

# Quality of epilepsy treatment and services: the views of women with epilepsy

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In three focus group discussions, 18 women with epilepsy were asked about their experiences of and satisfaction with care and treatment at both primary and secondary care, and for views on how epilepsy services might be improved. A fourth focus group was held with six epilepsy nurse specialists to seek their opinions on the service needs of women with epilepsy. Criticisms of services identified by both the women and nurses typically concerned four areas of care; organisation of services, technical competence, information provision and interpersonal skills, and health outcomes. Specific criticisms in each area included: lack of continuity of care and shared care; poor provision of information about side-effects of antiepileptic drugs (AEDs) and their effect on the contraceptive pill; and apparently haphazard prescribing of AEDs with consequent serious side-effects. Recommendations for improvements in services and treatment for people with epilepsy are suggested.

*Key words:* epilepsy; quality of care; patient satisfaction; qualitative research.

## INTRODUCTION

There is a burgeoning literature examining patient satisfaction with epilepsy treatment and services<sup>1–5</sup>. Few studies, however, have used qualitative research methods, such as in-depth interviewing or focus groups, to elicit epilepsy patients' views and preferences on treatment. This approach is valuable as it offers patients the chance to express their opinions on matters of their own choosing without being constrained by the researchers' imposed research structures and assumptions<sup>6</sup>. The aim is to discover and explore not only what people think, but how and why they think that way<sup>7</sup>. It is our belief that by better understanding patients' interpretations and meanings of ill health, the manner in which they cope with it, and the hopes and expectations they have of care and treatment, the better will health professionals be able to recognize and satisfy patients' health care needs in the widest sense. With this in mind, the purpose of this study was to explore, using focus group discussions, women's experience of and satisfaction with care and treatment for their epilepsy, and to seek views on how epilepsy services might be improved. On the basis of the results of these discussions, we conclude with some recommendations for improving epilepsy services.

## MATERIALS AND METHODS

Three focus group discussions were held at the Royal College of Physicians, involving 18 women with epilepsy in total. Group size ranged from 4–8 people. Recruitment was via leaflets displayed at the weekly Epilepsy Clinic at London's National Hospital for Neurology and Neurosurgery and also through the epilepsy support group network. As a means of validation, a further focus group discussion was held with six epilepsy nurse specialists from hospitals around England.

The purpose of the discussions with patients was to explore widely their experiences of and satisfaction with care and treatment over time and to elicit views on how services might be improved. The reason for involving only women in the groups was to enable discussion of issues particular to women which might have been inhibited by the presence of men. The discussion with the epilepsy nurse specialists sought opinions on the service needs of women with epilepsy at both primary and secondary care, based on their experiences of treating and counselling people with epilepsy. The discussions lasted one-and-a-half to two hours.

The focus groups were facilitated by two interviewers (HW and JS). A series of open-ended questions covering all aspects of care from diagnosis onwards was

used to give shape to the discussion but not with the intention of leading it. Participants were invited to describe and explore the issues of importance to them, to compare experiences and share anecdotes, and to comment on each others' points of view. The fact that focus groups encourage such interpersonal communication is one of the method's strengths, enabling richer data to be gathered than is often possible in structured one-to-one interviews. The discussions were audio-taped and transcribed verbatim. Content analysis guided by grounded theory methodology was carried out to identify common themes and concepts<sup>8,9</sup>.

## RESULTS

### Sample population

The demographic and epilepsy details of the 18 women interviewed are given in Table 1.

### Common areas of concern among patients and nurses

Criticism of services among both patients and nurses typically concerned four domains of care: organisation of services, technical competence, information provision and interpersonal skills, and health outcomes. These will be discussed in turn and illustrated using quotes from all the group discussions. (Initials of the participants have been changed.)

### Organisation of services

#### *Continuity of care and shared care*

The importance of continuity of care, i.e. seeing the same doctor at the hospital on each visit, was emphasized in all four groups. Continuity of care was seen to be important not only for establishing trust and confidence in the doctor but also for rationalizing treatment. As one participant described: 'one doctor will put you on one tablet, and then the next doctor will say 'I don't think you should be on that, I'll take you off that, put you on another'. Then you go back to the first doctor again and they say, 'no I think you should have stayed on that, and put you back on it. It is ridiculous.' (M)

Also frustrating for the women was having to repeat their history every time they saw a new doctor. It was felt to be a 'waste of time' taking up most of the consultation time and leaving no opportunity to talk about matters of greater concern to them.

The participants recognized there were organizational difficulties in achieving continuity of care and

accepted that doctors in training moved on to other appointments or that consultants were not always available. However, they all wanted to be given the opportunity to see the consultant sometimes, and found it particularly annoying when they were seen by another doctor having been told specifically they had an appointment with the consultant.

M: You were supposed to have the consultant, but you wouldn't see that consultant necessarily, you might get the registrar. So you would go there wanting to see the top neurologist and you would end up with his registrar minus two or something, whoever was convenient at the time, which really is annoying.

In discussions with both the epilepsy nurses and women with epilepsy, attention was also drawn to the problems that can arise due to poor organization of services between primary and secondary care. Lack of clarity about where GPs' and specialists' responsibilities for treatment lay meant patients were inadequately treated by both sectors.

Nurse A: They go to the consultant and he will give them some information, but they may not see the consultant for another 3–6 months; they may not see the GP at all during that time, because the GP thinks the consultant is looking after them. Therefore, he doesn't get involved and there is a huge gap in time, and during that time the patient could have a lot of problems that need sorting out and there is no one to go to.

Poor communication between specialists and GPs was identified to be a common source of error in patients' medication. Delays in letters being sent to GPs left patients without medication once they had finished their hospital supply and GPs without clear instructions as to which drugs they should be prescribing. Even when letters had been sent in good time, examples were cited of prescriptions which had not been updated, or of a GP deciding to revise the specialist's proposed treatment plan, e.g. changing from a branded to a generic product, thereby leaving patients confused as to which drugs they should indeed be taking. Such problems were a potential source not only of inadvertent non-compliance among patients but also deliberate non-compliance as patients' confidence in treatment was undermined and treatment taken into their own hands.

#### *Time in the consultation*

The amount of time spent in a consultation was also of concern. The women felt that consultations were of-

Table 1: Patients' demographic and epilepsy details

Mean age:	37 yr (range 24–66)	
Mean age at diagnosis:	13.3 yr (range 2 mo–31 y)	
Number undergone surgery:	4	
Seizure frequency:	4 had no seizures (3 of these had had surgery), 2 had seizures daily, the seizure frequency of the remaining 12 women, varied from weekly to only a few a year.	
Type of seizures/epilepsy: (as described by patients)	Temporal lobe (complex) partial Grand mal Petit mal Blackout/absences/déjà vu	4 3 8 5 2
Medication:	Everyone was taking at least one AED. Where number of drugs was known: 5 were on 1 drug 3 on 2 drugs 3 on 3 drugs 1 on 5 drugs	

ten rushed and there was never enough time to discuss all that they wanted, although this experience was not shared by everyone. One commented that she didn't mind waiting longer for her appointment on the day if she knew in the end she would get the time she wanted with the doctor. It was agreed that if doctors did not have the time to give patients longer consultations, the opportunity to see a specialist nurse or counsellor would be welcomed.

### Information provision

Obtaining information about epilepsy and antiepileptic medication from their doctor was often perceived to be a struggle and many of the women had looked to other sources for information. This was particularly apparent at diagnosis which several women commented had been very poorly handled: 'She [the doctor] was so blasé about it, 'oh you've got epilepsy, just take the drugs, and we'll see you next month'. 'Nobody ever bothered to explain the basics.'

While in one patient group it was acknowledged that a patient had as much responsibility to seek out and ask for information as a doctor had to give it, it was apparent from discussions in all groups that there were a number of barriers which made it difficult in practice for patients to take the initiative. These included: insufficient consultation time to address patients' information needs; the nature of the consultation itself which was seen to be a one-way process focused more on the medical treatment of the condition rather than a discussion between doctor and patient about wider issues of importance to the patient; inapproachability of doctors including lack of encouragement to ask questions; and lack of confidence on the part of patients to be assertive particularly at a time when they were feeling vulnerable.

The same problems were identified in the discussion with the nurses:

Nurse E: That's the difficulty with doctors, they see it very much from the medical point of view: 'How many seizures are you having, have some more carbamazepine'. [They] don't look at the other issues: the non-medical care, the advice, the information, the education, the much more practical issues that worry women. OK, the medical management must come first, be optimal, but once the medical management is optimal there is still an awful lot of work to do that is perhaps the role of the nurse specialist.

### Information about contraception

In all three patient groups, the women were concerned at the lack of advice and information they had received about contraception. They were also worried that their doctors did not always seem to have a complete understanding of the effects of AEDs on the oral contraceptive pill: one was advised she could not be on the pill; another had been put on a very low dose pill and became pregnant when a teenager; yet another had received different advice from the family planning clinic, the GP and the neurologist and was left feeling totally confused about the effectiveness of any form of oral contraception.

One participant described her experience of the pill:

L: [It] just stopped working. I could have got pregnant so easily within the first couple of months [of starting AED medication] because I had no idea. I kept bleeding in between times, I thought what is going on, I have never had this before. Inter-

viewer: Who prescribed the pill for you?

L: I had already been on the pill for 3 years, and I asked my doctor about it, I think my neurologist, and I said 'something is going on with my pill, does it affect it', but I had to ask him, and he said 'yes it does, it makes it not work, basically' . . . [and I was tried on another one] and nothing worked, absolutely nothing, and he said 'while you use this, use another kind of contraceptive', and I said 'why use both, why not just go off the pill', so I ended up going off the pill.

### Information about antiepileptic drugs in pregnancy

Many of the women also expressed anxieties about the risk of AEDs in pregnancy. Some felt they had not been given enough information and were therefore not clear what exactly the risks were. One was concerned that women were not told that they should seek advice before they became pregnant, although this was not everyone's experience. The two women who were pregnant at the time of the focus group, who knew each other, were concerned that they had been given conflicting advice by the same doctor about which was the best drug in pregnancy.

L: and I said 'well what about my drugs, they keep telling me that epilim is the best.' [And the doctor said] 'No, no tegretol is fine, you're fine on tegretol'.

But L was not entirely convinced nor reassured. The exchange continued. . .

S: I saw Dr X when I was pregnant with my little girl and he said to me I was on the best drug for pregnant women – that's epilim. He said, 'anybody who is wanting to become pregnant, we're putting them all on sodium valproate'.

L: Everybody is on epilim that's pregnant.

S: And when L said to me she was on tegretol I was a little bit surprised, but obviously there is a reason, perhaps that's the one that controls her fits, I don't know.

L: I've asked him why and, I think it's like, they don't want to get into too much detail. You know someone [to S] who was taking tegretol who had a blind, deaf and dumb child.

S: No, she was just deaf and she's got learning disabilities. But I think that was more than tegretol. And she had a second

child and she took the chance of coming off her medication and it was perfectly normal. But I would not be prepared to take that risk. I would rather stay on the drug.

L said she ultimately trusted her doctor but lingering doubts remained.

This conversation illustrates the difficulties for patients in reconciling conflicting information from different sources. As was discussed above, patients often supplement the advice they get from their doctor with information gained from sharing experiences with other people with epilepsy, from books or voluntary organisations. Where this conflicts with the medical advice they have received, patients may not always believe or accept the medical explanation at face value — in the discussions the women frequently commented that they felt they had not been told the full facts, or that certain information was being withheld. In satisfying the information needs of patients, therefore, patients' current beliefs, ideas and knowledge should be explored. Erroneous beliefs should not simply be dismissed without offering convincing alternative explanations.

A further issue that clearly caused confusion was the question of the inheritance of epilepsy.

L: They keep telling me it is not hereditary. That's another thing that is very misconceiving, it's the first thing they ask you, 'is it in the family?'. If it's not hereditary what difference does it make?

The same confusion was expressed in another patient group.

### Clinical competence and skills

In studies of patient satisfaction, it has often been suggested that health service users are not able to judge the clinical aspects of care, and typically frame their responses in terms of the doctor's personal qualities, or the comfort of the health care surroundings<sup>10</sup>. In this study we found this not to be the case. Many of our participants commented perceptively on issues of clinical competence. It is well recognised that patients, particularly those with chronic illnesses, frequently become 'lay' experts in their condition, and their understanding of their illness and treatment should not be underestimated.

### *Diagnosis and treatment*

In all four groups problems due to the shortage of specialists with an interest in epilepsy were raised. Both the nurses and women with epilepsy described experiences of delayed diagnoses and misdiagnoses, and

inappropriate drug management by both neurologists and general physicians.

The women also commented on the frustrating process of finding the right drug for their seizures. While they clearly accepted that this was often a process of trial and error, and were prepared to undergo lengthy and laborious changes in medication in the hope of gaining seizure control, it was evident that they drew a line between careful changes in medication and what they perceived to be ‘messing around’, ‘pumping’ or ‘playing’ with drugs. In so doing, they distinguished between what they felt were reasoned and rational changes in medication, and haphazard, somewhat directionless prescribing. This is illustrated by the following exchange, where, perhaps paradoxically, ‘fiddling’ was used in a positive sense:

A: I have to say that now they seem to be willing to fiddle rather than just pump more and more drugs into you.

R: Fiddling in terms of up or down you mean?

A: Yes, and also taking you off one drug and putting you on another. I mean at one time I was on about 5 drugs. Fiddling is much better than just pumping in more, because I was having side-effects with the drugs and also having seizures because of the drugs rather than the epilepsy.

H: This is what I found. . .

A: I have found that drugs that previously didn't work for me, now they are willing to spend more time fiddling, are working, which is interesting.

This experience of carefully tailoring medication to the patients' clinical circumstances was not shared by other participants:

C: They just ask me ‘how many fits have you had, what drugs are you taking, have you been taking your tablets regularly’. They don't look at what really is causing my fits. A lot of my fits are caused by depression, which [is] caused by the amount of drugs I am taking, which counterreact with antidepressants. They just don't really look at the whole situation. They just think, ‘oh she's had so many fits, we'll put it up by another so many milligrams’.

Across the groups, there were also comments about GPs' lack of knowledge about the different types of seizures and the appropriate drug treatment for them. For some, the GP was visited simply for repeat prescriptions and if problems arose the patient would be referred back to the specialist. Although some had had experience of very good GPs, the general impression

was that they were not very interested in epilepsy and preferred to leave its management in the hands of neurologists. As long as the women lacked confidence in the GPs' skills, this arrangement was apparently satisfactory, but improved training for GPs in managing epilepsy was considered necessary.

#### *Accident and emergency departments*

Accident and Emergency (A&E) departments were highlighted as an area for concern. It was felt that there was lack of awareness among clinical staff about the appropriate treatment of patients with epilepsy, particularly following a seizure. The women described how recovery was hindered by staff being insensitive to their needs, whether, for example, it was being left on a trolley under the glare of lights or not being allowed to sleep off the effects of the fit:

Interviewer: You are saying they discharge you too soon?

C: No, they leave you in a cubicle for 3–4 hours, but every 15 minutes they come in for observation and you are trying to sleep the fit off, and if you don't sleep it off you are going to have another one. . .and they just won't let you.

Not only in A&E, but hospital staff in general were criticized for not knowing what to do when someone was having a seizure. One participant described how she came around from a seizure ‘absolutely black and blue from head to toe’ while she was in hospital. Another had watched nurses try to put something in someone's mouth and hold them down. It was commented that cabin crew on aeroplanes were better trained than many hospital staff in managing a seizure.

## Outcomes of treatment

### *Side effects and seizure control*

Issues concerning side-effects of treatment were a common cause of dissatisfaction for patients. There were complaints about doctors' lack of awareness of the side-effects of the different drugs; their failure to inform patients of the side-effects they might experience with a particular drug; their apparent disbelief of the side-effects patients were reporting; and failure to seek patients' views on the desired balance between seizure frequency and side-effects. Although the women ultimately wished for seizure control they were not prepared to achieve it at all costs, several having experienced side-effects which were worse than the seizures themselves.

L: One of the things that made me so irritated at the beginning was that I would tell my doctor all these side-effects and he said 'well what do you want, fits or side-effects?' And you almost want to walk out; 'well, excuse me, I don't want to have either here. This is hard enough as it is'... And they [say], 'you have epilepsy, you will have this the rest of your life, well you'll just have to try the drug'. And then you tell them about the side-effects and they reply 'are you really having those, is that *really* what is going on here?'. So the drugs are very, very, very frustrating and I don't think the doctors help at all.

The problems with side-effects had led some of the women to take themselves off treatment. A number had tried complementary medication instead, in particular homeopathy, with apparently varying success.

#### *Living with epilepsy*

Some of the women were philosophical about the fact that they might never attain complete seizure control and for them the aim was to achieve a balance of seizures and side-effects that interfered as little as possible with their lives. The nurse specialists emphasized that enabling patients to lead a full life not only involved treating seizures and limiting side-effects, but also helping patients to cope with the impact epilepsy had on broader areas of their lives, whether it be for example, employment prospects, education or social relationships. In their opinion, too often this need was overlooked by health professionals, and patients were left to come to terms with living with epilepsy without professional support. This view was confirmed by the women's own experiences.

#### *Epilepsy surgery*

The four participants who had had surgical intervention for their epilepsy spoke generally positively of their experience. Three no longer had seizures, though they were still on medication, and were looking forward to the time when they might come off drugs altogether. Furthermore, the thought that they might soon be able to drive was an exciting prospect. Several of the participants expressed a wish to be able to drive and seizure freedom was therefore an important goal for them.

## DISCUSSION

The focus group discussions have drawn attention to some deficiencies in the current provision of services and treatment for people with epilepsy. Although the sample was small, the fact that similar issues were

raised repeatedly and unprompted in each discussion group with patients, and further confirmed by the epilepsy nurse specialists, suggests that the criticisms of services identified are valid and would be shared by a wider group of people with epilepsy. Previous quantitative studies have also identified similar deficiencies in services, and the focus groups have been valuable in adding to these data by exploring with patients exactly where the failings lie and seeking views on how they would like to see them remedied. The study does not, however, purport to be an exhaustive analysis of patients' views of services and treatment, nor to have represented all patient groups.

By virtue of the fact that the focus groups involved only women, one might have presupposed that more issues relating to women would have been raised. However, the wide age range of participants (see Table 1) and therefore their differing circumstances, together with the fact that few of them had children, may explain the more general issues about care and treatment which were highlighted. One of the weaknesses of focus groups is that they are not appropriate for exploring individual stories in-depth, and we could not therefore probe or dwell too long on experiences they had not all shared, such as in relation to pregnancy.

A large amount of data gathered in the focus groups was elicited from the interaction of participants with one another; the sharing of experiences, anecdotes, jokes and worries. While a criticism has been expressed that the force of certain personalities in a focus group may silence shyer participants, against this there is an argument that positive group dynamics will draw out quiet participants who gain confidence from hearing their views or experiences reinforced by other members of the group. We found that the focus groups provided a level of mutual support between participants in the expression of their views and concerns. From our experience of focus group work, we feel that the methodology is a valuable way of encouraging participants to explore areas for themselves and in turn develop their own analysis of shared views and experiences.

On the basis of the discussions, we would like to suggest that the following recommendations for improvements in services and treatment for people with epilepsy should be considered. Although some recommendations will have resource implications, the implementation of others requires a change in approach to the care of patients with epilepsy and in the nature of the doctor-patient relationship, rather than a major reorganization of services.

- Health professionals should pay greater attention to the information needs of patients with epilepsy, particularly around diagnosis and pregnancy. All patients should be informed of the various epilepsy voluntary organisations and how to contact them.

- Some consultation time should be dedicated to discussing wider issues around epilepsy, and not just its medical management, as prompted by the patient.
- Patients should be encouraged to take active part in treatment decisions, and their views on their desired aims of treatment, such as the balance of side-effects and seizure control, taken into account. In so doing, the various treatment options need to be clearly explained so that informed choices can be made.
- While recognizing the organizational constraints, patients should, as far as possible, be offered appointments with the same doctor on each visit, to maintain continuity of care. However, patients' requests to see another doctor, particularly the consultant, should be met, if possible.
- Establishing formal shared care agreements between primary and secondary care should be considered. Furthermore, the limits of the GPs' and specialists' responsibilities for management of a patient need to be agreed. The epilepsy nurse specialist also plays a key role in providing an effective link for the patient between primary and secondary care and also continuing clinical and non-clinical support for the patient. Their employment should be more widely encouraged.
- The use of local guidelines for managing patients with epilepsy in both primary and secondary care should be considered.
- Protocols for the management of patients following a seizure should be developed for medical and nursing staff in A&E.
- Within primary practice, the feasibility of assigning either a practice nurse (or specialist epilepsy nurse) or a GP to develop expertise in epilepsy and take responsibility for the review and recall of epilepsy patients should be considered, to ensure patients' care is properly reviewed on a regular basis.

- Within secondary care, specialists who regularly treat patients with epilepsy, but who do not have a special interest in the condition, should ensure that they are up-to-date with the latest developments in antiepileptic medication and are aware of the range of side-effects associated both with the new and old AEDs.

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## REFERENCES

1. Buck, D., Jacoby, A., Baker, G. A., Graham-Jones, S. and Chadwick, D. W. Patients' experiences of and satisfaction with care for their epilepsy. *Epilepsia* 1996; **37**: 841–849.
2. Mills, N. *et al.* Patients' experiences of epilepsy and health care. *Family Practice* 1997; **14**: 117–123.
3. Ridsdale, L., Jeffery, S., Robins, D., McGee, L., Fitzgerald, A. and the Epilepsy Care Evaluation Group. Epilepsy monitoring and advice recorded: general practitioners' views, current practice and patients' preferences. *British Journal of General Practice* 1996; **46**: 11–14.
4. Jain, P., Patterson, V. H. and Morrow, J. I. What people want from a hospital clinic. *Seizure* 1993; **2**: 75–78.
5. Chappell, B. Epilepsy: Patient views on their condition and treatment. *Seizure* 1992; **1**: 103–109.
6. Britten, N. Qualitative interviews in medical research. *British Medical Journal* 1995; **311**: 251–253.
7. Kitzinger, J. Introducing focus groups. *British Medical Journal* 1995; **311**: 299–302.
8. Charmaz, K. "Discovering" chronic illness: using grounded theory. *Social Science Medicine* 1990; **30**: 1161–1172.
9. Strauss, A. and Corbin, J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. London, Sage, 1990.
10. Fitzpatrick, R. Scope and measurement of patient satisfaction. In: *Measurement of Patients' Satisfaction with their Care*. (Eds R. Fitzpatrick and A. Hopkins). London, Royal College of Physicians, 1993.