# Personal continuity and the care of patients with epilepsy in general practice

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#### SUMMARY

**Background.** So far no study has shown that patients with a chronic illness benefit from seeing the same doctor in general practice although many believe this to be so.

Aim. Epilepsy was chosen as an example to test the hypothesis that if patients see the same doctor more often in general practice they are more likely to discuss personally important aspects of their illness.

**Method**. In this cross-sectional survey 99 patients aged 15–64 years with active epilepsy were interviewed at home and then their records were reviewed. The patients came from four large Southampton group practices, one with a strict personal list system and three with combined lists. Outcome measures included reported discussion of feelings about stopping medication, stigma and concealment and the patient's relationship with practice doctors. Continuity was assessed from the records.

Results. Discussion of epilepsy was not significantly associated with continuity of doctor but was significantly associated with ease of talking to one or more doctors.

Conclusion. Encouraging patients with epilepsy to see the same doctor may be less important than improving doctors' communication skills and paying specific attention to the psychosocial aspects of epilepsy as well as to seizure control. It is recommended that a simple checklist including these items is used when a patient's care is reviewed.

Keywords: epilepsy; continuity of patient care; doctorpatient relationship; communication skills.

# Introduction

NO one has yet shown that seeing the same doctor improves the care of a chronic condition in British general practice. Yet this must be an important part of any case for the retention of personal lists, now that there is pressure for care to be given by a group with shared responsibility. In particular the psychosocial aspects of a patient's problem would seem likely to receive more attention in an ongoing doctor-patient relationship built up over time.

This study set out to look for an association between personal continuity and the perceived quality of epilepsy care received by patients. Epilepsy was chosen because of its profound psychological and social consequences related to fear about the prognosis of an unpredictable condition and perceived mental defect with associated stigma and concealment.<sup>2,3</sup> It appeared less appropriate to determine whether seizure control would be improved with increasing personal continuity of care because any such benefit might too easily be confounded by an enthusi-

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astic practice policy, say, for monotherapy with antiepileptic drugs together with regular review checking plasma levels.

Most published work from general practice over the past 15 years has concentrated on the drug treatment of seizures,<sup>4-7</sup> although Jones noted that patients were not receiving enough counselling.<sup>8</sup> The work of Dowds and colleagues,<sup>9</sup> while seeking the perceived needs of patients, did not offer guidance as to how to meet these other than by allocating adequate time for the interview.

More specific advice has been given by the Royal College of General Practitioners epilepsy working party<sup>10</sup> which stated that 'the doctor will need to spend a great deal of time ... listening to anxieties of the patient and his family'. It was decided therefore to look for psychosocial benefits and awareness of the treatment plan as the indicators of better epilepsy care most likely to be associated with personal continuity of care. The aims of this study were to test the following hypotheses:

- If patients receive more personal continuity of care they will be significantly more likely to have discussed one or more of planned duration of therapy, stigmatization and concealment with a general practitioner in their practice, and to name a general practitioner as the person they would first approach with their most important unanswered query about epilepsy.
- Such discussion would be positively associated with a good perceived relationship between patients and at least one general practitioner in their practice.

# Method

Two pilot studies were carried out. The first was carried out in G F's practice in Southampton in 1987–88 and was devoted to unstructured exploration of patients' perceived needs. There was great consistency in the areas identified by the 38 patients, namely concealment (100%), stigma (97%), cause and prognosis (95%), need for more public education (87%), fear and depression (74%), driving (61%) and drugs (whether to cease medication) (53%). All but two patients felt that the general practitioner had or could offer valuable support.

The second pilot study was carried out in 1988-89 with 16 patients from two other local practices to finalize the interview schedule for the main study and to provide the basis for a power calculation. This predicted that 53 patients would be needed in each of high and low continuity groups to detect a 25% difference in the proportion discussing psychosocial aspects of their epilepsy with general practitioners, with an 80% chance of finding such a difference.

Prevalence data<sup>11</sup> suggested that each of the four study practices would provide 40–45 eligible patients; 30 of these would then be selected randomly, giving a total of 120 subjects. Three of the practices had combined lists (C1–C3), the fourth (P) ran a strict personal list system.<sup>12,13</sup> The four practices were chosen because the principals had expressed interest in the results of a previous survey on continuity of care and because they were large enough for the question of priority of personal continuity to be an issue. The study was carried out in 1989–90.

# Eligibility

To be included, patients had to have active epilepsy, defined as

having had a seizure in the past two years or currently taking antiepileptic medication. They had to be aged 15–64 years inclusive (to allow the possibility of employment) and had to be fit to be interviewed in their own right (assessed as unfit if the records noted mental handicap or personality disorder). They had to have been registered with the practice for at least two years and with at least three recorded consultations with a general practitioner, in order to have had the chance to experience some longitudinal continuity.

Eligibility was assessed by G F who inspected the records of all potential subjects. The interviewer (S R) did not see the records at this stage. Diagnosis was noted as confirmed by a neurologist or a paediatrician or else had to be supported by a clear clinical description of witnessed seizures. Patients who were severely ill with another unrelated condition or primarily suffering from alcoholism with secondary epilepsy were excluded.

# Identification of patients

As all antiepileptic medication is disease specific except carbamazepine it was possible to identify most patients from repeat prescription records. While the practices with combined lists all had computers in which repeat prescription data were stored, in practice P receptionists wrote out repeat prescriptions manually. As it was found to be more difficult to identify patients in practice P, doctors were finally asked for the names of their patients with epilepsy. In practice C2 the computer information was supplemented by a manual disease register which included epilepsy.

Fewer eligible patients were found than anticipated, thus a random sample was only necessary in practice C2. There were three reasons for this. The quality of records in practices P and C1 was worse than earlier experience had predicted, 11 the advent of the 1990 general practitioner contract midway through the study reduced cooperation from receptionists, again in practices P and C1, and practice C1 proved to have a higher than expected proportion of adult epileptic patients who were handicapped or otherwise ineligible.

### Interview

Eligible patients were first contacted by letter. This was followed up, where possible, by a telephone call to arrange a time for the interview. As the study was specifically looking at potentially sensitive psychosocial issues patients were interviewed in their homes. The interview was semi-structured and included the following sections: demography; education and employment; other long-term illness; past experience of epilepsy; current experience of epilepsy, including medication and its review, seizure control and discussion of prognosis (clinical items), and stigma, concealment, responsibility for care and an unanswered question about epilepsy (psychosocial items); doctors, including: access to and relationship with usual/any general practitioner, and importance of seeing the same doctor each time.

#### Discussion score

The hypotheses were tested using a discussion score which combined the patient's replies in four relevant areas chosen after the second pilot study — prognosis, stigma, concealment and an unanswered question about epilepsy.

Prognosis could be addressed by specifically linking it to the question of ceasing medication. Stigma is a delicate concept to ask about. It was decided to use Scambler and Hopkins' distinction between perceived and enacted stigma.<sup>3</sup> Patients were asked: 'Has your epilepsy been a problem in your everyday life?', 'Are there adjustments you have made to your daily life because of your epilepsy?' (perceived stigma); 'Have you ever lost out (been discriminated against) because of your epilepsy?' (enacted). To investigate concealment patients were asked whether

they had told their family, friends, employer or the DVLC about their epilepsy (the main concern about driving was the entitlement to a licence so disclosure to the DVLC was included as a concealment issue). For these three issues patients were asked if they had discussed these with a general practitioner, specialist or anyone else. To reflect the individuality of wants all patients were asked 'What question about your epilepsy would you most like answered?' and 'Whom would you ask?'

There were thus four opportunities for a patient to report actual or potential discussion with general practitioner, specialist or other resource. When combined, the results of the four questions gave the discussion score with five possible values (0-4) for each of three resources — usual general practitioner, other general practitioner and specialist. 14

#### Doctor-patient relationship

The doctor-patient relationship was assessed by three questions: 'Do you feel you have a good relationship with your usual doctor/any doctor in the practice?', 'Do you feel you know him/her sufficiently?' and 'Would you say it is easy to talk to your usual doctor/any doctor, and ask questions, or do you feel it is not possible to ask him/her as much as you would like?'.

#### Continuity

After the interview S R inspected the practice records of each patient to find out which doctors the patient had seen in the last 12 consultations and whether epilepsy was mentioned (after the first 27 patients this search was extended to the greater of five years or 12 consultations).

These data allowed the calculation of an index of usual provider continuity (UPC<sub>12</sub>), defined as the percentage of the 12 most recent consultations with the most frequently recorded doctor. This was compared with the results from two previous studies. <sup>12,13</sup> It was also possible to calculate an epilepsy specific index (by only including consultations with a mention of epilepsy) and to calculate the UPC index over any period up to five years.

# Analysis

The first hypothesis was tested by logistic regression.<sup>15</sup> The independent variable was UPC<sub>12</sub> and the four components of the discussion score formed the dependent variables. The results were expressed as odds ratios with 95% confidence intervals.

The associations between personal continuity (UPC<sub>12</sub>, the independent variable) and the doctor-patient relationship questions (dependent variables) were tested by simple linear regression, as were the associations between the summative epilepsy discussion score (dependent variable) and the questions about the doctor-patient relationship (independent variables). The increment for a clinically significant change in personal continuity was chosen as two out of 12 consultations (17%). A smaller increment was thought to be meaningless in day to day practice, while a larger one was thought to be impossible to implement without the full rigours of a strict personal list system such as in practice P.

#### Results

Of the 112 eligible patients approached 99 (88.4%) were interviewed — 22,17,32 and 28 in practices P and C1-C3, respectively. The mean age of the 99 patients was 42 years (range 15 to 64 years) and 64% were women. Two thirds of the patients were married (67%) while 73% had children. Fifty five per cent were currently employed and 74% were owner occupiers. The 13 patients who declined to be interviewed (12 from practices

C1-C3 and one from practice P, eight men and five women) were younger than the interviewed patients with a mean age of 36 years.

The mean continuity indices  $(UPC_{12})$  for the four practices were similar to those in previous studies<sup>12,13</sup> (Table 1); patients with epilepsy received somewhat more continuity than that received by all patients in practices C1 and C3. The 12 patients from combined list practices who declined interview had a lower mean  $UPC_{12}$  of 44%.

All of the 99 patients except two were taking antiepileptic drugs. Fifty one patients said they had discussed their medication within the past year (including one of those not taking any), 23 reported discussing medication between one and five years previously and 16 reported a longer time or said they had never discussed their medication; nine patients gave no definite answer. Similarly, 45 patients estimated a time interval before their next discussion of medication while 54 did not. Of the 74 patients specifying the next doctor with whom they would like to discuss their medication, 53 (72%) named their usual doctor, seven (9%) another general practitioner and 14 (19%) a specialist; naming the usual doctor was significantly associated with a higher continuity index (odds ratio 1.8, 95% confidence interval 1.2 to 2.7). Concern was volunteered about continuing as well as about stopping medication and patients felt they knew little about possible side effects.

#### Components of discussion score

More than half of 97 respondents (63%) felt they knew the future duration of their medication but only 40 of 95 respondents (42%) felt their feelings about stopping were known to any general practitioner (Table 2).

Less discussion was reported about stigma and concealment. While 77 patients reported some stigma only 14 of these patients (18%) reported discussion of this with any general practitioner. Concealment was reported by 72 patients; 22 (31%) of these reported discussion of this issue with any general practitioner as did 11 of the 27 patients who did not report any concealment (41%). A further three patients reported discussion of concealment with a specialist (Table 2).

When it came to the unanswered question patients would most like answered 20 of 91 respondents (22%) said they would turn to a specialist compared with 39 to their usual general practitioner (43%) and 47 to any general practitioner (52%) (Table 2). Eleven patients mentioned other, sometimes idealized sources, for example a doctor with the specialist's knowledge and the general practitioner's accessibility.

The mean discussion score for the 99 patients was 1.35 out of

**Table 1.** Mean index of usual provider continuity (UPC $_{12}$  — % of 12 most recent consultations with the most frequently recorded doctor).

	Mean UPC <sub>12</sub> by practice <sup>a</sup> (%)				
	Combined list				
	C1	C2	СЗ	C1-3	Personal list P
Present study (n = 99) Random interview	53	58	53	55	82
study $(n = 68)^{b,c}$	50	58	-	55	87
Random record <sup>c,d</sup> study ( $n = 510$ )	42	58	48	50	83

n= number of patients in study. <sup>a</sup> Practices C1, C2, C3 and P labelled as A, B, C and D, respectively, in earlier study. <sup>12 b</sup> Reference 13. <sup>c</sup> Patients aged 15–64 years only for comparison with present study. <sup>d</sup> Reference 12.

Table 2. Number of patients reporting discussion of the four components of the discussion score.

		Number of patients					
Discussion with:	Stopping treatment (n = 95)	Stigma ( <i>n</i> = 95)	Concealment (n = 99)	Unanswered question (n = 91)			
No one	52	78	63	13			
Usual GP	33	9	28	39			
Other GP	7	5	5	8			
Any GP	40	14	33	47			
Specialist	3	3	3	20			
Other	0	0	0	11			

n =total number of respondents.

a possible four (34%). Sixteen patients had a score of zero and 91 had a score of two or less.

# Association of continuity and discussion score

A higher continuity index was significantly associated with patients naming their usual doctor (that is, the most frequently recorded doctor) for discussion of three of the four issues; the trend for the second item (stigma) was not significant. When discussion with any doctor in the practice was included, however, there was no significant correlation for any of the four issues, either individually or when combined into the discussion score. Thus, better continuity with one doctor was not significantly associated with increased discussion overall. Differences between the practices were also not significant and so results from the four practices were combined (Table 3).

Association of doctor-patient relationship and discussion score

Towards the end of the interview each patient was asked the three questions about their relationship with one or more doctors in their practice. Positive replies to the third and most specific question, about ease of communication, was not associated with personal continuity received, but the other two were both significantly associated with higher continuity (Table 4).

Answers to all three questions were positively correlated with the summative discussion score of the four issues considered. The strongest association was with the third question, whether it was easy to talk to the doctor(s) and this was statistically significant (Table 5).

# Discussion

The results of this study did not support the first hypothesis — it seemed just as good (or as bad) to see several doctors as one doc-

Table 3. Likelihood that an increased continuity of two or more of the last 12 consultations with same doctor will be associated with discussion of the four components of the discussion score.

Discussion item	Odds ratio (95% CI)				
	Usual GP	Any GP			
Stopping treatment	1.3 (1.0 to 1.8)	1.0 (0.8 to 1.4)			
Stigma	1.3 (0.8 to 2.1)	1.1 (0.7 to 1.7)			
Concealment	1.6 (1.1 to 2.2)	1.2 (0.9 to 1.6)			
Unanswered question	1.7 (1.2 to 2.4)	1.1 (0.8 to 1.5)			

CI = confidence interval.

Table 4. Association between recorded continuity of care and responses to questions about doctor-patient relationship.

	Number of patients responding					
Question	No	Qualified <sup>a</sup>	Yes			
Good relationship						
UPC <sub>12</sub> <50%	11	5	25			
UPC <sub>12</sub> 50%+	3	5	48**			
Know sufficiently						
UPC <sub>12</sub> <50%	9	12	9			
UPC <sub>12</sub> 50%+	5	12	39**			
Easy to talk to						
and ask questions						
UPC <sub>12</sub> <50%	5	5	31			
UPC <sub>12</sub> 50%+	6	10	42			

Significance t of regression (significance of trend in average patient response): \*\*P<0.01. \*Neither a definite yes or no.

Table 5. Association between discussion score and patients' perceived ability to talk to general practitioner.

	Nun	Number of patients with discussion score				
Response to question 'Easy to talk to'	0	1	2	3	4	Total
No	4	5	2	0	0	11
Qualified <sup>a</sup>	2	8	4	1	0	15
Yes	10	28	28	6	1	73
Total	16	41	34	7	1	99

Significance t of regression (significance of trend in average discussion score): P < 0.05. <sup>a</sup>Neither a definite yes or no.

tor within the group, because an increase in the continuity index, equivalent to two extra consultations out of the last 12 with the same doctor, was not significantly associated with more discussion of the personal items studied. However, discussion of the personal items was associated with finding it easy to talk to a doctor and ask questions. Ease of talking to the doctor was not associated with the personal continuity index, although more general aspects of the relationship were.

Some patients with lower personal continuity managed to have some discussion with general practitioners other than their usual doctor. Yet overall the amount of discussion was small with the mean discussion score being 1.35 out of a maximum of four; 91 patients (92%) had a discussion score of two or less. Given the concern many patients expressed about the issues being considered this was a worrying finding.

The confidence intervals suggest that even had the planned total of 120 patients been interviewed the results would still not have shown a significant association as described in the first hypothesis. The eight patients reporting discussion of three or (in just one case) all four items did receive more personal continuity, but, this trend was not significant.

The findings from a study of patients with epilepsy cannot necessarily be generalized to patients with other chronic problems. Epilepsy is an unusually stigmatizing condition because it is characterized by patients unpredictably 'taking leave of their senses' as well as a usually undeserved association with more general mental handicap. Other conditions such as diabetes and asthma may be more socially acceptable. However, epilepsy was selected as a problem particularly likely to need the postulated benefits of personal continuity.

A number of patients in this study believed that a general practitioner would not be able to answer their unanswered question and only a small minority of these felt that a specialist would be able to do this. Indeed, a problem for some doctors may have been lack of confidence in dealing with epilepsy; the aetiologies are poorly understood and awareness of the everyday psychosocial consequences has had much less emphasis than the use of antiepileptic drugs with regular monitoring of blood levels. 4.16 While seizure control is the centrepiece of the medical task it may be all too easy to assume that the absence of seizures means that the epilepsy is not an active problem for the patient (of the patients interviewed, the one who seemed most affected by stigma had not had a seizure for some 30 years).

Hamilton<sup>17</sup> has shown how to widen the scope of a review consultation with her simple social situation checklist which included occupation, driving status and fears for the future. But does this go far enough? The results for the patients in this study confirmed the findings of the literature<sup>2,3,18</sup> and of the pilot studies that the questions of prognosis, stigma and concealment were indeed of great relevance to patients. Many expressed gratitude at the opportunity in the study interview to air their concerns even if this could not give them any answers. More concern was reported by the patients interviewed in this study (S R, personal observation) than by patients responding to a recent postal questionnaire study.<sup>19</sup> However, face-to-face interview is perhaps a better way of eliciting complex feelings. The consultation can offer such an opportunity, though this study suggests that this is not realized as often as patients might wish.

The answer to why better personal continuity did not make more difference may lie in the other questions, asked later in the interview, about the patients' relationship with their usual or with any other doctor in the practice. Where patients perceived difficulties in talking to a general practitioner there was a significant association with a low discussion score. These results suggest that good communication is needed for discussion of psychosocial issues but also that seeing the same doctor more of the time is not necessarily associated with such good communication (re-analysing these data using continuity indices derived over a longer period, or only from consultations where epilepsy was recorded, did not alter the results). While good communication does not necessarily require a high proportion of contacts to be with the same doctor this may still be preferred by many patients, particularly if this is a doctor they have been able to choose, 13 and by doctors.

It is worth remembering that while increased continuity was associated with more discussion of personally important issues with the usual doctor, this greater continuity meant less chance of discussion with other doctors. It seems likely that such other consultations made up for much of any disadvantage associated with less personal continuity. Indeed seeing a new doctor may create an opportunity for both sides to explore questions that previously have been taken for granted. Patients and general practitioners may sometimes persist with a relationship which would better be changed. In other words what is important is seeing the right doctor (the one the patient feels able to talk to) rather than seeing the same doctor.

Some doctors have less effective communication skills than others and patients may get less help having more consultations with them. In particular it is important for the doctor to understand the patient's agenda if his or her most salient concerns are to be addressed.<sup>20</sup> Analysis of the data by individual doctor did suggest differences in their patients' discussion scores but the numbers were too small to exclude chance. In any case the elucidation of such differences would require a study designed for this purpose and would need the consent of the participating doctors.

The importance of personal continuity for the doctors was not examined in this study, yet it could be here that its main benefits lie. 21,22 Patients who return willingly are an important source of job satisfaction in general practice and it seems needlessly complicated for a patient with a chronic condition to see several different doctors.

These results suggest that, for epilepsy at least, seeing the same doctor in a group practice did not in itself improve the rather low level of discussion of psychosocial issues. It is likely that such discussion is more directly related to doctors' communication skills, perhaps to the consistent differing styles exhibited by general practitioners in Byrne and Long's study.<sup>23</sup> Finding the right doctor to talk to may thus be more important for patients than sticking with the same doctor.

Rather than specifically encouraging personal lists in group practice, a better way to improve the care of epilepsy may be to help doctors enhance their communication skills, in particular, by indicating willingness to discuss the impact of the disease. More specific attention needs to be paid to some key psychosocial aspects of epilepsy, namely fear of the consequences of stopping or of continuing medication, social stigma, concealment of the diagnosis and addressing the patient's most important unanswered questions. It is suggested that these items are included on a simple checklist to be used when treatment is being reviewed.

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The complete interview schedule is available from GF.

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