

# Care of patients with epilepsy in the community: will new initiatives address old problems?

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**SUMMARY.** *Epilepsy is a serious neurological condition that has important medical, psychological and social consequences. Up to 90% of patients with epilepsy are not under hospital supervision at any one time; the role of the general practitioner is therefore of central importance. There seems little doubt that community care of people with epilepsy must be improved. This article reviews the research findings on the quality of care of people with epilepsy, examines the barriers to effective community care, and looks at local and national initiatives to improve the care of patients with epilepsy in the community. Finally, the review considers how care can best be provided in an efficient, effective and acceptable manner within the resources of present day general practice. A patient-centred model is proposed that would tailor care to the needs of the individual patient.*

**Keywords:** *epilepsy; management of disease; quality in general practice.*

## Introduction

EPILEPSY is the most common serious neurological condition, with a lifetime prevalence estimated at between 2% and 5%.<sup>1,2</sup> For between 50% and 70% of sufferers seizures may only occur over a relatively short period of their lives.<sup>1,3</sup> The point prevalence for people with active epilepsy (those with recent seizures or currently taking antiepileptic medication) has been estimated at between 0.4% and 1%.<sup>1,2,4</sup> The mortality rate is elevated among people with epilepsy: standardized mortality ratio for people with a confirmed diagnosis of epilepsy is 3.0.<sup>5</sup>

Although at initial general practice presentation over 90% of patients with epilepsy are referred to hospital<sup>1,6,7</sup> where treatment is initiated,<sup>1,6</sup> after an average of four visits the majority of patients are either discharged or do not attend for further follow up.<sup>1</sup> For example, in one study of a hospital-based epilepsy clinic as many as one third of patients defaulted from follow-up care.<sup>8</sup> Indeed, up to 90% of patients with a history of epilepsy are not under hospital supervision at any one time,<sup>1,5,7</sup> and thus the general practitioner becomes responsible for the care of the majority of patients with epilepsy. Moreover, the provision of neurologists per head of population in the United Kingdom is much lower than of other specialists<sup>9</sup> and specialist epilepsy clinics exist only in a few areas.<sup>9,10</sup> The demand for neurological services at the present time exceeds the provision of these services.<sup>9</sup>

It therefore seems that the general practitioner will, by necessity, have to take on an increased active role in the provision of care to people with epilepsy. Since the beginning of the National Health Service there have been several government reports which have considered service provision for people with epilepsy and most have emphasized the central role of the general practitioner.<sup>11-15</sup> Most people with epilepsy identify the general practitioner as being the doctor primarily responsible for their care.<sup>16</sup>

The care of people with epilepsy in general practice has been the focus of much recent attention with several major community-based research projects,<sup>17-20</sup> and nationwide initiatives to improve the community care of patients with epilepsy.<sup>9,21</sup> Recent years have also seen the introduction of several promising new antiepileptic drugs, for example lamotrigine, and new investigations for people with epilepsy, such as magnetic resonance imaging scanning. It therefore seems an appropriate time to consider a number of important questions.

First, what are the research findings on the quality of care for people with epilepsy in the community? Secondly what are the barriers to effective community care? Thirdly, what have recent local and national epilepsy care initiatives set out to do? Finally, how can care best be provided in an efficient, effective and acceptable manner within the resources of present day general practice? This review sets out to answer these four important questions.

## Method

International studies for inclusion in this review were identified by computerized searching of the literature using *MedLine* and the epilepsy electronic review database *Epidata*, as well as manual searching of references quoted in recent literature. All primary care studies relating to epilepsy published in peer reviewed journals were considered for inclusion and any methodological flaws in the studies are discussed. Hospital-based studies were included if the issue had not been adequately described in primary care based studies. General practitioner specialists and hospital specialists with an interest in epilepsy were also consulted and theses on the subject were considered.<sup>22-24</sup>

## Quality of care in the community for people with epilepsy

A consensus document from a panel of doctors, including a general practitioner, with a special interest in the care of people with epilepsy concluded that the overall care of patients with epilepsy is poor.<sup>9</sup> This document represented a broad overview of epilepsy care although the authors restricted their discussion to suggesting possible strategies to improve general practice care. Indeed there have been almost two decades of research that have identified specific problems and difficulties in the care of people with epilepsy in the community. These can be broadly categorized under the following headings:

- Lack of systematic follow up
- Inappropriate polypharmacy
- Patient non-compliance with medication
- Failure of general practitioner-patient communication
- Low levels of patient knowledge

### *Lack of systematic follow up*

Several studies have highlighted the lack of regular follow up by general practitioners and hospital specialists as a deficiency in the care of people with epilepsy in the community.<sup>6,7,16</sup> In 1977 it was observed that some patients with frequent seizures were neither being seen by their general practitioner nor being systemat-

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ically reviewed by a hospital specialist, while others who were relatively well controlled were being regularly followed up in hospital outpatient clinics.<sup>6</sup> The number of patients for whom deficiencies in care were identified was, however, relatively small and this study did not identify whether problems in the pattern of supervision were a result of active decisions by patients or poor service organization. A 1993 community-based study of people with epilepsy<sup>16</sup> highlighted the fact that most people with epilepsy had not been seen by their general practitioner in the previous year. Again the reasons for this were not explored.

It would be useful to characterize individuals with epilepsy who are not regularly reviewed in primary care in terms of the severity of their condition and to explore reasons for not being reviewed. If patients want and need follow up then appropriate service provision and allocation of resources should be a priority. The effectiveness of systematic follow up of people with epilepsy in improving care also needs to be evaluated in a large-scale study using a range of outcome measures.

### *Inappropriate polypharmacy*

Primary care studies have shown that between 48% and 60% of patients are on more than one drug for their epilepsy.<sup>7,25,26</sup> However the findings of a more recent, large study suggest that a lower proportion of patients (35%) are on more than one drug for their epilepsy.<sup>27</sup> It is now generally recommended that monotherapy should be the aim for most people with epilepsy.<sup>28</sup> Optimum seizure control can be obtained with a single drug for between 70% and 80% of patients.<sup>28-31</sup>

Polypharmacy for epilepsy not only greatly increases the risk of side effects from medication<sup>32</sup> but also makes monitoring more difficult. Addition of a second drug in poorly controlled epilepsy is often ineffective.<sup>31,33</sup> Side effects from antiepileptic drugs not only reduce the patient's quality of life but they may also lead to non-compliance with prescribed medication.<sup>32</sup>

One problem that arises in the reduction of polypharmacy is the risk of precipitating seizures. One study, however, found that the risk of precipitating seizures when converting from combined therapy to monotherapy was small and that there could be substantial benefits.<sup>34</sup> In this study 84% of patients who were poorly controlled on polypharmacy attained 'successful' long-term control of their epilepsy on monotherapy.<sup>34</sup> As only a brief description was given of the method and results of this study, these findings need to be interpreted with caution. For patients who have been free from seizures even a small risk of increased seizures may be unacceptable for them in view of the social sequelae of a recurrence (for example, driving and employment).<sup>35</sup> For patients with poorer levels of seizure control this may not be such a major issue. The importance of providing information to the patient to allow an informed decision to be made in partnership with the general practitioner is crucial in this regard.

### *Patient non-compliance with medication*

Studies of rates of compliance with antiepileptic medication have yielded a wide range of results, but rates of compliance of between 50% and 70% of patients have generally been found.<sup>36</sup> Most studies are based on patients' reports or on serum drug concentrations. Generally, lower rates of compliance have been found from patients' own reports.<sup>36</sup> One explanation for this finding is that compliance rates may increase before clinic visits.<sup>37</sup> The findings of one of the few general practice studies in which compliance was estimated differed from those of other studies in that a high compliance rate was reported (90%).<sup>38</sup> However, compliance in this study was estimated by calculating the ratio of repeat prescriptions to expected prescriptions, which may not be a valid method of assessment. Additionally, 60% of

patients in the study had serum antiepileptic drug concentrations below the therapeutic range, which again suggests that the estimate of compliance may have been erroneous.

Interestingly, the majority of patients who permanently discontinue antiepileptic medication seem to do this of their own accord.<sup>10,29</sup> Taking antiepileptic drugs is commonly considered by patients to be stigmatizing<sup>39</sup> and discontinuation of medication may therefore represent freedom from stigma in patients free from seizures.<sup>40</sup> This suggestion is supported by the findings of a Medical Research Council antiepileptic drug withdrawal study: few patients who had unsuccessfully attempted to withdraw medication regretted the decision.<sup>20</sup> Several new antiepileptic drugs, for example lamotrigine, have been introduced in the last few years with more favourable side-effect profiles compared with earlier drugs. It will be interesting to see whether these new drugs lead to increased adherence with medication regimens, given that decisions regarding compliance are usually multifactorial.<sup>41</sup> Non-compliance with antiepileptic medication may be an active decision by the patient rather than simple forgetfulness.<sup>40</sup>

Monitoring patients' compliance with medication is an important role for the general practitioner, and a discussion of the patient's perspective on taking medication may be crucial in the identification and management of non-compliance. The stigmatizing potential of medication is a factor that must be recognized by general practitioners. Regular review should facilitate opportunities for the discussion of medication which should include discussion of the possibility of discontinuing medication if the patient has been free from seizures for some time. Prognostic factors for increased risks of seizures recurring after discontinuation of drug therapy have recently been summarized.<sup>10</sup> This information should enable an informed decision to be made by the patient and general practitioner as to whether or not to attempt to discontinue medication.

### *Failure of general practitioner-patient communication*

Some studies have pinpointed difficulties in communication between general practitioner and patient.<sup>6,7,16,42</sup> A nationwide questionnaire survey suggested that about 50% of patients with epilepsy had anxieties about their condition and its treatment which they did not discuss with their general practitioner.<sup>26</sup> Although this was a large survey (of 377 patients), a selected 'research club' of general practitioners participated in the research so the sample may not be representative. Furthermore, no details were given of characteristics of non-respondents or how the questionnaire used was developed or tested. Findings from a pilot study of a large questionnaire-based community survey in Merseyside found that although two thirds of patients felt that their general practitioner was primarily responsible for their care, 40% did not find their general practitioner easy to talk to.<sup>16</sup> A survey of members of the British Epilepsy Association revealed that many of those surveyed would have liked more personalized information and felt they were often managed simply by being given a prescription.<sup>42</sup>

The importance of improving the communication skills of the medical profession has been highlighted and an increased emphasis on such skills is proposed in the new undergraduate medical curriculum.<sup>43</sup> Attention should also be paid to communication skills training in postgraduate education in order for doctors to identify patients' needs.

### *Low levels of patient knowledge*

Many patients with chronic conditions know little about their disorders.<sup>44,45</sup> There have been surprisingly few studies of patient knowledge about epilepsy. This is in sharp contrast to other chronic conditions, for example asthma and diabetes, where con-

siderable work has been done. One study found that the majority of people with epilepsy knew as much about their condition as did the general population.<sup>46</sup> However, the topics assessed by the questionnaire were limited to knowledge of types of epilepsy, possible precipitants and causes, and first aid. The response rate was less than 60% and no details were given about non-respondents.

A new, validated questionnaire has been developed in the last few years to assess patient knowledge of many aspects of epilepsy.<sup>47,48</sup> Although this questionnaire has been largely developed in a specialist setting (with validation and reliability analysis being undertaken in a hospital outpatient clinic) the questionnaire seems to be acceptable for use in a community setting (Ridsdale L, personal communication) and should prove useful for further work. This type of work is of importance given that people with epilepsy commonly highlight their desire for more information about their condition<sup>7,16,42,46</sup> and that provision of information may correlate with their level of satisfaction with the care they receive.<sup>16</sup>

Patient education has traditionally been provided using either a one-to-one approach or by using leaflets. One-to-one patient education is time consuming<sup>49</sup> and standard leaflets may not be effective.<sup>50</sup> Educating patients in small groups is less time consuming than one-to-one education yet appears to be equally effective.<sup>49,51</sup> Individually tailored patient leaflets have been shown to be effective and require only a modest time input.<sup>52</sup> These educational methods need to be evaluated for people with epilepsy, not only for effectiveness and efficiency but also for acceptability.

### Barriers to effective community care

The preceding section has highlighted the problems that exist in the current provision of care for people with epilepsy in the community. The solutions to these problems are complex, there being a number of important potential barriers to effective care. These barriers may be considered in terms of:

- Organizational barriers
- General practitioner related barriers
- Patient-related barriers

#### *Organizational barriers*

The identification of patients with epilepsy in the community is an important step, whatever system of care is used. The most common method of identifying people with epilepsy is by computer searches for patients on antiepileptic drugs. This is a quick method of identification, especially as most practices are now computerized, but inaccuracies in using this approach have been highlighted.<sup>1</sup> Problems include commencement of antiepileptic treatment without an accurate diagnosis of epilepsy, and antiepileptic drug use for conditions other than epilepsy, for example carbamazepine for trigeminal neuralgia. More accurate methods of case finding, for example notes review and interview, are time consuming.<sup>1</sup>

Having identified patients with epilepsy, a method of regular surveillance must be organized; this may present difficulties. Setting up and running a formal call-recall system for patients to attend either a surgery appointment or a dedicated clinic represents a considerable time commitment and may not be acceptable to patients. There may be a high default rate, as has been found in hospital epilepsy clinics.<sup>8</sup> There is also some evidence that non-attenders at primary care programmes may be those with higher levels of morbidity compared with attenders.<sup>53</sup>

The use of practice-based specialist epilepsy nurses has been advocated,<sup>54</sup> and would be one way to target these non-attenders but the resource implications are considerable. Other developments in epilepsy care such as surgery and the increasing use of magnetic resonance imaging scanning for people with epilepsy are new costs which would have to be considered in any economic evaluation of epilepsy services in primary or secondary care.

#### *General practitioner related barriers*

The results of surveys of the attitudes of general practitioners to the care of people with epilepsy by an 'epilepsy task force'<sup>9</sup> and *Doctor* magazine (6 October 1994) suggest that the majority of general practitioners consider the condition and its treatment to be complex and that they lack sufficient knowledge of the condition. A pilot study of general practitioners in Doncaster found similar problems, with two thirds of respondents acknowledging difficulties in diagnosis, counselling and the prescribing of drugs.<sup>54</sup> However, these findings need to be confirmed by a more rigorously designed study. Other studies have largely concerned themselves with the attitudes of general practitioners to people with epilepsy rather than with general practitioners attitudes to providing and organizing care for their patients.<sup>55-57</sup>

#### *Patient-related barriers*

The implications of having a chronic illness include biomedical, social and psychological factors. Social and psychological factors are often of greater importance to the patient than the biomedical implications of the condition. The stigmatizing potential of the label 'epilepsy' has long been noted. Nineteenth century notions were that seizures were a manifestation of being possessed. Treatment at the time commonly consisted of placing the unfortunate sufferer in an asylum. Even well into the 20th century epilepsy was regarded as a psychiatric illness, with treatment being provided by mental health professionals. As recently as 1965 a working party of the British Medical Association considered that people with epilepsy should not be allowed to immigrate to this country because of their condition.<sup>23</sup>

There are two types of stigma: 'felt' stigma (that is, being afraid of being discriminated against) and 'enacted' stigma (that is, actual discrimination). Earlier research found 'felt' stigma to be a more common problem than 'enacted' stigma.<sup>23,39</sup> 'Felt' stigma resulted in epilepsy sufferers hiding their diagnosis from the people around them. The findings of more recent studies, including the national general practice study of epilepsy,<sup>19</sup> suggest that this feeling of stigmatization may now be less prevalent, especially among people whose epilepsy is well controlled.<sup>19,58</sup> A study from Southampton, however, highlighted the feelings of stigma felt by many people with epilepsy.<sup>59</sup>

A relationship between stigma and the severity of the illness has been noted<sup>19</sup> and this may explain the apparent discrepancy between the above findings. People with chronic epilepsy who suffer frequent seizures may feel greatly stigmatized by their condition with the consequent considerable risk of social withdrawal. This can have important implications for the organization of care for people with chronic epilepsy as some individuals with epilepsy may avoid situations in which they are positively identified as having epilepsy, for example special clinics in primary care.

The attitude of the patient towards the providers of health care is of considerable importance.<sup>60</sup> The findings of one study suggest that some patients may not feel confident about their general practitioner's expertise in the management of their condition.<sup>59</sup> There is a need for more systematic evaluation of these attitudes as they may represent barriers to proposals for improvements in

care. An evaluation may provide an opportunity to reach out to people with epilepsy in a way that is sensitive to their concerns.

### Initiatives to improve care for patients with epilepsy in the community

#### Local initiatives

There has been remarkably little work describing and evaluating methods of providing care for people with epilepsy in general practice. Care for people with chronic diseases can be organized either opportunistically or in clinics. Follow up can either be primary care led or patient initiated.

Reports from individual practices suggest that regular opportunistic care and audit can improve the care for people with epilepsy in the community (Lloyd-Jones A, personal communication).<sup>35</sup> The use of practice-based epilepsy liaison nurses in the community and a district-based epilepsy service coordinated in a hospital has also been reported and provisional findings are promising.<sup>61</sup> An epilepsy liaison service is being developed in Birmingham which aims not only to improve liaison between primary and secondary care but also to act as a source of advice on audit in primary care and to provide educational material to general practitioners regarding epilepsy.<sup>62</sup> Some regions have developed guidelines for the diagnosis and management of patients with epilepsy in primary care.<sup>63-65</sup>

It is essential that these methods of care are evaluated in larger studies in terms of effectiveness, acceptability, practicality and efficiency. Evaluation studies are particularly important with the advent of recent national initiatives.

#### National initiatives

Two recent national initiatives which aimed to improve care for patients with epilepsy have been funded by Wellcome.<sup>9,21</sup> One initiative is the epilepsy task force<sup>9</sup> which comprises a multidisciplinary group of specialists, general practitioners and representatives from patients' groups. The task force evolved from the panel of experts who produced the 'epilepsy needs document', a review of the nature and quality of services for people with epilepsy.<sup>9</sup> The broad aims of the epilepsy task force are to raise public awareness of the condition, lobby for appropriate primary and secondary service provision and establish guidelines and minimum standards of care for hospital outpatient services. It has also set out to support research and initiatives that aim to evaluate and overcome barriers to increased practitioner involvement in the care of patients with epilepsy.

The second national initiative was the epilepsy liaison nurse programme which ran between October 1993 and October 1994.<sup>21</sup> Ten liaison nurses were trained and established in areas in which there was a hospital specialist epilepsy clinic. The overall aim was to help general practices improve the care of their patients with epilepsy by assisting practices in identifying patients with epilepsy, helping establish epilepsy clinics in primary care and then auditing the care of these patients. Over 600 practices have been involved in this programme nationwide. How effective the programme has been in a particular region, both in terms of establishing and running epilepsy clinics, as well as in terms of patient outcomes, needs to be evaluated before this model of care can be recommended.

### Conclusion

In this article research findings on the quality of care in the community for people with epilepsy have been reviewed and possible barriers and initiatives to improve care have been discussed. There seems to be little doubt that the care of many people with epilepsy needs to be improved. The role of general

practitioners is important, given that most epileptic patients are solely under their care. Government reports have emphasized the importance of the general practitioner in the management of patients with epilepsy,<sup>11,13-15</sup> and the need for better liaison between hospital services and the general practitioner has been stressed.<sup>3,9,62</sup> A number of initiatives to improve care, such as the Wellcome epilepsy liaison nurse programme, have been launched.<sup>21</sup>

A combination of opportunistic and planned review of patients, with additional input from liaison nurses and hospital specialists for certain specifically targeted individuals may be a successful method of care, given the different demands and needs of individual patients and practices. This patient-centred model of care is fully compatible with the international principles of general practice.<sup>66,67</sup> The aim of this model of care would be to tailor care to the needs and characteristics of the individual patient. In view of the research findings highlighted in this review, several important issues would have to be addressed before such a system of care could be successfully implemented:

- The costs of liaison nurses and organizational changes in establishing such a system of care would need to be measured and funded. A modest transfer of resources from the secondary to the primary care sector might enable some of this funding to be made available.
- General practitioner and patient barriers to epilepsy care would need to be overcome. Specific patient education programmes<sup>68</sup> and the use of guidelines<sup>63-65</sup> to overcome knowledge barriers would have to be evaluated. Clinical audit may act as a spur to improve services.<sup>54</sup>
- Patient information and education may not only help dispel misconceptions about the condition but may also reduce the psychosocial sequelae of epilepsy.<sup>68,69</sup> Patient education in small groups and the tailored use of patient education leaflets may minimize time involvement.
- Encouraging guided self management of epilepsy may be appropriate for patients who default from regular follow up. Self management would not only instil a feeling of control of the condition by the patient<sup>69</sup> but would also encourage a partnership role with the general practitioner. This may avoid situations in which patient decisions (for example, the discontinuation of medication) are made without professional guidance.<sup>29</sup>
- People with other chronic diseases, such as asthma and diabetes, are already predominantly cared for in primary care and this may represent competition for resources. However, the additional resources required for general practice care of people with epilepsy should be modest given the numbers of individuals involved (the average general practitioner has about nine patients with epilepsy on his or her list<sup>4</sup>). Many strategies used for the care of patients with diabetes and asthma may be adapted for use for people with epilepsy.

It is essential that any new proposal is fully evaluated. This review has highlighted the need for more research to be done on the provision of community services to people with epilepsy in order to identify the most effective, efficient and acceptable method of care.

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