DEVELOPING A NURSE-LED EPILEPSY SERVICE FOR ADULTS

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This article outlines the development and implementation of a community-based nurse-led epilepsy service for adults. The benefits that developing a specialist nurse role affords patients, such as better information-giving and self-management, are outlined and details given on plans to further develop the service.

INTRODUCTION

Reports over the past 55 years have criticised epilepsy care. Bradley and Lindsay (2001) summarised key criticisms as: a lack of systematic follow-up; inappropriate use of investigations; patients being seen in hospital by medical staff who are not neurologists; inappropriate drug combinations; non-adherence to treatment; poor communication between primary and acute care; poor communication with patients; and sparse patient knowledge.

Several reports have recommended employing epilepsy nurse specialists (ENSs) to address some of these issues. The Clinical Standards Advisory Group (1999) found that while only a minority of adults had seen an ENS, 74% of those who had done so thought nurses helped them to cope better. Stokes et al (2004) said ENSs should be an integral part of epilepsy care.

SERVICES AT THE PCT

Two consultant neurologists provided weekly general neurology clinics at the local district hospital. If patients had problems between clinics they could contact their GP or the neurologist’s secretary, who would forward messages. Although management of epilepsy in acute care was of a high quality, it was insufficient, and there was no specialist follow-up in the community. Patients had difficulty in accessing services and wanted more information.

An ENS post was set up just over three years ago, facilitated by Epilepsy Action as part of its Sapphire Nurse scheme. The ENS’s remit was to plan, implement and develop community services for adults with epilepsy.

MODEL OF CARE AND RATIONALE

One of the neurologists, who had a special interest in epilepsy, started a monthly acute care epilepsy clinic two months after the ENS took up the post. The ENS supported this clinic and followed up patients in nurse-led community clinics, liaising with primary and acute care.

Stokes et al (2004) advised that the ENS should be an integral part of the care network. Patients value these nurses for supporting the social aspects of care, providing information, reducing depression and improving independence (Mills et al, 1999). They can also titrate and prescribe antiepileptic drugs.

The trust decided to set up community-based nurse-led clinics offering accessible, patient-focused epilepsy management and timely, responsive interventions in informal settings, with adequate time for consultations and rapid access where needed. Telephone consultations were offered as an alternative to or in addition to clinic appointments.

EPILEPSY NURSE SPECIALIST ROLE

There are four key components to the role:

- Clinical management (including assessment and care planning, referral, managing risk, promoting self-management, prescribing, monitoring treatment and liaising with other agencies as required);
- Strategy (including developing and updating policy, protocols and proformas, clinical governance and liaising with other care providers and commissioners);
- Professional development (including extended nurse prescribing training, taking an MSc in Epilepsy Practice, mentorship and in-clinic learning, networking with other ENSs and writing articles);
- Education (including running teaching sessions for staff and organisations, holding joint clinics with practice nurses, carrying out annual epilepsy reviews, organising conferences and educational events).

DEVELOPING THE SERVICE

Until consistent practices were developed, the ENS took referrals from the acute care clinics only. Direct referrals are now taken from GPs. Neurology follow-up continues in acute care, and the ENS runs six clinics in different areas each month with additional clinics in less-populated areas and in two prisons. The neurologist refers some patients to the epilepsy nurse and some solely to primary care. Home visits and telephone consultations are offered.

A new diagnosis of epilepsy can carry associated stigma and may result in loss of self-esteem and independence. A significant number of people with epilepsy need support to make psychosocial adjustments and learn self-management behaviours.

Adherence to antiepileptic drugs is estimated at only 50% (World Health Organization, 2003). Education and patient empowerment may improve this. Patients can only self-manage if they understand access to titration of antiepileptic medication and improve communication between primary and acute care.

- Epilepsy nurse specialists can greatly improve access to services.

IMPLICATIONS FOR PRACTICE

- A community-based epilepsy service can improve access, communication, support in self-management and information-giving to patients.
- It can also give patients more timely consultation.

KEYWORDS NEUROLOGY ● EPILEPSY ● NURSE-LED SERVICE
BACKGROUND

- Prevalence of epilepsy is about 0.5% (MacDonald et al, 2000) and mortality in people with epilepsy is 2–3 times higher than in the general population. Sudden unexpected death accounts for around 18% of epilepsy-related deaths (Walczak et al, 2001).
- Significant morbidity is associated with epilepsy, including social exclusion, disability and stigmatisation. These affect employment, driving and relationships.
- Sander (2004) advised that optimal treatment could render 70% of people with epilepsy in the UK seizure free but Moran et al (2004) found that only 52% are actually seizure free.

...their condition, so they need good-quality information. It is important to remember that not all patients wish to self-manage.

The ENS explains and discusses the condition with patients in acute care after the consultation with the neurologist. This includes safety advice and information about drugs and titration. Patients are given Epilepsy Action booklets and they and their families can ask questions.

A survey of patient perceptions of the new acute care clinic was carried out in its first six months. As a result, an information leaflet was developed explaining what to expect during and following the outpatient appointment, giving basic safety advice and sources of information. The nurse issued cards with a named point of contact.

Communication

Communication remains a concern when there are several sets of notes. Patients’ acute care notes are kept at two different hospital sites. These are available at outpatient clinics and can be requested by hospital sites. There are several sets of notes.

As the nurse supports the neurologist’s clinic, these letters are discussed and acted on. The neurologist, nurses and GPs are copied in on letters to each other.

Requests for referrals to other professionals, such as psychology services, may be detailed. The nurse outlines the quality and outcomes framework indicators, and updates on drug reviews and seizures. The patient is copied into this letter. There is also communication by telephone.

The ENS faxes through details of drug changes made within one working day, with the more detailed clinic letter following.

PLANNED DEVELOPMENTS

A number of developments could improve and expand the services including:

- Introducing women’s groups and patient education groups;
- Hosting professional workshops;
- Helping with transition from paediatric services;
- Improving joint working with mental health services and primary care;
- Identifying and reducing non-elective hospital admissions;
- Increasing epilepsy awareness sessions with other agencies;
- Auditing waiting times for outpatient appointments and DNA rates;
- Monitoring adherence;
- Auditing and developing epilepsy management in prisons;
- Carrying out and publishing service audit and improvement.

Recognition of these led to the drawing up of a business plan outlining the need for a GP with an interest in epilepsy, a second

ENS and dedicated administration. The PCT supported this, securing funding, and the service is expanding. We hope it will be supported by a consultant neurologist with an interest in epilepsy. We also plan to develop a more robust epilepsy education programme for patients and staff, while a conference on the impact of epilepsy is being organised for autumn 2008.

REFERENCES

Bradley, P., Lindsay, B. (2001) Epilepsy clinics versus general neurology or medical clinics. Cochrane Database of Systematic Reviews; Issue 1: Art No: CD001910.


