General practice based diabetes surveillance: the views of patients

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SUMMARY. Forty three patients with non-insulin dependent diabetes registered at two suburban practices were interviewed at least one year after the introduction of an organized general practice based system of diabetic surveillance and the results compared with data gathered from interviews administered before the introduction of the system. Structured data from the two interviews were compared in relation to the importance which patients attached to diabetes and its medical review, patients' preference for place of future review and the health professionals from whom they wished to receive diabetes care. Patients' ratings of the performance of health professionals on various aspects of care were compared with the ratings given before the introduction of the new service. At the follow-up interviews the reasons behind patients' responses to the structured questions were explored using a qualitative method. The introduction of a general practice based diabetes service was marked by an improvement in attendance for diabetes monitoring (56% before introduction, 98% in the year following introduction). This was associated with an increase in the importance which patients attached to diabetes and its medical review. After experience of diabetes care in general practice, patients remained enthusiastic about general practice involvement and confident in their general practitioners' knowledge about diabetes management. In spite of an improvement in the patients' ratings of hospital doctors' communication skills, they continued to rate general practitioners significantly more highly in these skills ($P<0.01$) and in terms of convenience and accessibility ($P<0.001$). Enthusiasm for nurse involvement in diabetes care increased between baseline and follow-up interviews and six patients felt they would prefer to have their diabetes reviewed solely by nurses. Discrepancy was found between general practitioners' and patients' views about the appropriate place of future review for individual patients, with 42% of patients disagreeing with their doctor's preference. Sixty nine per cent of patients opted for continuing care involving their general practitioner, relating this preference to the quality of the relationship with the doctor and the accessibility of primary care; their general practitioners could 'afford to be individual'.

Keywords: non-insulin dependent diabetes mellitus; follow up; continuity of patient care; patient satisfaction; patient attitude; doctor attitude.

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Introduction

As part of the development of the Southampton diabetes care scheme,[1] the effects of introducing into general practice regular recall and surveillance of diabetic patients have been studied.

Interviews with non-insulin dependent diabetic patients from two selected suburban practices, with no previous experience of surveillance of chronic disorders, were carried out in 1985.[2] The interviews showed that the majority of patients with non-insulin dependent diabetes considered themselves to have a serious disorder warranting regular care, and expressed confidence in the primary care team's ability to provide such care. At this stage, only 12% of the patients had had experience of general practice surveillance of diabetes.

In 1986, a structured diabetes service was introduced into the two practices in which general practitioners each reviewed their own diabetic patients in collaboration with their practice nurse (described in detail elsewhere).[1] During the following year, practices identified their non-insulin dependent diabetic patients (0.7% of combined practice lists) and offered these patients annual review against agreed checklists, without altering any hospital input during the first year. In both practices a team approach was developed in which nurses extended their role beyond the technical aspects of diabetic surveillance, and receptionists and practice managers took on increasing responsibility for organizational aspects.

The aim of this study was to discover whether, and to what extent, patients retained their enthusiasm for general practice care of their diabetes after experiencing general practice care for one year. The study also aimed to explore the thinking behind patients' preferences in relation to place of care, and to compare this with the rationale used by the general practitioners, who were making the decision about whether to offer patients continuing diabetes surveillance in primary care or to refer them for hospital outpatient care.

Method

Patient sample

The patient sample was drawn from two suburban practices with a combined population of 15 000 and an average list size of 2000 patients per general practitioner. The practices had been selected to represent British general practices, without previous experience of organized care for chronic disorders.[2] During the first year of the new diabetes service, nine general practitioners were involved in the care of these patients. At the hospital these patients were seen by four different consultant teams, represented by 18 different doctors and one diabetic liaison nurse.

Patients eligible for inclusion in the study were non-insulin dependent diabetic patients aged between 30 and 70 years, diagnosed and registered with one of the two practices for more than one year before the start of the study, and able to speak English well enough to answer the questionnaire. Eligible patients were sent a letter signed by their general practitioner and hospital consultant, and this was followed up by a telephone call from the interviewer. Patients had been interviewed before the introduction of the new service (baseline interviews).[2] Both patients and their general practitioners were interviewed after the end of the first year of the new system between January 1987 and February 1988 (follow-up interviews). The baseline and

follow-up interviews were conducted in the patients' home. Patients' clinical characteristics were defined from their notes and diabetes record cards.

Patient interviews

A structured questionnaire was developed for use in both interviews, which were carried out by experienced interviewers (E M follow-up interviews). Respondents were asked how much of what happened to their health in the future would be due to diabetes (possible answers: much, little, do not know). They also rated the importance of future diabetic review in keeping them healthy, on a seven point scale from 1 (not at all important) to 7 (extremely important).

Respondents were asked to state which of four professionals (hospital doctor, general practitioner, practice nurse or diabetic liaison nurse), they would like to see, alone or in combination, for regular review of their diabetes. They rated each professional's performance in relation to seven aspects of care covering knowledge, communication, convenience and accessibility, as 0 (not very good), 1 (quite good) or 2 (very good). They were also asked which aspect of care they valued most.

At the follow-up interview, respondents' answers to each question were probed and they were encouraged to explain the thinking behind their responses. The responses were tape recorded and then transcribed, giving a qualitative data set.

General practitioner interviews

At the end of the first year of the service, the nine general practitioners were asked to state where they believed each patient should receive routine care for diabetes in the future. Comparison of patient and general practitioner preferences was chosen since the decision about whether or not to refer a patient rests with the general practitioner.

Consultation rates

Details of the total number of consultations with general practitioners, hospital doctors and practice nurses, and the number of consultations which related to diabetes during the first year of the new service were extracted for each patient from the general practice notes.

Analysis

The data from the questionnaire were analysed by computer using the *SPSSX* package. The significance of differences between baseline and follow-up groups were tested using either the paired *t* test statistic or the chi square test of significance as appropriate.

The qualitative data were examined, question by question, and coded using categories emerging from the data.[3] In an attempt to preserve the anonymity of both doctors and patients, words indicating the respondents' sex have been changed at random in the quotations.

Results

A total of 112 non-insulin dependent diabetic patients were identified in the two practices at the start of the study. Forty three patients did not fulfil the criteria for entry into the study. Of the 69 eligible patients, 14 left the practice or died during the study year; 55 patients were eligible and available throughout the study period. However, 12 patients refused the follow-up interview. Forty three patients therefore took part in both the baseline and follow-up interviews. This represents 62% of the 69 patients who met the initial entry criteria, and 78% of those who were still in the practices at the end of the study year. At entry into the study, the mean age of the sample was 60.3 years (standard deviation (SD) 6.8 years), 56% were women, the mean duration of diabetes was 6.4 years (SD 5.7 years), 74% were receiving oral antidiabetic drugs and the mean glycosylated haemoglobin level was 9.2% (SD 2.5%). There were no significant differences between respondents and non-respondents.

Diabetes care

During the study year 42 of the 43 patients received diabetic review. Forty one patients were reviewed in the practice or by the general practitioner visiting the patient at home. Twenty one patients attended the hospital diabetic clinic or were reviewed by a medical consultant specifically concerned with diabetes. This compared with 19 of the patients at the baseline interview having had regular review at the hospital diabetic clinic, five patients having received care in general practice which included some element of surveillance, eight patients having had no documented care for diabetes other than blood glucose monitoring and 11 patients having had no regular care for diabetes at all.

Of the 41 patients having diabetic review in general practice, 38 had their blood pressure measured during the study year, 37 had their height and weight measured and 31 had their urine analysed for proteinuria. Thirty six patients had their visual acuity measured and 30 had fundoscopy performed. Thirty five patients had their pedal pulses checked, 36 received advice on foot care, 35 received advice on stopping smoking and 31 had dietary review. Consultation rates during the first year of the organized general practice diabetes service are shown in Table 1. This group of patients was seen once a month on average in general practice and once every two months to discuss diabetes.

Table 1. Consultation rates for the 43 patients during the first year of organized general practice review of diabetes.

Consultation	Mean no. of consultations per patient per year (SD)
Total with GP	9.6 (4.6)
With GP about diabetes	3.3 (3.0)
With hospital doctor about diabetes	1.1 (1.3)
Total with practice nurse	3.2 (2.5)
With practice nurse about diabetes	2.8 (2.5)

SD = standard deviation.

Perceived importance of diabetes and diabetic review

At the follow-up interview, 25 patients (58%) believed that diabetes was important in determining their future health, compared with 35% (15) at the baseline interview (χ^2 = 8.85, 1 df; $P<0.01$). At follow up, 88% of patients rated the importance of diabetic check ups as 5 or above on the scale from 1 to 7, compared with 72% of patients at baseline. The mean rating rose from 5.7 (SD 1.9) at baseline to 6.4 (SD 1.2) at follow up (t = 2.1; 42 df; $P<0.05$).

At the follow-up interviews, check ups were seen by nine patients as offering opportunities for blood glucose monitoring and by 16 patients as offering surveillance leading to preventive advice and the early treatment of complications.

> 'They can tell you if you're doing something you shouldn't. If you didn't go they couldn't tell you and you wouldn't know.'

Likewise, check ups were believed by 12 patients to offer medical professionals information upon which to base interventions. Regular check ups were also seen by patients as offering psychological benefits, including reassurance, mentioned by seven respondents.

> 'I don't say they can keep me healthy, but they can keep my mind at rest.'

Nine respondents indicated that check ups gave them motivation to comply with advice, which seemed to come from the personal relationship with the doctor.

> 'You keep yourself in check and make sure you're not letting your doctor down.'

Patients' opinions about health professionals

Before the introduction of the new service both hospital doctors and general practitioners were rated highly on aspects of care relating to knowledge of diabetes, knowledge of the patients' problems with diabetes and ability to give clear information on diabetic management.[2] However, general practitioners scored significantly more highly than their hospital colleagues on aspects of care relating to communication skills, accessibility and convenience. This pattern was sustained in the follow-up interviews (Table 2), with general practitioners scoring significantly more highly than their hospital colleagues on being easy to talk to, being good at listening, and for time keeping and availability. The number of respondents varied with each aspect of care, according to whether they felt able to make a judgement about that variable for each professional. Forty patients had met practice nurses, but half of them felt unable to rate practice nurses on any aspect of care. Only six patients had met the diabetic liaison nurse. These two groups of nurses were therefore excluded from this analysis.

When patients were asked which aspects of care they most valued, the percentage of patients giving an aspect of care specifically related to diabetes rose from 66% in the baseline interviews to 79% at follow up.

Table 2. Patients' ratings[a] at follow-up interviews of general practitioners and hospital doctors for seven aspects of care.

Aspects of care	Mean score (SD)		
	Hospital doctor	General practitioner	*t*
Knowledge of diabetes ($n=35$)	1.8 (0.5)	1.7 (0.5)	1.5
Knowledge of a patient's problems with diabetes ($n=34$)	1.5 (0.7)	1.6 (0.6)	1.0
Ability to give clear information on diabetes management ($n=33$)	1.6 (0.8)	1.6 (0.6)	0.2
Ease with which can be talked to ($n=34$)	1.3 (0.8)	1.8 (0.6)	3.0**
Ability to listen ($n=34$)	1.3 (0.7)	1.8 (0.5)	3.2**
Time keeping ($n=34$)	0.8 (0.8)	1.7 (0.5)	6.1***
Availability ($n=18$)	0.8 (0.9)	1.7 (0.5)	4.7***

SD = standard deviation. *n* = number of respondents. [a]Scores from 0 (not very good) to 2 (very good). **$P<0.01$. ***$P<0.001$.

Patients' preferences for future care

Patients' preferences for future care are summarized in Table 3. In both the baseline and follow-up interviews, the majority of patients wanted diabetes review in general practice only. In the baseline year, 88% of patients chose some form of diabetic review involving the general practice team and 39% chose diabetic review involving the hospital diabetic team. In the follow-up year these percentages fell to 77% and 35% respectively. This fall was explained by a decrease in the number of patients opting for care shared between hospital and general practice.

At the baseline interview, 11 of the 43 patients expressed a wish for some involvement by nurses in their regular diabetes care. At follow up, 16 patients wished to have nurse involvement.

Table 3. Preferences of the 43 patients for future care.

Preference for future care	No. of patients
General practice-based care	
GP only	16
Practice nurse only	3
GP and practice nurse	7
Hospital-based care	
Hospital doctor only	5
Diabetic liaison nurse only	2
Hospital doctor and diabetic liaison nurse	1
Shared care	
Hospital doctor and GP	4
GP and diabetic liaison nurse	1
GP, diabetic liaison nurse and practice nurse	1
Diabetic liaison nurse and practice nurse	1
No care	1
No preference	1

Six of these patients wanted their regular care to be carried out by nurses without any doctor involvement, compared with one patient at the initial interview.

Reasons for choice of future care

Twenty of the patients (69%) opting for regular diabetic review involving their general practitioner related this preference to the quality of their relationship with the doctor. General practice was also seen as being more personal than the hospital clinic.

> 'They [general practitioners] concern themselves with you, whereas the hospital doctor concerns himself with diabetes.'

General practitioners were seen by seven patients as being able to provide continuity of care. They were believed to be able to draw on their knowledge of the personal and medical history of patients when managing diabetes.

> 'He sees me whatever's wrong with me and he should have a good general knowledge of me.'

Nine patients mentioned the respect and warmth with which they were treated in general practice. By contrast six patients said that they had been humiliated or treated rudely at the hospital clinic.

> 'I couldn't get on with her [hospital doctor]. She's very good in her field, but she's abrupt. Of course, she can't afford to be individual.'

The second theme emerging from discussions of patient preference for care in general practice was that of convenience and accessibility. Ten patients (38% of the 26 wanting practice based care), mentioned this factor as the reason for their choice of review in general practice. Again this was contrasted with the inaccessibility of the hospital clinic.

> 'When I've got a hospital appointment I have to take a whole afternoon off work ... If I went to my GP he'd give me an appointment for say 2pm and I'd know I'd get back to work.'

Among those patients who wanted to have their regular care exclusively in general practice, five expressed a willingness to attend the hospital clinic on a temporary basis, if their general practitioner judged that to be necessary. A similar attitude was

found among the four patients who wanted to have their care shared between the general practitioner and the hospital doctor. Three of these patients saw hospital involvement as necessary because of current problems.

> 'If I could just talk to him [hospital doctor] about it once. It's only that I'm worried about it at the moment. At other times, I'll be honest with you I'd just to go to him [general practitioner].'

Shared care was also seen as a means of securing more care, as expressed by one patient.

> 'They obviously can keep a check on me in between going to the hospital. Six months at the hospital is quite a long time between appointments.'

It was also seen by one patient as a way of combining the superior skill of the hospital doctor with the respect and understanding of the general practitioner.

> 'He [the hospital doctor] would be the professional because the GP doesn't know as much about diabetes as the specialist does ... She [the general practitioner] doesn't belittle me when I tell her something is wrong ... I wouldn't change her for the Queen's doctor.'

Six of the patients opting for hospital based review wanted the hospital doctor to be involved in the regular care of their diabetes. The other two wanted such care from the diabetic liaison nurse. Five of the patients who wanted to see the hospital doctors pointed to their specialized knowledge of diabetes to explain this preference.

Twelve of the 16 patients who wanted nurse involvement in their care chose to have the practice nurse involved in their care. Eight of these had received care from one nurse who had experience of caring for a diabetic relative and this was cited as the basis for confidence in her. Practical understanding of diabetes and the ability to pass on this understanding to the patient were seen as important qualities in the nurses by those who wanted them to be involved in care.

> 'The doctor does have the knowledge but when it comes to the practical the nurse has the practical.'

The listening skills and reassurance offered by nurses were also appreciated.

> 'I can talk to her and she'll explain everything to you, whereas possibly the hospital doctor might know more but he hasn't always got the time to explain to you.'

Only one patient refused regular diabetic review. She argued that diabetic care damaged her health.

> 'Hanging around at the hospital aggravates my blood condition ... I think diabetes is the lesser of the two evils, so blow it.'

General practitioners' perspectives on future place of care

When general practitioners were asked about where they thought their patients should be followed up in future, their views coincided with patient preferences in 58% of cases (Table 4).

General practitioners felt that six patients would be most appropriately reviewed exclusively by hospital physicians. Patients views' agreed in two cases, both of whom were receiving private treatment from their consultants. Three of the others had chosen care from the general practitioner alone, and the fourth wanted to be cared for by the general practitioner and the diabetic liaison nurse. Three of these patients had multiple disorders and were already receiving care for other conditions from hospital physicians. The general practitioners believed that these patients would prefer to have their diabetes reviewed by the same physicians. For example, one doctor said,

> 'I'm not sure I'd want to say, "You must come here for your diabetes." '

However, all three patients expressed particular appreciation for their general practitioner's role in relation to diabetes. The fourth patient in this group had recently had an amputation and had advanced retinopathy. Her doctor explained,

> 'I doubt if I could contribute anything to her care. If and when she needs me, I know the hospital would call me in.'

In fact, both the patient and her husband were very confused about simple primary care aspects of diabetes, diabetic control and diabetic complications. When asked why it might have been important to keep her blood glucose level down the patient replied,

> 'I don't really know what it is all about.'

General practitioners felt that 27 patients should be looked after in general practice alone; 21 patients agreed. Two of the remaining six wanted to be reviewed at the hospital, three wanted care to be shared between the general practitioner and the hospital doctor, and one rejected care. Generally, these patients found it difficult to explain why they wanted hospital involvement in their care. However, one said that she would prefer to have all her review in general practice but understood that the facilities she required were only available in hospital. A second patient was in a state of high anxiety about his diabetes and saw shared care as an opportunity for increasing the quantity of care for his condition.

> 'The GP, definitely him. I think the hospital doctor ... the hospital doctor might have more time ... It's only that I'm so worried about it at the moment.'

Table 4. Patient preference for future place of review by general practitioner preference.

General practitioner choice	Patient choice (no. of patients)					
	Hospital	General practice	Both	None	Anywhere	Total
Hospital	2	3	1	0	0	6
General practice	2	20	3	1	1	27
Both	4	3	3	0	0	10
Total	8	26	7	1	1	43

Discussion

In the previous study it was noted that patients with non-insulin dependent diabetes, whether attending hospital or receiving no regular care, were enthusiastic about receiving diabetic care in general practice. This study has extended those findings and confirmed that, when they were offered recall and comprehensive review of their diabetes, the majority attended in the first year. Moreover, their enthusiasm for primary care based review persisted after their first experiences of it. At the follow-up interview 76% of patients wished to continue with annual review involving general practice. This finding suggests that patients' initial enthusiasm for primary care review was not based upon unrealistic expectations.

While the sample studied was relatively small, it offered an opportunity to study in depth the views of a group of non-insulin dependent patients, aged between 30 and 70 years, attending for

diabetes care, in practices with no prior expertise in diabetes surveillance. The service patients were offered closely matched their earlier stated preferences; they were seen by their usual doctor and those attending hospital were not removed from hospital follow up until general practice care had been successfully instated.

There was evidence that primary care review of diabetes was associated in these patients with an increased sense of the importance which diabetes may have in determining their future health, and of the role of diabetic check ups in keeping them healthy. Both the verbal and non-verbal messages arising from the introduction of diabetes review into general practice may have contributed to the increased salience of diabetes and its care for these patients. The large number of procedures which were carried out at review could be expected to have drawn the potential risks associated with diabetes to their attention and the amount of effort which general practitioners and practice nurses put into offering the service might have suggested to patients that the professionals considered it to be very important.

One might have anticipated that the increased importance which patients attached to diabetes would have been associated with an increased demand for expert care from hospital diabetologists. This was not so. Although knowledge and expertise in the management of diabetes were given high priority by these patients, the majority did not discriminate between the ability of general practitioners and hospital doctors to offer such expert care.

Patients' preference for care in general practice seemed to be related to ease of communication with the doctor in this setting, and the convenience and accessibility of care. The patients believed that a good relationship between doctor and patient enhanced the effectiveness of the consultation. They felt it could increase personal motivation to follow the prescribed regimen, and enhance the reassurance which, for a number of patients, was the most important outcome of review. In this study, diabetes review was shared between nurse and personal general practitioner,[5] combining a structured team approach with the personal care which these patients obviously valued.

The extension of the role of the nurse in diabetes care was associated with a moderate increase in the number of patients who wanted nurses to be involved in their care. Particularly striking were the six patients who elected to have their regular review exclusively from nurses. The attributes of nurses which appeared to be most valued could be summed up as approachability and practical understanding.

Ease of communication and continuity of care were not seen simply as personal attributes of the individual doctors concerned, but rather as part of the potential of general practice. Unlike hospital doctors, general practitioners could 'afford to be individual' and had the benefit of an ongoing relationship with the patient, which allowed them to understand diabetes in the context of the health and social experiences of the patients.

Fewer patients opted for shared care after experiencing diabetes review in general practice. This suggests that patients may prefer to have their care supervised consistently in the same place. Patients generally expected their general practitioners to use the consultant service as such, and felt that they could usually get the diabetes care they needed in general practice.

The disparity between patient and general practitioner choices for place of future review suggests a lack of explicit negotiation of place of care between general practitioner and patient. It is clear from the interviews with both doctors and patients that both parties were being influenced in their choice of place of care by assumptions about the other's expectations, but that these were often mistaken. The evidence suggests that attendance improves when patients are offered care in the place they prefer. It is important, therefore, when the general practitioner believes referral to be necessary, that this should be adequately negotiated with the patient. Even where general practitioners feel inadequate, their patients may have unexpressed needs which lie within the scope of primary care.

The data presented here suggest that general practitioners have particular opportunities for exercising influence to persuade patients to follow their advice which is not so easily available to their hospital colleagues. In the context of current discussions about general practice's future organizational strategy,[6,7] the power of the therapeutic relationship to contribute to individual health care needs to be considered as carefully as the power of structured recall services to contribute to population coverage.

The value which patients place on their relationship with their general practitioner can be both used and abused. On the one hand, general practitioners might use it to excuse an inadequate clinical service because of popularity and good attendance rate. On the other hand, as the attendance rates in this study show, the opportunities for personal, continuing care which general practice can offer, provide an extremely positive background against which a soundly based clinical service can be delivered to patients. However good the clinical service may be, it will be ineffective if patients are unwilling to attend for surveillance or act upon the findings.

In 1969 a working party of the Royal College of General Practitioners defined a general practitioner as 'one who provides personal, primary and continuing medical care to individuals and their families'.[8] Recently, the need and indeed the ability of modern primary care teams to offer such care has been questioned.[9,10] This study suggests that this group of patients see this objective as a valued reality, and one which is associated with the willingness of the group to accept diabetes surveillance.

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