

# How general practice can help improve care of people with neurological conditions: a qualitative study

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The aim of this qualitative study was to examine the experiences and needs of patients and carers affected by one of three common neurological conditions and to explore how primary care can contribute to improvements in care. Data was drawn from five focus groups recruited from various geographical locations in the north of England served by seven primary care trusts and four neurological departments. Researchers in a semi-rural practice recruited 38 participants, 15 of whom were male and 23 were female. Ages ranged from 26 to 74 years. The participants were either patients or carers of people with epilepsy, multiple sclerosis or Parkinson's disease and were recruited from three settings: primary care (two groups), voluntary groups (two groups) and secondary care (one group). The results showed that neurological care could be patchy, overstretched and insensitive to the individual patients' needs. Communication between patient and health professional, and between different sectors of the health service is poor and often leads to time wasting and delays in treatment. The impact of these conditions on the patient and their family and their preferences for treatment varies. Specialist nurses are highly valued by patients and their families but the service is overstretched and access is difficult. General practitioners (GPs) are valued for their communication skills and their ability to act as advocate for the patient; however, there are doubts about their knowledge of neurological conditions. Problems of service access were identified. The skills of health professionals in general practice can be used to complement those in secondary care. GPs and nurses are considered a valuable resource that could be used better to improve neurological care, particularly in fostering patient participation in decisions about their care. Practice-based commissioning offers an opportunity to review services to make better use of the time and skills of all professionals involved in the provision of care.

**Key words:** epilepsy; general practice; neurological services; multiple sclerosis; Parkinson's disease; patients and carers; patient's preferences; primary care; qualitative community study

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## Background

Concern has been voiced not only by patients and professionals but also by the Department of Health about the provision and quality of care for people with neurological conditions. A number of

government reports in the UK have highlighted the problems of sub-optimal care (Clinical Standards Advisory Group, 2000; Department of Health, 1998; 2001). An alliance of patients' groups suggests that because of the complexity of these conditions the particular skills and expertise of neurologists are required (Neurological Alliance, 1996a; 1996b; 2000). This is echoed in studies involving patients (Mills *et al.*, 1997; Yarrow, 1999; Freeman and Thompson, 2000;

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Moran *et al.*, 2000). However, neurologists are in short supply in the UK (Goldstein *et al.*, 1997; Robertson *et al.*, 1998; Kmietowicz, 2001; Kale and Menken, 2004) and the very complexity of some conditions requires care from a number of different disciplines (British Epilepsy Association, 2000; Beatty *et al.*, 2003; Kale and Menken, 2004).

To address these concerns, guidelines have been developed for the three conditions of interest in this study (SIGN, 2003; NICE, 2003; 2004; 2006) and the National Service Framework for long-term conditions (Department of Health, 2005) includes standards for neurological care.

As a result of the new GP contract (General Practitioners Committee, 2003), practices are encouraged to commission services and this presents an opportunity to review and redesign services, foster multi-professional working and involve patients as experts in decisions about their care (Department of Health, 2001).

## Introduction

It is therefore timely to explore how primary care can improve care for patients with familiar neurological conditions. Perhaps 456 000 people are affected by epilepsy in the UK or 1 in 131 (Joint Epilepsy Council). The incidence is highest in the young and the old (30–60 per 100 000 under 16 years and 20–40 per 100 000 over 70 years) (Hall *et al.*, 1997). Age-specific prevalence throughout life is about 7 per 1000 with perhaps 0.5% of the population taking epilepsy medication. The majority of people with epilepsy will be well controlled (Sander *et al.*, 1990) on one anti-epileptic drug (AED) but a misdiagnosis rate of perhaps 20% should be anticipated (Chadwick and Smith, 2002).

Multiple sclerosis (MS) is an autoimmune condition that affects the production of myelin. Women are more commonly affected than men (1.5:1) and prevalence varies with geography and racial group. In the UK, prevalence is 1–1.2/1000 and incidence 3.5–6.6/100 000 (Richards *et al.*, 2002) which reflects data from Europe and the USA (Compston, 1997). Age of onset is broad but peaks at 20–40 years (Weinshenker *et al.*, 1989). The impact on the individual is variable from the mild to the severe. Early symptoms can masquerade as other physical or psychological conditions, so diagnosis can be difficult.

**Table 1** Approximate incidence and prevalence in a general practice of 8000 patients

	New cases	Established cases
Epilepsy	4–8 each year	36–52
MS	1 every 2–3 years	5–8
PD	1–2 each year	8–14

Parkinson's disease (PD) is a progressive neurological condition resulting from reduced dopamine production. It affects 100–180/100 000 in Europe with an annual incidence of 4–20/100 000. Prevalence rises with age and affects men and women equally (De Rijk *et al.*, 1997). The condition leads to extensive disability directly affecting the individual and indirectly affecting the family or carers (McKeown *et al.*, 2003). Diagnosis is based on clinical findings including tremor, bradykinesia and gait disturbance or muscle rigidity.

A general practice with a list size of 8000 patients may only expect to diagnose four to eight new cases of epilepsy each year, one or two of PD and may only have a new case of MS every couple of years (see Table 1). The neurological case-load may consist of about 50 people with active epilepsy, 8 with MS and perhaps 12 people with PD.

## Methodology

### Participants and setting

Five focus groups were organized by the researchers from the practice and conducted in four cities in the north of England this year. The respondents were recruited through secondary care (groups A&B) local voluntary organizations (group C) and general practice (groups D&E). Each group consisted of people over 18 years of age who had either been diagnosed with or cared for people with epilepsy ( $N = 14$ ), MS ( $N = 11$ ) or PD ( $N = 13$ ). Thirty-eight participants were recruited, 15 of whom were male and 23 were female. The age range was 26–74 (mean = 56) years. Each focus group consisted of patients and carers of the three conditions. People less than 18 years old and those with communication difficulties were excluded. Due to particular needs of people with multiple pathologies patients with more than one neurological condition were also excluded. The group interviews were held in locations with disabled access, local public transport

links and convenient parking facilities. Locations were chosen outside the National Health Service (NHS) in order to encourage a relaxed and open discussion. Each session lasted between 2 and 3 hours, including a break during which refreshments were provided. Times were offered either in the afternoon or evening.

### Data collection

After a literature search a panel discussion generated a topic guide for the focus groups. The panel comprised 15 people including representatives from four voluntary organizations, general practitioners (GPs), specialist and practice nurses and consultant neurologists. Five focus groups were then held between 2002 and 2005. All group interviews were moderated by at least one of the authors with tape-recording and note-taking assistance. There was less criticism of care in two of the groups. The participants may have been aware the moderator in these groups was a GP and so influenced their responses; accordingly non-medical members of the research team facilitated subsequent sessions. Each session was tape recorded with the respondents' permission, transcribed verbatim and the tapes then destroyed (Kreuger and Casey, 2000).

### Data analysis

Themes and concepts were identified from the transcript of the first focus group and compared to the transcripts of successive groups. The text was examined and sorted into themes using the long-table approach (Kreuger and Casey, 2000; Pope *et al.*, 2000). A coding index was developed and these codes were applied to the subsequent transcripts. As new themes emerged, new codes were developed and applied to the data. Emerging themes were tested by repeated examination of successive group data using the constant comparative method and continued until theoretical saturation had been reached. To enhance reliability, two investigators undertook analysis and independently sorted and coded the data. Findings were discussed in-depth until consensus was reached.

### Results

Analysis of the transcripts from the focus groups resulted in the generation of four main themes

that were highly valued by the respondents. A priority for the respondents was a good working relationship between the patient and the health professionals responsible for their care. The respondents wanted timely access to information and support that was tailored to their individual needs and preferences. They were also concerned about the lack of health professionals' knowledge of specific neurological conditions and the impact this had on their care. Finally the respondents wanted better access to neurological care with better co-ordination between primary and secondary care.

### Relationship and communication between patients and health professionals

Communication and the development of a good working relationship between the patient and the health professional are vitally important to patients with a chronic neurological condition. The respondents identified a number of communication problems in relation to their care. Patients felt that health professionals, specifically their neurologist, often did not listen to them, their appointments were frequently rushed and characterized by a paternalistic attitude that the doctor, not the patient, knows best.

A number of issues relating to communicating with health professionals were identified. For some respondents the diagnosis of a neurological condition was given with little regard to its impact on the patient and their family. One woman felt that her diagnosis was delayed by several years because the clinician did not listen to her or take her concerns seriously:

But if you've presented over the year, maybe over the years and months with a few different things why aren't they tying it together thinking oh well she's been in with this, she's been in with that ... instead I was a hypochondriac. Why doesn't he think well maybe she is ill, I'll send her for a scan or something?

(D2)

When the diagnosis was finally given it was done with little appreciation of the impact on the patient:

I went in and he said sit down. He smiled at me and went you've got Multiple Sclerosis, now go home and forget about it and just get on with things as usual and don't tell anybody. Goodbye, next please. I just started to cry and I didn't know what to do, what it

entailed, whether I was going to live, whether I was going to die. And I just thought that was awful how I was told.

(D2)

Several other respondents had similar experiences:

I was told I had MS, there was nothing that could be done about it and I just had to live with it.

(B1)

I found out through an insurance company that I put a claim in for. I received a letter saying that the insurance was invalid because I had MS and I didn't know anything about this. I actually rang the local hospital and I managed to get the specialist on the phone and I asked him why didn't he tell me and he said oh I don't think you should have known about it.

(C9)

We knew something was wrong but we just needed someone to sit down and tell us straight that you have got THAT.

(E4)

Communication problems continued long after diagnosis. Many respondents felt that their neurologist failed to listen to them, their appointments were frequently rushed and characterized by a paternalistic 'doctor knows best' attitude. As one woman commented:

Nobody particularly listened to me, they just thought they knew what was best for me without really consulting me ... you know its like being a child again when your mother's saying you can't do that and slaps you round the legs.

(D2)

Another female respondent further illustrates this:

I mean if you're sat with your consultant you know he just wants to get you out of the door and you forget everything you want to say.

(A5)

By contrast, respondents rated highly the communication skills of the specialist nurses. As a result some respondents preferred the specialist nurse to any other clinician. As one woman commented:

The best person we've seen is the Epilepsy nurse he's lovely.

(C5)

This view was shared by many of the participants as illustrated by the following conversation:

They [specialist nurses] do listen to what you have to say.

(A2)

They're very much on the nub of things aren't they? They're a specialist in their field and they're down there with you.

(A1)

They're more on your level whereas the specialist when you speak to her she talks down to you she tends not to listen to what you've said.

(A2)

But it actually seems like they want to talk to you and they've got the information.

(A5)

GPs were also highly rated for their communication skills and were viewed as advocates by many of the respondents. A 'good GP' was someone who would do whatever they could to help resolve any problems a patient was experiencing with their care. As one woman stated:

I mean if presumably you got into trouble and they weren't responding from the hospital you could go and tell your GP and he could stir things up a bit for you, if you had a good GP.

(D1)

The respondents felt that care was depersonalized and not tailored to their own emotional and psychological needs. Personalized care was perceived to be possible only if the same clinician provided it over a long period of time. This was a highly valued but rare experience for the respondents in this study:

If you've got one person that you see all the time you should be able to build up that doctor-patient relationship and I think that would build up a trust. So when they said something to you and said I think you should do this you're willing to give it a go. But when you see x number and not one of them is saying the same thing you tend to think oh well I'll just carry on as I am.

(D4)

It is so much effort to get to the hospital and then you are only in 5 min and it can take you that long to get a new doctor up to speed.

(E2)

Where I was before I used to see a different consultant every time. I went once a year and every time I went I would have to go through everything from the first symptom and I was like the notes are there read them.

(D3)

Good communication resulted in the establishment of trust between the patient and the clinician, a result of continuity of care. As one woman commented:

I don't think it matters who it is, whether it's your doctor or your employer, provided they know you, you can build up that trust with them, you can talk to them about it. But if you don't feel like you've got confidence in them, whether you've consulted the epilepsy nurse whoever, you're wasting your time.

(A6)

### The provision of information and support

The level of information and support currently provided by the health service may not meet the needs of many patients. Immediately following their diagnosis the respondents were often left with little information relating to their condition and how it might affect their lives. This left some respondents feeling frightened about the implications of their diagnosis and fearful for the future:

All we were told was this is it, [he] has got MS, I'll give you some leaflets and if you just read them and that'll be it. Not told that he'll not be able to walk in six months time.

(A2)

I kept thinking I'm going to die I'm going to die. I'm not going to see my daughter grow up I'm not going to see her, I don't know, go to university, bum around the world, I don't know, drop out, anything. I just thought I was going to die.

(D2)

A popular and valued source of information was the voluntary sector. Some respondents praised the high quality of the information provided by the organizations and welcomed the support available from other people with their condition. One carer commented:

When [he] was diagnosed with epilepsy we were just left, weren't we? And I looked

through the yellow pages and found [the chair of the local support group]. I spoke to her for a long time on the phone and that was the first time that anyone helped us really.

(C14)

However, some respondents did not want to receive help from local support groups because they did not want to be reminded of the potential severity of their condition. As one carer put it:

I think it is a fear with Parkinson's, MS and Epilepsy they've seen films about people in the later stages and they don't want to come to a meeting and see what they may become.

(A8)

Another respondent echoed this view:

A lot of people don't want to join initially because they don't want to go and look at what they are going to become and this must apply to all these conditions.

(D1)

A popular medium for obtaining information was the internet. Although some respondents felt the internet was a useful and convenient information source they also pointed out that it could be unreliable:

The internet is a brilliant medium but you've got to sort out the wheat from the chaff and find out the true answer.

(D4)

We've tried the internet. Was it any good? Well yes and no.

(E3)

It became clear that patients and their families have individual preferences for the type of information they require and how and by whom it is delivered. A popular suggestion was to have all the information available in one place for newly diagnosed patients, for example, a drop in clinic at the local hospital run by the specialist nurse or in collaboration with the voluntary organizations:

I think it would be wonderful you could pick your information up you'd have your specialist nurse there to talk to. Somebody who's going to give you some reassurance.

(C11)

But if there was just that once a month where you could go and gather all the information in one fell swoop. When you went to the hospital and you were diagnosed then they could say well the next meeting is x... we'd like you to attend you'll get all the information about whatever you need to know. At least then you know somewhere down the line somebody's going to tell you everything.

(D4)

Whatever the approach, provision of information needs to be flexible to ensure that it is delivered in a way that is sensitive to the individual's needs and accompanied by reassurance and support in the early stages following diagnosis.

**Perception of professional knowledge and preferences for treatment**

Patients wanted treatment by health professionals with a specialized knowledge of their condition. Participants in all groups felt there was not enough sub-specialization, particularly amongst neurologists, and this adversely affected the care they received. As one man with MS commented:

And can I just say a lot depends on the consultant, the neurologist, because if he's not interested in a particular item such as MS or Parkinson's you won't get anywhere because he's not interested.

(C9)

Patients and carers actively sought out, and changed to, a neurologist with a specialized interest in their condition:

We moved from [Hospital A] because the man there is interested in Multiple Sclerosis. I think we saw him once but mostly we saw his satellites. We saw a different one each time we went and somebody said the treatment for Parkinson's is much better at [Hospital B] because the chap there is interested in Parkinson's.

(D1)

Specialist nurses were considered the most knowledgeable of all health professionals providing their neurological care and many patients expressed a preference for seeing their nurse over any other clinician. This knowledge proved valuable because the

nurse could make decisions about care in the absence of the neurologist and act as mediator between primary and secondary care. For example:

We benefit from [the specialist nurse] who can actually come and say right we're going to change your medication. He'll come to us and from our house he'll ring the GP and say 'right we're changing this, it's going to be changed to that now and I'll get you a letter out covering it today' and it happens.

(C5)

And we find that people like the MS nurse have more knowledge even though she [the neurologist] is supposed to be the consultant. And she talks to you more than [the neurologist] does.

(A2)

Although there was generally great respect expressed for the GP's communication skills and contribution to maintaining an excellent doctor-patient relationship they were perceived as lacking in the specialized knowledge to take a central role in their patient's neurological care:

My GP is excellent really. He's not an expert on everything because they can't be.

(C7)

My GP who I rate as a very good GP freely admitted that he said you've lived with it all your life you know more about it than me. He would freely admit that and I have the highest respect for him.

(A6)

A lack of knowledge of neurological conditions by doctors and nurses working in non-neurological hospital units was seen to adversely affect care during inpatient stays. It was felt that if hospitals could not provide specialist neurological wards, clinicians working on general wards needed educating on the specific needs of the neurology patient:

On wards bank nurses on nights don't know the patients or their routines.

(D1)

This is a big fault with the local hospital here because if you go into hospital with MS you get shoved on any ward. The staff, unfortunately,

it's not their fault, the staff don't know anything about MS and all the problems.

(C9)

They [the hospital staff] don't appreciate that you need your tablets when you need your tablets not when the trolley comes by. Cause I was told you're all right you can just ask if you need your tablets and we'll get you them, ah you look all right so I'll deal with this lady over here, I'll come back to you in half an hour, by which time.

(C8)

Specialist knowledge of the three conditions was therefore highly valued and perceived as a crucial part of high quality neurological care.

### Access to neurological care

Patients and their carers experienced difficulties in accessing many aspects of neurological care. Timely access to high quality care often depended on the area in which the patient lived. One respondent explained their pattern of care:

I moved here about a year ago from S. Established treatment in C and in M but when I came to [current home] I was very disappointed with the service I got. It was at a time when I was changing medication and it took me nine months to get an appointment.

(A6)

Another participant further illustrates this point of view:

Care seems to be a bit of a lottery depending on where you live. I know of some people who have moved to [her home city] because of the services here that they couldn't get where they lived before.

(B1)

Some people also experienced difficulty in getting regular access to their clinicians. A wait of at least six months was common between neurologist appointments. For people undergoing medication changes or those who were very ill this was not acceptable:

I think one of the worst things for me is waiting for an appointment. Six months, seven months an appointment and nobody in between.

(C9)

Sometimes they can't see you quick enough and if you're really ill you need to be seen and you need to be taken in and given steroids if you're lucky.

(D2)

I do the advisory and counselling line for our organization locally and many people ring me up and say I'm having problems with headaches or I'm sick, I don't feel well, could it be the medication? I mean I can't give advice on medication. I do feel there is a real need for a much closer follow-up. It's no use saying come back and see me in six months, which so often people get, don't they, when they go to see the consultant.

(C2)

Specialist nurses were often viewed as an appropriate alternative to the neurologist. However, access to specialist nurses was also difficult due to high demand for their services and understaffing. This often meant priority was given to newly diagnosed patients:

I mean now that we've got the specialist nurses that are very good. But I mean it's getting access to them because I mean they're so busy as well.

(C2)

She only sees the newly diagnosed maybe [once] a year or so and then that's it. I mean you can contact her but she works two and a half days and she's never in her office because she covers a huge area.

(C4)

Across all groups the respondents experienced care that lacked structure within a fragmented health service. A major reason for this was a lack of communication between primary and secondary care, making co-ordinated care unusual:

But there was no ... I'm afraid you know ... why don't you go and see [the specialist nurse] about it or why don't you go and see ... you know there was no referral, there was no communication between the team. It was just, you know, if you didn't do it off your own back then nothing would get done.

(A5)

My husband's just been in hospital and whilst individual efforts have been very good, moving between the hospital and back to his GP and the district nurse has raised a number of problems to do with supply of drugs and materials and so forth. Simply because people do not communicate with one another. It seems to me what happens is that they do their own job and pass it on and the minute it's left their desk it's left their head. That's not what professionalism is about, it's about doing a job.

(D1)

## Discussion

Patients and carers wanted access to care that was tailored to their individual needs, provided by knowledgeable and understanding professionals with whom they had regular contact. This ideal seemed to be a rare experience. This finding is unsurprising, as it has already been well documented (Multiple Sclerosis Society, 1999; Freeman and Thompson, 2000; Neurological Alliance, 2000). Patient-centred consultations are associated with higher patient satisfaction (Baker, 1996); continuity of care is associated with a higher level of trust and may improve the quality and outcomes of care (Mainous *et al.*, 2001); while dissatisfaction with professional communication leads to poor compliance (Grosset and Grosset, 2005). Participants found that neurology clinics were unable to offer individual care because of a lack of time and the difficulties caused by seeing a succession of different doctors. The participants also felt neurologists lacked the understanding and empathy of GPs and that unless the neurologist had a specialized interest in their condition, the care they received was often unhelpful and a poor use of their time. Specialist nurses were regarded as the most knowledgeable and approachable health professional but access to them was often difficult.

This demonstrates the benefits of using the complementary strengths of primary and secondary care in the fragmented health service so links between practices and specialist services need strengthening. This has previously been advocated for epilepsy care (Jacoby *et al.*, 1996; Poole *et al.*, 2000) but could equally be applied to other neurological

conditions. While we in primary care cannot offer specialized knowledge and care, we should be able to improve communication between different parts of the health service and take on the role of co-ordinating services between primary and secondary care. Future research could focus on how we can do this most effectively.

Provision of information was crucial. We found that preferences varied considerably. It would appear there is no 'one size fits all' solution. Preferred sources included the voluntary sector, individual or group sessions with either the specialist nurse, their peers and the internet. The suggestions given in the literature for information sources also varies (Wollin *et al.*, 2000; Box *et al.*, 2003). Preferences did not appear to vary by condition type, however, a few MS and Parkinson's, patients expressed a view that they would not want to go to a support group because they 'did not want to see what they might become in the future'. There is some evidence that patient support groups are not suitable for everyone (Charlton and Barrow, 2002; Messmer Uccelli *et al.*, 2004). This conclusion supports previous work in this area (Wollin *et al.*, 2000; Couldridge *et al.*, 2002). Primary care could play a part in providing individualized information provision by, perhaps, incorporating a review of information needs into the review process.

The participants stressed the importance of being involved in decisions about care. Many felt their concerns were not taken seriously despite knowing more about their conditions than many of the clinicians responsible for their care. Improving patient participation in decision making has been widely advocated in the literature (Multiple Sclerosis Society, 2002; Parkinson's Disease Society, 2003; Epilepsy Action, 2004; Yorkston *et al.*, 2005) to foster better self-management. There is great potential for primary care to use the strong relationship with patients to develop a more collaborative approach to care that involves the clinician, patient and their families.

## Strengths and weaknesses of the study

Although the participants in one group were recruited through secondary care the other four groups were recruited through primary care and the voluntary sector in four cities in Yorkshire. This community emphasis is unusual in neurological studies.



The methodology did not allow for comparisons between patient and carer views as we chose not to conduct separate focus groups. Indeed, the focus for the study was to examine general experiences of care to determine how primary care may contribute to improving services, rather than to compare and contrast patient and carer views. It is possible that there would have been less concordance in the views of patients and carers had there been separate sessions. It was our experience, however, that having patients and carers in the same groups stimulated vigorous debate and discussion that challenged individuals' views. A further study separating patient and carers would be an interesting addition to the literature.

There were problems recruiting PD patients and as a result they were under represented in this study. This was because PD patients were more likely to be less mobile and therefore found it difficult to attend. However, we did invite their carers to attend in their place and all but one participated. It is worth considering how patients with severe disability can be better represented in studies like this. It may be more appropriate to offer to conduct one to one interviews in the patients' home.

While all groups generated similar themes, the group that was facilitated by a GP were less critical of health care. It is possible that the presence of a clinician affected the discussion in a manner that produced a more positive view of the health service. Clinical involvement in research of this kind may introduce systematic bias and is worthy of further investigation.

## Conclusion

This study highlights the need for individualized care. In an increasingly modular and busy NHS we would argue that co-ordination of care is done best by professionals who see the patient regularly over time and understand the specific needs and concerns of the individual. This is almost always the GP, practice nurses or practitioners with a specialized interest based in primary care. Patient participation is encouraged by a good patient professional relationship that can be developed through the structured review process where information needs can be addressed. The commissioning role of general practice can be used to define the

roles of both primary and secondary care to improve services.

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