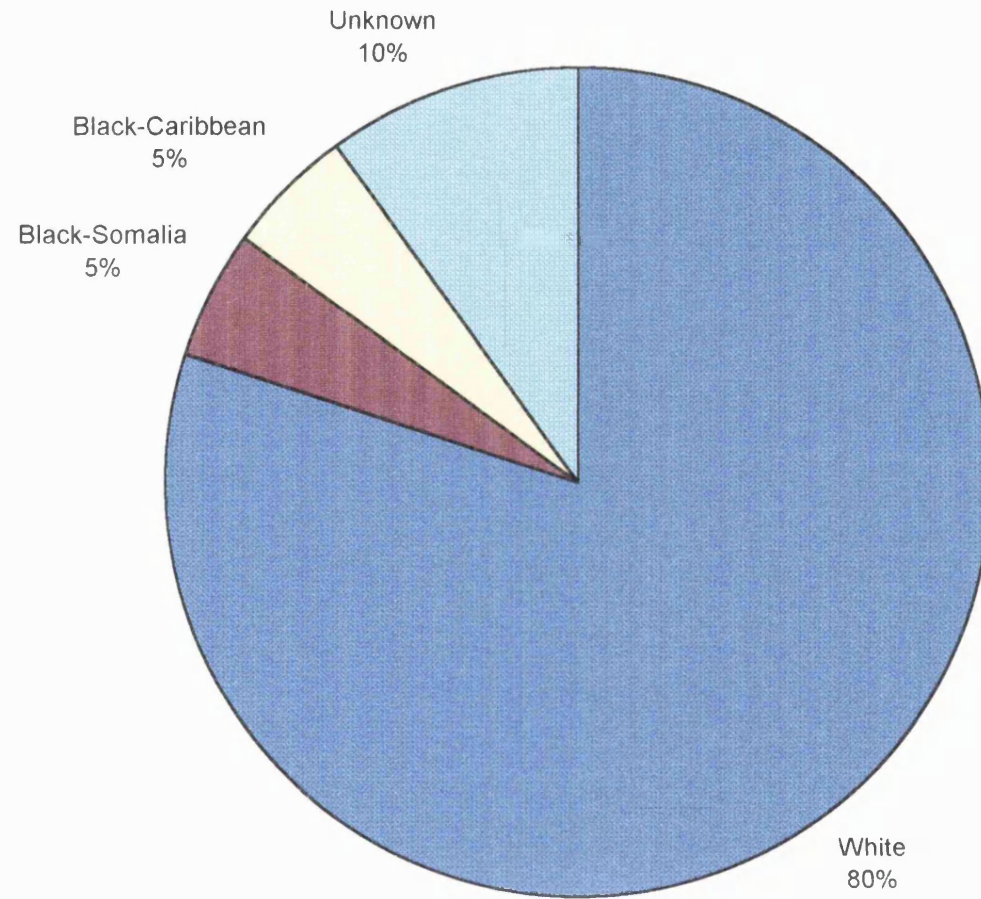
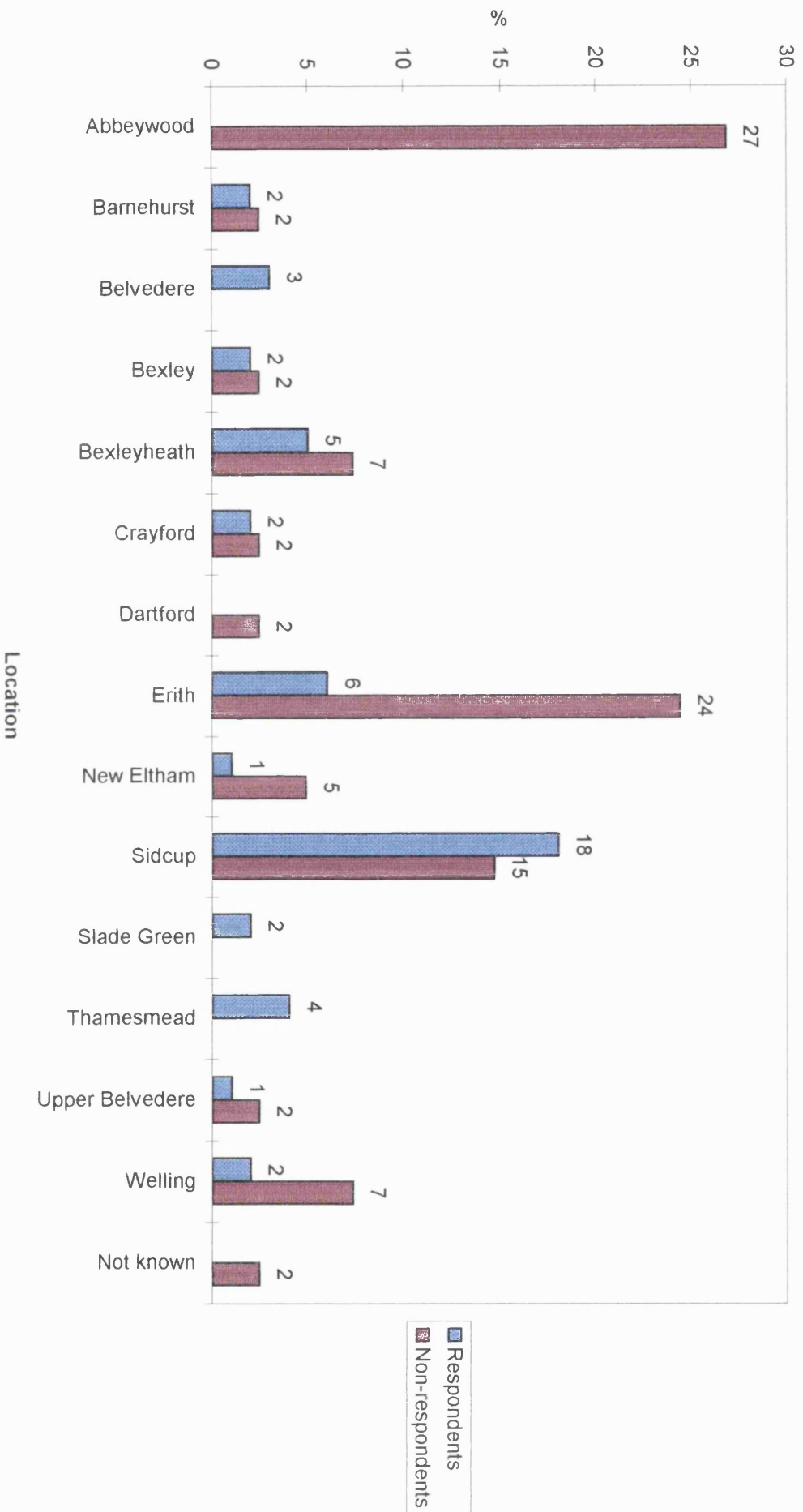


Table 24

Distribution by location of respondents and non-respondents



DISCUSSION

In our study, 88 children under the age of 11 were identified as having epilepsy in Bexley. **Ross et al (1980) refer to the importance of the knowledge of the size of the child population with epilepsy, in the planning of services.** They also point to several international studies that have estimated prevalence of epilepsy among children. The rates quoted have varied from 3.1 to 7.1 per 1000 population, between ages 10 - 20, for non febrile epilepsy. The variation had been due to differences in study methods and definitions. In their own study Ross et al report a prevalence rate of 4.1 per 1000 for non febrile epileptic seizures by the 11th birthday. Based on Ross et al estimate of 4.1/1000 we anticipated a figure of **at least 140 in Bexley.** There may be several explanations for the comparatively low figure in our study.

The most likely explanation for the low figure is that there has been under reporting of cases to us. The poor response despite reminders and telephone contact from General Practitioners may again be due to several reasons. Firstly, there may not be a register of children with epilepsy in their practices. **The importance of Registers cannot be over emphasised.** Disease registers and practice audits can be useful tools in monitoring and improving quality of care for chronic diseases such as epilepsy (Making Waves 1995).

A community-based study of people with epilepsy, showed that most people had not been seen by their GP in the previous year (Jacoby 1993). In the absence of an active Register of those suffering with epilepsy, the General Practitioner may have difficulty identifying those patients on their lists with epilepsy. Another possible explanation for our low figure is GP's not responding to the study despite data being available to them, either on computer or on a manual register. This may be due to time pressures, or even a problem relating to lack of enthusiasm for studies such as ours.

Another reason for our low figures is that the **hospital too did not have for the out patients, a clinical database**. Several studies have documented that the majority of patients with epilepsy after initial diagnosis and early follow-up visits, are either discharged or are lost to follow in hospital. It is estimated that 90% of patients with a history of epilepsy are not under hospital supervision at any one time (Goodridge & Shorvon 1983). Although the figures quoted is an overall one across different age groups, it is likely that this is at least partially true of children.

Unless a child has been admitted for epilepsy or related problems or epilepsy is given as a secondary diagnosis for children admitted for a different reason, the in-patient hospital records will not pick up those with epilepsy.

In our sample of 88 children with epilepsy, 32 (36%) were identified from the **special needs module**. (see Table 1). Identifying children with epilepsy from this source was an easier exercise to carry out. However it should be noted that the special needs module too may not have the names of all the children with special needs who have

epilepsy. In our local services in Bexley, the special needs register is in its early stages of development.

Bias

In our study the possible effects of **selection bias** should be noted. Selection bias in any study results from a number of circumstances relative to the way in which individuals are ascertained and selected for the study. In general these include factors such as differential surveillance, diagnosis or referral of individuals into a study. The under recognition of the effects of selection bias in scientific studies has been heavily criticised and the dangers highlighted (Ellenburg 1994). The evidence of bias in the selection of representative subjects enhances the ability to generalise the study results (Mark 1997). In our study, because of the possible under reporting and the likelihood of a high proportion of those identified coming from the special needs module, responses to the interview protocol may not be generalisable.

Of the 88 children identified, after repeated efforts, consent for interview was obtained from the parents of only 47 (53%). (see Table 1).

In any study those who agreed to participate are likely to differ from the **non participants** in a number of important ways. Again it is important to note the **non responder bias** especially because a large proportion of non respondents were from the socially disadvantaged areas of Bexley.

A way of assessing the possible effects of non response on either generalisability or validity involves a comparison of those who do and don't participate in a study.

The basic demographic data of respondents and non respondents were compared to see how representative the sample interviewed were of the study population

The age distribution, gender proportions, the geographical localities and related Jarman's "underprivileged area" scores and the seizure types were compared between the respondents and non respondents groups.

There were no significant differences as far as the age distributions and gender were concerned. However, with respect to the localities we found a greater proportion of responses to have come from the more affluent areas, in keeping with their Jarman indices. (see Tables 21,22,23) In the non respondents there was a high percentage of children from socially deprived areas with their Jarman indices reflecting this..

Parents who respond from affluent areas may be more keen and able to respond to any attempts to evaluate and improve health care. However, the non responders from the socially disadvantaged sectors may in fact be more in need of the services.

In our study there were four interviewers using the semi structured protocol. Therefore there is a possibility of **interviewer bias**. In order to minimise this, we trained the interviewers to adopt as similar an approach as possible.

COMPARISONS WITH TASK FORCE RECOMMENDATIONS

Register

For any provider unit that aims to address the Epilepsy Task Force Recommendations and plan a service for those with epilepsy, a fundamental requirement is a register of all persons suffering from epilepsy in their catchment area.

The difficulties caused by there being no register in Bexley are illustrated by the problems encountered in compiling a register with information from several sources, such as general practices, hospitals and special needs module in community services.

Similar difficulties in setting up an epilepsy Register have been outlined in a study from the Netherlands, in Groningen which has a population of around half a million. The importance of a Register and the difficulties in setting one up are discussed (Suurmeijer 1994).

It was found that there were no registers even in primary care in Bexley. This is something that could initially be achieved by consulting the repeat prescriptions list in general practice (Smith 1995), and compiling a list of those on long term anticonvulsants.

Staffing - access to specialists.

The Epilepsy Task Force with reference to recommendations regarding staffing levels for a service, advises **that every new paediatric patient suspected of having epilepsy should be referred to a Paediatric neurologist or a Paediatrician with a special interest in epilepsy.**

At initial presentation to the GP over 90% of patients with epilepsy are referred to hospital, where treatment is initiated (Thapar 1996). The majority of patients are either discharged or do not attend for follow-up. Moreover, the provision of neurologists per head of population in the UK is much lower than of other specialists and specialist epilepsy clinics exist only in few areas. In a comparison with Netherlands regarding provision of Neurology, it is reported that while in the Netherlands there are 50 million neurologists per population in the UK. There are only 5 per million (Suurmeijer 1994).

In our study, almost every patient has seen either a Paediatric Neurologist or a Consultant Paediatrician. 34% of our sample saw a Paediatric Neurologist and the rest a Consultant Paediatrician.(see Table 9). However, no one Paediatrician in Bexley declares a special interest in epilepsy nor are there any specialist epilepsy clinics. It should however, be again noted that just over one third of our patients were from the special needs module. These children in addition to epilepsies have other needs requiring specialist care. Also a large number came from relatively affluent areas and the parents are more likely to have sought specialist help.

The information obtained from the parents with respect to their children seeing Hospital Specialists was cross checked with Hospital records for assessing validity. The information from both sources were found to be tallying.

Investigations and Treatment

The Epilepsy Task Force recommends that **every newly diagnosed child must have at least one standard E.E.G. Also all children presenting with partial epilepsy should have neuroimaging investigations.**

In our study 98% of the children had had the E.E.G., 62% have had a CT scan and 34% had a MRI scan. (see Table 10).

This is encouraging, however, as mentioned previously, our study sample contained a high proportion of children with special needs and are therefore more likely to have had a specialised investigation.

The aim of good management in epilepsy is to use a single drug in the lowest dose that controls the seizure without producing the side effects. If the single drug produces a significant improvement but still does not give complete seizure control at the maximum tolerated dose, a second drug needs to be added.

In our study, 47% of the sample were on single anticonvulsants. 36% were on more than one anticonvulsant and 17% on none. (see Table 11). Considering that 42% of our sample came from special schools this finding, although based on parental reports, is encouraging. Medication is an aspect that parents are closely involved and take

responsibility for and with the domiciliary interviewing used, the responses should be considered reliable.

Protocol for Information and Advice

One often neglected aspect of management is the provision of adequate information for patients and relatives with regard to various aspects of Epilepsy.

Better education of society regarding epilepsy is necessary to remove the many pre-conceptions and prejudices that still prevail. It is important to encourage self confidence in the patient and to avoid over protection (Tatternbourn & Kramer 1992).

The aim of a Liaison Service for epilepsy is to encourage the development of an effective, co-ordinated approach to epilepsy and to empower people with this condition by providing them with information and advice that is tailored to their specific needs (Smith 1995)

In a large study of patients with epilepsy in a single health region in the UK, surveying 1341 patients (0.8% of the total population of 31 general practices), it was found that a sizeable proportion of patients reported that they received insufficient information about epilepsy, both from hospital doctors and general practitioners.

In our study **only about 26% of the parents interviewed reported that they had received adequate information** regarding their child's epilepsy.(see Table 13).

Overall 66% of our sample, patents of 47 children with epilepsy rated the information they received as of poor quality.(see Table 16).

While great advances have been made in the understanding and treatment of epilepsy, patient ignorance appears to remain high. People with epilepsy not only have to cope with the fear and confusion of seizures, they also have to undergo complex medical examination, follow a strict anti-convulsant regime, adhere to a lengthy list of medical and social restrictions, and be accurate reporters on the type and frequency of seizures. Therefore knowledge of epilepsy in general and of how it relates specifically to the individual helps reduce the emotional impact of both seizures and treatment and helps the individual cope with the social and vocational limitations enforced by the seizure disorder. (Farire et al 1993).

It is recommended that not only should information be provided, **but it must be checked whether the patient has been able to comprehend what was told to them.**

The information has to be clear and jargon free and preferably given in writing so that the patient or carer could refer to it later.

Jarine et al (1993) went further and devised an epilepsy knowledge profile general (EPK - G), a short self-administered questionnaire designed to assess patients knowledge, misconceptions and fears about epilepsy. They emphasised that communications is a two way process and often the patients perspective is that they feel disadvantaged and in some respects intimidated during consultations due to their lack of knowledge.

Only one fourth of our sample had received **written information**. Again it is important to note that this is despite 42% of our sample coming from special schools and with special needs. (see Table 7).

The provision of information to the parents or carers has to be **timed so that not only adequate details can be provided it can be done with the utmost sensitivity at the right time**.

Of the parents of 11 children (23%) of our sample who had received written information only 6 had received it within six months of diagnosis.

With regard to the **sources of information**, in our sample only 15 (32%) reported receiving information from professional staff. (see Table 14). In the absence of an epilepsy liaison nurse the sources of professional information had been mainly medical staff who had seen the child and the parent. As described earlier, the quality of information provided had been rated as poor by 66% of our sample. (see Table 16).

In their pioneering study in Doncaster, of the benefits of a community based specialist liaison nurse and guidelines for shared care, Taylor et al (1994) drew particular attention to the **advantages reported by patients in having contact with a specialist nurse**. The time given to explanation had been valued by patients and perceived by doctors to reduce their workload. Also patients reported more being able to raise issues in their own homes and unrecognised problems and psycho-social needs were more readily identified.

In our study the **areas in which the parents wished to have more information** and discussion were, causes of the child's epilepsy, investigations, medication - reasons for changes to and side effects, and guidance on what the child can and cannot do. In the open ended part of the interview protocol where parents were asked about other concerns, they reported anxieties about long term outcome, special education etc.

REHABILITATION

Liaison with primary care.

One of the key recommendations of the Epilepsy Task Force is that a **system of liaison between primary and secondary health care teams should be set up**, preferably through an epilepsy specialist nurse.

Most people with epilepsy identify the general practitioner as being the doctor primarily responsible for their care. The care of people with epilepsy in general practice has been the focus of much recent attention with several major community-research programmes (Thapar 1996).

Betts & Smith (1994) refer to one of the main deficiencies in the relationship between general practice and secondary care - **the poor quality of information that passes between the two and lack of a shared information base.**

The results of surveys of the attitudes to GPs to the care of people with epilepsy by the Epilepsy Task Force and Doctor Magazine (1994) suggests that the majority of GPs consider the condition and its treatment to be complex and that they lack sufficient

knowledge of the condition. A pilot study of GPs in Doncaster found similar problems, with two thirds of respondents acknowledging difficulties in diagnosis, counselling and the prescribing of drugs (Taylor 1987).

Liaison Nurse

The studies in Doncaster, (Taylor et al 1994) described a novel feature of the new district epilepsy service that was developed - the appointment of a **community based specialist liaison nurse for epilepsy**.

The nurses' intended role was:

1. the provision of advice and support to patients and their families.
2. to act as a link between the hospital clinic and general practice.
3. to foster links with other NHS Departments, Social Services, disability resettlement advisers, schools, residential homes, voluntary organisations etc.
4. to arrange training for health care professionals.

The priorities described were:

1. to implement planned care at home in collaboration with either specialist or GP
2. the investigation and management of non compliance.
3. to provide information, education and counselling.

Epilepsy can be a devastating diagnosis and has serious implications for an individual's psycho-social well being. The non-medical management is, therefore of equal importance and complements the medical management. To provide the best "holistic" care, liaison with all members of the multi-disciplinary team is vital. The majority of

people with epilepsy are managed in the community placing increasing demands on school nurses, GPs, practice nurses, midwives, health visitors and district nurses, Epilepsy Specialist Nurse are ideally placed to bridge the gap between everyone involved, to be the “key“ worker.

There is a role for the Epilepsy Specialist Nurse in client care at all stages, starting at diagnosis right through to planning for the longer term.

Provision of education, support, advice and counselling should be available to all individuals with epilepsy, their family, carers, teachers, employers and anyone else the client feels is necessary. It is therefore vital that a specialist epilepsy service allows for consultations to take place in any number of locations, such as the clients home or place of employment. This is often extremely useful not only to the client, but for the professional team. In these situations the Epilepsy Specialist Nurse can gain important knowledge on client lifestyle, which in turn may have direct implication on their health gain. (Goodwin 1996)

In one of the first trials reported of the feasibility and effect of nurse run clinics for patients with epilepsy in general practice was a randomised control trial of nurse run clinics versus what was termed “usual care”, involving a total of 251 patients aged over 15. (Ridsdale et al 1997). Those in the intervention group were offered an appointment with a nurse with special training in epilepsy while the others attended either a GP or a Specialist for their usual follow ups. It was found that most patients were willing to attend a nurse run neurology clinic in primary care. The nurse had been

able to identify possible improvements in the drug management of over a fifth of the patients seen. The level of advice that was recorded as having been given on drug compliance, adverse drug effects, driving, alcohol intake, and self help groups increased significantly. It should be noted however that the findings here may not be directly relevant to our study as the age group studied did not include anyone under 15. Also of note is that the study concentrated more on process than outcome and there was no follow-up to evaluate whether there were in fact changes in the level of patient knowledge of their condition.

The Wellcome Foundation funded a national initiative which ran between October 1993 and October 1994, (Wellcome Foundation 1993). Ten liaison nurses were trained and established in areas in which there was a hospital specialist epilepsy clinic. The overall aim was to help general practices improve the care of their patients with epilepsy by assisting practices in identifying patients with epilepsy, helping establish epilepsy clinics in primary care and then auditing the care of these patients.

Over 600 practices were involved in this programme nationwide.

The burgeoning interest of providing specialist nurses for epilepsy in line with those provided in the UK for patients with Asthma and Diabetes, received a shot in the arm with the British Epilepsy Associations launch in 1995 of the Sapphire Nurse Scheme. This helped to increase the number of epilepsy specialist nurses and will enable their roles to be classified and developed further (Goodwin 1996).

There is at present no Epilepsy Specialist Nurse in Bexley.

LIAISON WITH SCHOOL HEALTH SERVICE

Children with a history of epilepsy have special medical, social and educational needs that must be met by the school health service if they are to make the most of their school years. Ross et al (1993) pooled the results of a number of studies in the UK and abroad and found an overall prevalence rate of 4 in 1000 **school children** to have a history of past or present non febrile epilepsy. In their earlier National Child Development Study (NCDS 1980) the majority of children with epilepsy were found to be attending ordinary schools.

In our sample, 20 of the 47 (42% of the respondents) children attended special schools. (see Table 7).

It is vital that teachers, parents, and health professionals recognise the major educational problems that affect students with epilepsy. Children with epilepsy should be placed in the least restrictive schooling environment so that social, emotional, and educational requirements can be met in a setting best suited to the individual's needs and future development. Personal assessment and monitoring of progress form an equally important part of a child's educational program in integrated schools, but there is a need to develop suitable instruments to assist teachers in their assessments and decision making. In Australia, the National Epilepsy Association has developed an "Alert Kit" based on the Epilepsy Foundation of Americas "School Alert Kit" (Gourley 1990).

A questionnaire survey undertaken among 142 schoolteachers in North Staffordshire revealed most of the respondents did not feel confident when teaching children who had epilepsy and a minority considered their knowledge of the subject to be adequate. Only four teachers had received recent specific instruction on childhood epilepsy and the majority requested training on epilepsy and other medical conditions. Despite this lack of confidence and specific training, the respondents demonstrated good general knowledge of epilepsy and adequate awareness of the difficulties encountered by epileptic schoolchildren. If optimal care is to be achieved for children with epilepsy, then teachers must feel confident with the subject. School health services have a clear role in ensuring that teachers have sufficient knowledge of childhood epilepsy, that they have adequate support, and that communications between teachers, parents, and paediatricians is encouraged. (Bannon et al 1992).

In a Danish study, looking at the level of understanding about epilepsy among teachers it was found that only 18% of them had had any training on epilepsy despite 63% stating a desire for training. A considerable lack of confidence and knowledge on issues such as provoking factors, surveillance and management including medical treatment was found. It was recommended that to achieve optimal care for children with epilepsy, a sufficient knowledge and confidence is necessary among teachers concerning epilepsy is introduced for teachers who have pupils with epilepsy. Such education could be provided via the local health service (Madson 1996).

In our sample **parental perception as to whether the school was aware of the diagnosis** of epilepsy in the child was examined. Parents of 42 of the 47 (90%) children felt that the school was aware of their child's epilepsy. Looking specifically at the children in special schools, 19 out of 20 (95%) of the parents felt confident that the school was aware of the child's epilepsy.(see Table 17).

When asked **whether they felt that the school was adequately informed**, only 34 of the 47 (73%) of the parents answered in the affirmative.(see Table 17). Again, when we looked at the children attending special schools the results were only slightly better, with parents of 16 out of the 20 children reporting that they felt the school was adequately informed. (see Table 17).

Liaison with Voluntary Agencies

It is important for the parents to be introduced to voluntary agencies such as the British Epilepsy Association. Both GPs and specialists must aim to address the wish of parents for more detailed information by introducing them to voluntary organisations, which are able to provide literature and other visual aids. In our study of the parents of 47 children only 5 had been introduced to the British Epilepsy Association or other voluntary bodies.(see Table 18). Of the 5 only 3 had information within 6 months of their child being diagnosed as having epilepsy.(see Table 18). Also of the 42 families which had not been informed of the British Epilepsy Association or other voluntary bodies 28 expressed the view that it would have been very useful had they had access

to such associations early following the diagnosis. There is clearly a need for professionals to be more aware of this deficiency in current service provision. Nearly 80% of the parents interviewed expressed a wish for a local self help group and 63% were offering to be actively involved in setting one up.(see Table 18). This is an area that needs further development.

Counselling

There have been several studies of parents perceptions of the effect of epilepsy on their children. For parents and their affected children the unpredictability of the occurrence of seizures creates a sense of helplessness and lack of control, with subsequent feelings of rejection, anxiety and depression. Efforts to help parents deal with their children's seizures have included education groups and individual or group counselling to increase understanding of the child's reactions to seizures and adopt strategies to cope with their children's seizure disorders.

In a randomised control trial of efficacy of a Children's Epilepsy Programme, a child centred family focused intervention developed and pilot tested in the USA, using a counselling model for parents, it was found that although the parents overall knowledge of epilepsy was relatively high initially, it improved considerably in both comparison and experimental groups. With regard to anxiety, at the five month evaluation experimental group parents in particular were more likely than control parents to state that they were less anxious. The authors concluded that it was encouraging that a relatively brief, intervention had the potential to reduce anxiety

among parents and perhaps help them to view their children more positively. Further sessions to reinforce efforts to improve parenting practices related to living with a child with epilepsy were recommended. (Lewis et al 1996). The same group conducted a similar randomised control trial of a programme to enhance the competencies of children aged between 7 and 14 with respect to psycho-social issues. They found that in the experimental group there was significant enhancement of knowledge in areas related to management of seizures and unnecessary restrictions of their social and play activities. However, there was no impact on the childrens disclosure of their diagnoses to friends and others.

In our study parents of 19 of the 47 children (40%) expressed concern about behavioural difficulties in their children. Nearly 75% of the parents expressed anxieties about the child's future. There were also other areas of concern such as school work, medication etc. (see Table 24).

In a study of parental attitudes and coping behaviours in families of children with epilepsy, it was found that parents with positive attitudes were able to cope better with their childrens epilepsy and associated problems. (Austin & McDermott 1988).

The incidence of psychiatric problems has been found to be higher in children with idiopathic epilepsy (28.6%) than for children with other chronic physical problems (11.6%) or in the general population (6.6%) (Rutter, Graham & Yule 1970).

Maladaptive coping with parents is often cited as a major reason for increased incidence of emotional problems in children with epilepsy. It is believed that parental

maladaptive coping is a result of negative parental attitudes, which is a result of the social stigma associated with epilepsy (Bagley 1971).

There is an important need for adequate provisions for counselling and support to parents and their children with epilepsy.

RECOMMENDATIONS

This evaluation of the services for children (under age 11) with epilepsy and their families in the Borough of Bexley, with a special emphasis on parental perceptions, using the relevant sections of Epilepsy Task Force Recommendations as guidelines for good practice, brought out several issues that deserve attention at a local and national level to improve practice and efficiency.

1. **Epilepsy Register**

There is currently no register for children with epilepsy in Bexley whether it is in Hospital Paediatrics or in the Community Child Health Services.

To organise a service for children with epilepsy and for subsequent evaluations, one fundamental requirement is a comprehensive register.

In accordance with the Task Force recommendations, each provider, be it a General Practice, Hospital or Community Child Health Service, must set up a register of names of children with epilepsy. This could be collated into a main Register.

It is proposed to seek the assistance of the Commissioners to embark on this major but essential task.

2. Staffing

a) Access to specialists:

The situation in Bexley could be seen as satisfactory.

However, in line with the Task Force recommendations a Specialist Epilepsy Clinic with a Consultant Paediatrician with a special interest in Epilepsy leading this would further improve the co-ordination and delivery of services.

b) Epilepsy Specialist Nurse:

There is no specialist nurse in Bexley.

It is recommended that in accordance with Task Force guidelines and in line with developments in many other Health Authorities local commissioners consider the appointment of an Epilepsy Specialist Nurse.

3. Information:

There are major deficiencies with respect to provision of Information - relating to the adequacy, quality and timing of the information given.

It is recommended that in line with the Task Force guidelines, a protocol for information and advice to persons with epilepsy and their carers is prepared in collaboration with Hospital Specialist Paediatricians, Primary Care, Community Child Health Services, Schools, Parents and Voluntary Organisations.

4. **Rehabilitation**

a) Liaison with Primary Care.

At present in Bexley there is no agreed protocol on the shared clinical management of epilepsy in the community. Our literature review also highlights the concerns of General Practitioners in relation to the management of epilepsy and raises issues regarding training

between the primary and secondary care services.

It is recommended that urgent steps be taken for the primary and secondary care services to jointly draw up guidelines for shared clinical management of patients with epilepsy in the community. The shared care could be facilitated by the presence of an epilepsy specialist liaison nurse.

b) Liaison with School Health Services

We found that many parents had concerns about their child's life at school especially relating to school work, relationships with peers, restriction of activities, safety etc.(see Table 24).

Our literature review brought out concerns reported by teachers for example, with regard to their lack of knowledge about epilepsy, fears regarding the ability to manage crises, use of emergency medications etc.

Liaison between paediatricians, parents and schools should improve. This again could be facilitated by the appointment of an Epilepsy Specialist Nurse.

Steps should be taken to further expand the current arrangements in Bexley to provide training to Teachers and other school employees.

c) Liaison with Voluntary Services.

There was very little evidence that there was a system by which parents or carers were introduced to the British Epilepsy Association or other Voluntary Organisations. Parents reported a keen interest in receiving information and joining such organisations, with a substantial proportion wishing to be involved in a local group themselves.

The protocol for information and advice should include information on access to voluntary organisations.

Organisations such as British Epilepsy Association and the National Society for Epilepsy should be requested to consider facilitating local groups with an emphasis on children and their carers.

d) Counselling

This is an aspect where major inadequacies were highlighted in our study. There does not appear to be any formalised system for the provision of counselling and support with respect to the total care of children with epilepsy.

The literature review also highlights that even a relatively brief child centred, family focused timely intervention has the potential to reduce anxiety among parents and helps them to improve their parenting practices related to living with a child with epilepsy.

This is a major task that needs further consideration.

As a first step vulnerable families could be identified and the primary care and community services could liaise with the Psychology services and Voluntary Organisations for the provision of appropriate interventions, counselling and support.

It is recognised that this study has focused on children under the age of 11. However, it is important to recognise that older children and adolescents too face equally difficult or perhaps even worse problems. Adolescence is in itself a traumatic time when complicated by epilepsy it poses a significant challenge to not only the person but also to their carer and physicians. Transition to the adult service presents additional problems. These issues also need to be addressed in Bexley.

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QUESTIONNAIRE

MANAGEMENT OF EPILEPSY IN THE COMMUNITY

Name of Child: Sex: Male / Female

Age: DOB:

Address: (including postcode)

.....

.....

Name of GP:

Address:

.....

.....

Ethnic Origin: White / Black - African / Black - Caribbean / Black - Other / Indian / Pakistani / Bangladeshi / Chinese / Asian - Other / Other ethnic group (please specify)

What is your first language?

Seizure History:

- 1) Age at onset of epilepsy:
- 2) Classification of Epileptic Seizures:

Partial Seizures		Generalised Seizures	
a)	Simple partial - consciousness not disturbed, eg simple motor seizure	d)	Absence seizures - with 3c/s spike-wave EEG
b)	Complex partial - consciousness disturbed, eg with a sense of distortion of time or reality; such seizures used to be called 'temporal lobe' seizures.	e)	Primarily generalised tonic-clonic seizure
c)	Either simple or complex partial seizures may evolve to a secondary generalised tonic-clonic seizure	f)	Other types: Myoclonic seizures

3) **Has your child's seizure pattern changed? YES / NO**

If YES, please specify:

.....

4) **Seizure Frequency During the Last Year:**

- i) more than one/day
- ii) daily
- iii) more than one/week
- iv) weekly
- v) monthly
- vi) less than once/month **If so, how often?**

5) **How many hospital admissions with fits has your child had during the last year?**

6) **Medication:**

Is your child on medication to prevent seizures at present?

YES (go to question 7)

NO (go to question 8)

7) **If YES, please specify:**

i) **age at which medication commenced:**

ii) **drugs currently taken:**

.....

.....

iii) **Has your child ever had a blood test to check the medication levels? YES / NO**

- a) within the last 6/12
- b) 6/12 - 1 year ago
- c) 1 - 2 years ago
- d) longer than 2 years ago

8) **If NO:**

Has your child ever been on medication? YES / NO

If so, when was the medication stopped?

<1 year ago

1-2 years ago

>2 years ago (please specify)

Has he/she had any fits since stopping medication?

YES, if so how many?

NO

Epilepsy Management:

9) **Have you had any advice on the immediate management of fits at home?**

YES / NO

10) **Do you feel confident about managing your child?**

YES / NO

11) **Do you keep rectal Valium at home?**

YES / NO

12(i) **Who does your child see to monitor his/her epilepsy?
(please give the doctor's name if known)**

a) **Hospital General Paediatrician**

b) **Hospital Paediatric Neurologist**

c) **Community Paediatrician**

d) **School Doctor**

e) **General Practitioner**

If the answer to this question is your GP, has your child ever seen any of the doctors a), b), c) or d) for an assessment of his/her epilepsy?

YES If so, how long ago? (please specify)

NO

- 12(ii) **How often is he/she seen?**
- monthly
 - 1 - 3 monthly
 - 4 - 6 monthly
 - more than 6 monthly

13) **Where is your child seen to monitor his/her epilepsy?**

- a) **GP Surgery**
- b) **Hospital Clinic**
- c) **Child Development Centre**
- d) **Community Clinic**
- e) **At School**

14) **Did you seek medical help at the time of your child's first fit, ie calling out your doctor, or taking the child to the surgery or casualty?**

YES / NO

15) **How was your child's first fit managed?**

- i) **he/she was admitted to hospital**
- ii) **he/she was seen in casualty & discharged home**
- iii) **managed by the GP**
- iv) **other (please specify)**
-

16) **By whom was the initial diagnosis of epilepsy confirmed?**

- i) **Hospital Paediatric Neurologist**
- ii) **Hospital Paediatrician**
- iii) **Community Paediatrician**
- iv) **General Practitioner**
- v) **Other (please specify)**
-

17) Investigations:

Has your child ever had:

- | | | |
|------|-------------------|-----|
| i) | an EEG | YES |
| | | NO |
| ii) | a CT scan of head | YES |
| | | NO |
| iii) | an MRI scan | YES |
| | | NO |

18) Does your child have any other health problems, apart from epilepsy?

YES If so, please specify:

.....

.....

NO

Information:

19) Have you been given any information about epilepsy? Who gave it to you?

- i) friends and relatives
- ii) your GP
- iii) the health visitor
- iv) the hospital
- v) community paediatrician
- vi) The British Epilepsy Association
- vii) the library
- viii) other (please specify)

20) Have you been given any written information about epilepsy?

- a. **YES:**
 - i) at the time of diagnosis
 - ii) within 6 months of the diagnosis being made
 - iii) more than 6 months after the diagnosis was made

b. **NO:** If not, would you have found this helpful?

YES / NO

21) **Were you put in touch with the British Epilepsy Association or a local epilepsy support group?**

- YES** - at the time of diagnosis
 - within 6 months of the diagnosis
 - more than 6 months after the diagnosis
 - NO** - if **NO**, do you think that this would have been helpful?
- YES / NO**

22) **Do you feel that you have been given enough information about epilepsy?**

YES / NO

How do you rate the information you were given?

poor / fair / adequate / good / excellent

23) **Which areas would you like further discussion about? (please circle answer)**

- a) **Guidance as to what your child can or cannot do (safety, etc).**
- b) **Cause of my child's epilepsy.**
- c) **Names of drugs.**
- d) **Side effects of drugs.**
- e) **Reasons for changing drugs.**
- f) **Reasons for and results of investigations.**
- g) **Other (please state)**
.....
.....
.....

24) **Which of the following areas concern you about your child?**
(please circle answer)

- a) **Behaviour**
- b) **Concentration**
- c) **Academic progress at school**
- d) **Friendships**
- e) **Difficulties taking medication**

- f) **Safety, ie what my child can/cannot do**
- g) **The future**
- h) **Other (please state)**
.....
.....
.....
.....

FOR CHILDREN OF SCHOOL AGE

25) Is your child in mainstream education?

YES - If YES, do they have any extra help in school?:

- i) **extra small group teaching**
- ii) **an ancillary helper**
- iii) **an individual support teacher**
- iv) **other (please specify)**
- v) **none**

NO (please specify school)
.....
.....

26) Is the school aware of your child's diagnosis of epilepsy?

a. **YES (please go to question 27)**

b. **NO (please specify reason)**
.....
.....

27) Do you feel that the school is adequately informed about your child's epilepsy?

a. **YES**

b. **NO (please specify reason)**
.....
.....

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28) **Are there any restrictions on your child's activities at school?**

YES (please specify)

.....

.....

NO

29) **Has your child ever had a fit at school?**

YES / NO **If YES, how many?** : 1

: 2 - 5

: 6 - 10

: 10 - 20

: 20

30) a. **If your child needs rectal Valium, does the school keep a supply for your child?**

YES / NO

b. **To prevent fits, does your child need to take regular medication during school hours?**

YES / NO

If YES, how is this managed? (please describe below)

.....

.....

31) **What concerns, if any, do you think your child has?** (please circle answer)

a) **Worries about school work**

b) **Problems making friends**

c) **Difficulties talking to others about epilepsy**

d) **Feeling unsafe**

e) **Feeling restricted in doing things**

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- f) **Worries about taking medication**
- g) **Worried about the future**
- h) **Other (please state)**
.....
- i) **No concerns**

32) What worries do you have about your child?

- a) **Worries about school work**
- b) **Problems making friends**
- c) **Difficulties talking to others about epilepsy**
- d) **Feeling unsafe**
- e) **Feeling restricted in doing things**
- f) **Worries about taking medication**
- g) **Worries about the future**
- h) **Other (please state)**
.....
.....
.....
- i) **No concerns**

33) Have you ever felt it would be helpful to talk about any worries or concerns you have about your child with someone other than a doctor (ie nurse, psychologist)?

YES / NO

34) How satisfied are you with the overall management of your child's epilepsy?

- a) **very dissatisfied**
- b) **fairly dissatisfied**

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- c) neither satisfied nor dissatisfied
- d) fairly satisfied
- e) very satisfied

35) Do you feel that there are any ways in which the management of your child's epilepsy could be improved? eg:

- a) more information about the diagnosis
- b) more information about the drug treatment
- c) more investigation
- d) more opportunities to discuss the effect of your child's epilepsy on his/her life and on your family
- e) Other (please specify)
-

36) Do you think that a parents' support group would be helpful?

YES / NO

If YES, would you be prepared to be involved in the group?

YES / NO

37) Is there any other comment which you would like to make?

.....
.....

SIGNED: **DATE:**

NAME: *(please print in capital letters)*

RELATIONSHIP TO CHILD: *(mother, father, etc)*