The role of primary care nurses in the review of stable epilepsy

Primary care nurses have been involved in the management of chronic diseases such as diabetes and asthma for some years, with positive outcomes (Vrijhoef et al, 2002; Dickson et al, 1997). More recently their role has extended into cardiovascular disease (Murchie et al, 2003). In partnership with an epilepsy specialist nurse, they have also been involved in the management of patients with epilepsy, with measurable benefits (MacDonald et al, 2000). This article reports on a study undertaken in 26 GP practices within a primary care trust (PCT), which sought the views of primary care nurses on taking an active role in epilepsy management.

Although it is the commonest chronic neurological disease seen in primary care, in the past epilepsy has not been given a high priority. However, the new GP contract (Department of Health, 2003) has included it as a core measure of quality care. This means practices can earn quality outcome points towards extra payment if certain targets are achieved, providing an incentive and an opportunity to improve services to patients with epilepsy.

The prevalence of epilepsy is around 0.5 per cent (Sander, 2003), so each GP can expect to have 10–15 patients with active epilepsy on their list, some of whom will be children under paediatric care (in Chester this was defined as all those under 16 years). Among the adult patients 30 per cent will have ‘difficult’, uncontrolled epilepsy. Each practice will therefore have a small number of stable patients with epilepsy – those with a good diagnosis whose illness is controlled and who are not considering withdrawal from medication.

A recent unpublished audit undertaken in primary care in Chester found that only 19 per cent of patients with epilepsy were receiving a regular annual review and 60 per cent had not seen their GP about their condition in the previous year. This demonstrates a significant unmet need for this group of patients and led to the study reported here.

Results

Regarding their suitability for the work, there was a significant positive response from practice nurses and district nurses but less so from health visitors, while district nurses and health visitors did not feel they had the spare capacity for the work.

Conclusion

Inclusion of epilepsy as a quality indicator in the new GP contract means practices are likely to ask primary care nurses to take a role in managing patients with stable epilepsy. From this study there is evidence of some interest in taking this work on but there are issues around capacity, manpower, and funding.

The study

The objective was to assess the feasibility of primary care nurses reviewing patients with ‘stable’ epilepsy.

The participants of the study were drawn from all 26 practices in Cheshire West PCT, divided as follows:

- Practice nurses (n=62);
- Health visitors (n=38);
- District nurses (n=78).

Cheshire West PCT serves a population of 168,164, of whom 998 patients of all ages have active epilepsy. Fifty per cent of these patients had not seen any doctor in the previous year about their epilepsy. There was only evidence of a regular annual review in 178 patients in primary care, 35 of whom were in one practice.

Method

All patients with active epilepsy in the 26 practices within Cheshire West PCT were audited between September 2001 and December 2003. During the audit process practice managers distributed questionnaires to nursing staff and collected them after completion. The questionnaires related to the management of patients considered to be stable and requiring an annual review. It asked two closed questions:

- Do you feel this is suitable work, either at the surgery or in the community?
- Among all the other things you do, bearing in mind the small numbers, do you think you have the capacity to do this?

Nurses’ responses were scored from 1–5 ranging from ‘strongly disagree’, ‘disagree’, ‘unsure’, ‘agree’, and ‘strongly agree’.

Two open questions gave the respondents opportunities to make general comments:

- What are your training needs around this condition?
- Any other thoughts or comments?

It was emphasised that only stable patients with a firm commitment to review patients considering withdrawal from medication.

The study was presented at the annual meeting of the Royal College of Nursing in London on 20 March 2004, where a significant proportion of nurses were in attendance.

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ABSTRACT


Aim

To assess the feasibility of primary care nurses reviewing patients with ‘stable’ epilepsy.

Sample

Practice nurses, health visitors, and district nurses drawn from all GP practices in Cheshire West Primary Care Trust.

Method

Questionnaires were distributed to nursing staff about the management of patients considered to be stable but who require an annual review.
diagnosis of epilepsy, whose illness was well controlled and who were not considering withdrawal from medication, would be reviewed by nurses. The numbers would not be large and patients would only need to be seen once a year. The nurses’ role would include encouraging concordance with treatment, monitoring side-effects, ensuring good control was being maintained, and giving information and lifestyle advice. Research has shown that epilepsy specialist nurses perform the last two functions more effectively than doctors (Taylor et al, 1994).

Results
The response rates (by nursing group) of those invited to participate was 64 per cent for practice nurses (n=40), 76 per cent for health visitors (n=29), and 46 per cent for district nurses (n=36).

Regarding the question of the suitability of the work, there was a significant positive response from practice nurses and district nurses but less so from health visitors, while district nurses and health visitors did not feel they had the spare capacity to carry out the work.

Average responses to the question of the work’s suitability were closest to 3 (unsure) for health visitors and closest to 4 (agree) for both district and practice nurses. Average responses for the question on nurses’ capacity to do the work were 4 (agree) for practice nurses, whereas the average response for district nurses and health visitors was closest to 3 (unsure).

Statistical analysis of these responses was performed using the Kruskal-Wallis test.

Table 1 illustrates statements that were common to two or all of the groups, or which are statistically significant. These figures were analysed using the Fisher’s Exact Test which, like the chi-square test for fourfold (two by two) tables, examines the relationship between the two dimensions of the table (classification into rows versus classification into columns). The null hypothesis is that these two classifications are not different. The following summarise comments specific to each group.

Comments specific to practice nurses included:
- ‘Who will be supporting me in this role?’
- ‘What will be the benefit to patients?’
- ‘Other national service frameworks have a higher priority’
- ‘Will there be protected time to do this work?’
- ‘I used to see patients with epilepsy, few needed help and the clinic was stopped due to pressure elsewhere’
- ‘We need information on driving regulations’
- ‘I believe this is a much neglected area of health care’
- ‘I think these patients are somewhat forgotten, an annual check and discussion, and time given would be much appreciated’
- ‘I believe this is a much-neglected area of health care and would support any advancement in patient care’

There were no comments from practice nurses that suggested the work was not suitable.

All of the comments that were specific to the health visitors who responded were related to the suitability of the role:
- ‘I would need to discuss it with my health visitor manager’
- ‘Is a health visitor the right person?’
- ‘It should be for under-16s only’
- ‘It should be for children and parents only’
- ‘Practice nurses and district nurses are more hands-on in these fields, and are more appropriately placed to work in this area’
- ‘It should be the practice nurse or district nurse as they do more clinical roles’
- ‘It’s inappropriate for my role – too specialist. Chronic disease management is not my role’
- ‘It is inappropriate as I only see 0–5 year olds and am not involved in chronic disease management’
- ‘I feel it would be important to take on the work as a primary health care team, not just dump it on one group of nurses’
- ‘The role of health visitors is expanding, and perhaps they can fill this gap in services’

Table 1 illustrates statements that were common to more than one group of nurses.

### Table 1. Statements Common to More Than One Group of Nurses

<table>
<thead>
<tr>
<th>Statement</th>
<th>Practice Nurses (n=40)</th>
<th>Health Visitors (n=29)</th>
<th>District Nurses (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expressed need for a ‘general update’</td>
<td>18</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td>Admitted to no knowledge around the subject</td>
<td>10</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Advocated a role for an epilepsy specialist nurse</td>
<td>0</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Required education in lifestyle issues</td>
<td>8</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Required education in prescribing</td>
<td>8</td>
<td>1 (p=0.047)</td>
<td>2 (p=0.049)</td>
</tr>
<tr>
<td>Said that not all members of their team need to be involved</td>
<td>0 (p=0.03)</td>
<td>0</td>
<td>4 (p=0.04)</td>
</tr>
<tr>
<td>Expressed a need for protocols</td>
<td>5</td>
<td>0 (p=0.03)</td>
<td>0 (p=0.03)</td>
</tr>
<tr>
<td>Said workload would prevent them taking on this work</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Calculations made using Fisher’s exact test. Values shown are comparisons against practice nurses.

This article has been double-blind peer-reviewed.

For related articles on this subject and links to relevant websites see www.nursingtimes.net

**KEYWORDS** | Neurology | Epilepsy | Primary care

**REFERENCES**


Rogers, G. The future of epilepsy care in general practice, a role for the GP with special interest. *British Journal of General Practice*; 52: 872–873.

Discussion

This study posed two questions:

- ‘Should primary care nurses be involved in the review of patients with epilepsy?’
- ‘If so, who is best placed to perform this work, bearing in mind the training and support required?’

Epilepsy is associated with significant morbidity and mortality, much of which is preventable (Hanna et al, 2002). While the Clinical Services Advisory Group (2000) emphasises that GPs have a pivotal role in epilepsy management, if the Chester audit is representative of the situation countrywide then these patients are not being reviewed regularly in general practice.

However, although epilepsy is a core quality measure in the new GP contract, the condition has been awarded only 16 points out of a total of 1,050. This compares with:

- 99 points for diabetes;
- 72 points for asthma;
- 257 points for cardiovascular disease.

Table 2 illustrates how the points can be gained. There have already been articles suggesting that GPs ‘cherry pick’ their work to maximise points but epilepsy does not appear to be in the list of cherry pickings (Slingsby and Taylor, 2003).

Epilepsy can be difficult to diagnose, investigate and treat, and may be perceived as being more appropriately managed by doctors than nurses. However, while GPs should have a working knowledge of the condition from undergraduate teaching and postgraduate clinical exposure, this can vary greatly (Thapar et al, 1998; Brown et al, 1993), and patients may see their GP as having a poor level of knowledge (Freeman and Richards, 1994).

Once it has been diagnosed, epilepsy management is usually pharmacological, putting the emphasis on medical staff. However, the disease has a significant impact on patients’ psychological health (Jacoby et al, 1996). Many doctors lack the communication and counselling skills required to manage this (Scrambler, 1994), and are poor at providing the information on lifestyle required by patients with epilepsy. This problem could be addressed by the creation of a role of GP with special interest in epilepsy (Rogers, 2002).

The role of an epilepsy specialist

The epilepsy nurse specialist has an important role in coordinating multidisciplinary care and could stimulate the setting up of primary care-run epilepsy clinics similar to those for diabetes and asthma. However, while epilepsy nurse specialists are hospital-based but generally work

| TABLE 2. ALLOCATION OF POINTS FOR EPILEPSY SERVICE PROVISION IN THE NEW GP CONTRACT |
|---------------------------------|----------------|----------------|
| **INDICATOR** | **POINTS** | **MAXIMUM THRASHOLD** |
| **RECORDS** | | |
| EPILEPSY 1. The practice can produce a register of patients receiving drug treatment for epilepsy | 2 | |
| **ONGOING MANAGEMENT** | | |
| EPILEPSY 2. The percentage of patients aged 16 and over on drug treatment for epilepsy who have a record of seizure frequency in the previous 15 months | 4 | 90 per cent |
| EPILEPSY 3. The percentage of patients aged 16 and over on drug treatment for epilepsy who have a record of medication review in the previous 15 months | 4 | 90 per cent |
| EPILEPSY 4. The percentage of patients aged 16 and over on drug treatment for epilepsy who have been convulsion-free for the past 12 months recorded in the previous 15 months | 6 | 70 per cent |
in the community, many have experienced barriers to working in the primary care setting (Mills et al, 2002), even though patients with epilepsy find such nurses in primary care both acceptable and satisfactory.

Their main role is to record information and provide advice (Ridsdale, 2000). For example, a project run jointly by an epilepsy nurse specialist and practice nurse invited patients with epilepsy to come for a check-up, and achieved an attendance rate of 71 per cent, with a 92 per cent willingness to return. Out of a total of 175 patients, 30 were referred to the GP, of whom 15 were referred to hospital.

The initiative resulted in improved documentation of seizure frequency, and information and advice being given on various aspects of epilepsy including contraception and pregnancy, support services, benefits, concessionary travel, employment issues, and prescription exemption (Mills et al, 1999).

The appropriate nurse for the role

If it is decided that nurses should have a specific role in epilepsy management, the question of who is best placed to carry out this work will perhaps depend on the dynamics of the individual practice.

Since 1990 practice nurses have been increasingly involved in chronic disease management. This study implies that they believe the work is suitable but think they have less capacity. Acceptance of the new GP contract will no doubt lead to practice nurses being expected to focus more on the cardiovascular, diabetes, chronic obstructive pulmonary disease, and asthma targets.

District nurses also feel the work is suitable but that they do not have the capacity. They are involved in chronic disease management, but as their time is spent in the community they would not be best placed to run a clinic in surgery.

Health visitors clearly feel unsure that the work is suitable and they are also unsure that they have the capacity to become involved. While some health visitors may not feel it is an appropriate use of their time, this may be because chronic disease management has not previously been part of their remit. However, as roles change and develop and their routine screening role is significantly reduced, their extensive skills in enabling could be used in this area.

It is important to look at the competencies required to undertake epilepsy management and to match them to the available workforce. Health visitors work both in practices and in the community, and while much of their feedback implied a ‘children-only’ approach, they do care for patients of all ages.

Health visitors in Chester, for example, are involved in cardiac rehabilitation following myocardial infarct. As many cases of epilepsy begin in childhood and adolescence, health visitors may know the child and family and be best placed to advise and support. However, government targets are for patients over 16 years old.

Hall and Elliman (2003) suggest that the traditional role of the health visitor may change in the near future with much of the screening they currently perform being phased out because there is little evidence to support it. The ‘best buy’ proposal suggests that after the third immunisation at four months, health visitors negotiate the nature of subsequent reviews with parents. If so, they may have more capacity to move into other areas of primary care. Epilepsy would seem an ideal project to enable health visitors to extend their role into chronic disease management. Table 3 compares the criteria that may be seen as relevant in selecting the ideal nurse group to take on the work.

### TABLE 3. COMPARISON OF NURSES’ SUITABILITY TO TAKE ON THE MANAGEMENT OF EPILEPSY

<table>
<thead>
<tr>
<th>Practice-based</th>
<th>PRACTICE NURSE</th>
<th>DISTRICT NURSE</th>
<th>HEALTH VISITOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Training in epilepsy</td>
<td>Not usually</td>
<td>Not usually</td>
<td>Not usually</td>
</tr>
<tr>
<td>All age groups</td>
<td>Yes</td>
<td>Mainly adults</td>
<td>Yes</td>
</tr>
<tr>
<td>Involvement with patients with ‘special needs’</td>
<td>Not usually</td>
<td>Not usually</td>
<td>Yes</td>
</tr>
<tr>
<td>Experience in chronic disease management</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (less so)</td>
</tr>
<tr>
<td>Involved in the screening of older people</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

### Conclusion

The new GP contract has raised awareness of the need to provide adequate services for patients with epilepsy. The audit of patients found clear evidence that the care they currently receive is substandard. Although this was a small pilot study, and more consultation is needed to address the issues raised, it opens up the discussion on how to move forwards and address poor standards of care for this often neglected condition.

To some extent, whatever is decided will involve all members of the primary health care team, even though some may take more active roles than others. Quality audit, ongoing training, and integration with hospital care will be essential to ensure the quality and continuity of care, while funding issues will need to be resolved. However, primary care nurses are well placed to support patients with stable epilepsy in the ongoing management of their condition, and to ensure they are referred appropriately if their needs change.

### REFERENCES


