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A Quality of Care Audit of Children Referred with Suspected Epilepsy to Two Hospitals in Pietermaritzburg, KwaZulu-Natal.

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A research report submitted to the Faculty of Health Sciences, Department of Community Paediatrics, University of the Witwatersrand, Johannesburg, South Africa, in partial fulfilment of the requirements for the degree of Master of Science in Medicine (Child Health Neurodevelopment Option) by Coursework.

Johannesburg, 2009

DECLARATION

I, Matilda Ntombizonke Madekurozwa, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Medicine (Child Health Neurodevelopment Option) in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

11th day of May 2009

Dedicated to all children with epilepsy and their caregivers

ABSTRACT

Introduction

Two public sector hospitals in Pietermaritzburg, KwaZulu-Natal, Edendale and Grey's have specialist clinics for children with epilepsy. Children with suspected epilepsy are referred to Edendale and Grey's hospital Paediatric Outpatient Department for their assessment from primary health care clinics, level 1 and level 2 hospitals. Health care workers managing children with suspected epilepsy do not adhere to childhood epilepsy guidelines and protocols and therefore find epilepsy a difficult condition to manage.

The purpose of this clinical audit was to assess the quality of care of children referred to Edendale and Grey's hospital with suspected epilepsy. Information obtained from this audit will be used to improve the quality and consistency of patient care and therefore reduce childhood morbidity and mortality from the complications of epilepsy among children in Area 2, KwaZulu-Natal.

Materials and Methods

The Paediatric Outpatient Department registers at Edendale and Grey's hospital were used to identify children referred with suspected epilepsy, and their case notes were retrieved. Children who met the inclusion criteria for the study were: i) those referred to the Paediatric Outpatient Department, Neurodevelopment or Epilepsy clinics for their first assessment with a diagnosis of suspected epilepsy and ii) children aged ≤ 14 years at Grey's hospital and ≤ 10 years at Edendale hospital.

Children excluded from the study were those i) with febrile convulsions; ii) who had repeat visits and iii) not referred with suspected epilepsy.

Letters from referring hospitals and patient case notes were reviewed and this information was used to fill in the audit forms. A modified British Paediatric Neurology Association audit tool was used for the study.

The study period covered was from January 1st 2004 to January 31st 2006.

Results

From the two-site audit, 232 folders were retrieved and of these 119 case notes met the inclusion criteria and were reviewed, 83 from Edendale and 36 from Grey's hospital. The median age of the patients at Edendale hospital was 4-years (age range 2-months to 10-years) at Grey's hospital the median age was 3-years (age range 8-months to 12-years). Sixty-six patients were male and fifty-three were female.

At Edendale hospital, the majority of patients, 88% were seen within a week of referral, with only 2% seen more than a month later. Of these patients, 37% were assessed by interns and 16% by paediatricians. At Grey's hospital the majority of patients were seen more than a month after booking for their first assessment and were assessed by registrars (35%), paediatricians (28%) and senior medical officers (14%), none of the patients were assessed by interns. From reviewing the history, examination, diagnosis, treatment, communication and future care it was found that the overall care of children presenting with suspected epilepsy to both hospitals was poor.

Conclusion

This was a retrospective study that relied on the availability and review of patient case notes and adequate documentation by the assessing health care workers.

The findings from this audit suggest that the quality of care of children presenting with suspected epilepsy to Edendale and Grey's hospital is inadequate, with a lack of

adherence to guidelines as shown by the lack of adequate statements from history taking, diagnosis, inappropriate use of investigations and inadequate counselling on treatment and future patient care. To improve the management of children referred with suspected epilepsy there should be an improvement in health care worker training to ensure that epilepsy guidelines are adhered to. There should also be an improvement in caregiver and child counselling and education; and strengthening of systems - record keeping, research, and audit with a regular review of epilepsy guidelines.

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NOMENCLATURE

Acronyms and abbreviations	Explanation
AED	Antiepileptic drugs
ADHD	Attention Deficit Hyperactivity Disorder
BPNA	British Paediatric Neurology Association
CDG	Care Dependency Grant
CHeRP	Child Health Electronic Resource Package
χ^2	Chi-squared
CP	Cerebral Palsy
CSE	Convulsive Status Epilepticus
CSG	Child Support Grant
CSMO	Community Service Medical Officers
CT	Computed Tomography
CWE	Children With Epilepsy
ν	Degrees of freedom
EDH	Edendale District Hospital
ECG	Electrocardiogram
EEG	Electroencephalogram
ESA	Epilepsy South Africa
GP	General Practitioners
HCW	Health Care Worker
IALCH	Inkosi Albert Luthuli Central Hospital
ILAE	International League Against Epilepsy
KZN	KwaZulu-Natal
MO	Medical Officers
MOPD	Medical Outpatient Department
MRI	Magnetic Resonance Imaging
NASA	Neurological Association of South Africa
NCD	Non-communicable disease
NGO	Non-governmental Organisation
NICE	National Institute for Clinical Excellence
P	Probability
PHC	Primary Health Care
Paed.	Paediatrician
PMO	Principal Medical Officers
POPD	Paediatric Outpatient Department
PGSES	Psychological Guidance Special Education Services
Psych.	Psychologist
Reg.	Registrar
SAMA	South African Medical Association
SMO	Senior Medical Officers
STG	Standard Treatment Guidelines
UKZN	University of KwaZulu-Natal

1 INTRODUCTION

Epilepsy (*Isifo Sokuwa or 'falling down disease'* in Zulu) is the most common neurological condition in South Africa and it affects about 1 in every 100 people (Epilepsy South Africa, 2008). Epilepsy may result in un-witnessed or less frequently witnessed sudden death and it enhances the risk of accidents, particularly drowning (Breningstall, 2001). In 2000, epilepsy was the tenth leading cause of death in South African male children aged five to nine years (1.7% of deaths), it also accounted for 3.1% of deaths among boys aged 10 to 14 years and 3.4% of deaths among girls in the same age group (Bradshaw, 2003). In KwaZulu-Natal (KZN) in 2000, 3.4% of the deaths of male children aged 5 to 14 years were related to complications of epilepsy (South African National Burden of Disease Study, 2000). The complications of childhood epilepsy include convulsive status epilepticus (CSE), one of the commonest neurological emergencies in children. The outcomes of CSE in childhood include death, behavioural problems and impaired cognition (Novorol, 2007).

Background

Epilepsy is described as "a condition characterised by recurrent seizures associated with abnormal paroxysmal neuronal discharges" (Standard Treatment Guidelines and Essential Drugs List, 2006). Epilepsy is a chronic non-communicable condition, it is neither a disease nor a disability and yet when poorly controlled is disabling (Personal communication, Social worker Epilepsy South Africa, 2006).

Common co-morbid conditions occurring in children with epilepsy (CWE) include attention deficit hyperactivity disorder (ADHD); sleep disturbances, autism spectrum

disorder, cerebral palsy (CP), behavioural and psychiatric disorders and intellectual disability; these co-morbidities are often not recognised or are under-treated (Raspall-Chaure, 2008). From a study by Molteno and Krajewski in Cape Town, epilepsy was found to be an associated complication in 28.7% of cases of intellectual disability and as the disability increased in severity, epilepsy became more frequent. Associated disabilities in CWE were cerebral palsy (46%), sensory handicaps – blindness, deafness (40%), and behavioural problems (40%) - aggression, self-injury, hyperactivity and autistic features (Molteno and Krajewski, 1997).

There are no actual figures for the number of CWE in South Africa or in KZN. Studies have however looked at the prevalence of seizure disorders and childhood epilepsy in South Africa – 9/1000 in Manguzi, KZN (Couper, 2002) and 6.7/1000 in Bushbuckridge, Limpopo province (Christianson, 2000).

Epilepsy occurs in both industrialized and developing countries. In industrialized countries the prevalence is 3-9 per 1000 population (Senanayake, 1993). In developing countries, figures vary, with studies showing annual incidence rates of up to 190 per 100 000 people in developing countries and 50-70 per 100 000 in industrialized countries (Sander, 1996). Studies from industrialized countries have shown that males tend to be affected more frequently than females, although the difference is not often statistically significant (Senanayake, 1993).

Of the estimated 50 million people in the world with epilepsy, four fifths live in developing countries and an estimated 90% of these people need treatment but do not

receive it (Scott, 2001). This is known as the treatment gap (Kale, 2002). The treatment gap is very high among children in developing countries including South Africa, with one study in Manguzi, KZN showing that up to 79% of CWE were not on any antiepileptic medication (Couper, 2002), and another study in Bushbuckridge revealing that over half of the CWE (57.1%) had never received any treatment, with more than one third of the children never taken to any type of health care service – traditional or formal (Christianson, 2000).

As a result of poor perceptions about epilepsy, CWE are often stigmatized (Global campaign against epilepsy, 2003).

1.1.1 Health care worker management of children with epilepsy

Up to 39% of children with refractory seizures are misdiagnosed by health care workers (HCW), the result of this is that a large number of children are unnecessarily treated with antiepileptic drugs (AED) and subjected to the social and psychological implications of carrying such a diagnosis (Uldall, 2006; Obeid, 2007).

HCW often do not explain to patients the mode of action and side effects of medication because of a lack of knowledge about the drugs (Personal observation as a specialist in Paediatrics at Edendale hospital). Doctors may have too many other clinical obligations (in addition to caring for CWE) and a heavy workload (Frost 2003). HCW may over treat CWE by using inappropriate drugs, by using AED in children who do not require treatment or by the use of polytherapy (when the majority

of seizures respond well to monotherapy) with an increase in side effects of the AED (Holmes, 2002).

1.1.2 Caregivers and children with epilepsy (CWE)

Patients who live far from the hospitals are difficult to follow-up in the long term and they default on their medication once their drugs have run out at home (Leary, 1973). Their caregivers lose days at work or are unable to seek employment because they care for CWE. Poor compliance by children on antiepileptic medication commonly occurs because they rely on their adult caregivers to enable them to have access to medical services and to give them their medication (Beghi, 2005).

The annual medical cost of treating newly diagnosed and established epilepsy in South Africa is not known, nor can the financial and emotional cost to parents of caring for a child with epilepsy easily be determined. As pointed out by Eastman in a review of epilepsy, the burden of epilepsy in South Africa is largely unknown but (it) is likely to be as large as that typically found in developing countries (Eastman, 2005).

The treatment of epilepsy as a chronic non-communicable condition is free, however the financial cost of managing childhood epilepsy is high when seizure control is poor (frequent hospital visits and hospitalisation), for example, the daily cost of an inpatient admission to Edendale hospital is approximately R1684.00 (Personal communication, Edendale hospital records office manager, 2008).

The cost of therapy is further increased by co-morbid conditions – as children are managed on a combination of drugs (Chisolm, 2005). Other causes of an increased cost of therapy are poor compliance with medication, seizures resistant to therapy, inappropriate investigations and inappropriate drug treatment (Beghi, 2005).
CWE come from homes with low socio-economic status and they often have financial problems. They experience difficulties with transport costs because they live far away from Primary Health Care (PHC) clinics in the rural areas; they therefore travel long distances to get their medication, which may be unavailable (Shorvon and Farmer, 2005).

The use of alternative or traditional therapy in addition to antiepileptic medication (from the formal health sector) may be an attempt by caregivers to solve these problems, as traditional healers are available and accessible to them and their children (Baskind, 2005). Traditional medicines may however compound the side effects of the antiepileptic drugs (AED). For caregivers, CWE and HCW communication problems exist because of language barriers and this, in addition to low literacy among caregivers, reduces adherence to medication (Gardiner, 2006).

1.2 Statement of the problem

Knudsen and Auk (2000) in Denmark reviewed quality of care in their epilepsy clinic and compiled a checklist list of questions. These questions act as a guide when considering the need for an epilepsy audit to evaluate and improve the service in any centre managing CWE:

i) Friendliness, dedication and experience of staff;

ii) Adequacy of basic standards of care for CWE;

iii) Satisfactory standards for the management of emergencies – e.g. convulsions and status epilepticus;

iv) Satisfactory standards for first assessment of children referred with suspected epilepsy;

v) Early referral and consideration of surgery in children with poorly controlled epilepsy;

vi) Availability of written information on epilepsy for caregivers and children;

vii) Updated, comprehensive guideline on epilepsy management;

viii) Proper case-note keeping and clerking of children presenting with suspected epilepsy;

ix) Access to a nurse educator, social worker, psychologist (clinical, educational and counselling);

x) Access to schools with staff trained and educated in epilepsy care (mainstream and special schools);

xi) POPD specialist clinic with doctors trained in childhood epilepsy management;

xii) Link with local epilepsy support organization;

xiii) Availability of a clinic for adolescents and teenagers with age-appropriate counselling;

xiv) Appropriate timing of referral for adolescents to Medical Outpatient Department (MOPD) [Knudsen and Auk, 2000].

Patients with poorly controlled seizures have to be admitted to both Edendale and Grey's hospital for seizure control and management of complications. This puts a strain on scarce resources and overworked and de-motivated HCW (personal observation as a specialist in Paediatrics).

Different caregivers come for review to the epilepsy clinics with the same child – this compounds the problems of non-compliance and lack of knowledge about the medication. Caregivers are Zulu and yet instructions are written in English on medication sachets, seizure charts and diaries. When prescription errors occur in the pharmacy, caregivers who are illiterate and not English speaking are unable to note the errors (Principal specialist IALCH, personal communication, 2008).

The AED preparations are not always available in the hospital pharmacies and are often not available at rural health centres. Small children for example need to take anti-epileptic drugs in syrup form because they are not able to swallow tablets. Control release

(CR) drugs are not available in smaller doses i.e. drug preparations are limited (Personal observation as a specialist in Paediatrics).

Anecdotally it has been observed that junior inexperienced HCW assess referred patients whose management is therefore incomplete. This occurs more often at Edendale hospital. First assessments are difficult for junior HCW who are unsure of the drugs, doses, side effects and drug interactions.

Counselling messages from HCW are different and at times inconsistent as they are not sure of the management of the condition (Personal communication with the Principal Medical Officer, Christ the King Hospital, 2008).

It is possible that the medical school curriculum has not been strengthened to place emphasis on teaching undergraduate medical students the management of seizure disorders and epilepsy. Continuing Medical Education (CME) courses in epilepsy management for HCW involved in managing epilepsy are not mandatory, and protocols and treatment guidelines on seizure management are not being adhered to despite the fact that they are available (Personal observation as a specialist in paediatrics at Edendale hospital).

Doctors tend to use the guidelines that they were taught in medical school and they may use these guidelines in their clinical practice despite the fact that Pietermaritzburg (PMB) Metropolitan Hospital complex has guidelines for epilepsy management.

There is no selected provincial guideline for use in all hospitals in KZN to ensure uniformity in the management of CWE (Personal observation as a specialist in paediatrics at Edendale hospital).

Children presenting to Edendale and Grey's hospital often have secondary or symptomatic epilepsy as a result of perinatal complications e.g. birth asphyxia; and postnatal conditions e.g. infections (meningitis, encephalitis and neurocysticercosis) as well as traumatic brain injury caused by motor vehicle accidents (Personal observation as a Specialist Paediatrician at Edendale hospital). A Western Cape study that looked at the causes of recurrent seizures in children noted a similar trend (Leary, 1988).

Children are referred to Edendale and Grey's hospital with complex epilepsies - these children have poorly controlled seizures that are difficult to manage.

The following points are based on personal observations:

1. Patients with seizures that are difficult to control are referred early to IALCH but the waiting time for the paediatric neurology clinic is long (≥ 4-months). The neurosurgical clinics at IALCH have a shorter waiting time (≤1 week).
2. Health care workers do not adequately counsel caregivers about their child's condition, management and prognosis and the caregivers as a result do not know their child's medication, dose or dose schedule.
3. At Edendale hospital there is no written information (booklets, pamphlets or posters) on childhood epilepsy available for caregivers.

4. There is no database at Edendale or Greys hospital with patient names, hospital numbers, current medication, review dates and financial resources [sources of income, care dependency grant (CDG), child support grant (CSG) applications].

5. There is no epilepsy research and there are no clinical audits conducted to monitor and evaluate the quality of health services for, and care of CWE at the two hospitals.

6. Support services for CWE are not well coordinated at Edendale and Grey's. Paediatric consultants responsible for epilepsy care at the two hospitals rarely consult on patient management.

7. Edendale and Grey's hospitals do not have a team of HCW dedicated specifically to childhood epilepsy management.

8. The referral system for CWE to supporting services and step down clinics and hospitals does not work efficiently.

Community support by social workers is not adequate and social workers have a large workload (too many patients and other responsibilities), they tend to focus on client education and not on counselling (Personal communication with Social worker Epilepsy South Africa, 2007).

Epilepsy South Africa (ESA), KZN Midlands is a non-governmental organisation dedicated to working with and supporting people with epilepsy. It offers advice and information, counselling and employment, training, residential care, education and literature, representation and encourages self-help programmes and works closely with

individuals and organisations carrying out research into aspects of epilepsy. It also liases with the Departments of Child Welfare, Mental Health, KZN Blind and Deaf South Africa and Psychological Guidance Special Education Service (PGSES) (Epilepsy South Africa, 2008).

1.3 Justification for the study

Improving the quality of care of CWE is in line with the South African Government Health Sector Strategic Framework (1999-2004) that aims to ensure the provision of specialized care to patients who need it.

The strategic framework objectives are to ensure that: i) hospital services are equitably accessible to patients; ii) the care of patients is provided for at the level of facility most appropriate to the level of care needed; iii) there is the promotion of a clear and efficient referral system to hospital clinics; iv) hospital services for patients are planned rationally and delivered in line with modern, efficient, cost-effective and caring practices; v) the services for patients are sustainable and affordable, and that long-term funding for the services are available; vi) planning choices are made as explicit as possible – by consulting with caregivers about the quality and type of service they expect from HCW.

Improving health services for CWE is in line with the Millennium Development goals. Goal 4 (target 5 and health indicators 13 and 14) aims to reduce childhood mortality. (Millennium Development Goals, 2000).

Legislation for children with chronic non-communicable conditions (i.e. vulnerable children) is enshrined in South Africa's constitution Sections 8 (8.1 and 8.3) and 9 (9.3) of the Constitution of South Africa deal with equality. Legislation relevant to and promoting the rights of children with chronic conditions (including epilepsy) and disabilities are as follows:

1. The Children's Act 38 of 2005 – section 11 (1, 2 and 3) relates to the rights of a child with a disability or chronic condition and refers to support for caregivers.
2. The Children's Act 38 of 2005 – section 13 relates to the rights of a child to have access to information on their health care and includes information on the rights of a child with a disability (Constitution of South Africa 2005).

The management of CWE should be based on clinical guidelines and there must be basic standards of care for these children to improve the quality and consistency of their care, and reduce morbidity and mortality from the complications of epilepsy. A quality of care audit for childhood epilepsy had not been done in the Pietermaritzburg Metropolitan Hospitals Complex. The eventual aim of the study was to identify specific problem areas and weaknesses in order to improve the care of CWE so that there is consistency, adherence to guidelines, a proper and thorough patient assessment, investigations, treatment, and a clear follow-up plan.

1.4 Literature Review

The principle benefit of clinical guidelines is to improve the quality of care received by patients, specifically an improvement in health outcomes i.e. a reduction in morbidity and mortality and an improvement in the consistency of care i.e. patients are cared for in the same manner regardless of where or by whom they are treated (Woolf, 1999).

Quality of health care is defined as "the degree of excellence of health care activities in relation to the present level of knowledge and technological development" (Foundation for professional development handbook, 2007).

There are several written guidelines for the management of epilepsy in developing countries including South Africa. These guidelines specify the standards of care for the management of the child with epilepsy.

The Standard Treatment guidelines (STG) of South Africa (Essential Drugs Programme, 2006), define epilepsy; explain the pathogenesis; state the diagnostic criteria on which a diagnosis of epilepsy is made (clinical and investigations); classify seizures into generalised seizures, partial seizures and epileptic syndromes; note the referral criteria and treatment objectives for CWE. They divide epilepsy management into non-drug and drug treatment and also have notes on patient education and follow-up. This is the guideline selected for use in this study. The standard treatment guidelines have no audit tool and the BPNA audit tool has been adopted and modified for use in this study. The STG and National Institute for Clinical Excellence (NICE) guidelines are similar but an audit tool should ideally be devised and based on the STG.

An epilepsy guideline was written by the Neurological Association of South Africa (NASA) and endorsed by the South African Medical Association (SAMA) for primary health care level of CWE. Section 11 of this guideline describes the standards of care for the management of CWE. It classifies the childhood epilepsies and explains the influence of age on epilepsy with respect to the presentation, outcome and metabolism of AED. The guideline also explains the causes and treatment of the common clinical epilepsy syndromes in neonates, infancy, early childhood, childhood and adolescence and gives details on the differential diagnoses and the management of the childhood epilepsies, the mechanisms of action of anti-epileptic drugs, the use of a ketogenic diet, special investigations and when to refer patients with epilepsy for further management to level two and three hospitals (Neurological Association of South Africa, 2000).

Paediatric consultants in the Department of Paediatrics and Child Health developed a six-step guideline on 'Managing Epilepsy'. This guideline has information on the classification, diagnosis and differential diagnoses of epilepsy, causes of seizures, associated problems, treatment, follow-up and future care of CWE (Child Health Resource Package, 2005).

Very few quality of care audits have been performed. The three epilepsy audits using the tool to be used in this study were carried out in the United Kingdom. The first of these audits was done in 1998 when an advisory group in the UK drew up and validated the audit tool that was used by the BPNA who carried out a national audit. The study was observational and retrospective; its objective was to determine whether or not a set of

predetermined criteria was being met when assessing children referred with suspected epilepsy on their first outpatient visit. Only a small number of centres (three) participated and only a few audit forms (fifty) were returned by these centres for analysis, in addition the audit cycle was not completed (by later repeating the audit in the participating centres) and so it was difficult to draw meaningful conclusions from the audit (Appleton, 1998).

In 2000, Mar et al used the BPNA audit tool to compare service delivery in two clinics, a Seizure Clinic (SC) and a General Paediatric Clinic (GPC). The study was conducted retrospectively in a large Regional Children's hospital and at a District General Hospital in Birmingham, the United Kingdom. The findings were that the SC better documented the history and description of seizure episode; it was also more likely to define the seizure type and epilepsy syndrome compared to the GC. It was found in this study that the audit tool does have limitations e.g. it relies on documentation as evidence of occurrence (if the assessing health care worker has not written down their findings from the patient assessment, the assumption is that the relevant questions were not asked or that the examination was incomplete) and it does not take into account other sources of information e.g. nursing records, patient held records or inpatient notes. Its advantages are that it is brief, simple and easy to use (Mar, 2005).

The third audit using the BPNA audit tool was carried out in Nottingham City region in the UK between January 2001 and March 2002. Only 147 children met the inclusion criteria, a number of children's case notes could not be found, documentation was poor, some of the questions in the tool were found to be subjective and it was thought that the

tool did not assess the process sufficiently to be clear as to whether the diagnosis and management were appropriate for each child. As a result of this study improvements are being made with regard to the quality of documentation and clinical assessment, diagnosis, investigation, epilepsy service provision and consideration is also being given to the development of an improved or 'ideal' audit tool (Dunkley et al, 2005).

In one of the earliest two-period (1992-93 and 1994-95) paediatric epilepsy audits at Southampton General Hospital, basic standards for the process of childhood epilepsy care were identified and used. The selected standards were the quality of correspondence when referring patients, health care professional prescribing practices, the use of drug monitoring, MRI and CT scans and the quality of EEG requests. An assessment was also made of parental satisfaction with health care professional communication, clinic visits and clinical staff courtesy.

The findings were that recording by referring health care professionals on frequency of seizures; children's school performance and parental advice on the side effects of drugs were inadequate. There was also parental dissatisfaction with information provided by health care professionals about epilepsy (Webb et al, 1998).

Factors affecting the implementation of good practice guidelines for epilepsy care among health care professionals were looked at in a study carried out in England and the findings were that some good initiatives in clinical practice were being implemented. Some of these were use of a fast track/first seizure clinic to reduce the time to first assessment for new patients, patient access to information, links with other HCW (e.g.

occupational therapy, social worker, psychologist) and training and professional development (Frost et al, 2003).

Stewart et al (1998) in an audit carried out in the South Tees area, UK looked at the knowledge caregivers of CWE have about childhood epilepsy and its management. They concluded from their study that aspects of management in CWE with poor seizure control needed to be improved on and these were: i) on teaching caregivers about safety issues for example first aid measures; ii) ensuring that caregivers and CWE are knowledgeable about the condition and that they express their concerns and needs to HCW when reviewed in the epilepsy clinics; iii) ensuring that there are specialist (dedicated) epilepsy clinics for CWE with patient and caregiver support groups; iv) ensuring the dissemination of written information on childhood epilepsy treatment including the side effects of drugs; v) ensuring support and guidance for families of CWE from local and national epilepsy support groups and specialist epilepsy nurses who would also liase with medical staff; vi) ensuring increased awareness among school staff on CWE abilities and needs so that their children's activities are not limited by the condition.

1.5 Aims and objectives

1.5.1 Overall aim

The aim of the study was to audit the quality of care of children referred with suspected epilepsy to two hospitals in Pietermaritzburg.

1.5.2 Specific objectives

1. To identify the number, age and sex of children referred with suspected epilepsy to Edendale and Grey's hospitals over a two-year period.
2. To determine the time from referral to first assessment at the hospitals.
3. To determine the referral pattern by HCW.
4. To identify the location of first assessments by HCW.
5. To identify the assessing HCW at the hospitals.
6. To review the management of the referred patients.

2 MATERIALS AND METHODS

This section describes the study design, setting and population. It outlines the study criteria, audit tool and sources of bias.

2.1 Study design

This was a retrospective folder review that involved assessing patient case notes and referral letters and filling in an audit questionnaire.

2.2 Study setting

The study was carried out in Pietermaritzburg, KwaZulu-Natal.

KZN on the east coast of South Africa is the third smallest and most populous province with a population, of approximately 9 426 017 people (Census 2001). The province notably has high levels of unemployment and poverty (South African National Burden of Disease Study, 2000). In 2001 there were 2 255 982 people with various forms of disability in the country. KZN had the highest number of disabled people by province, 470 588 and had a prevalence of reported disability of 6.7% from the National disability survey (CASE 1999) and 5.0% according to the 2001 Census.

The city of Pietermaritzburg in Umgungundlovu district (DC 22, Area 2) is in the midlands of KZN. It is the administrative capital and has a population of approximately 966 360 people (DHIS estimate, July 2005). Its' catchment population is approximately 3.5 million people, 1.3 million of these being children.

Umgungundlovu district has 48 fixed clinics, 12 mobile clinics, four community health centres, and nine hospitals. Of the nine hospitals Appelsbosch, Montebello and Northdale are district hospitals; Edendale is a district-regional hospital (that offers services to Umgungundlovu district and parts of Sisonke, Umzinyathi and Ethekwini); Fort Napier,

Townhill and Umgeni are specialized psychiatric hospitals; Doris Goodwin is a specialised tuberculosis hospital and Grey's is a regional-tertiary hospital. (Umgungundlovu district brochure, 2005).

2.3 Study population

Paediatric public sector hospital services in Pietermaritzburg are metropolitan and are based at three sites (figure 2.1) – Greys (level 3, regional-tertiary), Edendale (level 2, regional-district) and Northdale (level 1, district).

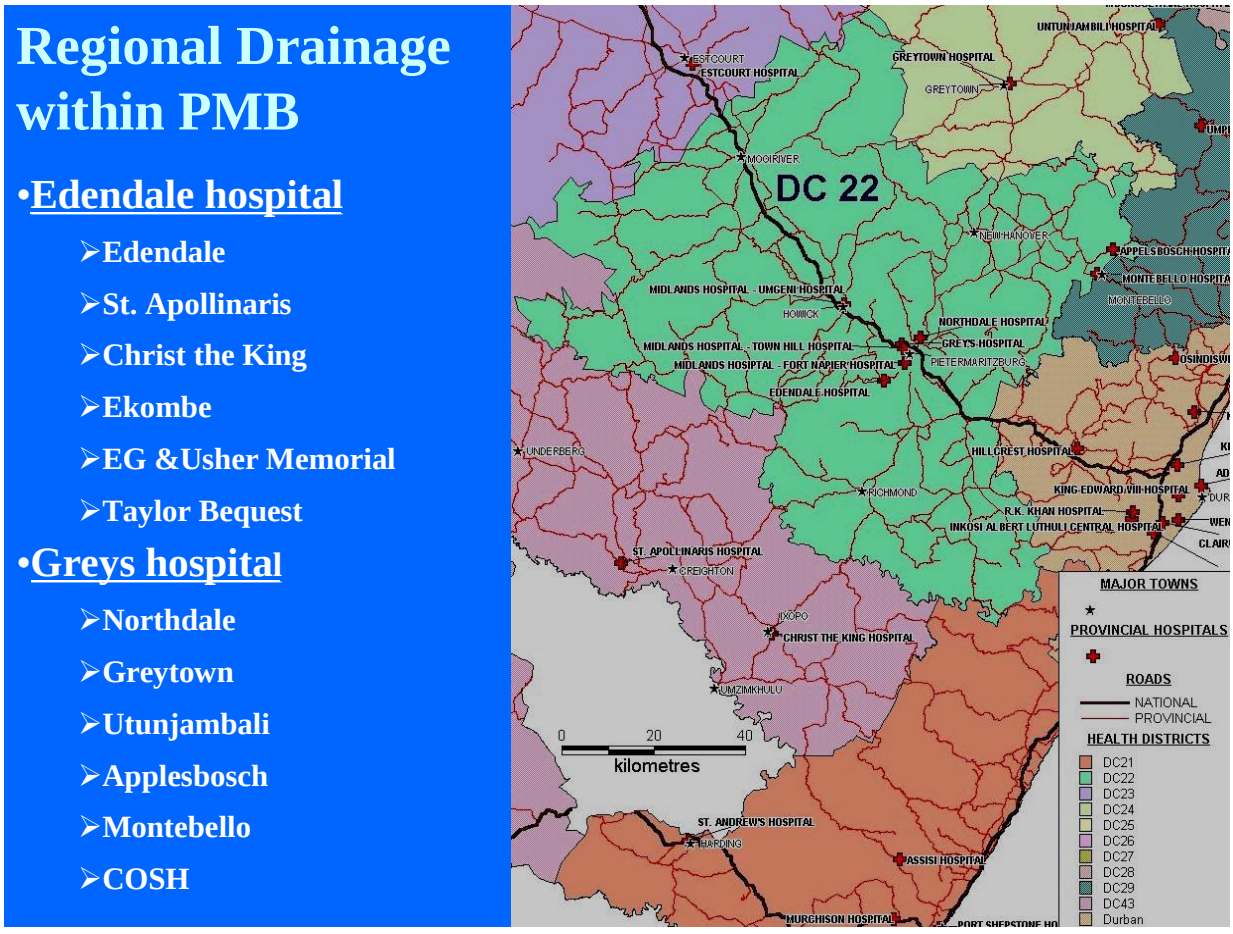


Figure 2.1 Level 1 and 2 hospitals in Area 2 (DC22), KZN referring patients to Edendale and Grey's hospitals (Edendale hospital presentation by MH Broughton, 2006).

The audit was carried out at two public sector hospitals – Edendale and Grey's. These two hospitals were selected as sites for the study because they are the only hospitals in the district that run specialist clinics for CWE. The weekly specialist clinics at Grey's and Edendale hospitals are run by paediatric consultants with an interest in epilepsy, registrars, medical officers (MO), and occasionally by interns. At the time of the study, Edendale hospital attended to children up to the age of ten years and Grey's hospital to children up to 14-years-old.

The children coming to the epilepsy clinics are referrals from local clinics and hospitals within the district and province. Children needing an assessment from a Paediatric Neurologist are referred to IALCH in Durban.

The study period covered was from January 1st 2004 to January 31st 2006.
The researcher carried out the allocated tasks (figure 2.2). The paediatric outpatient department registers were used to identify children listed with the diagnosis *'Epilepsy'* at Edendale and Grey's hospital. The case notes were then collected from the records office. The notes were separated for those children who had come in for their first assessment and met the study inclusion criteria and those who did not. The case notes and referral letters were reviewed and the audit tool questionnaires were completed. The audit data was captured using *Microsoft Excel* and analysed using the *Chi-squared* test.

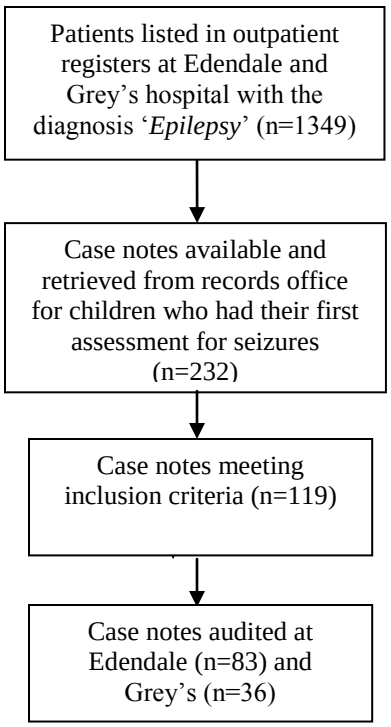


Figure 2.2 Allocation of tasks in the quality of care audit.

2.4 Criteria for the study

Inclusion criteria for the study were children with seizures who were:

1. Referred to the POPD, Neurodevelopment or Epilepsy clinics.
2. Coming for their first visit.
3. Coming in with a diagnosis of suspected epilepsy.
4. Aged ≤ 14 years at Grey's hospital and ≤ 10 years at Edendale hospital.

The exclusion criteria for the study were as follows:

1. Children diagnosed with febrile convulsions.
2. Children making repeat visits to the clinic, having been previously assessed for epilepsy or a seizure disorder.
3. Children referred without a diagnosis of epilepsy or suspected epilepsy.

2.5 The audit tool

Permission to use the audit tool was granted by Drs C Dunkley and W. Whitehouse of the BPNA (Appendix G). The audit tool explanatory notes are in Appendix A and the audit tool questionnaire is in Appendix B.

2.6 Bias

Anticipated problems and potential sources of bias were the following:

1) Missing, incomplete, inadequate and poor records. The records at Edendale hospital and Grey's hospital are incomplete because of a heavy patient load, the Records Office is not computerized and finding the case notes was difficult, notes were often misplaced or lost, and the patient registers from where the case note hospital numbers are retrieved were badly kept and torn.

2) Poor documentation by doctors assessing the children on their first assessment.

3) The age difference between patients recruited at Grey's and those recruited from Edendale Hospital.

2.7 Ethical clearance

Ethical approval for this study was applied for and granted by the Ethics Committees at Edendale and Grey's hospital and from the Human Research Ethics Committee (Medical) at the University of the Witwatersrand (Appendices D, E and F).

2.8 Risks and benefits

No animal or human subjects were involved in the study and all information collected was confidential. The names, addresses and hospital numbers of the patients were not recorded on the questionnaires.

2.9 Sample size

Two hundred and thirty-two case notes were found and reviewed from both hospitals and of these 83 met the inclusion criteria at Edendale hospital and 36 were reviewed at Grey's hospital.

2.10 Feasibility study

A feasibility study was carried out once clearance from the Postgraduate Committee at University of the Witwatersrand and ethical approval from the Ethics Committees at Wits University and the two hospitals had been obtained. A two-month audit of case notes at one site, Edendale hospital was then conducted.

3 RESULTS

This section gives details on the results of the audit. It describes the demographics of the study population; time from referral to first assessment, referring and assessing health care workers, location of first assessment and patient management.

3.1 Age and sex of patients

In total there were 1349 patients listed in the Paediatric Outpatient registers with the diagnosis *'Epilepsy'*, 729 patients at Edendale and 620 at Grey's. Two hundred and thirty-two case notes were retrieved from the outpatient's record offices at both hospitals of patients who had been referred for their first assessment. Of these files, one hundred and nineteen patient case notes were reviewed that were complete, adequate and met the inclusion criteria for the study. Of these case notes, eighty-three were from Edendale and thirty-six from Grey's hospital. Sixty-six patients were male and fifty-three patients were female.

Of the patient files reviewed at Edendale hospital, forty-six patients referred to the clinics for first assessment were male (55%) and 37 (45%) were female (figure 3.1; appendix C, table C1). The median age of the patients was 4-years (age range 2-months to 10-years).

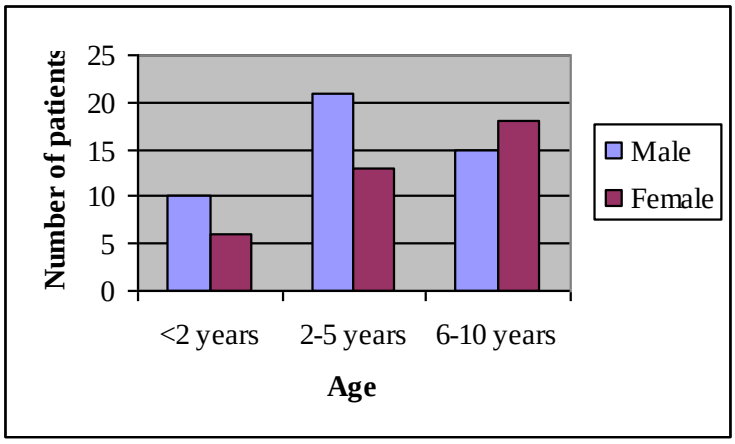


Figure 3.1 Age and sex of patients referred for first assessment to Edendale hospital

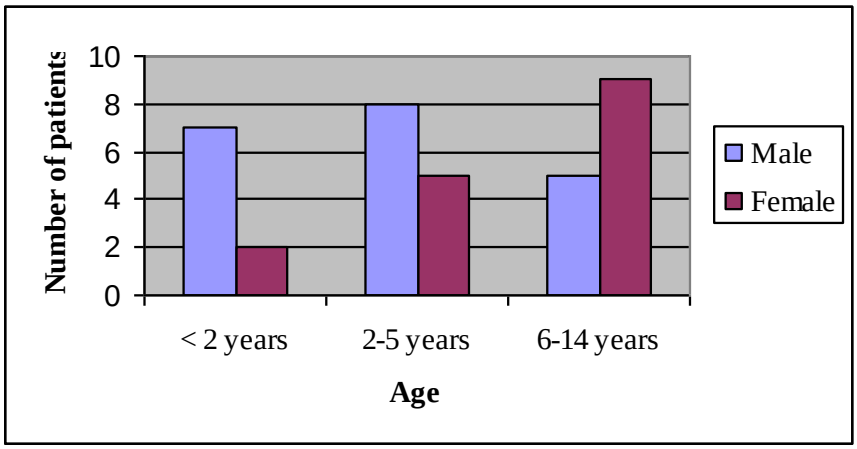


Figure 3.2 Age and sex of patients referred for first assessment to Grey's hospital

Of the patient case notes reviewed at Grey's hospital, twenty patients referred to the clinics for first assessment were male (56%) and 16 (44%) were female (figure 3.2; appendix C, table C2). The median age of the patients was 3-years (age range 8-months to 12-years).

3.2 Time from referral to first assessment

As shown in figure 3.3 (Appendix C, table C3), seventy-three patients (88%) at Edendale hospital were seen within a week of referral, 2 patients (2.4%) were seen more than a month later. Information was not available for one patient.

At Grey's hospital, eleven patients (31%) were seen less than a week after booking for an assessment; thirteen (36%) were seen more than a month after booking. The time to first assessment from referral was not available for four patients (11%).

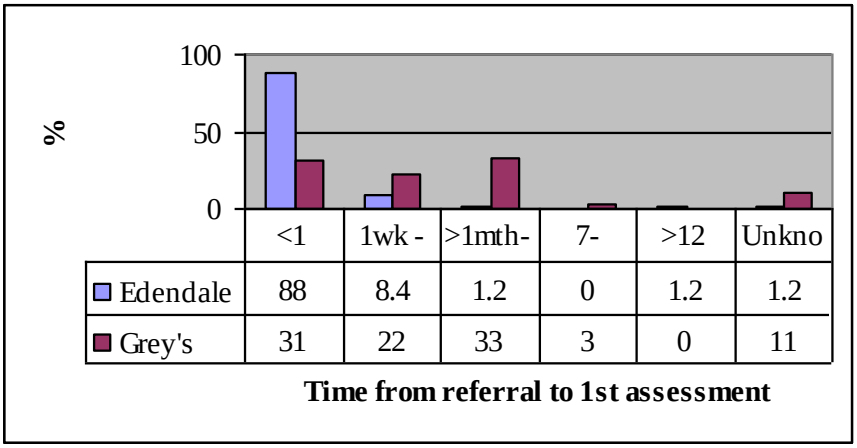


Figure 3.3 Time from referral to first assessment - Edendale and Grey's hospitals

3.3 Health care workers referring patients for first assessment

At Edendale hospital (Figure 3.4; Appendix C, table C4), of the patients referred for first assessment, 41 children (49%) were sent to the hospital by PHC clinic nurses and 12% by MO. One patient had been seen and referred to Edendale by a Paediatrician and in 25% of the cases, the referring HCW could not be determined because of missing or poor quality of the referral letters.

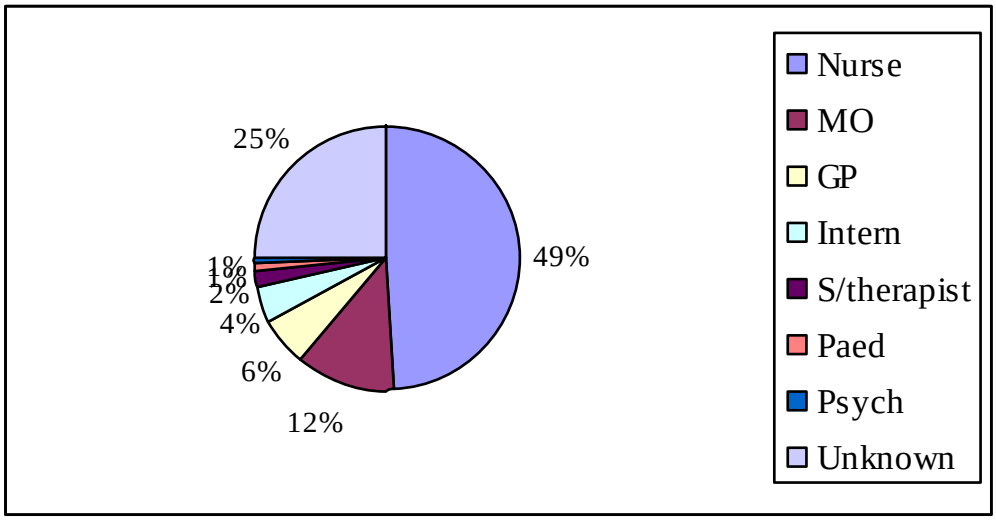


Figure 3.4 Health care workers referring patients for first assessment to Edendale hospital

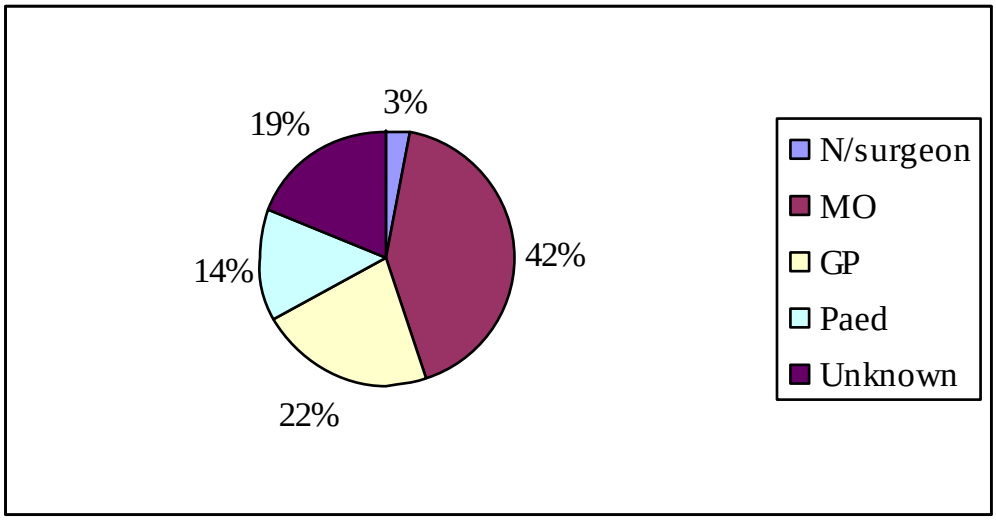


Figure 3.5 Health care workers referring patients for first assessment to Grey's hospital

At Grey's hospital (Figure 3.5; Appendix C, table C5) 42% percent of HCW referrals were from MO, 22% from GP and in 19% the source of the referrals was unknown as the referral letters were either absent or illegible.

3.4 Location of first assessments

The location of first assessments was similar at both hospitals, at Edendale, sixty-five children were seen in POPD (78%), 15 (18%) in the Epilepsy clinic and three (4%) in the neurodevelopment clinic. At Grey's twenty children (56%) were seen in the neurodevelopment clinic (because this is a regional-tertiary hospital and these patients are referred in for a specialist assessment); ten (28%) in the Epilepsy clinic, five (14%) children were seen in POPD, and one (3%) in a general clinic.

3.5 Health care workers performing first assessments

At Edendale hospital, 13 patients (16%) were seen by a Paediatrician - either a General Paediatrician or one with an interest in epilepsy, 12 (15%) were seen by a PMO or CSMO, with the majority of patients being assessed by interns, 32 (39%) as shown in figure 3.6 (Appendix C, table C6).

Eighteen patients (22%) were never assessed by a paediatrician, despite being reviewed at Edendale hospital on subsequent visits.

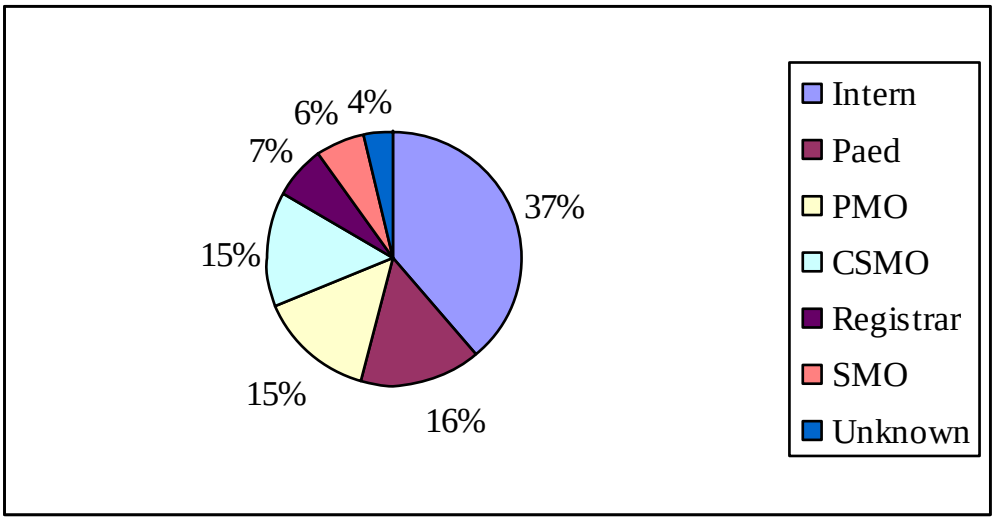


Figure 3.6 Health care professionals performing first assessments at Edendale hospital

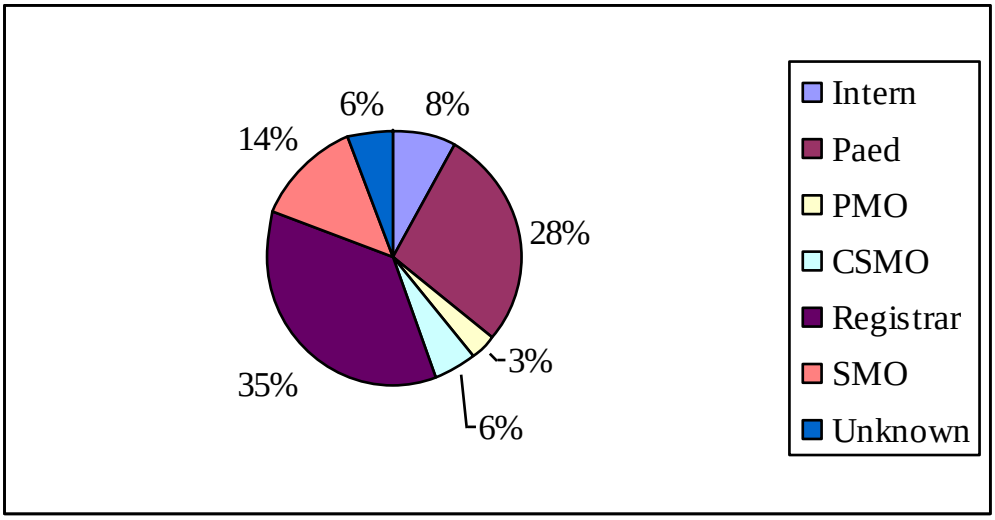


Fig 3.7 Health care professionals performing first assessments at Grey's hospital

At Grey's hospital (Figure 3.7; Appendix C, table C6), a paediatrician assessed ten (28%) of the patients; the majority of patients, 13 (35%) were assessed by registrars, three 8% by interns, and two 6% by CSMO.

In summary, at Edendale hospital, the majority of patients were referred by nurses from PHC clinics and assessed by interns and medical officers (CSMO and PMO) within one week of referral. At Grey's hospital, most children were referred from MO, GP and paediatricians. They were assessed by registrars and paediatricians and had their first assessment more than a month after being referred.

3.6 History and examination

Table 3.8 'Yes' history and examination statements at Edendale and Grey's hospitals

Statement describing	Edendale	Grey's
a. Age at onset of episode(s) *no. (%)*	57 (69)	23 (64)
b. Sequence of events during episode(s) *no. (%)*	42 (51)	16 (44)
c. Duration of each type of episode *no. (%)*	35 (42)	13 (36)
d. The frequency of the episode(s) *no. (%)*	42 (51)	17 (47)
e. The presence or absence of any provoking or relieving factors/circumstances *no. (%)*	16 (19)	11 (31)
f. History obtained from an eyewitness *no. (%)*	10 (12)	3 (8)
g. Presence or absence of a family history of epilepsy *no. (%)*	28 (34)	10 (28)
h. Presence or absence of a relevant past medical history *no. (%)*	34 (41)	26 (72)
i. Child's physical and neurological examination *no. (%)*	53 (64)	32 (89)
j. Child's neurodevelopment assessment *no. (%)*	13 (16)	22 (61)

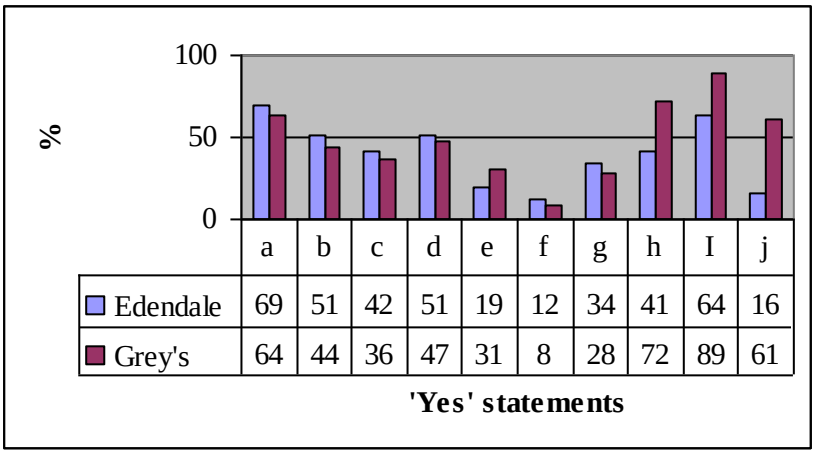


Figure 3.8 History and examination statements at Edendale and Grey's hospital

At Edendale hospital (Table 3.8; figure 3.8), best-recorded statements were the age at onset of the seizures, and information on the child's physical and neurological examination. The most poorly recorded statements were the presence or absence of any provoking or relieving factors/circumstances; history obtained from an eyewitness and the child's neuro-developmental assessment.

At Grey's hospital (Table 3.8; figure 3.8), well-recorded statements were the age at onset of seizures, presence or absence of a relevant past medical history, child's physical and neurological examination, and the child's neurodevelopment assessment.
Poorly recorded statements were the sequence of events during episode(s), the duration of each type of episode, the frequency of the episode(s), the presence or absence of any provoking or relieving factors/circumstances, whether or not the history obtained from an eyewitness, and the presence or absence of a family history of epilepsy.

3.7 Diagnosis

3.7.1 Edendale hospital

Of the patients assessed, in sixty-eight cases (82%) the episodes were considered to be epileptic, all sixty-eight children had more than one episode, none were diagnosed as non-epileptic and fifteen (18%) were diagnosed as uncertain (Appendix C, table C7). Of those diagnosed as epileptic, eight children (12%) had a single seizure or isolated cluster of seizures; in seven (10%) it was not known whether it was single or an isolated cluster. The seizure type was identified in 31 patients (37%), 22 (71%) had generalized seizures; nine patients (29%) had partial seizures. Of those diagnosed as uncertain, nine had no differential diagnosis, two were diagnosed as cerebral palsy, one with poor concentration, and one with syncope, one with postoperative seizures, and one with intellectual disability.

The stated seizure types were recognized in International League against Epilepsy (ILAE) classifications in only three cases.

An epilepsy syndrome (category diagnosis) was made in three cases (4%) - temporal lobe epilepsy in one patient and idiopathic epilepsy in two cases.

In 13 patients (19%) a statement was made concerning an underlying cause for the epilepsy in all these the cause was stated as being symptomatic - seven birth asphyxiated, three head injured, one with hydrocephalus, one with a history of prematurity, and one post surgical. In only 14 patients (21%) was there a statement about a cause for the epilepsy.

Only eleven files (16%) recorded the child's development. Forty-seven patients were of school going age, but only five had a statement on their current school performance.

3.7.2 Grey's hospital

Of the patients assessed, thirty-three (97%) were diagnosed with epilepsy; three (8%) were diagnosed as uncertain (Appendix C, table C7). Of the patients diagnosed with epilepsy, all the children had more than one episode of seizures. The seizure type was identified in 18 patients (54%), nine of the 18 had generalized seizures and the rest had partial seizures. Of those diagnosed as uncertain the only differential diagnosis was '*seizures'*. The stated seizure types were recognized in ILAE classifications in only one case where an epilepsy syndrome (category diagnosis) was made of primary generalised epilepsy. In twelve patients (36%) a statement was made concerning an underlying cause for the epilepsy. In all these the cause was stated as being symptomatic (10 had birth asphyxia; in two patients no cause was given). In 24 patients (73%) no statement concerning a cause for the epilepsy was made.

Eighteen cases (50%) had no statement on the child's development in the first two years of life. Fourteen patients (39%) were of school going age, but only one child had a statement on current school performance.

3.8 Investigations

Table 3.9 Patient investigations at Edendale and Grey's hospitals

Investigation	**Edendale (n=83)**	**Grey's (n=36)**
EEG requested *no. (%)*	37 (45)	22 (61)
CT scan requested *no. (%)*	23 (28)	20(56)
ECG requested *no. (%)*	2 (2)	1(3)

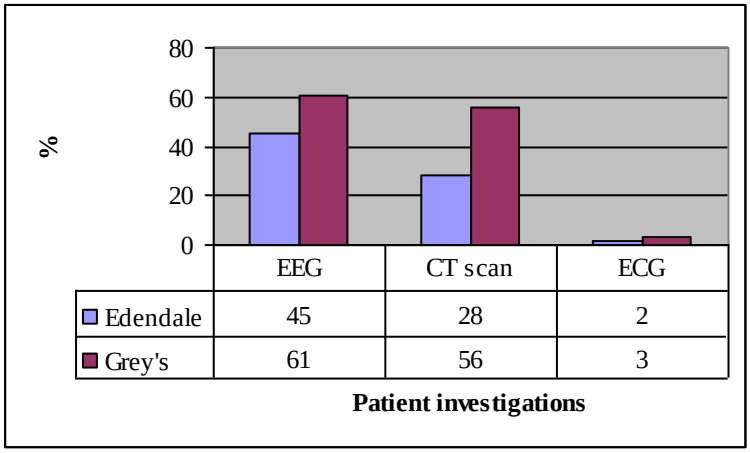


Figure 3.9 Patient investigations at Edendale and Grey's hospital

Requests for EEG and CT scan were higher at Grey's hospital; few patients had requests for an ECG at both hospitals (Table 3.9; figure 3.9).

At Edendale other investigations requested were as follows:

Bloods (including glucose, calcium, magnesium, phosphate, urea, electrolytes, full blood count, and liver function tests) were requested in eight patients, one patient had a drug level request, two had a chest X-ray, two had an MRI and one had an ophthalmology consult.

In sixty-nine patients there was no record of any other investigations or assessments.

At Grey's other investigations requested were as follows:

Bloods (including glucose, calcium, magnesium, phosphate, urea, electrolytes, full blood count and liver function tests) were requested in ten patients, hearing and (or) a visual assessment in four patients and a drug level in one patient.

3.9 Treatment

At Edendale hospital (Table 3.10; figure 3.10) well-recorded statements were on current treatment (82%), dose of drugs (100%), and weight of the child recorded (95%), poorly recorded statements were on possible adverse effects (3%) and written dose schedule given to parent, carer or child (3%).

Table 3.10 'Yes' Statements on drug treatment at Edendale and Grey's hospital

Statements on	**Edendale (n=83)**	**Grey's (n=36)**
a. Current treatment *no. (%)*	68(82)	30(85)
b. Dose or doses of drug(s) *no. (%)*	68(100)	29(83)
c. Weight of the child recorded *no. (%)*	79(95)	32(89)
d. Possible adverse effects *no. (%)*	2(3)	1(3)
e. Written dose schedule given to parent, carer or child *no. (%)*	2(3)	1(3)

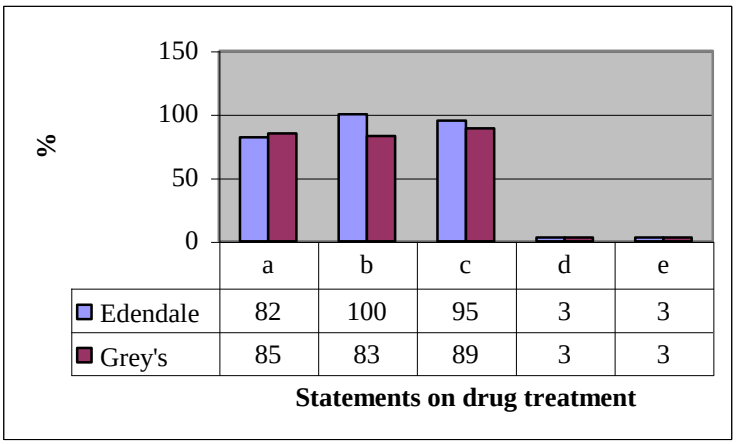


Figure 3.10 Statements on drug treatment at Edendale and Grey's hospital

At Grey's hospital (Table 3.10; figure 3.10), well-recorded statements were on patient's current treatment (85%); dose of drugs (83%) and the child's weight (89%). Poorly recorded statements were on advice to carers on possible adverse effects (3%) and no written dose schedule being given to carers (3%).

3.10 Communication and future care

At Edendale hospital (Appendix C, table C8), none of the patient notes had statements on acute seizure management; activities and safety issues; contraception and pregnancy; death in epilepsy; opportunity for the child to be seen alone; referral to epilepsy support group/association; copy of clinic letter to parents or epilepsy information leaflets. Of the 47 patients of school going age, only two (4%) had statements concerning communication with the child's school. Eighty patients (96%) notes had statements on who was responsible for their follow-up.

At Grey's hospital (Appendix C; table C9) ninety-seven percent of the case notes had no statements on acute seizure management, activities and safety issues and communication

with child's school. None of the case notes reviewed had statements on contraception and pregnancy, death in epilepsy, opportunity for the child to be seen alone, referral to an epilepsy support group/association, copy of letter or epilepsy information leaflets being given to the parents/caregiver. One patient had no note on who was responsible for patient follow up.

4 DISCUSSION

This was an observational study and there was therefore no control over the final number of case notes audited. The POPD registers at Edendale and Grey's hospitals listed 1349 patients with the diagnosis '*Epilepsy'*. This figure includes new and review patients. Of these case notes only two hundred and thirty-two case notes were found and after assessing these notes only119 met the study inclusion criteria; the rest (113) had seizure disorders or various other diagnoses (e.g. meningitis, encephalitis, and hypoglycaemia). Therefore information was only obtained from about a fifth of the study group and this affected the accuracy of the results. Only 83 case notes were found at Edendale hospital, and 36 at Grey's. The sample size here does however represent one that is comparable to published audits using this tool. Dunkley et al., (2005) using the BPNA audit tool reviewed 210 case notes out of 263 and had 147 case notes meeting their inclusion criteria.

4.1 Age and sex of patients

At the time of the audit the mean age of the children seen at the two hospitals was similar, despite the fact that Edendale hospital only saw patients up to the age of 10-years and Grey's up to 14-years. This accounts for the difference in the upper limit of the age range of the patients seen in the study, ten years for Edendale and twelve years for Grey's hospital. The majority of the children seen at both hospitals were male and they tended to be younger than the female patients. This was similar to findings from other studies done in South Africa that profiled seizure disorders in children (Leary, 1988; Leary, 1999; Christianson, 2000).

4.2 Time from referral to first assessment

Patients referred to Edendale hospital were seen earlier than those referred to Grey's. As Grey's hospital is regional-tertiary, patients referred to specialist outpatient clinics are booked. At Edendale however patients are either booked for the specialist clinics or are assessed in POPD. As a result first assessments are more likely to be done on the day of or soon after referral by junior staff in POPD. Time from referral for children should ideally be as short as possible with first assessments done by senior staff, preferably by a paediatric neurologist or paediatrician with training in epilepsy management, however this is not viable or practical in resource poor settings in public sector hospitals. Guidelines and recommendations on referrals should be implemented in order to improve the management of CWE especially urgent cases that need early assessment e.g. seizure onset <2 years, associated developmental regression or prolonged recurrent seizures.

In order to support quality improvement initiatives in KZN, patient waiting-time is one of the provincial indicators for improving access by patients to health care (KZN DOH policy document n.d.). However, there is no provincial hospital standard for time from referral to first assessment for children referred for outpatient assessments. The United Kingdom NICE guidelines recommend that a specialist in epilepsy management should see all children who have had a first non-febrile seizure as soon as possible so that the diagnosis is made early and appropriate therapy is commenced (NICE guidelines, 2004). In a review article that detailed recommendations and implications of the NICE guidelines, Dunkley and Cross (2006) noted that the first assessment in an outpatient

setting for a patient with a first non-febrile seizure should be urgent and this is defined as occurring within two weeks.

In an audit of general practice and hospital-based care (Hanna, et al., 2002) it was noted that the majority of patients were seen within one week of referral from GP but there was a delay (between one and six months) by GP in referring them for assessment. From their audit, which included adults, up to 15% of the patients had to wait more than six months for a specialist assessment.

The time from referral to first assessment is important because:

i) Children who have been misdiagnosed with epilepsy, in whom epilepsy is an uncertain diagnosis, or who are not responding to treatment can be referred for reassessment by a paediatric neurologist or by a paediatrician trained in or with an interest in epilepsy management.

ii) Children not referred early for an assessment may develop complications e.g. convulsive status epilepticus.

Long waiting times may also lead to inappropriate health seeking behaviour by caregivers; this also has implications in South Africa where support for health care workers managing difficult paediatric cases at PHC clinics and hospitals are limited.

It would therefore be appropriate to communicate with a specialist before the first assessment is made at the hospitals in order to improve patient care - referring clinics and hospitals are able to initiate appropriate management with guided support from paediatricians at Edendale and Grey's hospitals.

4.3 Health care workers referring patients for first assessment

The majority of referrals to Edendale hospital were primary referrals from PHC clinic nurses, this is because Edendale is a regional-district hospital, and patients referred to Grey's were secondary referrals from other hospitals. Patients were therefore assessed later (by appointment) at Grey's; this was not the case at Edendale hospital.

The unknown referrals were because of missing or illegible referral letters in the case notes; from these referral letters it was not possible to determine whether the referring doctors were CSMO, PMO or SMO.

Another limitation of the audit was that it was not possible to determine if the referrals to hospital were appropriate, the Standard Treatment Guidelines, (2006) cite the reasons for referral of a child with a seizure disorder for assessment.

4.4 Location of first assessments

First assessments are made in POPD because specialist clinics run on specific days of the week, in addition patients present after hours. At Edendale hospital, patients were seen on presentation after referral, and therefore the location of the first assessments was in POPD, whilst at Grey's hospital the patients were seen in specialist outpatient clinics.

4.5 Health care workers performing first assessments

The access to clinicians was faster at Edendale hospital but the level of the assessment was influenced by the more junior inexperienced staff. The recommendation is that better training, supervision and enforcement of guidelines be implemented.

4.6 History and examination

The history, assessment and patient management were better at Grey's hospital, a reflection of the assessments being made by more senior and experienced staff.

At both hospitals, well-recorded statements from the history were the age at onset of the episodes (69% at Edendale and 64% at Grey's hospital) and the child's physical and neurological examination (Edendale 64% and Grey's 89%).

In comparison to the BPNA audit standards these assessments would be considered to be poorly done. Dunkley et.al. (2005), noted two areas of weakness and these were the presence or absence of any provoking or relieving factors (64%) and the child's early neurological development (74%).

At Grey's the past medical history (72%) and neurodevelopmental assessment (61%) were better recorded compared to Edendale, but were still not well recorded. This may be a reflection as cited previously of the assessments being made by more senior staff (registrars and paediatric consultants).

At both hospitals the history obtained from an eyewitness was poorly recorded (12% at Edendale and 8% at Grey's), and at Edendale the neurodevelopmental assessment was poorly recorded (16%) although it is possible that the information was obtained and that the assessments were done but not recorded.

As noted previously, the eyewitness account of a seizure disorder is important as conditions that mimic seizures may be overlooked (e.g. syncope or sleep disorders) and the epilepsy misdiagnosis rate may therefore increase. In addition, an absent neurodevelopmental assessment may result in incomplete patient management as other associated problems and co-morbid conditions may be missed. A comparison could not

be made with the BPNA audits as the question on neurodevelopment was added on as a modification to the tool. If history taking is inadequate or incomplete, the diagnosis of a seizure disorder becomes more difficult, it is also difficult to classify and manage the seizures appropriately.

4.7 Diagnosis

At Edendale hospital, the majority of children assessed were considered to be epileptic (82%), with 18% diagnosed uncertain, a similar finding at Grey's where the majority were diagnosed with epilepsy, 92% with 8% uncertain. This figure compares with those cited in the study by Appleton et.al. (1998), with 90% of cases diagnosed epileptic and 10% diagnosed uncertain. However one of the principle concerns with such a high proportion of patients being diagnosed epileptic is the possible high rate of misdiagnosis. This makes a re-audit in a year's time crucial so that the patient notes can be reviewed (Dunkley et.al. 2005). The large number of patients diagnosed as epileptic at Edendale hospital may be a result of junior staff carrying out first assessments on children. The diagnosis of epilepsy in the recruited patients was therefore not certain.

At both hospitals the seizure type was not well documented – only 31% at Edendale hospital and 50% at Grey's hospital. The slightly higher figure at Grey's may be a reflection of the assessments being done by more senior doctors.

In only 21% of the patients at Edendale was an underlying cause for the epilepsy documented, compared to 36% at Grey's hospital (although the smaller sample size at Grey's makes a comparison with Edendale difficult). All these patients had secondary

(symptomatic seizures). In only 4% of cases at Edendale hospital and one case at Grey's hospital was an epilepsy syndrome (category diagnosis) made. This was also noted in the study by Hughes and Appleton (1995), where epilepsy syndromes were not frequently used in seizure classification. This may be a reflection of inexperienced, junior staff assessing patients.

4.8 Investigations

It is difficult to assess the appropriateness of other investigations done at both hospitals. From the results of investigations requested at Edendale, requests for blood tests by the assessing doctors may reflect that children were referred with poorly controlled seizures. The investigations done at Grey's – a higher number of requests for EEG and CT scan/MRI may indicate both more experienced staff performing the assessments and easier access to the investigations. The appropriateness of the investigations could not be determined; in addition the audit did not assess how these investigations influenced patient management. However, according to the Standard Treatment Guidelines (2006), an EEG, must only be done a week after a convulsive episode, and the indication is only in children with recurrent or syndromic seizures where the diagnosis cannot be made on clinical grounds alone. The indications for a CT scan/MRI are:

i) An unknown cause for a Glasgow Coma Scale that is persistently low <12/15;

ii) Raised intracranial pressure;

iii) Suspected focal intracranial pathology (STG, 2006).

4.9 Treatment

Patient weight was very well recorded (95% at Edendale and 89% at Grey's hospital), as were the doses of the drugs (100% at Edendale and 83% at Grey's hospital) and current treatment (82% at Edendale and 85% at Grey's hospital). Poorly recorded statements were possible adverse effects and a written schedule given to the caregiver (3% at both Edendale and Grey's hospital). These low figures imply that the information was neither obtained nor was any information imparted to the patients and this may result in poor adherence to medication due to AED side effects. HCW may be unaware of the implications of not informing caregivers about possible side effects and not explaining drug doses to patients.

It was not possible to determine the appropriateness of treatment; it would be useful to know which drugs were prescribed and whether or not they were appropriate. As cited in the audit by Appleton (1998), from the BPNA audit form the number of children given a different drug at first assessment could not be determined and as a result determining the amount of information caregivers were given on side effects of prescribed AED could not be done.

4.10 Communication and future care

Patients assessed at the hospitals were young and it was there not appropriate to discuss contraception and pregnancy with caregivers, or to ask if the child could be seen alone. However communication with caregivers was poor, as important issues (e.g. advice on acute seizure management, activities, safety and schooling) were not discussed.

A lack of communication with caregivers has a negative impact on patient compliance and adherence to medication. From Appleton's audit (1998) only 24% of patients were informed about a voluntary epilepsy supporting organization.

4.11 Problems encountered

i) Missing case notes:

It was difficult to find the case notes, and as the filing system was being changed at Edendale hospital. There was no cross-referencing done when case numbers changed to *date-of-birth* in the records office, outpatient register information was therefore not useful and important information was lost during the audit.

ii) Illegible signatures and transcription errors:

It was difficult to identify which doctors saw patients during their first assessments as often their signatures were not legible and they did not print their name or designation. The handwriting was often difficult to read in the outpatient registers and transcription errors for case note numbers and patient names were made, as a result the researcher could not find case notes for some patients. Staff in POPD inaccurately entered or at times forgot to enter the assessing doctor's names in the outpatient register. Some patients in the outpatient register had no diagnosis recorded (they may have had epilepsy) and as a result their case notes were not audited.

iii) Lost notes and poor record keeping:

Patients were recorded with the diagnosis '*Epilepsy'* in the outpatient registers when they actually had a different diagnosis e.g. febrile seizures or a movement disorder. This resulted in many case notes needing to be pulled out of the records office unnecessarily -

a time-consuming process. Junior staff (interns and MOs) had assessed these patients and were probably unclear about the definition of epilepsy.

The audit tool was not difficult to use but as there was only one researcher, filling in the questionnaires was time-consuming. It would have been useful to have another researcher to check and correlate the information collected from the case notes.

At Edendale hospital some patients were noted to have more than one case note number depending on how many times their notes had been lost in the record office.

Patients were listed in the Grey's hospital outpatient registers by initial and surname only, common names appeared the same and it was difficult to decide whether or not case notes had already been audited.

The records office staff members were unable to find a large number of the patient case notes, at Grey's only 36 were found that met the study inclusion criteria.

4.12 CONCLUSION

The findings from this audit indicate that the quality of care of children presenting with suspected epilepsy to Edendale and Grey's hospital is inadequate, with a lack of adherence to guidelines as shown by the lack of adequate statements from history taking, diagnosis, inappropriate use of investigations and inadequate counselling on treatment and future patient care. To improve the management of children referred with suspected epilepsy there should be an improvement in health care worker training to ensure that epilepsy guidelines are adhered to. There should also be an improvement in caregiver and

child counselling and education; and strengthening of systems - record keeping, research, and audit with a regular review of epilepsy guidelines.

As this audit was retrospective, it relied heavily on good record keeping and this was inadequate at both hospitals. For a meaningful assessment and then comparison on quality of care to be made, an adequate number of case notes need to be reviewed. The findings from this epilepsy audit have implications for allocation of resources and improvements with patient care as well as the training of HCW. Despite the audit tool limitations and poor record keeping, the management of patients at both hospitals was poor. The results of the audit will be presented to hospital management at Edendale and Grey's as well as to the Pietermaritzburg Metropolitan Hospitals Department of Paediatrics and Child Health so that improvements in care can be made and the audit repeated in a year.

5 RECOMMENDATIONS

HCW should receive adequate training in childhood epilepsy management to ensure their use of and adherence to protocols and standard treatment guidelines for the care of CWE. In-service training courses for health care professionals in level one, two and three hospitals for the management of children with seizure disorders and epilepsy should be mandatory, affordable and available. New staff should be recruited, appointed, in-service trained and educated in epilepsy management. This should ensure a subsequent reduction in children with poorly managed and uncontrolled epilepsy.

There should ideally be one guideline selected for use in all hospitals throughout KZN province to ensure uniformity in the management of CWE and seizure disorders.
Childhood epilepsy guidelines should be on the intranet and all wards. There should in addition be protocols on different aspects of patient care for example on how and when patients should step-down to level one and two hospitals, the referral criteria for further assessments, and subsequent review dates for patients.
Referrals must have legible letters with detailed patient management, the reason for transfer clearly stated and explained to caregivers.

Ideally first assessments should only be done by paediatric consultants. If first assessments are done by senior staff including PMO and registrars this must be under the guidance of a consultant. All patients should be regularly reassessed and reviewed by paediatric consultants and there should be an in house referral protocol from junior staff to consultants.
All referred children with suspected epilepsy should have a completed intake form with their history; examination, diagnosis, investigation, treatment, communication (counselling) and future care with relevant comments. This will ensure that there is a subsequent reduction in the percentage of children with poorly managed epilepsy.
There has to be regular monitoring, evaluation and auditing of patients with complete first assessments done.

Caregiver support groups need to be formed and other HCW should be actively involved in caregiver support and education. Psychosocial services need to be

improved to ensure that the referral system for CWE to supporting services and step down clinics and hospitals works efficiently.

Other HCW must be involved in childhood epilepsy management, nurse educators need to be appointed to support and assist with the counselling and education of caregivers of CWE. In addition, coordination and improvement of services for CWE have to include psychological and psychosocial support and care from psychologists, child psychiatrists and social workers with input from occupational therapists, physiotherapists, speech therapists and counsellors.

There needs to be improved cooperation between the department of health and NGOs – Epilepsy South Africa, Mental Health Society, Blind and Deaf Association - to improve social support, education and counselling of caregivers and children.

There also needs to be regular monitoring, follow-up and recording of the number of children with active epilepsy receiving AED treatment and adhering to medication.

There should be participation in epilepsy research and regular clinical audits need to be conducted - to monitor and evaluate the quality of health services for, and care of CWE. There has to be regular ongoing clinical auditing of the quality care of CWE and also epilepsy research in the department of Paediatrics and Child Health so that improvements in the service are monitored over time. The case notes for in and outpatients must easily be found and accessible. There must be a reduction in the percentage of 'lost notes' in the records office at Edendale and Grey's hospitals.

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APPENDIX A: Instructions for the use of the modified BPNA audit tool for first clinic attendance of children referred with suspected epilepsy to Edendale and Grey's hospitals.

A.1 General points

- This questionnaire has been developed by the BPNA audit group to allow assessment and comparison of epilepsy services. It is adapted from the previous audit tool used as part of a national audit in the UK published in 1998.
- The top "tear off" section is for local data that uniquely identifies the patient. This can be removed and retained by the local team. This allows anonymization should data be analysed elsewhere.
- The questions should be answered by referring to the clinic letter and relevant entry in the notes. Information entered at subsequent visits should not be considered for this "first assessment form". If relevant data is included in the referral letter then this can be recorded as positive evidence.
- Just because this audit asks a question does not mean that it is implying that the particular practice is appropriate in each situation, e.g. discussion of death in epilepsy. Some questions are only of interest in those with a diagnosis of epilepsy.

A.2 Specific points

Audit no. The 1st 3 digits/letters should identify your base for the audit, e.g. EDH for Edendale District Hospital or GYH for Grey's Hospital; the next digits should be generated locally as consecutive forms completed 001-999. The same number should appear on both sections of the audit questionnaire. This number will uniquely identify each patient within the audit and link the 2 questionnaire sections.

k One or more individuals may be involved with assessment, e.g. Senior Medical Officer (SMO) supervised by a Consultant.

l,m,n Inclusion criteria questions. If these questions are not answered 'yes' then the patient does not meet the inclusion criteria for this audit.

2e If there is evidence that seizure types have been considered but have been diagnosed as unclassified then answer 'yes'.

2g Refer to table 3 (Engel J, 2001). If there is evidence that syndromes have been considered but diagnosed as unclassified then answer 'yes'

2j Refer to table 4 (Engel J, 2001)

4a If the patient was not on drug treatment tick 'N/A' = Not applicable

4d If a new drug was not started tick 'N/A'

5e If the family have refused this option then this should still be answered 'yes'

6a This question should be answered 'yes' if there is documentation that the child has been discharged.

A.3 Outcomes

A number of other parameters can be obtained from the information collected:

- Time to appointment from referral
- In those diagnosed as having an epilepsy who was the most senior person involved in the assessment
- Percentage of children, in whom the diagnosis was uncertain, referred for EEG
- Percentage of children, in whom the diagnosis was non-epileptic, referred for EEG
- Percentage of children, in whom epilepsy was diagnosed, referred for EEG

A.4 Modifications to the audit tool

Specific points:

- Use of the first three digits/letters to identify the audit base GYH and EDH.
- The lettering has been altered, it starts with 'k' and 'j' has been left out.
- SHO has been altered to SMO.
- "Expertise as defined by BPNA was left out.
- 2g, 2j, 3a, 3d, 5h and 6b from the epilepsy questionnaire have been left out.
- 4b has been changed from dose expressed in mg/kg to weight of the child.

APPENDIX B: Audit of first clinic attendance of children referred with suspected epilepsy (Dunkley/Whitehouse 2004)

Audit number		Referring clinic	
Hospital		Date of referral	
Consultant's name		Patient code	

.....

Audit of First Clinic Attendance of Children Referred with suspected epilepsy

a) Consultant		f)Date of referral?	
b) Audit no.		g) Date first appt offered?	
c) Audit base		h) Date attended?	
d) Date of birth			

e) Sex Male□ Female□
i) Who made the referral? Paed□ GP□ MO□ CSMO□ Nurse□ Other□
j) Where was the child assessed? Epilepsy clinic□ Neurodev clinic□ POPD□
k) Which person(s) carried out the assessment? Paed□ CMO□ PMO□ SMO□ CSMO□ Reg□ Intern□
l) Was epilepsy considered a possibility by the referrer or the assessor? Yes□ No□
m) Was this a new patient referral? Yes□ No□
n) Was this the first assessment for this problem? Yes□ No□

1. HISTORY AND EXAMINATION

Was there a statement describing:
1a) The age at onset of the episode(s)? Yes□ No□
1b) The sequence of events during the episode(s)? Yes□ No□
1c) The duration of each type of episode? Yes□ No□
1d) The frequency of the episode(s)? Yes□ No□
1e) The presence or absence of any provoking or relieving factors/circumstances? Yes□ No□
1f) Whether or not the history was obtained from an eyewitness? Yes□ No□
1g) The presence or absence of a family history of epilepsy? Yes□ No□
1h) The presence or absence of a relevant past medical history? Yes□ No□
1i) The child's physical and neurological examination? Yes□ No□
1j) The child's neurodevelopment assessment? Yes□ No□

2. DIAGNOSIS

2a) Was there a statement on whether the episode(s) were considered to be:
Epileptic□ Non-epileptic□ Uncertain□
2b) If 'non-epileptic' what diagnosis was made?
2c) If 'uncertain' what differential diagnosis was made

2d) Was it a single episode or isolated cluster (confined to 24h) of episodes? Yes□ No□ Not known□

Axis 1-2

If the episode(s) were diagnosed as epileptic seizures:

2e) Was the seizure type(s) identified? Yes□ No□

2f) What are they?

Axis 3

2g) Was an epilepsy syndrome or category diagnosis made? Yes□ No□

2h) What was the name of any epilepsy syndrome or category diagnosis made?

Axis 4

2i) Was there a statement made concerning an underlying cause for the epilepsy? Yes□ No□

2j) If 'Yes' was it Symptomatic□ Cryptogenic/probably symptomatic□ Idiopathic□

2k) If symptomatic what was the underlying diagnosis?

Axis 5

2l) Was there a statement on the child's development in the first 2 years of life? Yes□ No□

2m) If of school age was there a statement on current school performance and progress? Yes□ No□

3. INVESTIGATION

3a) Was an EEG either requested or already available? Yes□ No□

3b) Was a CT scan head either requested or already available? Yes□ No□

3c) Was an ECG either requested or already available? Yes□ No□

3d) What other investigations were requested?

4. TREATMENT

Was there a statement on or record of:

4a) The current anti-epileptic drug treatment whether prescribed previously or initiated at this visit? Yes□ No□

4b) The dose or doses of these antiepileptic drugs? Yes□ No□ N/A□

4c) The weight of the child? Yes□ No□

If a new epileptic drug was prescribed, was there a statement on:

4d) Possible adverse effects? Yes□ No□ N/A□

4e) Whether a written drug dosage schedule was given to the parent, carer or child? Yes□ No□ N/A□

5. <u>COMMUNICATION</u>

Was there a statement:

5a) Concerning a discussion regarding the acute management of a seizure? Yes□ No□

5b) Concerning a discussion regarding activities and safety issues? Yes□ No□

5c) Concerning issues related to contraception and pregnancy? Yes□ No□

5d) Concerning the risk of death in epilepsy? Yes□ No□

5e) Concerning opportunity given for the child/young person to be seen alone? Yes□ No□

5f) On whether the family were informed of the existence of a local or national voluntary epilepsy association? Yes□ No□

g) On whether a copy of the clinic letter was sent or given to the parents? Yes□ No□

h) On whether epilepsy information leaflets were given to the family? Yes□ No□

i) Concerning communication with the child's school? Yes□ No□

6. <u>FUTURE CARE:</u>

Was there a statement on:

Who is to be responsible for the continuing follow-up? Yes□ No□

7. <u>COMMENTS:</u>

APPENDIX C: Tabulated results and *Chi-squared* analyses

Table C1 Age and sex of patients referred for first assessment to Edendale hospital (n=83)

Age	**Male**	**Female**	**Total**
<2 years	10	6	**16**
2-5 years	21	13	**34**
6-10 years	15	18	**33**
Total	**46**	**37**	**83**

χ^2- calculated = 2.23 (χ^2 - tabulated = 5.991); $\nu = 2$; $p > 0.05$

Table C2 Age and sex of patients referred for first assessment to Grey's hospital (n=36)

Age	**Male**	**Female**	**Total**
<2 years	7	2	**9**
2-5 years	8	5	**13**
6-14 years	5	9	**14**
Total	**20**	**16**	**36**

χ^2 - calculated = 4.26 (χ^2 - tabulated = 5.991); $\nu = 2$; $p > 0.05$

Null hypothesis – Age in patients referred to Edendale and Grey's for first assessment is not associated with gender.

Accepted: There is no association between age and gender in patients referred for first assessment to Edendale and Grey's hospital.

Table C3 Time from referral to first assessment at Edendale and Grey's hospital

Time to first assessment	**Number of patients Edendale hospital (n=83)**	**Number of patients Grey's hospital (n=36)**	**Total**
< 1week *no. (%)*	73 (88.0)	11(31.0)	**84**
1 week to 1 month *no. (%)*	7 (8.4)	8 (22.0)	**15**
>1 month *no. (%)*	2 (2.4)	13 (36.1)	**15**
Unknown *no. (%)*	1 (1.2)	4 (11.0)	**5**
Total	**83**	**36**	**119**

χ^2 - calculated = 44.1(χ^2 - tabulated = 7.815); $\nu = 3$; $p < 0.05$

Null hypothesis: There is no difference in time from referral to first assessment at Edendale and Grey's hospital.

Rejected: Time to first assessment from referral is not the same for the two hospitals i.e. it is significantly different.

Table C4 Health care workers referring patients for first assessment to Edendale hospital

Referring health care worker	**Number of children (n=83)**
Nurse *no. (%)*	41 (49)
Medical officer *no. (%)*	10 (12)
General practitioner *no. (%)*	5 (6)
Intern *no. (%)*	3 (4)
Speech therapist *no. (%)*	2 (2)
Paediatrician *no. (%)*	1 (1)
Psychologist *no. (%)*	1 (1)
Unknown *no. (%)*	20 (25)

Table C5 Health care workers referring patients for first assessment to Grey's hospital

Referring health care worker	**Number of children (n=36)**
Neurosurgeon *no. (%)*	1(3)
Medical officer *no. (%)*	15(42)
General practitioner *no. (%)*	8(22)
Paediatrician *no. (%)*	5(14)
Unknown *no. (%)*	7(19)

Table C6 Health care workers performing first assessments at Edendale and Grey's hospital

Health care worker	**Number of children at Edendale (n=83)**	**Number of children at Grey's (n=36)**
Intern *no. (%)*	32(39)	3(8)
Paediatrician *no. (%)*	13(16)	10(28)
PMO *no. (%)*	12(15)	1(3)
CSMO *no. (%)*	12(15)	2(5.5)
Registrar *no. (%)*	6(7)	13(36)
SMO *no. (%)*	5(6)	5(14)
Unknown *no. (%)*	3(4)	2(5.5)

χ^2 - calculated = 29.9 (χ^2 - tabulated = 12.592); $\nu = 6$; $p < 0.05$

Null hypothesis: There is no association between the two hospitals and which health care workers perform first assessments.

Rejected: There is an association between the hospital (location) and which health care workers perform first assessments on patients.

Table C7 Statements on patient diagnoses at Edendale and Grey's hospital

Diagnosis	**Edendale (n=83)**	**Greys (n=36)**	**Total**
Epileptic *no. %*	68 (81.9)	33 (91.7)	**101**
Non-epileptic *no. %*	0 (0)	0 (0)	**0**
Uncertain *no. %*	15 (18.1)	3 (8.3)	**18**
Total	**83**	**36**	**119**

χ^2 - calculated = 1.85 (χ^2 - tabulated = 5.991); $\nu = 2$; $p > 0.05$

Null hypothesis: There is no association between hospital (location) and patient diagnosis at first assessment.

Accepted: There is no association between Edendale and Grey's hospital and patient diagnosis at first assessment.

Table C8 Statements on communication and future care at Edendale hospital

Statement	Yes	No
a. Acute seizure management *no. (%)*	0 (0)	83 (100)
b. Activities and safety issues *no. (%)*	0 (0)	83 (100)
c. Contraception and pregnancy *no. (%)*	0 (0)	83 (100)
d. Death in epilepsy *no. (%)*	0 (0)	83 (100)
e. Opportunity for child to be seen alone *no. (%)*	0 (0)	83 (100)
f. Referral to epilepsy support group/association *no. (%)*	0 (0)	83 (100)
g. Copy of clinic letter to parents *no. (%)*	0 (0)	83 (100)
h. Epilepsy information leaflets *no. (%)*	0 (0)	83 (100)
i. Communication with child's school *no. (%)*	2 (2)	81 (98)
j. Follow-up *no. (%)*	34 (41)	49 (59)

Table C9 Statements on communication and future care at Grey's hospital

Statement	**Yes**	**No**
a. Acute seizure management *no. (%)*	1 (3)	35 (97)
b. Activities and safety issues *no. (%)*	1 (3)	35 (97)
c. Contraception and pregnancy *no. (%)*	0 (0)	36 (100)
d. Death in epilepsy *no. (%)*	0 (0)	36 (100)
e. Opportunity for child to be seen alone *no. (%)*	0 (0)	36 (100)
f. Referral to epilepsy support group/association *no. (%)*	0 (0)	36 (100)
g. Copy of clinic letter to parents *no. (%)*	0 (0)	36 (100)
h. Epilepsy information leaflets *no. (%)*	0 (0)	36 (100)
i. Communication with child's school *no. (%)*	1 (3)	35 (97)
j. Follow-up *no. (%)*	35 (97)	1 (3)

APPENDIX D: Copy of letter from Ethics Committee at Edendale hospital

HEALTH
KwaZulu-Natal

Edendale Hospital
Private Bag X 509, Plessislaer, 3216
Tel.: 033 395 4040, Fax: 033 395 4060
Email.:heather.findlay@kznhealth.gov.za
www.kznhealth.gov.za

OFFICE OF THE HOSPITAL MANAGER

Enquiries : Rowena Dawood
Tel No.: 033 395 4040
Date: 27.09.06

Dr MN Madekurozwa
C/o Department of Paediatrics

Re: Request for permission to undertake a quality of care audit of children referred with suspected epilepsy to two hospitals in Pietermaritzburg, KwaZulu Natal.

I refer to your request regarding the above; your proposal was placed before the research committee on 27th September, 2006.

The decision of the committee was that approval be granted, provided that the name, outpatient number and address of the patient be removed from Appendix 2. The committee was of the opinion that these details were not relevant to the audit, and breach confidentiality.

However, if you wish to keep your own personal record of such details for cross-reference, this would be in order.

The research committee wishes your well with your study.

Thank you.

MS H.M. FINDLAY
HOSPITAL MANAGER

APPENDIX E: Copy of letter from Ethics Committee at Grey's hospital

HEALTH
KwaZulu-Natal

PIETERMARITZBURG DEPARTMENT OF INTERNAL MEDICINE
Private bag X9001
PIETERMARITZBURG
3201
Tel: 033 - 8973290 Fax: 033 - 8973409
Email: jim.muller@kznhealth.gov.za
Internet: www.kznhealth.gov.za/medicine.htm

Madekurozwa2Nov06/Fjm

30 November 2006

Research Ethics Committee
University of the Witwatersrand
Johannesburg

Re: Quality of Care Audit on Epilepsy – Dr Matilda Madekurozwa

The Greys Hospital Ethics Committee has considered Dr Madekurozwa's response to concerns raised about her proposal for an Audit of the Management of Epilepsy in Children at Greys Hospital and Edendale Hospital in Pietermaritzburg.

The Committee is satisfied with Dr Madekurozwa's response, but wished to make one further recommendation. The Committee suggested that Dr Madekurozwa consider using an anonymised, individualised coding system for her audit, and not using the hospital folder numbers as she proposes.

Subject to this condition, the Committee is satisfied for Dr Madekurozwa to go ahead with her study.

Dr FJ Muller FRCPC
Chair of Ethics Committee

Dr KB Bilenge
Acting Hospital Manager

APPENDIX F: Copy of clearance certificate from Human Research Ethics Committee

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Madekurozwa

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M060938**
PROJECT	A Quality of Care Audit of Children Referred with Suspected Epilepsy to Two Hospitals in Pietermaritzburg, KZN
INVESTIGATORS	Dr MN Madekurozwa
DEPARTMENT	Community Paediatrics
DATE CONSIDERED	06.09.29
DECISION OF THE COMMITTEE*	APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 06.12.11 **CHAIRPERSON** .....
(Professors PE Cleaton-Jones, A Dhai, M Vorster, C Feldman, A Woodiwiss)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr N McKerrow

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/~~We~~ fully understand the conditions under which I am/~~we~~ are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/~~we~~ undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G: Approval for use of BPNA audit tool

From: Colin Dunkley [c.dunkley@virgin.net]
Sent: 14 August 2006 02:55 PM
To: Matilda Madekurozwa
Cc: William Whitehouse
Subject: Re: Epilepsy Audit

Dear Matilda

You may of course use our tool. We have designed it specifically with reference to NICE and SIGN recommendations. I have attached the full questionnaire/tool as used in the current regional audit and a poster demonstrating the data we produced from it (From ILAE UK Chapter, Belfast 2005). In my experience it is worth being very clear about inclusion criteria and we have opted to include children with seizure or seizures whether or not they turn out to be recurrent or epileptic. The tool can be applied to other cohorts however.

Clearly I would be grateful if myself (Dr Colin Dunkley), William P Whitehouse and the BPNA Audit Group could be acknowledged/referenced if the tool is used.

Interested to hear of your experience with tool and results. Let me know if I can be of any more help...

Best wishes

Colin

From: William Whitehouse [William.Whitehouse@nottingham.ac.uk]
Sent: 31 August 2006 04:45 PM
To: tillym@mweb.co.za
Cc: c.dunkley@virgin.net
Subject: Sorry

Sorry

Have lost your email. I remember it sounded good. Just acknowledge the BPNA in any communications please.

Can you send me and Colin Dunkley another copy of your email? (sorry)

bw

William

This message has been checked for viruses but the contents of an attachment
may still contain software viruses, which could damage your computer system:
you are advised to perform your own checks. Email communications with the
University of Nottingham may be monitored as permitted by UK legislation.

Dear Colin

This is good, if you agree, can you reply that we would be delighted, and can they just reference it in any presentations and papers they produce using it?

bw

wm

PS keep her contact details in case we want to collaborate in future.

>>> "Matilda Madekurozwa" <tillym@mweb.co.za> 12/08/2006 16:26 >>>

This message has been checked for viruses but the contents of an attachment may still contain software viruses, which could damage your computer system: you are advised to perform your own checks. Email communications with the University of Nottingham may be monitored as permitted by UK legislation.

From: Colin Dunkley [c.dunkley@virgin.net]
Sent: 03 September 2006 10:21 AM
To: Matilda Madekurozwa
Cc: William Whitehouse (E-mail); William Whitehouse
Subject: Re: Re: Epilepsy Audit

Hi Matilda

There have been several changes in the audit tool over the years as it has developed. This has been essentially to make sure we collect sufficient data to describe the cohort properly and also to adjust to published guidelines. The data collected by the tool is quite extensive. This does however allow the user to interrogate the dataset to meet their own needs.

There are problems with the tool however. The tool has been designed principally to allow retrospective casenote analysis as this is often practically easier to achieve. Particularly when auditing communication it is difficult to conclude whether something has been communicated or just not documented (improving documentation is an important outcome aim though).
Also there is no system of independently verifying any diagnoses etc being made by the clinicians involved. Again this was not included for practical reasons. This means that when auditing whether management is appropriate etc for a given child you can only assess whether the management was appropriate given the diagnoses made. (i.e it is looking for internal consistency rather than any absolute/independent measure of quality).
I included the poster to demonstrate to you the actual standards/parameters we chose as 'meaningful'
I would be more than happy to discuss any aspect with you further and am very pleased to hear that you feel it may be of some use to you. Good luck

Best wishes

Colin Dunkley